

**Diabetes  
Mellitus  
Interagency  
Coordinating  
Committee**

**A N N U A L R E P O R T**

**Fiscal Year 2000**



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Mellitus  
Interagency  
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**CONTENTS**

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Introduction

Activities of Member Organizations **1**

Meeting Summaries **33**

National Diabetes Education Program **63**

Appendix A

DMICC Authorizing Language **99**

Appendix B

DMICC Roster **101**

Appendix C

FY2000 Budget Actuals **107**



## **INTRODUCTION**

In accordance with Section 429 of the Public Health Act, the Diabetes Mellitus Interagency Coordinating Committee (DMICC) prepares an annual summary report of its activities as well as other Federal research activities in the field of diabetes. It is submitted to the Secretary, Department of Health and Human Services (DHHS), and the Director of the National Institutes of Health (NIH). This is the annual report of the DMICC for Fiscal Year (FY) 2000.

## **LEGISLATIVE MANDATE**

The DMICC was authorized by Public Law 93-354 and established in fall 1974; subsequent legislation modified some of the charges to the Committee. The legislative authority of the Committee is presented in Appendix A. The charge to the DMICC is to coordinate the research activities of the NIH and other Federal agencies relating to diabetes mellitus and its complications and to contribute to the adequacy and technical soundness of these activities by providing a forum for communication and exchange of information.

The Committee includes representatives from Federal agencies whose programs are relevant to diabetes mellitus and its complications. The chairman, designated by the Director, NIH, is the Director, Division of Diabetes, Endocrinology, and Metabolic Diseases, National Institute of Diabetes and Digestive and Kidney Diseases (NIDDK). In FY 2000, the DMICC membership included representatives of 21 Federal organizations. A roster of Committee members as of the close of the fiscal year is included as Appendix B.

## **ACTIVITIES OF THE DMICC**

The DMICC facilitates cooperation, communication, and collaboration among agencies that conduct or support diabetes-related activities. These activities may range from support for biomedical research to direct provision of health care services. The DMICC provides both a forum for initiating interactions and a mechanism for tracking progress.

During FY 2000, Dr. Allen Spiegel, the newly appointed Director of NIDDK, has elevated the chairmanship of the DMICC from the Director of the Division of Diabetes, Endocrinology and Metabolic Diseases to the Director of the NIDDK. Under the new leadership of Dr. Spiegel, the DMICC is positioned to respond to the recent congressional mandate addressing the issue of minority health disparities. In this regard, the DMICC significantly focused its efforts during FY 2000 on type 2 diabetes in American Indian and Alaskan Native children. Also during FY 2000, the DMICC focused on diabetes quality improvement by working closely with the Health Care Financing Administration and its Diabetes Quality Improvement Project.



# ACTIVITIES OF MEMBER ORGANIZATIONS

## **Agency for Healthcare Research and Quality (AHRQ)**

The Agency for Healthcare Research and Quality has had a broad range of activities and initiatives in diabetes designed to improve the quality of health care, reduce its costs, and broaden access to essential services which are impacting policies and practices across the country.

### **Current Activities:**

The Diabetes Quality Improvement Project (DQIP)—based in large part on the work of the Diabetes Patient Outcomes Research Team (PORT) and led by Principal Investigator, Sheldon Greenfield, this project is a collaboration of the National Committee for Quality Assurance, the Health Care Financing Administration, the American Academy of Family Physicians, the Department of Veterans Affairs, the American Diabetes Foundation and the Foundation for Accountability. It has developed a common core set of diabetes performance measures that allow fair comparisons and stimulate quality improvement among health plans and providers. Reporting on the DQIP measures is now required by HCFA of managed care plans and will be publicly available. Initial analysis of the reports suggests that many of the process and outcome measures have improved but that some target levels have not been met. The measures have also been included by NCQA in its HEDIS reporting set. Work has begun on developing DQIP 2.0

The Agency has funded a large number of studies including an assessment of diabetes care in community health centers, an assessment of compliance with ADA guidelines, and a study of dyslipidemia in African Americans with Type 2 DM. In addition, diabetes was included as one of the target conditions for an RFA focused on improving our understanding of racial and ethnic health disparities and identifying strategies to eliminate them. This initiative, called EXCEED (Excellence Centers to Eliminate Ethnic/Racial Disparities), will fund over \$45 million of research and demonstration projects. Four of the centers will be focused, at least in part, on diabetes. Diabetes was also a target of the Translating Research into Practice (TRIP) II RFA and a number of studies will focus on identifying strategies to effectively and efficiently reduce the gap between what is know and what is done in diabetes care. One project is focusing on the use of multimedia presentations to improve patient knowledge and self-management of their condition.

### **Future Activities:**

No additional diabetes-related activities were reported.

### **Funding for Diabetes Research:**

FY 2000 funding information was not provided.

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## Centers for Disease Control and Prevention (CDC)

The mission of the Centers for Disease Control and Prevention's Division of Diabetes Translation is to reduce the burden of diabetes in the United States by combining support for public health-oriented diabetes control programs nationwide and translation of diabetes research findings into widespread clinical and public health practice.

### Current Activities:

CDC's diabetes prevention and control program includes:

- Diabetes control programs (DCP) in all 50 States to develop or expand diabetes control efforts.
- Applied translational research focusing on the application of findings from recent randomized control trials in real world settings.
- Public and private partnership of the National Diabetes Education Program (NDEP) to educate patients, providers, and the public.
- Developing surveillance systems for use at State and local levels, especially for monitoring the diabetes burden among certain racial and ethnic populations.
- Developing and implementing innovative interventions and prevention strategies for eliminating racial and ethnic health disparities.

### Major accomplishments in FY 2000 include:

- *Involving Business in Diabetes Control through the National Diabetes Education Program.* Published the NDEP's Business and Managed Care Workgroup's *Making a Difference: The Business Community Takes on Diabetes*, in December 1999. This document, which focuses on business and diabetes, outlines the economic costs and health consequences of diabetes. It also shows the importance of employers investing in the prevention and early detection of diabetes complications at the worksite.
- *Improving Methods To Understand the Public Health Burden.* Constructed a new model to forecast the future burden of diabetes in the United States population. The forecasting model will strengthen CDC's ability to address the future diabetes public health challenge.
- *Collaborating To Improve Diabetes Care in Community Health Centers (CHCs).* Partnered with the Bureau of Primary Health Care and the Institute for Health Care Improvement in the National Diabetes Collaborative. In 1 year, the Collaborative resulted in a three-fold increase in the number of persons receiving two HbA1c tests annually. Thirty-five of CDC's DCPs have been trained on the Improvement Models and are working with CHCs. The collaborative's mission is zero disparities, 100 percent access, and two HbA1c tests annually.
- *Building a National System To Monitor Childhood Diabetes.* Established a multicenter childhood diabetes registry system to conduct childhood diabetes surveillance. The centers will characterize the types of diabetes, develop case definitions, study the prevalence and incidence, describe the natural history of diabetes in children, and describe the quality of care received during follow-up. These activities of the childhood diabetes registry centers will inform CDC's efforts to develop and implement a national public health strategy to address type 2 diabetes in children and adolescents.

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**Future Activities:**

As funds become available, CDC will continue to build a multifaceted National Diabetes Program by:

- Funding *every* State program at the Comprehensive level.
- Expanding surveillance activities to better understand the diabetes burden in at-risk populations, including racial and ethnic minorities, women, and children.
- Enhancing prevention research to improve understanding of the risk factors and health outcomes of diabetes.
- Undertaking prevention research activities to identify effective methods for preventing devastating diabetes complications and for translating scientific findings on primary prevention of diabetes into public health practice.
- Expanding the National Diabetes Education Program's education activities and partnership network that is comprised of national public, private, and voluntary organizations concerned with the health of persons with diabetes. CDC would also strengthen efforts to raise awareness about the increased health risks people with diabetes face.
- Undertaking specific activities to address the unique diabetes control and prevention needs of racial and ethnic minorities.

**Funding for Diabetes Research:**

FY 2000 funding information was not provided.

**Health Care Financing Administration (HCFA)****Current Activities:**

- On December 28th Medicare announced expanded coverage of training for beneficiaries in self-managing diabetes. The Health Care Financing Administration announced the final rule for expanded coverage enabling beneficiaries with diabetes to get training from qualified providers in self-managing their disease. Under the regulation, any provider who is already eligible to bill Medicare, and who meets quality standards for this benefit, can provide the training for Medicare beneficiaries eligible for the service. The regulation will take effect 60 days after publication in the Federal Register. To qualify for this training, a beneficiary must be either newly diagnosed with diabetes, or did not receive training at the time of diagnosis, or is at significant risk for complications from the disease.
- HCFA is also working with four communities to target Hispanic, Asian Americans, and American Indians for self blood glucose monitoring.
- HCFA is working with the American Podiatric Medical Association developing a foot health program with the Centers for Disease Control and Prevention, the National Institute of Diabetes and Digestive and Kidney Diseases, and AOA.
- In addition, HCFA is running a campaign "Power to Control Diabetes is in your Hand." The campaign is a multi-media promotion plan.

**Future Activities:**

No additional diabetes-related activities were reported.

**Funding for Diabetes Research:**

FY 2000 funding information was not provided.

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## **Health Resources and Services Administration (HRSA)**

The Bureau of Primary Health Care (BPHC) of the Health Resources and Services Administration established two strategic goals: the elimination of health disparities and 100 percent access for minority and underserved populations. The strategy, which supports the President's Initiative on Race, focuses on diabetes mellitus for the initial stage of the initiative. The other health disparity issues (infant mortality, immunization, cancer, cardiovascular disease, and HIV) will be addressed in subsequent years.

### **Current Activities:**

- The first goal of the initiative is to delay or decrease the complications of diabetes by implementing a care model developed at the Sandy MacColl Institute for Healthcare Innovation. This evidence-based model, pioneered by Edward Wagner, MD, at the University of Washington, is part of a 5-year grant from the Robert Wood Johnson Foundation that focuses on chronic disease care. The model of care is a population-based model that relies on knowing which patients have the illness, ensuring that they receive evidence-based care, and actively aiding them to participate in their own care. It has five basic elements: patient self-management, clinical decision support, delivery system redesign, a clinical information system, and strong partnerships with local government and community organizations.
- The second national project goal is that 90 percent of patients with diabetes will receive two HbA1c tests annually, at least 3 months apart. Additional project measures used by health centers focus on patient self-management, control of glucose levels, prevention of cardiac complications, and prevention of microvascular complications such as eye, kidney, and foot diseases. To implement this care model, an improvement model created by the Associates in Process Improvement (API) and a learning model developed by the Institute for Healthcare Improvement (IHI) is applied. These models stress rapid testing and change and learning through action and measurement over a 1-year period in a community of other organizations. This learning strategy is based on the IHI Breakthrough Series and is termed "learning collaborative."
- An infrastructure was also created in each of HRSA's five clusters. This support system includes a full-time trained coordinator and information system specialist based in a lead primary care association/clinical network, a lead HRSA field office clinician, and partnerships with the Centers for Disease Control and Prevention (CDC) and State diabetes control programs. The support system also includes faculty and technical assistance from IHI and the Sandy MacColl Institute, Internet communications among health centers and faculty, and regular conference calls, site visits, and monthly reports.
- Eighty-eight health centers successfully completed the year-long diabetes collaborative.
- Thirteen learning sessions were completed.
- The outcomes from 2 national sessions and 11 cluster-based sessions was extremely impressive. Diabetes registries were created at each health center. Approximately 15,000 persons with diabetes were enrolled in these registries, which enabled centers to track and manage the health of these patients. Health center team performance was excellent. At the end of the collaborative, the average team score was approximately 3.5, which signified modest to significant improvement. HbA1c performance was increased by almost 300 percent, from about 20 percent to 60 percent. The national average for this measure is about 20 percent. In addition, a significant number of health centers achieved decreases of 1 percent or more in HbA1c levels, a measure of glucose control that translates as a 17 percent reduction in mortality for persons with diabetes.

- State diabetes control programs (DCPs) from 15 States participated in the collaborative. A survey conducted by CDC in the last quarter of 1999 assessed technical assistance and/or resources provided during the past year that were generated by this project. These outcomes included assistance for registry development and implementation, on-site training, flowcharts, patient guidelines, and inclusion of health centers in DCP State advisory councils.
- Through a partnership with IHI, CDC, the Washington State Diabetes Program, and the BPHC, a software program for managing patients with diabetes was developed for health centers in the collaborative.
- Five cluster coordinators were hired and trained; an additional five information system experts were also hired and are now being trained to provide support for information systems to help manage diabetic patients.
- Partnerships were established with the Bayer Corporation, which resulted in increased access to HbA1c analyzers.
- In addition to diabetes, approximately 40 health centers began an IHI Breakthrough Series collaborative in February 2000 on depression and asthma.

#### **Future Activities:**

- In January 2000, the first group of health centers completed the diabetes collaborative and are now continuing to improve, document, and report performance in diabetes care and outcomes. A second group of 125 health center teams began a second diabetes collaborative on January 22, 2000. Joining the second collaborative are 22 State

diabetes control programs. Like the first group, these health centers will work for 12 months on implementing the care model and improving and measuring diabetes care in the following areas: patient self-management, glycemic control, prevention of cardiac complications, and prevention of microvascular complications. An additional parameter has been added to the second collaborative: influenza and pneumococcal vaccines.

- The support system, with added information system capacity, will design and implement two to three cluster-based learning sessions, followed by a national congress. There are a number of exciting cluster- and State-based initiatives as well. For example, through a partnership with the State diabetes program in South Carolina, additional coordinators will be hired and trained to spread this initiative to all practices that provide care to the underserved in South Carolina. There are also additional partnerships being developed with Bristol, Myers, Squibb and the Microsoft Corporation.
- During the next 12 to 18 months, the IHI Breakthrough Series approach utilized for diabetes will be applied to cardiovascular disease. The first collaborative for cardiovascular disease and a third diabetes collaborative are scheduled to begin in April 2001.

#### **Funding for Diabetes Research:**

Funding remains level at about \$5 million for the Diabetes Collaborative. Due to the success of the collaborative, during FY 2000 CDC, in partnership with HRSA, contributed an additional \$2 million to the State Diabetes Control programs to assist diabetes control officers in collaboratives with the community health centers.

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## Indian Health Service (IHS)

### Current Activities:

- *Special Diabetes Program for Indians, 1997 Balanced Budget Act.* The Indian Health Service Diabetes Program administered Year 3 of the *Special Diabetes Program for Indians* of the 1997 Balanced Budget Act. Thirty million dollars is distributed annually through 286 non-competitive grants administered at 318 sites throughout Indian country. Eighty-four percent of the grants are held by tribal entities. In January 2000 the IHS National Diabetes Program submitted its Interim Report to Congress on the status of this grants program, including summaries from the quantitative and qualitative evaluations conducted on these grant programs. Eight regional meetings with grantees were held around the country in 2000 to showcase successful grant programs, share concerns, offer help, and promote regional networks. It allowed the IHS Diabetes Program to provide updates on the grants process, provide recent surveillance information, and promote advocacy for continuing grant funds. We worked closely with the Tribal Leaders Diabetes Committee to administer this program.
- *Podiatric Funding.* In order to address the extensive unmet podiatry needs in IHS, the American Podiatric Medical Association (APMA) lobbied Congress in Year 2000 for increased funding. For FY 2001, an additional \$1 million was appropriated to IHS to begin hiring podiatrists and building infrastructure to support these positions. It was determined by the National Council of Indian Health Podiatrists (NCIHP) that this amount of funding would support 5 to 6 surgical podiatrists. The IHS National Diabetes Program provided the opportunity in January 2001 for a representative member of the Executive Council of the NCIHP to meet with the Tribal Leaders Diabetes Committee to ensure that tribal input is provided to the process of determining location of positions and to begin to plan strategies for advocacy that will increase funding in the future. The IHS National Diabetes Program has become actively involved in APMA's collaborative workgroup. This group is currently designing and planning the implementation of a national campaign to "reduce foot and leg amputations in persons with diabetes."
- *Joslin Vision Eye Network.* In FY 2000 and FY 2001, an additional \$1 million was appropriated to the IHS budget in order to address screening for diabetic retinopathy through a collaborative project with the Joslin Diabetes Center using the Joslin Vision Network (JVN). The JVN is a remote site diabetes retinopathy screening system that uses low-level illumination and does not require pupil dilation. The acquired retinal image is sent electronically to a reading center and the analysis sent back to the remote site. IHS has established a demonstration site at the IHS Phoenix Indian Medical Center. The examining station has been set up in the Primary Care Building with the reading station in the Eye Department. Staff have been hired to implement the process and screening is currently underway. The feasibility of setting up a remote screening station site at the Sells PHS Indian Hospital located south of Tucson, Arizona, on the Tohono O'odham (formerly Papago) Reservation is being evaluated. The acquired retinal images will be electronically sent to the reading station at PIMC. A third site outside of Arizona is being considered for the future. A primary challenge to the implementation of JVN at remote sites beyond PIMC includes availability of communication lines and staffing.
- Members of the National Institute of Diabetes and Digestive and Kidney Diseases met with the Tribal Leaders Diabetes Committee (TLDC) in February 2000 to propose a collaborative relationship to address issues of concern related to diabetes and American Indian and Alaska Native communities.
- In May 2000, the National Institutes of Health hosted the TLDC regularly scheduled meeting one day prior to the DMICC meeting on "Type 2 Diabetes in American Indian and Alaska Natives: Focus on Children."

- NIH, IHS National Diabetes Program, TLDC, and representatives of the American Indian Higher Education Consortium have met to establish a working relationship that will address the lack of American Indian and Alaska Native students in biomedical sciences, particularly research.
- There is close collaboration on the National Diabetes Prevention Center project in Gallup, New Mexico.
- The Director of the IHS Diabetes Program serves on the Centers for Disease Control and Prevention (CDC) Division of Diabetes Translation Advisory Committee.
- CDC provides educational and epidemiologic support to the IHS National Diabetes Program with two full-time positions.
- IHS provides expert guidance related to program development and modification based on participant evaluation for the American Diabetes Association's outreach initiative program for American Indian and Alaska Natives: *Strong in Body and Spirit*.
- IHS participates on the committee and helps with distribution of program materials for the Association of American Indian Physicians subcommittee initiative of the National Diabetes Education Program.
- Four diabetes sessions were held as part of the National Indian Health Board's annual Consumer Conference.
- IHS co sponsored a lipid consensus conference at the Center for Native American Health.
- IHS developed an automated audit for the National Indian Council on Aging monograph series.
- IHS established a partnership with the Board of the American Indian Higher Education Consortium (AIHEC) to help build tribal college and university capacity and infrastructure for diabetes programming activities in American Indian and Alaska Native communities.
- *Education Standards*. The IHS National Diabetes Program, with agency and Tribal leader support, is taking the lead in establishing an Indian Health Diabetes Education Accreditation Program. This will allow the development of a flexible process to certify Indian health diabetes education programs and allow American Indian and Alaska Native education programs to seek medicare reimbursement.
- *Clinical Standards (Diabetes Care and Outcomes Audit)*. The IHS National Diabetes Program updated the IHS Standards of Care for Diabetes in 2000 to reflect new science and best practices. These standards are distributed to providers IHS-wide through a network of regional Area Diabetes Consultants and local Diabetes Coordinators.

**Future Activities:**

The National Diabetes Program is coordinating an obesity prevention initiative targeting Head Start children (0-5), families, staff and communities. Five tribal Head Start programs were recently selected to pilot the initiative. Each site will develop a comprehensive multi-faceted approach in addressing obesity based on current best practices and each site's respective community need.

**Funding for Diabetes Research:**

FY 2000 funding information was not provided.

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## National Cancer Institute (NCI)

The National Cancer Institute supports several areas of research that are relevant to diabetes and that could potentially lead to new knowledge not only about cancer, but also about diabetes and other diseases. There is a similarity in certain of the disease-causing and disease-modifying pathways that may be important to understanding both cancer and diabetes. For example, studies of the epidemiology of renal cell cancer may help to determine whether subgroups of the disease, characterized by different genetic alterations, are associated with different modifying factors — including obesity, hypertension, and diabetes. Researchers are also striving to determine the existence of a major susceptibility gene for pancreatic cancer by examining possible risk modifiers, including diabetes and pancreatitis. Other research is testing whether an association between pancreatic cancer and factors such as energy intake, obesity, or diabetes mellitus is mediated through insulin-like growth factors and binding proteins.

### Current Activities:

- Because obesity is a risk factor for cancer, diabetes, and several other diseases, one research team is focusing on two interrelated pathways for the association of obesity with estrogen and insulin. First, obesity and associated hyperinsulinemia may influence cancer risk directly through its effects on insulin-like growth factor and its binding proteins, and second, obesity may also influence cancer risk indirectly through its effects on estrogen levels. A multicenter study is therefore being conducted to examine the role of genes that influence obesity, insulin, and insulin receptors in the etiology of breast and endometrial cancer. The role of selectin ligand-carbohydrate interactions in tumor cell metastasis is the subject of another NCI-supported study that may aid in the development of therapeutic interventions for cancers, diabetes, and possibly other diseases.
- The National Cancer Institute also supports research on immunologic mechanisms of disease that are relevant not only to cancer, but also to type 1 diabetes, a disease in which the body's immune defense system attacks and destroys the insulin-producing cells of the pancreas. NCI-funded investigators are studying transgenic mice carrying insulin-promoted SV40 T antigen genes that target the development of islet cell carcinomas. They hope to determine: (1) the cellular and molecular changes necessary to induce malignant transformation in this system; (2) the mechanisms and interrelationship of self-tolerance, autoimmunity, and the failure of tumor immunity; and (3) the nature of alternative immune tolerance or autoimmunity toward pancreatic beta cells, which are the target of autoimmunity in human type 1 diabetes.
- Another research project on dendritic cell biology and therapy is examining the mechanism of dendritic cell-based tumor immunization as well as dendritic cell-mediated therapy of autoimmune diabetes. The observation that the anti-tumor effect of alpha-galactosylceramides is mediated by NKT cells, a specialized set of T cells, has led to an investigation of the consequences of NKT cell activation during the course of neoplastic, infectious, and autoimmune conditions, including autoimmune diabetes in the non-obese diabetic (NOD) mouse strain.
- An important biologic mechanism involved in both cancer and diabetes is angiogenesis, the spread of new blood vessels. Angiogenesis not only promotes the growth and spread of tumors, but it is also involved in wound healing and in the development of many disease conditions, including diabetic retinopathy — in which the proliferation, breakage, and leakage of blood vessels in the eye can lead to blindness. A metabolite of linoleic acid, 13-hydroxy-10,12-octadecadienoic acid, promotes angiogenesis in the chick chorioallantoic membrane. Because linoleic acid is the major polyunsaturated fatty acid in the American diet, as well as one of the most abundant

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fatty acids of phospholipids in the arterial wall, studies are underway to confirm its angiogenic properties in a mammalian system. Potential targets of anti-angiogenesis therapy include the integrin alpha5beta1 and its ligand, fibronectin. The expression of these molecules is being characterized in the blood vessels of normal and diseased tissues in preparation for the development of new approaches to the therapeutic modulation of angiogenic disease.

- In both cancer and diabetes, several underlying cellular mechanisms, such as those involved in cell signaling and cell regulation, are thought to play a major role in disease processes. These mechanisms include membrane transport of hormonal substances, maintenance of intracellular communication pathways, functioning of cellular growth factors, and expression of genes that influence insulin and obesity. Importantly, the findings of basic research in either cancer or diabetes may have considerable application to the other disease, as well as broad relevance across a wide spectrum of diseases.

**Future Activities:**

No additional diabetes-related activities were reported.

**Funding for Diabetes Research:**

FY 2000 funding for diabetes-related research was approximately \$5.5 million, an increase of \$1.1 million over FY 1999.

**National Center for Health Statistics (NCHS)**

The Centers for Disease Control and Prevention (CDC), National Center for Health Statistics is the Nation's principal health statistics agency. NCHS's mission is to provide statistical information that will guide actions and policies to improve the health of the American people. Inherent to this is the emphasis to respond to major public health issues, especially diabetes.

**Current Activities:**

- The National Health and Nutrition Examination Survey (NHANES), currently in the field, is collecting the following diabetes-related measures: fasting plasma glucose, glycosylated hemoglobin, blood pressure, lipids, micro-albuminuria, anthropometry, nutritional status, diabetes family history, peripheral vascular disease and peripheral neuropathy, visual acuity, oral health, physical functioning, and access to care. Information is collected on people with diagnosed and undiagnosed diabetes.
- NHANES continues to collect DNA and sera and NCHS is a national repository of surplus sera and over 8,000 DNA cell lines. Specimens are available for serologic or DNA studies, such as the study of GAD antibodies in collaboration with the University of Pittsburgh that began in FY 2000.
- The National Health Interview Survey (NHIS), which has been in continuous operation since 1957, obtains national prevalence data of type 1 and diagnosed type 2 diabetes.
- NCHS, working with the Health Care Financing Administration (HCFA), has produced a linked data set that looks at the longitudinal progression to end-stage renal disease (ESRD) for people with and without diabetes. NCHS contracted with Johns Hopkins University to analyze data and to produce national fact sheets on diabetes-related ESRD.

- NCHS staff collaborated with other organizations and researchers in academia and in the private and public sector to release new diabetes health statistics and study findings, including baseline measures of Healthy People 2010 national health objectives, which include 17 objectives on diabetes, new growth charts for infants and youth (which are relevant to those interested in the emerging concern of type 2 diabetes in children), and uniform State-specific estimates of diabetes risk factors, prevalence, ESRD attributed to diabetes, and mortality (in collaboration with the Council of State and Territorial Epidemiologists, the Association of State and Territorial Chronic Disease Program Directors, and Centers for Disease Control and Prevention colleagues).

#### **Future Activities:**

The Center plans to continue collecting and analyzing diabetes information from NHANES, NHIS, and other health information systems. This information will be used to monitor progress toward achieving the Healthy People 2010 national health objectives for diabetes, assist the National Diabetes Education Program by providing health statistics about diabetes and its complications, and provide national health data for diabetes researchers.

- NCHS also will continue to collect, store, and share DNA and serum specimens from NHANES.
- NCHS will make available the new NHANES/Medicare national follow-up data on chronic kidney disease primarily due to diabetes.
- Finally, the Center is planning to improve the reporting of diabetes mortality data by working with the States to introduce electronic death certificate systems that interact with physicians through a series of prompts to assure high quality reporting.

#### **Funding for Diabetes Research:**

FY 2000 funding information was not provided.

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#### **National Center for Research Resources (NCRR)**

The National Center for Research Resources develops and supports research technologies and shared resources that are critically important to the research efforts directed at maintaining and improving the health of our Nation's citizens. To facilitate health-related research, NCRR also supports the development and use of sophisticated instrumentation and technologies, animal models of human disease, and clinical research environments. NCRR programs provide support for the career development of biomedical investigators who address new and emerging biomedical technologies for both patient and veterinary research on diabetes. The current NCRR diabetes research portfolio includes approximately 600 basic and clinical research subprojects. Selected highlights of NCRR-supported research activities and future plans that relate to diabetes are presented below.

#### **Current Activities:**

- Adherence to high-fiber diets by patients having type 2 diabetes results in improved glucose control and lowered cholesterol and triglyceride levels.
- The body fat of AIDS patients is redistributed in a manner that results in insulin resistance and increased risk for cardiovascular disease. This is thought to be a result of changes in the immune system.
- Polycystic ovarian disease is a common cause of infertility. Treating these women with metformin improved their rate of ovulation and consequent rate of conception.

- A new assay revealed that infants having insulin auto-antibodies were much more likely to develop type 1 diabetes before the age of 4. A mouse model that mimics this observation was also developed.
- NMR spectroscopy revealed in rats a basis for connecting glycogen levels in the brain with diabetes-related hypoglycemia. Hypoglycemia unawareness develops in insulin-treated patients with recurrent hypoglycemia who are no longer able to detect symptoms of hypoglycemia until they develop confusion or lose consciousness.
- A new sensor system to monitor oxygen movement into single clonal pancreatic beta cells demonstrated a clear oxygen flux oscillation that exhibits a periodicity equivalent to the known fusion and release of insulin containing vesicles, implying a pivotal role for the organelles in the release process.
- Early gestational androgen excess in the rhesus monkey may impair insulin secretion by pancreatic beta cells, and late gestational androgen excess alters insulin sensitivity.
- Stem cell regulatory pathways have been defined through genome-wide gene expression analyses. This database will be an invaluable resource for understanding pancreatic islet and other stem cell and tissue replacement.
- The association between obesity and the percentage of Hawaiian ancestry, unexplained by differences in diet and physical activity, suggests genetic factors play an important role in the high prevalence of obesity observed among Native Hawaiians.
- The General Clinical Research Centers (GCRCs) are home to many national cooperative diabetes programs (e.g., Diabetes Prevention Program (DPP), Diabetes Prevention Trial for Type 1 Diabetes, EDIP, EDIC) as well as corporate-sponsored drug trials.
- The impact of diabetes on minority communities is studied within the GCRCs.
- Pancreas and kidney transplant protocols are active at GCRCs.
- MRI cores are used to evaluate not only the anatomic consequences of diabetes but real-time metabolic changes within major organ systems.
- Microarray technology cores have been established to study genomic mutations that could identify individuals at risk for developing diabetes and related disorders.
- Nursing-intense insulin clamp studies continue at most GCRCs.
- K23, K24, and K30 training programs support career development of biomedical investigators to develop new and emerging biomedical technologies for diabetes research.
- Strategies for islet cell xenotransplantation in macaques are being optimized to treat diabetes.
- Gene probes were used in mouse models to map traits, including obesity, which is significant in diabetes pathogenesis.
- Porcine models were used to investigate the significance of coronary artery disease in type 2 diabetes.

**Future Activities:**

- NCCR has been joined by the National Institute of Diabetes and Digestive and Kidney Diseases and the Juvenile Diabetes Research Foundation International to develop up to six Resource Centers to harvest, isolate, study, and distribute clinical grade, human islet cells suitable for transplantation into qualified type 1 diabetics. Applicants that receive a favorable peer review should be able to begin operation in fall 2001. NCCR will dedicate approximately \$11 million over the next 5 years to establish and support the infrastructure of this effort.

- NCRR is developing Centers of Clinical Research Excellence (CCRE) at Research Centers in Minority Institutions (RCMI). One of these CCREs will focus on diabetes in minority populations, particularly on the epidemiology, genetics, and treatment of diabetes. This Center could synergistically collaborate with RCMI grantees and existing diabetes centers. NCRR anticipates that further development of the Regional Mutant Mouse Centers program will increase the demand for use of genetically altered animals in research including diabetes.

### **Funding for Diabetes Research:**

Additional FY 2000 funding information was not provided.

### **National Eye Institute (NEI)**

The National Eye Institute's (NEI) mission is to conduct and support research, training, health information dissemination, and other programs concerned with blinding eye diseases, visual disorders, mechanisms of visual function, preservation of sight, and the special health problems and requirements of the blind. Diabetes is responsible for diabetic retinopathy, an eye disease that is the leading cause of blindness in people between the ages of 24 and 70 years. This disease is characterized by a progressive breakdown of the normal retinal vascular system.

### **Current Activities:**

- NEI sponsored a workshop entitled "Genetics of Diabetic Retinopathy" on September 21–22, 2000, in Bethesda, Maryland. The workshop brought together clinicians, epidemiologists, statistical geneticists, and molecular geneticists in order to further research on diabetic retinopathy. The workshop explored the epidemiological evidence

for genetic factors in diabetic retinopathy. Recommendations from the workshop will have a direct impact on determining the direction of future research aimed at improving the treatment and management of diabetic eye disease.

- NEI joined the National Institute of Diabetes and Digestive and Kidney Diseases (NIDDK), the National Institute of Dental and Craniofacial Research (NIDCR), the National Institute of Neurological Disorders and Stroke (NINDS), and the National Heart, Lung and Blood Institute (NHLBI) in a program announcement (PA) on "The Role of Growth Factors in the Development of Diabetic Complications" (PA-99-159). This PA encourages grant applications on the role of growth factors in the etiology and pathogenesis of the micro- and macrovascular complications of diabetes.
- NEI is helping to support both the ACCORD (Action to Control Cardiovascular Disease Risk in Diabetes) and Look AHEAD (Action for Health in Diabetes) studies, large multicenter trials supported by NHLBI and NIDDK to assess treatments to reduce risk of cardiovascular disease in type 2 diabetes. For this trans-NIH effort, NEI is sponsoring an eye examination component in order to collect epidemiological data.
- Through its National Eye Health Education Program (NEHEP), the Institute coordinated the National Diabetes Month Eye Initiative in November 1999. This initiative increases awareness of diabetic eye disease and the importance of dilated eye exams for everyone with diabetes and is sponsored by the NEHEP Partnership, which represents over 60 leading public and private organizations. In addition, diabetic eye disease awareness information was disseminated to both English and Spanish print, radio, and television media.
- Consistent with the recommendations of the congressionally established Diabetes Research Working Group (DRWG), the NEI will support

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two new initiatives. The first involves evaluation of new treatments for diabetic macular edema. These include both medical and surgical approaches. A pilot study is being developed at the NEI clinical center to pilot methods to evaluate less intense photocoagulation, vitamin E supplementation, and lipid lowering. The pilot study is intended to set the stage for a major multicenter randomized clinical trial for the treatment of diabetic macular edema. The second initiative seeks to identify genetic associations in patients with microvascular complications of diabetes. NEI will supplement the FIND (Family Investigation of Nephropathy and Diabetes) study funded by NIDDK to investigate the genetics of individuals and special populations of patients with renal disease. NEI will support detailed eye examinations for these patients and will search for genetic associations with microvascular disease.

#### **Future Activities:**

- NEI will continue to incorporate the scientific priorities outlined in the Report of the Congressionally Established Diabetes Research Working Group in making funding decisions.
- NEHEP will continue to develop and implement out-reach activities for people with diabetes.
- NEI will co-fund with the Juvenile Diabetes Foundation International and the American Diabetes Association, as well as others organizations, a workshop entitled "Implementation of Screening and Eye Exams for Diabetic Retinopathy" on February 27–28, 2001. This workshop will address the challenge of providing screening and eye exams for diabetic retinopathy from a health services research perspective. The meeting will provide an overview of retinopathy examination and screening strategies and the need for these examinations. The goal of the workshop is to develop strategies for the health services community.

#### **Funding for Diabetes Research:**

NEI's FY 2000 expenditure for diabetes-related projects was approximately \$27 million.

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#### **National Heart, Lung and Blood Institute (NHLBI)**

The National Heart, Lung and Blood Institute has developed a comprehensive research program to understand the pathogenesis, improve treatment, and develop effective prevention strategies to address the cardiovascular complications of diabetes, the major cause of death in patients with diabetes. Despite reductions in cardiovascular disease (CVD) mortality in the general population, patients with diabetes continue to have 2 to 4 times the CVD rates of non-diabetics of the same age and gender, and studies indicate that current treatments to prevent these complications may be somewhat less effective among those with diabetes than in the non-diabetic population.

#### **Current Activities:**

- NHLBI funded two major clinical trials to evaluate therapy to reduce cardiovascular complications of diabetes. The Action to Control Cardiovascular Disease Risk in Diabetes (ACCORD) trial will study 10,000 patients and evaluate the benefits of intensified control of hyperglycemia over more conventional glucose control and also test the benefits of aggressive blood pressure control and intensified control of the dyslipidemia associated with diabetes on CVD rates. The Bypass Angioplasty Revascularization Investigations II Diabetes (BARI 2D) trial will study 2,800 patients and evaluate whether elective coronary artery revascularization plus optimal medical management of cardiovascular risk factors and symptoms is superior to optimal medical management alone. It will also evaluate the important issue

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of whether reducing insulin resistance provides protection against cardiovascular complications by testing whether insulin-sensitizing drugs are superior to insulin or oral insulin secretagogues at levels of glycemic control that are attainable with current conventional treatment regimens.

- NHLBI is also helping to fund the National Institute of Diabetes and Digestive and Kidney Diseases' (NIDDK's) SHOW trial, which will evaluate the effect of obesity treatment on cardiovascular complications in type 2 diabetic patients.
- While the above trials will provide important information for clinicians on ways to reduce the burden of cardiovascular complications in patients with diabetes, it remains difficult to achieve and maintain normoglycemia over the long periods necessary to minimize complications. Studies of how diabetes causes excess CVD should lead to development of new therapies that can reduce the adverse effects of diabetes on the heart and large vessels without requiring intensive efforts at glucose control. NHLBI has expanded basic research related to macrovascular complications of diabetes, including five large program project grants co-sponsored with the Juvenile Diabetes Foundation. Topics include the role played by hyperglycemia and insulin resistance in the genesis of cardiovascular disease in diabetes; the effects of chronic hyperglycemia and dyslipidemia on atherogenesis; the effect of diabetes on endothelial function and oxidative stress; the possibility that the cardiac and vascular sequella of diabetes are due to chronically accelerated generation of lipid second messengers; and studies in a type 1 diabetic cohort assessing factors that have been found to relate to carotid artery wall thickness or involved in atherosclerosis and clinical CVD, including the lipoprotein subclass profile, LDL-antibody complexes, and markers of inflammation. Other studies are evaluating the atherogenic effect of the accumulation of advanced glycation end products (AGE) in patients with diabetes.

- NHLBI has also participated in the program of small, innovative grants aimed at improved understanding of diabetic macrovascular complications. These have involved studies of the effects of diabetes on vascular smooth muscle cells, its effect on circulating growth factors, and the effect of salt restriction on insulin sensitivity. A new initiative was funded to understand the etiology of diabetes-associated cardiomyopathy. This may be more important than previously recognized since population studies have shown that diabetic patients have an excess of unexplained congestive heart failure.

Taken together, these clinical and basic studies should provide better guidance for physicians to reduce cardiovascular complications of diabetes in the near future and provide easier to use, more effective therapies to achieve in later years.

#### **Future Activities:**

- In response to the strong recommendation of the Diabetes Research Working Group, NHLBI is cooperating with NIDDK in developing improved animal models of diabetic complications, a crucial limiting factor in expanding studies of how diabetes produces chronic micro- and macrovascular changes.
- While collaborating on the NIDDK mouse model initiative, NHLBI will also prepare an initiative to develop larger animal models for studies of vascular complications of diabetes.

#### **Funding for Diabetes Research:**

NHLBI support for studies of diabetes-related macrovascular disease has continued to increase, rising to \$58,956,099 in FY 2000, an increase of approximately \$16,500,000 over the funds provided in FY 1999. Funding for this work will expand further as the major clinical trials begin actively recruiting participants in FY 2001.

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## **National Human Genome Research Institute (NHGRI)**

The National Human Genome Research Institute supports two ongoing diabetes projects being conducted by investigators in the Division of Intramural Research and their collaborators. Both studies aim to identify genetic variations that lead to increased susceptibility to type 2 diabetes mellitus.

### **Current Activities:**

- *Africa America Diabetes Mellitus Study (AADM).* During the past several years, the National Institutes of Health's (NIH's) Office of Research on Minority Health (ORMH) has supported an innovative research collaboration between investigators from Howard University in Washington, D.C. and scientists in the intramural research program of NHGRI. The goal of these studies is to establish a Center at Howard University for collaborative research on genomic analyses of diseases that disproportionately affect African Americans. The collaboration involves support for a project involving African Americans affected with diabetes. Initial efforts to define the scientific focus and objectives of the Center have been addressed through peer-reviewed contracts with Howard University as the Coordinating Center for the Africa America Diabetes Mellitus Study.

Because of the high frequency of environmental risk factors for diabetes in the African-American population, it is potentially more powerful to study genetic risk factors in West Africans, since they are thought by many anthropologists to be the founding population of modern African Americans and have fewer dietary and nutritional confounding variables. Five recruitment sites in Nigeria and Ghana were selected through a peer review process. Patient samples and other clinical data are sent to the AADM Coordinating Center at Howard University. Based on the successful recruitment of study participants during a 1-year pilot project, a full-scale study was implemented

in September 1998 with an anticipated total of 400 pairs of siblings affected with diabetes mellitus. This goal was met in the fall of 2000. Genotyping of samples from West Africa is currently underway at the Center for Inherited Disease Research in Baltimore. The study has not only started to yield high-quality data, but has assisted in the recruitment of several top-flight scientists to the Center at Howard University.

- *Finnish-US Investigation of NIDDM (FUSION) Genetics.* NHGRI assisted in the development of a consortium of groups who have agreed to pool their linkage data on type 2 diabetes in order to study the genetic factors involved in this disease. The consortium currently has support from the National Institute of Diabetes and Digestive and Kidney Diseases and includes all of the major groups in the United States with large family collections and a few European groups as well. The Institute's intramural program includes a major project, known as the Finland-United States Investigation of Non-Insulin Dependent Diabetes Mellitus (abbreviated FUSION), which is studying a large cohort in Finland of sibling pairs affected with type 2 diabetes and their relatives. The data from the FUSION project represents a major component of the type 2 consortium's effort. Data collection includes blood samples and clinical data.

This project involves a whole genome search for genes conferring susceptibility to diabetes, or intermediate traits such as insulin resistance, in 2,500 DNA samples. More than 1 million genotypes were performed in phase I of the study, the results of which were published recently (Ghosh et al., 2000; Watanabe et al., 2000). In the past year, a whole genome search was performed on a replication sample; analysis of these data is ongoing. The project already has identified at least two regions on chromosome 20 that seem to harbor susceptibility genes. These and several other potential gene locations are being followed up by candidate gene evaluation and linkage disequilibrium analysis in this unique population.

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**Future Activities:**

No additional diabetes-related activities were reported.

**Funding for Diabetes Activities:**

FY 2000 funding information was not provided.

**References:**

Ghosh et al. (2000) The Finland-United States investigation of non-insulin-dependent diabetes mellitus genetics (FUSION) study. I. An autosomal genome scan for genes that predispose to type 2 diabetes. *Am J Hum. Genet.* 67(5): 1174-1185.

Watanabe et al. (2000) The Finland-United States investigation of non-insulin-dependent diabetes mellitus genetics (FUSION) study. II. An autosomal genome scan for diabetes-related quantitative-trait loci. *Am J Hum. Genet.* 67(5): 1186-2

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**National Institute of Allergy and Infectious Diseases (NIAID)**

The National Institute of Allergy and Infectious Diseases supports research into the immunopathogenesis of autoimmune diseases, including type 1 diabetes. NIAID also promotes the application of basic immunology research to the clinical investigation of autoimmune diseases, including type 1 diabetes mellitus, and to studies that could improve kidney and islet transplantation outcomes. The objectives of this research are to increase understanding of pathologic immune responses in order to prevent, diagnose, or treat individuals with autoimmune diseases or those needing organ transplants. NIAID's support for research on autoimmune diseases, including research related to diabetes, has increased significantly in the past year.

**Current Activities:**

- NIAID's Autoimmunity Centers of Excellence, a cooperative network of centers, performs clinical trials of novel immunotherapies in multiple autoimmune diseases, including type 1 diabetes, and conducts basic research into the pathogenesis of autoimmunity, immune modulation, and self-tolerance. The network is developing a trial of anti-CD3 antibody for prevention of diabetes in individuals at risk for development of type 1 diabetes. The National Institute of Diabetes and Digestive and Kidney Diseases (NIDDK), The National Institute of Arthritis and Musculoskeletal and Skin Diseases (NIAMS), and the National Institutes of Health's (NIH's) Office of Research on Women's Health (ORWH) co-sponsor this program.
- Through the Immune Tolerance Network, NIAID, NIDDK, and the Juvenile Diabetes Research Foundation International are co-sponsoring a multinational study designed to replicate the very promising results with islet transplantation achieved in 12 brittle diabetics at the University of Alberta, all of whom no longer require insulin injections, with some islet transplant recipients as long as 14 months post-transplantation. The "Edmonton" protocol for islet preparation and clinical transplantation will be expanded to 40 patients at 10 sites in the United States, Canada, and Western Europe. This new approach is based on a steroid-free immunosuppressive regimen and rapid transplantation of an increased number of islet cells prepared to maximize viability.
- Also through the Immune Tolerance Network, NIAID is supporting a phase II clinical trial of anti-CD3 antibody in patients with new onset type 1 diabetes to prevent the loss of C peptide function. This approach has shown promise in a phase 1 study.

- Through the Request for Applications (RFA), "Cooperative Study Group for Autoimmune Disease Prevention," NIAID is supporting a cooperative program focused on the development of toleragenic vaccines for the prevention of autoimmune diseases with an emphasis on type 1 diabetes. The focus of this program is the development through animal and human studies of the basic knowledge of the immune response necessary to rationally design preventive interventions. The Study Group funded under this RFA will develop a plan articulating the goals of the Group and will have significant means through support of innovative pilot projects, clinical studies, and cooperative resources to implement the plan to discover potential targets for interventions to prevent human disease. NIDDK, NIAMS, the National Institute of Child Health and Human Development (NICHD), the National Institute of Dental and Craniofacial Research (NIDCR), NIH's ORWH, and the Juvenile Diabetes Research Foundation International are co-sponsors.
- In FY 2000, NIAID joined several Institutes and Centers and the Juvenile Diabetes Research Foundation International in supporting the 13th International Histocompatibility Working Group (IHWG), an international network of laboratories that will collect and share data on genes of the human leukocyte antigen (HLA) complex and their association with diseases like type 1 diabetes in which susceptibility is linked to the HLA. In addition, IHWG will launch a project to discover single nucleotide polymorphisms (SNPs) in potential type 1 diabetes-related genes. Once SNPs are identified, researchers in type 1 diabetes will be able to analyze their patient populations for the presence of these variations. The results of these projects will provide a much greater insight into the mechanisms of autoimmune diseases and increase our ability to predict an individual's disease predisposition.
- The NIAID, together with Merck Genome Research Institute, the Juvenile Diabetes Research Foundation International, and the Wellcome Trust, is supporting the transfer of the non-obese diabetic (NOD) congenic strains developed at the Merck Laboratories by Linda Wicker and John Todd to Taconic Farms. Merck Laboratories is closing down its NOD mouse program and this will allow these unique strains to be available for use by investigators seeking to understand the pathogenesis and genetics of type 1 diabetes and other autoimmune diseases.
- The NIAID Multiple Autoimmune Disease Genetics Consortium (MADGC) is a repository of genetic and clinical data and materials from families in which three or more individuals are affected by two or more distinct autoimmune diseases (<http://www.madgc.org>). This resource will provide materials to promote research aimed at discovering the human immune response genes involved in autoimmunity, including type 1 diabetes. MADGC began enrolling families in May 2000. To date, 15 families have been enrolled with 20 more in process.
- The Non-Human Primate Transplantation Tolerance Cooperative Study Group, supported by NIAID and NIDDK, evaluates the safety and efficacy of promising tolerance induction treatment strategies in non-human primate models of kidney and islet transplantation. Dr. Norma Kenyon's (University of Miami) data on costimulation blockade for islet transplantation shows that anti-CD154 induction and maintenance therapy results in long-term graft survival to over 800 days in some animals. The results of these large animal studies are providing information critical to the design of scientifically sound and ethically acceptable human clinical trials.

- NIAID funded an RFA (FY 2000) on “Innovative Research in Mucosal Immunity” to support novel projects to advance our understanding of mucosal immune response, which is likely to be important in the development of antigen-specific approaches to modulate the immune response in type 1 diabetes and understanding the oral complications of diabetes. NIDCR and the Crohn’s and Colitis Foundation co-sponsored this initiative.
- NIAID issued an RFA, “Hyperaccelerated Award/Mechanisms in Immune Disease Trials,” to support studies of mechanisms underlying clinical trials for immune-mediated diseases. In order to meet the timeline of industry-supported clinical trials, NIAID in collaboration with the Center for Scientific Review has established a process whereby review and award of applications is greatly accelerated (13 weeks). The National Institute on Aging, NIAMS, NIDDK, and the National Institute of Neurological Disorders and Stroke also support the RFA.
- NIAID co-sponsors, along with NIDDK, NICHD, and other Federal and private partners, the Diabetes Prevention Trial for Type 1 Diabetes, a multicenter clinical trial to determine whether early intervention with parenteral or oral insulin in at-risk relatives of individuals with type 1 diabetes can delay the development of the disease. In addition, in FY 2001, NIAID and NICHD will co-sponsor the NIDDK Type 1 Diabetes TrialNet to support new approaches to treat or prevent type 1 diabetes.
- NIAID, in collaboration with NIDDK and NICHD, issued an RFA for “New Strategies for Treatment of Type 1 Diabetes” to support the development of novel strategies, including immunomodulatory therapies, for the treatment of type 1 diabetes. This RFA was supported by funds allocated for type 1 diabetes (FY 2000).

- NIDDK, NIAID, and the National Heart, Lung and Blood Institute issued an RFA, “Gene Therapy Approaches for Diabetes and Its Complications,” to support the development of novel gene therapy approaches for the treatment of diabetes and its complications. Awards for successful applicants are planned for FY 2001.

**Future Activities:**

No additional diabetes-related activities were reported.

**Funding for Diabetes Research:**

FY 2000 funding information was not provided.

**National Institute of Arthritis and Musculoskeletal and Skin Diseases (NIAMS)**

Currently, the National Institute of Arthritis and Musculoskeletal and Skin Diseases has no grants or initiatives or immediate future plans for diabetes-related activities.

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## **National Institute of Child Health and Human Development (NICHD)**

Consistent with the National Institute of Child Health and Human Development's mission to promote the development of healthy children, understanding the factors that contribute to the development of diabetes is a particularly important issue, given the prevalence of both type 1 and type 2 diabetes in children and the serious complications of diabetes later in life. To this end, NICHD has focused its efforts on the earliest pathogenesis of type 1 diabetes and on optimizing insulin therapy in children with type 1 diabetes. In addition, NICHD has targeted research on the origins of type 2 diabetes in adolescents and on gestational diabetes mellitus in pregnant women.

### **Current Activities:**

In efforts to prevent this disease, NICHD has pioneered methods in ascertaining risk factors and stratifying levels of risk for type 1 (juvenile) diabetes mellitus according to genetic and immunologic markers. This work forms the basis of the Diabetes Prevention Trial for Type 1 Diabetes, a major collaborative, trans-NIH study aimed at preventing or delaying the onset of type 1 diabetes. Among its more recent efforts, NICHD:

- Is working with the Juvenile Diabetes Foundation International to co-fund a large prospective study of infants who have relatives with type 1 diabetes, to ascertain the earliest changes in gene expression in those infants who become diabetic.
- Initiated a clinical research study entitled "Tolerability and Pharmacokinetics of Inhaled Insulin in Children 6-11 Years of Age with Type 1 Diabetes." Up to 36 units of insulin per day can be delivered through the airway system of the lungs. If researchers can show that inhaled insulin is as efficacious as insulin injected subcutaneously, this will be a great milestone in treatment of diabetes, overcoming the children's fear of injections and difficulty complying with intensive insulin therapy.
- Initiated a 16-site, 5-year, prospective, international study of hyperglycemia and adverse pregnancy outcomes. This study of gestational diabetes mellitus will enroll 25,000 women early in their pregnancy and will follow them through their gestation, delivery, and postpartum period. Their infants will be studied as well.
- Is co-sponsoring several initiatives that address the prevention and treatment of diabetes, including those to study the following: (1) Development of the Endocrine Pancreas; (2) Type 2 Diabetes in the Pediatric Population; and (3) Fetal Origins of Adult Disease.

### **Future Activities:**

Upcoming diabetes activities for NICHD include:

- Collaborating with the National Institute of Diabetes and Digestive and Kidney Diseases (NIDDK) and the National Institute of Allergy and Infectious Diseases (NIAID) in seeking to develop a Network of 20 centers to perform clinical trials of new immunomodulatory agents to treat or prevent type 1 diabetes.
- Joining NIDDK and NIAID in funding four Centers of Excellence in immunology research to develop vaccines and other new immunomodulatory agents designed to treat, delay, or prevent type 1 diabetes.
- Funding a clinical trial designed to ascertain how to implement effectively the principles of the Diabetes Control and Complications Trial (DCCT) in children with type 1 diabetes in an effort to reduce the incidence of hypoglycemia.

### **Funding for Diabetes Research:**

FY 2000 funding information was not provided.

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## **National Institute of Dental and Craniofacial Research (NIDCR)**

The mission of the National Institute of Dental and Craniofacial Research is to support research on the causes, prevention, diagnosis, and treatment of oral and craniofacial diseases and conditions, including oral complications associated with diabetes. These complications include greater prevalence and severity of periodontal diseases and increased susceptibility to oral mucosal infections, salivary gland dysfunction, and neuropathies resulting in loss or alteration of taste, smell, and mucosal sensory perception. NIDCR also supports research on the effects of oral diseases and conditions on metabolic control of blood glucose.

### **Current Activities:**

- As part of its strategic planning process, NIDCR held a workshop on the oral complications of diabetes (December 6-7, 1999).
- The Institute's basic science research efforts included studies in the following areas:
  - The role of non-enzymatic glycation of extracellular proteins in periodontal diseases (FY 1997 Balanced Budget Act).
  - Impaired macrophage/monocyte function in patients with diabetes.
  - Gingival connective tissue destruction in patients with diabetes.
  - Regulation of B-cell autoimmunity by Interleukin-10.
  - Characterization of diagnostic pancreatic auto-antigens in serum and saliva of type 1 diabetes patients (FY 1997 Balanced Budget Act).

- Clinical research areas included:
  - Diabetes as a risk factor for periodontitis.
  - Investigations into the associations between periodontitis, diabetes, and heart disease.
  - Treatment of periodontitis in Southwest Native Americans with type 2 diabetes.
  - Randomized clinical trial to evaluate the effect of treating periodontal infection on improving glycemic control in type 2 diabetes patients.
- Translational research focused on salivary gland dysfunction in animals and humans with diabetes.
- NIDCR conducted several diabetes-related behavioral and health promotion programs on (1) oral health and diabetes; (2) glycemic control in older diabetics; and (3) population-based approaches for oral health care in diabetes patients.
- NIDCR's training and career development program provided clinical research opportunities in oral and systemic diseases including diabetes.

### **Future Activities:**

- NIDCR and the American Academy of Periodontology will co-sponsor a conference in April 2001 to look at the relationship between oral health and diabetes. In planning this conference, the Institute will work closely with other Institutes and Centers of the National Institutes of Health such as the National Institute of Diabetes and Digestive and Kidney Diseases as well as the American Association for Dental Research and the American Diabetes Association.
- In addition, NIDCR will support supplements to examine the oral microbiology and immunology of patients with type 1 diabetes (FY 1997 Balanced Budget Act).

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### **Funding for Diabetes Research:**

The NIDCR support for diabetes research in FY 2000 was approximately \$4.1 million. Of this total, \$2.0 million was for intramural research and \$2.1 million was for extramural research.

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### **National Institute of Diabetes and Digestive and Kidney Diseases (NIDDK)**

The National Institute of Diabetes and Digestive and Kidney Diseases is the lead agency of the Federal Government for research efforts to combat diabetes and its complications. The Division of Diabetes, Endocrinology and Metabolic Diseases has responsibility for extramural programs related to diabetes research and research training. Additional diabetes-related activities are supported by the Division of Intramural Research, the Division of Digestive Diseases and Nutrition, and the Division of Kidney, Urologic, and Hematologic Diseases. In addition, NIDDK is responsible for overseeing the deployment of special funds to support research on the prevention and cure of type 1 diabetes provided through the Balanced Budget Act of 1997 and its subsequent extension.

### **Current Activities:**

NIDDK supports a vigorous program of both basic and clinical research to further understanding of the development, treatment, and prevention of diabetes and its complications. To maximize research on diabetes, the Institute has fostered collaborations among the many Institutes and Centers of the National Institutes of Health (NIH), as well as with the Centers for Disease Control and Prevention (CDC), the Juvenile Diabetes Research Foundation International, and the American Diabetes Association. Some examples of ongoing activities and new initiatives for FY 2000 follow:

- *Prevention of Type 1 Diabetes.* Type 1 diabetes is an autoimmune disease in which there is destruction of the insulin-secreting beta cells of the pancreatic islets.
  - NIDDK is spearheading a major clinical trial, the Diabetes Prevention Trial for Type 1 Diabetes (DPT-1), to determine whether early intervention, using the antigen-based therapies of insulin injections or oral insulin, can delay the onset of the disease in at-risk, non-diabetic relatives of individuals with type 1 diabetes. The DPT-1 is also supported by the National Institute of Allergy and Infectious Diseases, the National Institute of Child Health and Human Development, the National Center for Research Resources, the American Diabetes Association, the Juvenile Diabetes Research Foundation International, and industry.
  - A new NIDDK initiative that will greatly facilitate additional clinical research to prevent or reverse type 1 diabetes is the type 1 Diabetes TrialNet—an approach recommended by the congressionally established Diabetes Research Working Group. Spearheaded by NIDDK, this effort is co-sponsored by the National Institute of Allergy and Infectious Diseases and the National Institute of Child Health and Human Development. The TrialNet will include clinical centers, recruitment networks, and a coordinating center. It will provide the research infrastructure needed for future design and execution of pilot studies and expanded clinical research. With the TrialNet, more rapid clinical testing of novel approaches to treatment and prevention will be possible as soon as they emerge from fundamental investigations. The TrialNet will thus enable efficient performance of intervention studies to preserve pancreatic beta cell function in new-onset cases of type 1 diabetes and, ultimately, to prevent onset of the disease.

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- *The Beta Cell.* Gaining knowledge about the beta cells of the pancreatic islets is important to both type 1 and type 2 diabetes because they are the key to insulin production and resulting glucose control. A conference entitled, "Stem Cells and Pancreatic Development" was sponsored by NIDDK, with support from the Juvenile Diabetes Research Foundation International and the American Diabetes Association. This conference brought together an international group of physicians and scientists to discuss the knowledge base and opportunities for further research.

- *Islet Transplantation for Type 1 Diabetes.* The congressionally directed Diabetes Research Working Group set forth islet transplantation as an extraordinary research opportunity.

- In pursuing this area of research, NIDDK, in a collaborative effort with the National Institute of Allergy and Infectious Diseases and the Juvenile Diabetes Research Foundation International, has funded numerous centers to develop improved protocols for islet transplantation in humans. In addition, the NIDDK Division of Intramural Research has initiated a clinical research program that will explore new approaches to both kidney and islet transplantation for diabetes—in collaboration with the Department of Defense, the National Institutes of Health Clinical Center, and the Diabetes Research Institute of the University of Miami.

- NIDDK and the Juvenile Diabetes Research Foundation International are also co-sponsoring the Immune Tolerance Network (ITN) initiative, a collaboration involving numerous research institutions spearheaded by the National Institute of Allergy and Infectious Diseases. The ITN will solicit, develop, implement, and address clinical strategies, including biological assays, for the purpose of inducing and maintaining immune tolerance in patients receiving kidney and islet transplants. The Transplantation and Autoimmunity

Branch of the NIDDK Division of Intramural Research is one of 11 centers participating in the ITN's testing of the "Edmonton Protocol" in performing transplant procedures in a larger number of patients. This clinical research will further assess the effectiveness of the technique and identify any long-term risks associated with steroid-free immunosuppressive therapies. Researchers hope the study will serve as a platform for testing new treatments in which the permanent reversal of diabetes can be achieved without the lifelong need for immunosuppressive drugs. In addition, the NIDDK will support two additional studies to determine if one pancreas can provide sufficient islets for transplantation into one patient. In support of all of these efforts, the National Center for Research Resources of NIH is establishing several centers aimed at maximizing islet harvesting processes.

- *Genetic Underpinnings of Diabetes and Its Complications.* Diabetes and its complications have strong genetic determinants. Even though diabetes appears to develop as a result of many factors, virtually all forms appear to have genetic influences, with the likely involvement of multiple genes. NIDDK is involved in major initiatives to capitalize on new knowledge about the human genome and the genetics of diabetes.

- The Institute is a leading partner in support of the International Type 2 Genetic Linkage Analysis Consortium. The purpose of the Consortium is to combine data from multiple genome scans and thus increase the probability of gene discovery. The groups involved in the Consortium are pursuing a fine mapping effort of potential susceptibility genes for type 2 diabetes located on several chromosomes. Intensified support for the Consortium will also permit additional analyses to determine whether unique susceptibility genes exist in African Americans, who are disproportionately affected by type 2 diabetes.

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– NIDDK and the Juvenile Diabetes Research Foundation International are working closely to establish a Type 1 Diabetes Genetics Consortium. The initial objective would be to pursue the results of three genome-wide scans for type 1 diabetes, which have recently been completed. These scans have identified several genetic regions as likely containing diabetes susceptibility genes. A combined analysis of these three datasets could identify the most promising areas for further study of genes that confer susceptibility to type 1 diabetes.

– To identify the genes responsible for the kidney complications of diabetes, the Institute is now launching a new genetics initiative called “FIND”—the Family Investigation of Nephropathy and Diabetes. This initiative will focus on family studies designed to uncover candidate genes associated with type 1 or type 2 diabetes, genes associated with development of complications, and genes relevant to those identified in animal models. A specific objective will be to search for susceptibility genes in subpopulations of Caucasians, African Americans, Hispanic Americans, and Native Americans across the United States.

• *Type 2 Diabetes In Children.* Type 2 diabetes has traditionally been considered a disease of adults because the age of onset is frequently after age 40 and it is often associated with obesity. Children with diabetes usually have been presumed to have type 1 diabetes; however, in recent years, an increasing number of children who appear with elevated blood glucose levels are being diagnosed with type 2 diabetes. The increase in reports of type 2 diabetes among children parallels a similar rise in the adult population, as obesity has become a major public health concern. In children, the increased incidence of type 2 diabetes appears to be occurring largely in minority populations—Hispanic Americans, African Americans, and Native Americans—again paralleling the disproportionate burden this disease places on the same minority populations in adulthood.

To combat type 2 diabetes in children, NIDDK, along with the National Institute of Child Health and Human Development, is supporting research to promote greater understanding of its causes, to refine diagnostic criteria, to define metabolic abnormalities, and to formulate treatment options. In addition, NIDDK recently issued two research solicitations for a coordinating center and clinical centers to develop community or school-based primary prevention programs that can be applied in a cost-effective manner to decrease the risk factors for type 2 diabetes and to reduce the incidence of this disease in children and adolescents. Treatment options will be studied to determine the safest, most effective, and cost-effective strategies to achieve and maintain normal blood glucose levels in the pediatric population.

• *Type 2 Diabetes.* Two factors play an important role in the growing public health burden of type 2 diabetes—the changing demographics of America in terms of age, ethnicity, and race and the increasing prevalence of obesity, a major risk factor for the disease. Diabetes is the sixth leading cause of death in the United States and the third leading cause of death in some minority groups. It places an especially heavy burden on growing segments of the U.S. population—elderly and minority groups. NIDDK is spearheading NIH-wide research efforts to combat diabetes and obesity in order to stem the tide of this devastating disease.

– A clinical trial of great significance to type 2 diabetes is “Look AHEAD”—Action for Health in Diabetes. This large, multicenter trial is designed to determine whether interventions to produce sustained weight loss in obese individuals with type 2 diabetes will improve health. The trial is expected to recruit a patient population whose overall ethnic and racial composition will reflect the prevalence rates for diabetes in the United States. NIDDK is sponsoring this trial along with the National Heart, Lung and Blood Institute, the National Institute of Nursing Research, the National Center for Minority Health and Health

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Disparities, the National Institute of Health's Office of Research on Women's Health, and the Centers for Disease Control and Prevention.

- For those at risk for type 2 diabetes, an ongoing NIDDK clinical trial may provide important knowledge about prevention strategies. The Diabetes Prevention Program (DPP) is comparing three regimens: the current conventional advice regarding diet and exercise; a more intensive lifestyle intervention of diet and exercise; and the drug metformin—a medication approved for treatment of type 2 diabetes. The DPP has now completed patient recruitment, with a total of more than 3,800 participants—45 percent of whom are from minority groups. Findings from this study may help advance understanding of the factors that lead to the development of type 2 diabetes and provide strategies for its prevention.
- The National Diabetes Education Program (NDEP), a collaborative initiative of NIDDK and the Centers for Disease Control and Prevention, involves 200 public and private partnerships to promote early diagnosis and improve the treatment and outcomes for individuals with diabetes. A key feature of the program's partnership is the participation of individuals who represent communities of African Americans, Hispanics/Latinos, Native Americans/Alaska Natives, and Asian and Pacific Islanders.

The NDEP is currently conducting a series of diabetes awareness campaigns using the theme, "Control Your Diabetes for Life." This theme is built on the landmark clinical trials that showed the importance of blood glucose control in preventing diabetic complications. By reinforcing this theme, the NDEP encourages patients with diabetes to manage the disease closely in order to live healthier lives. The campaigns target both general audiences and the populations disproportionately affected by diabetes. Television, radio, and print public service announcements, educational materials, and information kits for the media and for communities are helpful products

of the NDEP. The program is currently developing campaigns to encourage health care providers to work with their patients to improve glucose control, and to identify, diagnose, and treat children with type 2 diabetes.

NIDDK is expanding its commitment to the NDEP to develop and promote diabetes messages that reflect the most up-to-date scientific evidence about diabetes control, treatment, and prevention. NIDDK has also featured type 2 diabetes in its Health Disparities Strategic Plan.

- *Complications of Diabetes.* NIDDK is undertaking several new and expanded initiatives designed to further understanding of the key mechanisms involved in development of the complications of diabetes and the means to reduce or prevent them. For example, a solicitation entitled "New Therapies for Diabetic Foot Disease" encourages research on the etiology and pathogenesis of diabetic foot ulcers and development of effective prevention and treatment modalities. It is hoped that this solicitation will lead to new diagnostic, prognostic, and therapeutic strategies to reduce the burden of diabetic foot disease. The National Institute of Nursing Research is also supporting this initiative.
- A solicitation entitled "Race/Ethnic Disparities in the Incidence of Diabetes Complications" will investigate differences among contemporary populations in the United States, categorized by race, ethnicity, and other factors, in risk factors for the development and rates of complications in diabetes. Research supported through this initiative may also aid in determining the extent to which other factors, including metabolic and genetic variations, medical care, socioeconomic status, and behavior account for these differences.
- At the more basic science level, another initiative will support research to further understanding of the pathogenesis of endothelial dysfunction in diabetes at the molecular and cellular level. Advances from this research may provide new

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targets for pharmacologic or genetic manipulations to prevent complications of the disease. In addition, NIDDK will establish national centers for the purpose of detailed metabolic phenotyping of mouse models potentially useful for understanding diabetes and its complications and obesity.

- An initiative sponsored by the National Institute of Neurological Disorders and Stroke, and supported by NIDDK and the Juvenile Diabetes Research Foundation International, may lead to increased understanding of the mechanisms by which diabetes results in painful, disabling peripheral neuropathy, autonomic neuropathy, impaired counterregulation and hypoglycemia unawareness, and other neurological complications. It is the intent of this initiative to attract basic neuroscientists to the study of diabetic neuropathy and neurobiology relevant to diabetes and enhance interdisciplinary approaches to research in this area.
- In November 1999, NIDDK, the National Institute of Allergy and Infectious Diseases, the National Heart, Lung and Blood Institute, the National Center for Research Resources, the Juvenile Diabetes Research Foundation International, and the American Diabetes Association sponsored a meeting entitled, "Gene Therapy Approaches for Diabetes and Its Complications." One of the recommendations from the meeting was to support additional studies to develop novel approaches using gene therapy for the treatment of diabetes and its complications. There are many approaches to interfering with the development of type 1 diabetes and to treating the complications resulting from both type 1 and type 2 diabetes that would appear to be amenable to gene therapy technology. A solicitation spearheaded by NIDDK also encourages development of gene therapy approaches for type 1 diabetes and its complications and to their application in appropriate animal models or small pilot studies.

#### **Future Activities:**

No additional diabetes-related activities were reported.

#### **Funding for Diabetes Research:**

FY 2000 funding information was not provided.

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#### **National Institute of Environmental Health Sciences (NIEHS)**

Juvenile diabetes is an autoimmune disease that strikes early and can create problems throughout life. Recent studies have raised the possibility that environmental factors, such as nitrates in well water, increase the risks of juvenile diabetes. The possibility of finding controllable environmental factors in the etiology of juvenile diabetes has widespread support. Studies in the United Kingdom, Finland, and Colorado indicate that the incidence of childhood diabetes is higher in areas with elevated levels of nitrate in the drinking water. This finding is significant for agricultural communities because well water can have elevated nitrate levels in areas where there is extensive use of fertilizers.

#### **Current Activities:**

- The association between nitrates and juvenile diabetes is preliminary but merits further investigation in a rigorous prospective study, such as would be possible within the Agricultural Health Study.
- NIEHS is currently studying diabetes along with other health outcomes in the Agricultural Health Study.

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- NIEHS investigators are also investigating the role of menstrual and reproductive risk factors in diabetes and are looking at mechanisms of how environmental agents can affect pancreatic cancer cells.

**Future Activities:**

No additional diabetes-related activities were reported.

**Funding for Diabetes Research:**

FY 2000 funding information was not provided.

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**National Institute of General Medical Sciences (NIGMS)**

The National Institute of General Medical Sciences supports research and research training in the basic biomedical sciences that provide the foundation for a better understanding of fundamental life processes. Some of this work has relevance to understanding and treating diabetes.

**Current Activities:**

- NIGMS supports the Human Genetic Cell Repository, a collection of over 6,600 cell lines from individuals with a wide variety of genetic disorders, including diabetes, and from normal individuals. Cell lines in the collection include those from individuals with various types of diabetes, including insulin-dependent diabetes mellitus (IDDM) and diabetes mellitus and insipidus with optic atrophy. The repository includes an extensive collection of cell lines from members of an extended pedigree with maturity-onset diabetes of the young. This collection is of value in studies designed to map and characterize the gene(s) responsible for the disorder. NIGMS has an interest in understanding how genetic and environmental components interact to result in complex diseases such as diabetes.
- The Institute supports a portfolio of grants to develop better statistical methods for mapping and identifying genes underlying complex traits, develop mathematical models for studying gene-gene and gene-environment interactions, investigate DNA sequence variation and its evolution, examine gene activities and the consequences of abnormalities in these activities, and optimize sampling strategies.
- NIGMS also supports pre- and postdoctoral training that emphasizes statistical and computational skills and workshops to provide additional training in statistical methods to biologists.
- NIGMS support for research on the mechanisms underlying individual variations in drug response, while not specifically targeting diabetes, has the potential to have an impact on the treatment of diabetes and its complications. Researchers are studying the structural features of a powerful peripheral vasodilator related to insulin and identified as an important prospective drug for peripheral angiopathies associated with diabetes.
- NIGMS, in conjunction with several other Institutes, is supporting a mouse mutagenesis and phenotyping center whose emphasis is the high-throughput generation and identification of mice with mutations in developmental defects, including those that affect organogenesis.
- NIGMS is also participating in the Trans-NIH Zebrafish Initiative, whose goal is to improve the genomic resources for the zebrafish, a potentially valuable model for diabetes.

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- For many of the cell lines in the Human Genetic Cell Repository, DNA is also available. In a major new initiative, the Repository has cooperated with the National Human Genome Research Institute to acquire a collection of cell lines, and DNA, from 500 unrelated individuals representative of the diversity of the U.S. population. This resource has already been of great value to researchers for the discovery of DNA polymorphisms, an important step in identifying genes involved in complex genetic disorders such as diabetes.

#### **Future Activities:**

NIGMS will continue to support basic research that focuses on underlying mechanisms and principles that are expected to shed light on both normal and disease processes and to lead to the development of new modes of treatment and prevention.

#### **Funding for Diabetes Research:**

FY 2000 funding is estimated to be \$4,964,000, which represents an increase over the \$3,704,000 spent in FY 1999.

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#### **National Institute of Mental Health (NIMH)**

The National Institute of Mental Health supports research on co-morbid mental and medical disorders (e.g., depression or anxiety disorders and diabetes) when there is a central and explicit focus on a mental disorder(s)/symptoms/or related disability. Studies of risk and protective processes linking the co-morbid mental and medical disorders are encouraged, as are the development and initial testing of interventions aimed at preventing or treating adverse outcomes in both domains. NIMH supports intervention research when the prevention or treatment of mental disorders/symptoms/related disability are among the primary outcomes of the study. When the

prevention or treatment of diabetes and its complications, or improved adherence to regimens for diabetes and its complications, are the primary focus of study, studies should be assigned to the National Institute of Diabetes and Digestive and Kidney Diseases (NIDDK).

#### **Current Activities:**

- With NIDDK and the National Institutes of Health's (NIH's) Office of Behavioral and Social Sciences Research, NIMH developed plans for an FY 2001 Request for Applications (RFA) and related conference on co-morbid depression and mental disorders in patients with diabetes, renal disease, and obesity/eating disorders. The conference was scheduled for January 29–30, 2001, at the Natcher Center on the NIH campus. The RFA is planned for release in spring 2001.
- In addition to the FY 2001 RFA and conference, NIMH solicits research on co-morbid mental disorders and diabetes under its ongoing program announcement, "Research on Co-Morbidity: Etiology and Prevention," PA-99-071, which may be found at <http://www.nimh.nih.gov/grants/99-071.html>.

#### **Future Activities:**

Going forward, this central and explicit focus on mental disorders will be a critical criterion for the funding of new grants related to diabetes and its complications. NIMH activities include a range of grants, some with a primary focus on mental disorders and diabetes, as well as some where the focus on these co-morbid disorders is not as central and explicit.

#### **Funding for Diabetes Research:**

FY 2000 funding information was not provided.

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## **National Institute of Neurological Disorders and Stroke (NINDS)**

Fiscal Year 2000 (FY 2000) information was not available.

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## **National Institute of Nursing Research (NINR)**

The National Institute of Nursing Research supports and conducts research and research training on the biological and behavioral processes that underlie promotion of health, amelioration of illness and its sequelae, and effective delivery of care. One purpose of this research, specific to diabetes, is to understand how to promote health-sustaining behavior and to improve quality of life by relieving the effects of disease processes and their progression. Nursing research focuses on how physical and psychological responses to diabetes symptoms and treatment of the disease affect health throughout the lifespan. NINR research programs pay particular attention to special populations affected by diabetes.

### **Current Activities:**

NINR activities are designed to support research related to diabetes interventions, self-management, quality of life, special and diverse population needs, problems of defined age groups and across the lifespan, basic research, genetics, and other initiatives relevant to clinical practice and client outcomes.

- Two program announcements (PAs) were published in January and June of 2000 specific to diabetes research, "Enhancing Adherence to Diabetes Self-Management Behaviors" and "Diabetes Self-Management in Minority Populations." These PAs are consistent with the Diabetes Research Working Group (DRWG) recommendations. NINR was a participant in this working group.

- Funded grants relating to diabetes research included career development, postdoctoral training, and research. Diabetes-specific topics included ethnic variation in type 2 diabetes prevention knowledge, cardiac risk factors in type 1 and 2 adolescents, autonomy and self-care in type 1 diabetes adolescents, Spanish language self-management programs, an intervention study of American Indian groups on behavior change in type 2 diabetics, a description of the process of integrating diabetes self-care in Mexican-Americans with type 2 diabetes in the southwest, interventions for African-American women with diabetes, an intervention for parents of young children with newly diagnosed diabetes, and biophysical determinants of diabetes foot ulcer healing.

### **Future Activities:**

In 2001, NINR plans to continue to support research that focuses on problems experienced in diabetes populations. Research efforts will be guided by the following goals:

- NINR plans to focus support on promising ongoing and new diabetes research areas while building on recent nursing science advances.
- NINR will work collaboratively with other Institutes and organizations to increase and facilitate diabetes research activities.

### **Funding for Diabetes Research:**

In response to an FY 2000 Area of Opportunity on "Enhancing Adherence to Diabetes Self-Management Behaviors," NINR had a significant increase in diabetes funding from \$1.3 million in FY 1999 to \$3.9 million in FY 2000.

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## **National Institute on Aging (NIA)**

The mission of the NIA as it relates to diabetes research and related issues, is to support biomedical and behavioral research leading to improved therapies to prevent diabetes and its complications, as well as improved quality of life of older diabetic patients.

### **Current Activities:**

- The NIA continues to support studies on how known risk factors associated with vasculopathy influence the synthesis and function of advanced glycosylated endproducts (AGE) receptors, and to provide a molecular basis for future epidemiology studies and treatment of diabetes- and age-related vascular disease.
- Studies are also focusing on the development of interventions to reduce abdominal fat and on the factors mediating regional differences in body fat noted in older non-insulin dependent diabetes mellitus (NIDDM) patients. Previous studies supported by NIA have demonstrated that age-related changes in the quality of skeletal muscle may play a role in insulin resistance. For example, it has been shown that there is an age-related decrease in GLUT4 levels in skeletal muscle, in conjunction with the development of insulin resistance. To date, much of the intervention development efforts have focused on different types of exercise to either reduce central adiposity or to improve GLUT4 levels. NIA-supported investigators are also examining the time line of the metabolic benefits of exercise. For example, these studies will help to identify how often older NIDDM patients need to exercise to maintain exercise-induced improvements in glucose metabolism.
- Insulin resistance is a metabolic disorder that may precede the development of type 2 diabetes in older adults. Since physical inactivity and obesity are the two main factors contributing to insulin resistance, previous studies had compared the effects of short-term endurance exercise versus reduced caloric intake on insulin sensitivity in older obese men and women. These findings indicated that short-term exercise is more effective than diet in enhancing insulin action in older individuals with abnormal glucose tolerance. However, data from animal models suggest that caloric restriction can prevent and/or delay the onset of age-related pathologies, including insulin insensitivity. NIA is currently exploring the clinical implications of caloric restriction in the development of future interventions for the prevention of diabetes in old age.
- NIA was a co-sponsor of the National Institute of Diabetes and Digestive Diseases' (NIDDK's) Request for Applications (RFA) "Innovative Approaches to Prevention of Obesity." The NIA is supporting two studies resulting from this RFA. These studies will specifically explore strategies to prevent weight gain in menopausal women and in older women following smoking cessation.
- The NIA continues to be a co-sponsor of the NIDDK study, Diabetes Prevention Program (DPP).

### **Future Activities:**

No additional diabetes-related activities were reported.

### **Funding for Diabetes Research:**

FY 2000 funding information was not provided.

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## **National Institute on Alcohol Abuse and Alcoholism (NIAAA)**

The National Institute on Alcohol Abuse and Alcoholism (NIAAA) encourages research to understand the role of alcohol consumption as a risk factor in the development of diabetes mellitus. NIAAA also supports research to determine the effects of moderate alcohol consumption on diabetes. Several studies suggest that alcohol consumption may directly or indirectly contribute to the development of type 1 diabetes. This contention is based on the following observations: (1) alcohol may impair the release of insulin from the pancreas; (2) chronic alcohol intake can increase plasma levels of TNF, which has been shown to cause apoptosis of pancreatic beta cells that in turn may decrease beta cell number and insulin secretion; and (3) chronic alcohol consumption may impair beta cell function by eliciting immunotoxicity.

Chronic alcohol consumption also has been implicated in the development of type 2 diabetes based on the following findings: (1) chronic alcohol feeding in rats reduces the number of insulin binding sites on isolated hepatocytes; (2) alcohol impairs insulin-mediated tyrosine phosphorylation of insulin receptors in a tumor cell line; (3) chronic alcohol exposure blunts tyrosine phosphorylation of insulin receptor substrate-1 in rat hepatocytes and a tumor cell line; and (4) chronic alcohol exposure inhibits the activity of rat hepatocyte phosphatidylinositol-3kinase, which stimulates glucose transport. These effects of alcohol may lead to insulin resistance and impaired glucose transport.

### **Current Activities:**

NIAAA supports six projects that investigate the relationship between alcohol intake and diabetes. The following research areas are under investigation:

- Impact of moderate alcohol consumption on the risk of diabetes mellitus.
- Effects of fetal alcohol exposure on the biochemical and physiological changes in the insulin response and glucose homeostasis.
- Mechanism of induction of P450-2E1 (an alcohol-inducible enzyme) in diabetes.
- Molecular mechanisms of disruption of insulin-mediated glucose transport by ethanol.
- Alcohol consumption effects on glycemic control and compliance in type 2 diabetics.
- Fatty acid changes in blood components as determinants of insulin resistance in the diabetic state.

Significant findings in FY 2000 include:

(1) moderate alcohol consumption (15-29 g/day) was associated with a 36 percent lower risk of type 2 diabetes; (2) alcohol feeding disrupts insulin-stimulated glucose uptake in rats by impairing intracellular translocation of GLUT4 (a glucose transporter protein) to the plasma membrane and by disrupting the ability of GLUT4-containing vesicles to dock and fuse with the plasma membrane of adipocytes; and (3) fetal alcohol exposure in rats can induce insulin resistance in the muscle tissue of adult male offspring, suggesting that fetal alcohol exposure has a long-term effect on the response to insulin.

### **Future Activities:**

No additional diabetes-related activities were reported.

### **Funding for Diabetes Research:**

In FY 2000, the total amount of funding for the above-described six research areas was \$536,000.

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## The Veterans Health Administration (VHA)

The Veterans Health Administration is the largest national integrated health care system. VHA's mission is to decrease the prevalence of adverse health outcomes in veterans with diabetes. This will be accomplished through systems-level integration of guidelines, performance measurement, and data feedback in order to facilitate adherence to preventive and treatment measures. VHA reports the following progress in FY 2000.

### Current Activities:

- *Performance Measurement (Office of Quality and Performance)*. In FY 1999, independent contractors from the External Peer Review Program (Headquarters Performance Office) reviewed 18,882 charts of veterans with diabetes. The mean percentage of patients having chart documentation of the following diabetes-specific measures within 12 months of chart review is as follows: (1) glycosylated hemoglobin test (93%); (2) foot ulcer risk screening examination, including visual examination (96%), palpation of pulses (84%), and a sensory examination (78%); (3) dilated retinal examination (67%); (4) nephropathy screening (44%); and (5) LDL-C measured (73%). Based on 3rd quarter FY 2000 audits, HbA1c was <9.5% in 87 percent and <8.0% in 63 percent; LDL-C was <130 mg/dl in 72 percent, and BP was <140/90 in 51 percent of veterans with diabetes and hypertension. VHA has adopted the Diabetes Quality Improvement Project Measures.
- *National Diabetes Registry (Office of Policy and Planning)*. VHA has developed a nationwide diabetes registry consisting of all veterans with diabetes identified through administrative codes, pharmacy prescriptions, and hemoglobin A1c. A conservative period prevalence for FY 1999 based on HEDIS (Health Plan Employer Data and Information Set) administrative criteria and pharmacy data is 16.3 percent, or 503,000. Based on analysis of registry data, the mean HbA1c for FY 1999 was 7.65; and the mean LDL-C was 111 mg/dl. In addition to cardiovascular disease, the cohort had a high prevalence of co-morbid conditions, including mental health conditions.
- *Lower Extremity Amputation Reduction (Office of Policy and Planning)*. In collaboration with the Centers for Disease Control and Prevention's Division of Diabetes Translation, a 10-year Lower Extremity Amputation (LEA) Registry has been created. From FY 1997 to FY 1999, the age-adjusted rate of LEA has decreased from 2.61 to 1.65 per 1,000 VHA users (at least one clinical visit). Based on the cross-sectional identification of individuals with diabetes, the age-adjusted rate of LEA has decreased from 8.48 to 7.48 per 1,000 users from FY 1998 to FY 1999.
- *Guideline Development (Offices of Patient Care Services and Quality and Performance)*. VHA, in partnership with the Department of Defense, issued a revision (February 2000) of its Diabetes Clinical Practice Guidelines. The guidelines, covering outpatient management of glycemia, blood pressure, hyperlipidemia, diabetic retinopathy, foot care, and renal disease, are explicitly evidence-based in contrast to other existing guidelines. Version 1.0 was developed in collaboration with the executive committee of the National Diabetes Education Program.
- *Research*. From a programmatic perspective, three additional Juvenile Diabetes Foundation/VHA diabetes Centers of Excellence were funded. VHA funded a 5-year cooperative study (CSP 465) to evaluate the effect of near normal glycemic control on cardiovascular outcomes in type 2 diabetes. The Diabetes Quality Enhancement Research Initiative has been funded for translational research, including education, foot care, eye care, case management, and provider feedback. VHA is also a participant in the Department of Defense Telemedicine Project for Non-Mydriatic Retinal Examination in partnership with the Joslin Vision Center.

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- *Standardization of Glycated Hemoglobin Testing.*

The Under Secretary for Health mandated that all VHA facilities use methodology traceable to the Diabetes Control and Complications Trial (DCCT) standard as recommended by the National Glycosylated Hemoglobin Standardization Program.

- *Education.* VHA has 30 facilities that have obtained American Diabetes Association Recognition of their patient education programs. VHA hosted the 2nd annual National Diabetes Symposium for endocrinologists and primary care providers, as well as the annual VHA Diabetes Educators Conference.

**Future Activities:**

No additional diabetes-related activities were reported.

**Funding for Diabetes Research:**

FY 2000 funding information was not provided.

## **Diabetes Mellitus Interagency Coordinating Committee (DMICC) Meeting**

*Type 2 Diabetes in American Indian and Alaska Natives: Focus on Children*

May 11, 2000  
NIH Campus, Building 45 (Natcher), Room E1/E2  
45 Center Drive  
Bethesda, Maryland

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### **MEETING SUMMARY**

*Welcome/Introduction/The DMICC: An Overview and the Charge for Today—Type 2 Diabetes in American Indian and Alaska Native Children*

Dr. Sanford Garfield, Senior Advisor, Biometrics and Behavioral Science, National Institute of Diabetes and Digestive and Kidney Diseases (NIDDK), welcomed all to the meeting and introduced Dr. Allen Spiegel, the newly appointed Director of NIDDK. Dr. Spiegel announced his role as chair of the DMICC, following the departure of Dr. Richard Eastman. The key to the DMICC, Dr. Spiegel explained, is coordination, which implies communication and partnership. The Committee is well positioned to respond to a recent Congressional mandate to address the issue of minority health disparities, including a focus on diabetes in American Indian peoples. The goal of the current meeting is to concentrate on the disproportionate prevalence of this condition in American Indian and Native Alaskan children and young adults. The DMICC is positioned to play a role in helping to bring advances in diabetes research, many of which provide hope for improved diabetes outcomes, by furthering communication through established and developing partnerships with the Indian Health Service (IHS), Tribes, and Tribal leaders.

## **Tribal Blessing**

Mr. Alvin Windy Boy, Sr., of the Chippewa Cree Tribe, offered a Tribal blessing to guide the meeting participants and attendees in their presentations, discussions, and deliberations.

## **IHS: Role in Tribal Health and Diabetes**

Dr. Kelly Acton, Director, IHS National Diabetes Program, opened her presentation by noting that the American Indian/Alaska Native population is diverse in many ways—in traditions, cultures, history, language, food, living environment, and governance, among many other facets. More than 550 Tribal groups are Federally recognized, reside within 34 States, and speak more than 200 different languages. About one-half of the Native American/Alaska Native population live in urban areas; some one-third live in poverty, as compared with about 13 percent for the total U.S. population. As Dr. Acton pointed out, the Native American/Alaska Native population is a growing one, with a 1994 population of 2.2 million and a projected population of 4.3 million by 2050. With this diversity and anticipated growth, Dr. Acton commented, it is important to keep in mind that no one method or approach to health care will work for all.

The Public Health Service (PHS) has overseen Indian health care, first through the Bureau of Indian Affairs and more recently through the IHS, since 1955. The IHS is unique among government health care-related agencies in that its mission is to elevate, through direct service mechanisms, the health status of a specific population; unlike many other government programs, such as Medicare, the programs funded by IHS are not entitlements. Dr. Acton noted that, overall, PHS/IHS has a positive record in addressing, raising awareness about, and assisting in ameliorating many serious public health problems within the American Indian/Native Alaskan population. However, for diabetes and other health issues, the IHS is severely underfunded. The limited budget authority and changing role of the IHS, whose

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major health-related programs have undergone reductions with medical inflation and increased administrative costs, can now meet only 30 to 40 percent of the health care needs of the populations it serves. For example, the per capita health care resources available for American Indians and Alaska Natives through IHS is approximately \$1,500/year versus approximately \$3,000/year for Medicare recipients; the actual annual costs associated with treating diabetes average \$5,000 to \$9,000. Thus, IHS funding for individuals with diabetes falls very short of what is needed. Because many American Indians and Alaska Natives live in rural settings, they are isolated, which presents an additional barrier to receiving adequate and appropriate health care.

It has long been known that adults in the American Indian/Alaska Native population have high prevalence rates of diabetes. National data on American Indian/Alaska Native populations collected by the IHS between 1991 and 1997 from 151 IHS service units and analyzed by the Centers for Disease Control and Prevention (CDC) reveal an increase in the prevalence of diabetes in all of the age groups during the time period studied. The greatest increases were found in adolescents aged 15 to 19 (up 32 percent), young adults aged 20 to 24 (up 36 percent), and in adults aged 25 to 34 (up 28 percent). The increase seen in young men was about twice that seen among young women. Dividing up the American Indian/Alaska Native data by region, it was apparent that the Alaskan region has the lowest prevalence of diabetes in children, adolescents, and young adults. All of the regions showed a steady increase in diabetes between 1991 and 1997.

Several steps and actions have been taken in the past two decades to remedy health care issues and problems facing American Indians and Alaska Natives. In 1979, Congress established the IHS National Diabetes Program (NDP) in response to research showing the very high prevalence of diabetes and related complications among Pima Indians. This program, which extends to the entire American Indian population, is based on standard

clinical and public health models. One key component of the NDP is the Diabetes Care and Outcomes Audit, an ongoing audit that has been conducted annually since 1987. The audit now includes 87 different elements of standard of care, based on medical record reviews (e.g., foot exams, eye exams, blood pressure, glycemic control, kidney function, etc.). Outcomes measures are used as QA tools and as the means to identify gaps in care and outcomes and practices to improve care. Dr. Acton noted that lifestyle changes have a big impact on improving or at least maintaining the health of diabetics. At present, the very limited per capita funds available to American Indians and Alaska Natives with diabetes are insufficient to provide many of the fundamentals, including medications, to stem the effects and progression of the disease. The growing number of Indian youth with diabetes is another critical issue that must be addressed.

The NDP needs additional staff and resources to identify and study gaps and implement further changes to improve outcomes. It is looking to the NIH, CDC, and other entities to develop, and strengthen, partnerships to assist in this endeavor. The Tribes also are considering the 333 grant programs as an alternative resource to fund studies of diabetes in Indians. Another newer approach that the Tribal population has undertaken to have a more direct role in the health care of its peoples stems from the self-governance movement, which was instituted as a demonstration project in 1989. This movement has grown in the past decade, and now more than one-half of all Tribes have contracted to provide their own health care. As this movement has grown, however, the role of IHS has become less clear and less certain. Dr. Acton recognized the importance of the joint efforts of government agencies and Tribes and pointed to the Tribal Leaders Diabetes Committee as a good example of such partnerships.

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## **The Tribal Leaders Diabetes Committee — Description and Responsibilities**

Mr. Windy Boy, Sr., Co-Chair of the Tribal Leaders Diabetes Committee, echoed many of the points put forth by Dr. Acton about the importance of partnerships, such as the Tribal Leaders Diabetes Committee; adequate funding for medical care and research; self-governance and increased involvement of Tribal leadership at all levels of Tribal life; and understanding, retaining, and incorporating traditional ways, beliefs, and values into all aspects of health care. As the self-governance movement has grown, Tribal leaders are taking the initiative in determining the best path for their people, with a key messages of “Go back” to traditions and to nature to keep mind, body, and spirit in balance. The messages of the Tribal leaders focus strongly on lifestyle, which is known to be critical to influencing the development and management of type 2 diabetes. Although lifestyle changes must be made by an individual, the family, health care providers, and community can serve as strong sources of support and information. As with other chronic diseases, most cases of type 2 diabetes have both environmental (e.g., lifestyle) and complex genetic components. Thus, simpler messages such as “eat less, exercise more,” while helpful, will not be able to solve the entire problem.

To its credit, Mr. Windy Boy commented, NIH is moving forward in including as partners Tribal leaders and Tribal communities in discussions to direct research and improve health and medical care of native peoples; this is especially important in the area of diabetes, which has been devastating to Indians of all Tribes. It is important to keep in mind, however, the different primary missions of the various health-related government agencies (e.g., NIH, CDC, IHS, FDA, AHRQ) with respect to research; prevention, screening, and treatment; regulation and policy; public health; and educational and translation efforts.

Mr. Windy Boy outlined several steps taken by both the Federal government and Tribal governments in the past 25 years to address health care among Indian peoples. In the mid-1970s, President Nixon signed a law allowing Tribes to contract health care services with the IHS. In 1989, the self-governance demonstration project, which gave Tribes flexibility to redirect health care monies and services, was launched. This program has grown and now includes 253 contracts or compacts, each of which is specific to the contracting Tribe. In 1994, though a Planning Grant from IHS, the self-governance health care contract budget allowances grew from \$3.2 to \$8 million per year and expanded to include orthodontic care, pharmaceutical coverage, other health disciplines, and Tribal health wards. These changes overall have helped the diverse American Indian and Native Alaska populations to start to identify and fill health care needs specific to each Tribe.

## **Diabetes in Alaska Natives**

In this presentation, Ms. H. Sally Smith, Chair, Bristol Bay Area Health Corporation; President, National Indian Health Board; and member, Tribal Leaders Diabetes Committee, summarized recent changes in Tribal roles and responsibilities for health care systems and delivery, her traditional upbringing in Alaska, and the dramatic changes in Alaska Natives’ day-to-day lives that have occurred in the past few decades.

Ms. Smith noted that the National Indian Health Board (NIHB) serves 528 Tribal nations while addressing 12 health areas and upholding all Tribal government agreements. The initial Board was established in 1972 in an effort to improve Indian health care and medical services. In the 1980s, the IHS sought Tribal consultations to obtain feedback in continuing these efforts. In the 1990s, the government elevated the level of these consultations and began to support the movement toward self-governance. As Ms. Smith explained, Tribal sovereignty, through which Tribal nations seek to protect their interests and engage in treaty making,

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has long been part of American history. In the 1880s, the Federal government treated Indian Tribes as quasi-independent nations, whereas in the 1990s, the solid shift toward self-governance has allowed for clear recognition of the many Tribes as independent nations that maintain their own constitutionally developed political and legal rights. Contemporary Indian health problems, such as diabetes and kidney disease, which, in many Tribes, occur at rates that are three to five times higher than the general U.S. population, are now being addressed at a variety of levels through different agencies (e.g., CDC, NIH, IHS) and private organizations (e.g., Juvenile Diabetes Foundation, American Diabetes Association [ADA]). However, the lack of sufficient funds remains in question, and, as Ms. Smith noted, the NIHB, among others, seeks a 300- to 500-percent increase in Federal health care funds for Indian programs.

Alaska is home to 171 remote Indian villages, each with an average of 100 to 400 residents. The location of most of these villages in isolated, rural areas presents unique health care challenges and barriers that make outreach and delivery of care and follow up to diabetic patients difficult. Added to these challenges is that, despite their isolation, the villages and their residents are not immune to “Western” influences such as a high-fat, high-sugar, low-fiber diet; computer and video games; television; and increased to exclusive reliance on motorized vehicles that can adversely affect health and reduce regular physical activity.

The adoption of “Western” lifestyle is in stark contrast with the traditional lifestyle of Alaska Natives just one or two generations ago, when farming and fishing; high levels of physical activity, such as kayaking, harvesting, and walking; and indigenous foods of the land and sea, including low-fat caribou and heart-healthy fishes, were integral to day-to-day life. Today, Ms. Smith noted, even the smallest towns have pizza parlors and take-out restaurants, and residents use airplanes, sport utility vehicles, and snowmobiles as the prime modes of transportation, which contribute to a sedentary lifestyle.

These lifestyle changes have had pronounced effects on the physical attributes and health of many Alaska Natives. Through a series of slides, Ms. Smith showed Natives of previous generations, who were slender, lean, fit, and strong, even among the elderly, in contrast with current generations of young and older alike, who tend to be heavier and less fit. She noted that the rate of diabetes among some Alaskan Tribes in the 12 regions of the State has increased by 200 percent over the 13-year period between 1985 and 1998; type 2 diabetes in preteen Native Alaskans is on the rise; and more diabetes cases are being reported in outpatient clinics. As a regular service of the Indian health care system, community health aides, including educators, nurses, and advocates, supplement doctors’ care by meeting with diabetic patients 2 weeks before the doctors’ visits to collect blood and urine, answer questions, and provide other support as needed. With resources stretched to the limit, the Alaska Native compact as well as the NIHB welcome thoughtful input, support, and resources, and encourage the continued growth of new and established partnerships.

### **Questions/Comments**

In a brief break following the previous presentations, Ms. Smith noted that 1993 was a key time for health care for Alaska Natives. During this year, all Tribes in the State were brought together under the Alaska Tribal Health Compact, which oversees the entire Tribal health care system in Alaska. Through this Compact, each Tribe can opt in or out of the State-wide system, giving each Tribe flexibility and the opportunity to join in on local, State, and national partnerships and collaborations. Many of the changes made in health care in Alaska were initiated in light of the positives associated with the self-governance movement and following nationalization of the IHS budget, in which the Service’s shares and funds were divided among all Tribes.

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Currently, Dr. Yvette Roubideaux noted, approximately 47 percent of the IHS budget is under Tribal control. However, in recent years, the IHS has experienced major program reductions and absorptions and reductions in funds to support the remaining programs. The level of funding has become very critical, especially when these program and financial changes are considered in conjunction with medical inflation, increased health care administrative costs, and the growing importance of preventive care. As noted by previous speakers, annual per capita diabetes funds through IHS are approximately one-half of Medicare funds and only one-fifth of per capita funds available through the VA system. Thus, not only are funds insufficient for adequate diabetes-related clinical health care but also providers interested in conducting even the simplest of research studies must look elsewhere. Ms. Smith added that many Tribes already have maximized alternative financial resources, with the bulk of funds needed for staff time and patient treatment.

Dr. Spiegel acknowledged the importance and success of the shift in the role of IHS governance to self-governance and agreed that, given the factors cited, the IHS has had to severely ration health care services and is able to meet only 30 to 40 percent of the current health care needs of American Indians and Alaska Natives. An important next step is determining the effectiveness, including a cost-benefit analysis, of primary prevention, which likely will be key in childhood diabetes. Dr. Spiegel noted the recently appropriated diabetes seed money of \$30 million for 5 years includes \$2 million for prevention and \$11 million for treatment. Some attendees suggested using some of these funds to identify an inexpensive, simple, and practical screening test that could replace the "gold standard," the oral glucose tolerance test. Others suggested using a portion of these funds to develop a plan to identify the messages, resources, and treatment and prevention strategies to implement.

### **The Tribal Role in Research: Impact on Diabetes**

The Honorable Malcolm Bowekaty, Governor, Pueblo Zuni Nation, challenged the research community to rethink its strategy, infrastructure, and agenda for diabetes in general and Indian populations specifically. He noted the wealth of data already available from the many descriptive, epidemiologic, basic, and clinical research studies conducted over the past decades. These data should be sufficient to provide the fundamental ideas for a cure or, at the very least, the tools and information necessary to make significant progress to stem the epidemic of diabetes (and related conditions, such as kidney disease) among American Indians, Alaska Natives, other high-risk groups, and the population at large as well. These tools include best practices and standards for clinical care and home-based care; requiring higher standards for hospitals and service units; an increase in the number of available dialysis machines; and the training of caring, knowledgeable, and culturally sensitive professionals.

He emphasized the need for NIH, in conjunction with Indian communities and leaders, to develop a definitive diabetes research agenda with clear and defined goals. To achieve this, Tribes should be involved in all phases of the research engine, from planning and design to implementation of a study to translation or research results into practice; Tribal input should be required before approval of any projects that use Native peoples as participants. The government and Tribes must work together to foster a relationship based on deep trust and prosperity. The Zuni Tribe, a nation of approximately 9,200, have participated in numerous studies, Gov. Bowekaty commented, sometimes at a high cost to the participants or the community.

Gov. Bowekaty identified several strategies and issues to consider for future projects and endeavors. For example, funding should be increased for the recruitment and training of minority researchers and to support minority research centers. For sample size and data analysis and evaluations, researchers

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should strongly consider pooling data or establishing collective data centers to increase statistical power to obtain meaningful results. Educational efforts and materials should reflect competence, advocacy, and cultural understanding, while being scientifically accurate. Interagency coordination is key to ensuring success.

Gov. Bowekaty pointed to a set of critical and interconnected issues associated with treating and curing diabetes among Indians of all ages. Reaching youth should be a priority, with a primary focus on primary prevention and cure; ensuring a future of healthy adults benefits both individuals and the community in many ways. The focus for adults, who serve as role models, should be on quality of life, prevention, and standards of care. For the elderly diabetic population, areas of concern are maintaining quality of life, which, at this time, includes dialysis. The roles of different agencies, including the NIH, IHS, CDC, BIA, and Tribes, are varied. All agencies should be called on to provide funding and to seek the best approach within the agency infrastructure to reach a cure. Other primary roles include the conduct of basic and clinical research, establishing or enforcing standards of care, setting policy, and public health outreach and education.

The ultimate goal of diabetes research and care should focus on cure and treatment; tangible benefits can be achieved through revising standards of care that will improve individuals' quality of life as well as their medical condition per se. Gov. Bowekaty stated that Tribes will support the moving forward of research with merits for a cure and are highly motivated to participate in the review of proposed research projects.

### **Navajo Nation Special Diabetes Project (Focus on Navajo Children)**

Ms. Marla Jasperse, Executive Director, Navajo Nation Division of Health, described this project, which uses a collaborative, holistic model to better understand the diabetic patient, that includes a focus on Navajo children. The "total health concept" model that forms the basis of the Navajo Nation Special Diabetes Project incorporates family, community, and traditional approaches to treatment and education using the components of spirituality, knowledge, physical needs, emotion, and society. It recognizes the importance of ascertaining the existing habits of a Tribal community, how those habits are linked to each other, what functions they serve within the community, and what they mean.

This model provides for a better understanding of the diabetic patient; increases collaborations between health care providers, patients, the family, and the community; maximizes resources; and allows for an increased role for traditional treatment and education. Under the spiritual component, the model encourages the use of prayer and daily thanks for well being; incorporates traditional therapies such as herbs and ceremonies; and emphasizes traditional values, beliefs, spiritual teachings, and respect for self and others. The knowledge component focuses on incorporating traditional teachings and education, defining diabetes and related conditions in the Navajo language (e.g., "sugar disease"), and developing culturally appropriate educational materials. Physical needs include a variety of aspects of daily living, such as nutritious food, exercise, availability of running water and electricity, and other physical supports associated with a diabetes diagnosis. The emotional feature of the model addresses an individual's ability to accept or deny diagnosis, provides for support groups, and recognizes the importance of family. Ms. Jasperse noted that the societal component is often the most difficult to develop and implement because it moves into and seeks support through a variety of community venues, such as supermarkets and restaurants (e.g., to help disseminate nutrition and health information), Tribal leader-

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ship involvement (e.g., coordinating regular walks with the President of a Tribe, promoting an outreach and health message), border town support, schools (e.g., health promotion and disease prevention), and different types of support groups.

Ms. Jasperse noted that the model, which has many benefits to individuals and the Tribe at large, has been introduced to and has seen great success within schools and communities as a preventive and educational strategy.

**The IHS Diabetes Program:  
Special Program for Indians and Epidemiology  
of Type 2 Diabetes in Indian Children**

During this presentation, Dr. Acton focused on two key issues: the Balanced Budget Act (BBA) Grants Fund and the extent of the IHS's knowledge about type 2 diabetes mellitus in children. The BBA Grants Funds provides for a total of \$33 million/year (including a \$3-million/year Interior Department appropriation) over a 5-year period beginning in FY98. The legislative intent of this program was to establish a special diabetes program for Indians. The program established a work group, the Tribal Leaders Diabetes Committee, to advise the IHS and other organizations about diabetes-related issues. National efforts targeted toward American Indians before the BBA Grants Fund consisted of a network of 13 area diabetes consultants, 19 model diabetes programs, and 333 diabetes grant sites that have evolved and developed over 21 years.

The IHS recently surveyed grantees to evaluate its diabetes programs, with a focus on new components and results of these programs. In programs for the target age groups, the survey found that approximately 50 percent of the programs target young adults, 40 percent are geared toward adolescents, 30 percent focus on elementary school children, 20 percent are designed for Headstart or preschool children, 50 percent focus on family members with diabetes, and 40 percent target overweight youth. Additional programs focus on providing nutritional information to specific target groups; developing

and implementing methods to increase physical activity using BBA Grants Fund monies; and tracking screening, referrals, and treatment modes for diabetes complications associated with the feet, eyes, dental/oral health, blood pressure, urine, and protein metabolism. The IHS survey identified several new or improved facets used to develop diabetes programs, including a diabetes team, diabetes registry, diabetes clinic, chart audits, and flow charts or flow sheets. Many IHS-supported diabetes programs also incorporate traditional approaches, such as story telling and talking circles, and 60 percent of the programs provide education, outreach, and training to health professionals. Survey respondents indicated that the two most significant barriers to implementing programs are lack of space and difficulties in hiring new staff.

Expanding on her earlier presentation, Dr. Acton summarized trends of IHS's ongoing Diabetes Care and Outcomes Audits, which have been conducted annually since 1987 and now include 87 different elements for which data are collected using manual medical record reviews (e.g., foot exams, eye exams, blood pressure, glycemic control, kidney function, and other measures). The audits use a systematic random sampling of records from various IHS and Tribal registries across the country; elements are tracked by age of patients and follow the population over time. One favorable outcome observed in all age groups was improvement in hemoglobin A1c (Hgb-A1c), which serves as a measure of glycemic control. Overall, however, the youngest persons had the worst HgbA1c levels. The audits also demonstrate that the prevalence of diabetes has increased across all age groups since they began, with the greatest increase in prevalence seen in youngest persons (ages 15 to 34) between 1991 and 1997. During this time, the prevalence of diabetes increased by 32 percent, 36 percent, and 28 percent among those 15 to 19 years old, 20 to 24 years old, and 25 to 34 years old, respectively. Among children under 15 years old, the prevalence of diabetes mellitus increased by 6 percent. As Dr. Acton noted, these data clearly demonstrate that diabetes is a growing problem among American Indians, particularly in younger persons.

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## **National Indian Council on Aging: The Role of Elders**

Mr. David Baldrige, Executive Director, National Indian Council on Aging, provided background and demographic information on Indian elders in this country. Currently there are approximately 236,000 Indian elders and 550 Federally recognized Indian Tribes in the United States. Some 80 percent of the Indian elders live west of the Mississippi River, and 50 percent live in a rural setting. Ten percent of older Indians have no formal education, and 26 percent are high school graduates. Overall, Indian elders are more likely to live in poverty than older persons in other populations. The life expectancy for older American Indians also is less than that for other Americans; for example, Indians born in 1941 have a life expectancy of 51 years, compared with a life expectancy of 65 years for white Americans. This gap appears to be closing, however, for younger persons. Indians born in 1989 or 1994 have a life expectancy of 71 and 72 years, respectively, compared with a life expectancy of 75 years for whites born in either 1989 or 1994.

In continuing his presentation, Mr. Baldrige noted that most Indian Tribes place high value and importance on family and community life and recognize the integral role of elders in their communities. He explained that there are many different ways of “defining” or identifying elders within the Indian culture. Elders may be spiritual leaders of a Tribe, possessing characteristics such as connectedness and selflessness and following traditional ways. Elders also may be cultural guardians who are a living history for a Tribe and who protect values and carry knowledge and the history of their ancestors. Tribal elders serve as role models who teach by example, who often have overcome significant adversities, and who are self-reliant. A holistic approach to medicine and health within Tribal life recognizes and incorporates the physical, mental, and spiritual aspects of an individual, family, and community; supports strong family involvement in home care; and stresses the importance of caregivers. The IHS supports 145 health service units and 40

clinics that serve 350 Tribes. Although there are 12 Indian nursing homes, more than 90 percent of long-term care for Indians is done by family members.

Data show that more than one in five Indian elders have type 2 diabetes and that in some communities, more than one-half of Indian elders have this disease. Thus, Mr. Baldrige commented, the prevalence of diabetes among older Indians has reached epidemic proportions. Efforts to increase awareness and educate the general Indian population and health professionals about this problem ideally should focus on developing simple, clear, and culturally appropriate messages; using known and trusted persons, such as family members and elder role models, to deliver messages and incorporate visual learning into outreach programs. The IHS’s 5-year diabetes education initiative involves developing a comprehensive education program, training, pilot testing the program, evaluating the results of the pilot testing, and expanding the program to accommodate a larger audience.

To reverse the trend of increased prevalence of diabetes among Indian elders, and among Indians overall, programs need to engage a variety of partners, including insurance providers, researchers, Federal agencies, advocates, and families/communities. These partnerships can help create a holistic approach that incorporates families, in-home care, patient education, and benefits counseling.

### **Diabetes Research: The Pima Indians**

Dr. Robert Nelson, Staff Clinician, NIDDK, described the history and findings of the longitudinal population study in the Pima Indians of the Gila River Indian Community in Arizona. He described past studies and some current research issues, including the extent of diabetes mellitus in children.

In the mid-1960’s, at the start of the longitudinal study, Pima Indians lived in primitive conditions; many did not have access to running water. At that time, researchers found high levels of obesity and

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a high rate of diabetes mellitus in the population. Oral glucose tolerance testing (OGTT) revealed that the prevalence of diabetes among the Pima was related to age and sex, with the greatest proportion of affected persons (40 percent of men, 65 percent of women) over the age of 35 years. The overall prevalence of diabetes mellitus in the adult population (about 50 percent for those 35 to 64 years old) is higher than in other American Indian populations (e.g., 29 percent among adult Navajo), and the prevalence of type 2 diabetes is increasing even in the children. Increased exposure to diabetes in utero appears to be at least partly responsible for the rising prevalence in Pima children.

The longitudinal population study includes anthropometric measurements, a medical history, EKG, physical examination, and numerous lab tests (e.g., OGTT/glucose, lipids). Major accomplishments of the study include establishment of the criteria for diagnosing diabetes mellitus, identification of insulin resistance as specific to type 2 diabetes, and demonstration that infants who are breast fed are less likely to develop diabetes than those that are not breast fed.

This study demonstrated that development of diabetes is a two-step process. The first step is transition from normal to impaired glucose tolerance, for which insulin resistance is the main determinant. The second and later step is worsening from impaired glucose tolerance to diabetes, in which the pancreas becomes unable to keep up with the insulin demand. In addition, the study showed a significantly higher prevalence of type 2 diabetes in children of mothers with diabetes during pregnancy. The children not only developed diabetes more frequently but did so at an earlier age than those whose mothers were not diabetic during pregnancy. The study also found that exposure to maternal diabetes is on the rise.

Researchers found that the prevalence of end-stage renal disease in Pima Indians was 75 times that in U.S. whites, and the rate of kidney failure is rising. In addition, detailed studies of kidney function

demonstrated high rates of glomerular filtration in those with diabetes. Intrauterine exposure to diabetes was associated with a twofold increase in the risk of kidney disease.

### **American Indian Community Intervention**

Dr. Jeanette Carter, Associate Professor, University of New Mexico School of Medicine, was joined by two other researchers from the University of New Mexico (UNM), Ms. Marla Pardilla and Ms. Jackie Two Feathers, in discussing the Native American Diabetes Project, conducted by investigators at the UNM School of Medicine. The study, which included adult women in the state aged 18 to 88 years was initiated after the discovery that mortality rates among Indian and Hispanic women with diabetes increased markedly between 1958 and 1994, while rates for diabetic white women remained relatively stable.

In an effort to address and counter this trend, a comprehensive, multifaceted intervention program was developed. The initial phase of the project included holding community meetings, focus groups, and in-person interviews (to collect baseline information) and producing a draft curriculum; the proposed program components were reviewed by bilingual community members and pilot tested, which resulted in additional changes to the program. The key messages of the program and curriculum were "Get more exercise," "Eat less fat," "Eat less sugar," "Together we can," and "Stay on the path." The curriculum developed incorporated stories (e.g., "through the eyes of an eagle"), hands-on activities, local and community functions, role-playing, and prayers. The program was implemented using community members as "mentors" who taught the various elements of the curriculum at neutral sites. The study included three intervention arms: group participation, one-on-one intervention, and "usual care" (delayed intervention). Evaluation measures included reviewing COOP charts, tracking food intake and level of physical activity, monitoring HgbA1c levels, and following changes in exercise and diet and related factors (e.g., weight, height).

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A total of 206 persons were interviewed at baseline, which was 1 year before the intervention phase began. Study participants were matched according to age, duration of diabetes, and other relevant factors. Retention to the study was high (89 percent following intervention), and 95 percent of participants reported high satisfaction with both the one-on-one and group interventions and expressed interest in having the program continue after the study ended. Weight and glycemic control improved among those in the focused intervention groups (one-on-one, group) but worsened or did not improve among those receiving usual care. An unexpected finding was that, among all participants, HgbA1c decreased steadily with age, from 10.1 percent among those 18 to 39 years old to 7.7 percent for those over 70 years old. BMI (body mass index) also dropped as age increased; thus, the youngest participants were the most obese and most out of control. Findings from the study have been disseminated to local communities and nationally through a grant from the Bristol Myers Squibb Foundation. The national ADA has incorporated the intervention program into their Awakening the Spirit program, an outreach to Native American Communities. To date, 94 Tribal community teams have been trained with 60% implementing the program. Future research includes evaluation of facilitating factors and barriers to implementation.

### **NHLBI: Strong Heart Study**

In her presentation, Dr. Barbara Howard, President, MedStar Research Institute, outlined key points of the Strong Heart Study (SHS), whose objectives are to measure rates of cardiovascular disease (CVD), measure levels of risk factors for CVD, evaluate the effect of diabetes on CVD, and follow up on and evaluate the determinants of CVD. Participants include approximately 4,500 persons from 13 communities in Arizona, North Dakota, Oklahoma, and South Dakota. Men and women 45 to 74 years old at the time of enrollment were eligible to participate. Communities are involved in all phases of the study: planning, recruitment, conduct of exams, and use

of data. The participating communities receive several benefits from the study such as referrals for health care, feedback to individuals on results and educational materials, training, and updated progress and status reports.

Phase I of the study ran from 1988 through 1991 and included physical examinations and a Community Mortality Study based on information from death certificates. Phase II ran from 1991 through 1996 and included physical examinations and surveillance for CVD and risk factors for all Phase I participants using medical records reviews. Phase II also continued the Mortality Study. Phase III began in 1996 and is slated to run through 2000; it continued physical examinations and CVD surveillance on Phase I participants and initiated a Family Study, in which 30 families with at least 30 members over the age of 18 years are studied more extensively with respect to the other components of the larger investigation.

Participation rates overall have been good, with at least 90 percent of the initial enrollees who are still alive still active in the protocol. Surveillance results show that CVD and total mortality rates, CVD incidence, and prevalence of atherosclerotic plaques were higher among SHS participants than whites and blacks combined from comparable NIH-funded population studies. The study found that cholesterol levels among American Indians are lower than levels in whites and the general population, but data indicate that LDL cholesterol is one of the strongest predictors of CVD. For American Indians, as LDL levels increased, the increase in risk for CVD was higher than that for whites and the general population with the same LDL values. Rates for heart disease in Indians with diabetes were very high and the greatest risk for CVD was for diabetics with kidney disease. In addition, the study found that heart disease starts very early in life; because risk for CVD and diabetes appear to be closely related, it is important to consider both diseases in tandem for investigating, preventing, screening, and treating these conditions, even in children.

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## **NIDDK: Type 2 Diabetes in Children Conference and Future Directions**

Dr. Barbara Linder, Program Director, Clinical Endocrinology and Diabetes Complications Program, NIDDK, provided an overview of the July 1999 DMICC meeting, which focused on type 2 diabetes in children, with an emphasis on African American, Hispanic American, and American Indian youth. Results of descriptive epidemiology studies indicate that type 2 diabetes (T2D) in the pediatric population is increasing at alarming rates in the three groups of interest. In contrast, the prevalence of type 1 diabetes (insulin dependent diabetes mellitus) in children has remained relatively stable over time.

Several presentations at the July 1999 DMICC meeting focused on diabetes in North American Indian children. Dr. Kelly Moore, Acting Chief Medical Officer/Area Diabetes Consultant at the Billings Area IHS, described Canadian aboriginal data from Dr. Heather Dean's studies, in which the average age at diagnosis of type 2 diabetes was shown to be 10 to 14 years, similar to other populations. These data also show that the BMI for diabetic males is nearly always above the 95 percentile and that type 2 diabetes tends to be more common in females in this population, whereas type 1 diabetes tends to occur equally in males and females. Another statistic indicated that 76 percent of Canadian aboriginal children with type 2 diabetes have mothers with diagnosed diabetes. Dr. Moore also compared the Canadian data on diabetes with data collected from the Pima Indians in Arizona. Most cases are first diagnosed in Pima children between 10 to 19 years of age, with the gender ratio for type 2 diabetes favoring females; recent data show relative increases in male incidence of type 2 diabetes, however. In addition, the Pima diabetes population shows a high percentage of exposure to diabetes in utero, which is proposed to be a major risk factor in this population for the development of type 2 diabetes.

In a discussion of fasting insulin levels, Dr. Moore presented data from the Canadian study showing that about 62 of 103 (60 percent) study participants

have increased insulin levels. Hyperinsulinemia has been shown to be a good predictor for the development of type 2 diabetes in Pima children; the 10-year diabetes incidence rate is much higher in those children with elevated fasting insulin. Frequency distribution data of fasting insulin and fasting glucose levels show that Pima children have markedly higher levels than do white children, with a marked rightward shift of the distribution curves.

Dr. William Knowler, Chief, Diabetes and Arthritis Epidemiology Section, NIDDK, remarked during the July 1999 meeting that diabetes prevalence in Pima Indian adolescents, which is historically high, has dramatically increased between 1976 and 1996. The type 2 diabetes prevalence rate is now 8 to 10 times higher than rates in comparable reference white populations from Rochester, Minnesota. Risk factors for type 2 diabetes in the Pima population include family history of diabetes; if only one parent has diabetes, the risk for the child is greater if the mother, rather than the father, has diabetes. The strongest family risk factor, in fact, is in utero exposure to a diabetic mother, rather than simply inheritance of diabetes susceptibility genes. Dr. Knowler showed that much of the recent increase in type 2 diabetes prevalence is attributable to the increase in the proportion of Pima women who are diabetic while pregnant. Another risk factor for type 2 diabetes is birth weight. Either very low or very high birth weight markedly increases the risk for diabetes. An independent risk factor for type 2 diabetes is bottle feeding.

Also during the July 1999 meeting, Dr. Heather Dean, Professor of Pediatric Endocrinology and Metabolism at the University of Manitoba, discussed several regional studies on diabetes prevalence in aboriginal populations in Canada (also known as First Nation). The largest language grouping is the Algonquin, which is Cree-Ojibwa; they also have the highest rate of diabetes. Diabetes prevalence is lowest in the Haida community in the west and in the Inuit communities in the north. In contrast to the U.S. Native American community, 70 percent of the First Nation inhabitants live on reserves, not in urban

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areas. In Manitoba, there are 60,000 First Nation inhabitants, 70 percent of whom live in small isolated villages in the north. Prevalence data from the 1990s from three regional diabetes registries all show type 2 diabetes prevalence between 1.7 per 1000 and 2.5 per 1000. Among three youth populations screened in the mid-1990s, prevalence rates averaged around 16 per 1000, that is, about 10 times higher than the prevalence rates from the registry data.

Dr. Dean identified four research priorities for future investigations: (1) Development of standard diagnostic criteria; (2) use of standard age groups (e.g., 0–4, 5–9, 10–14, 15–19); (3) universal differentiation between type 1 and type 2 diabetes in registry databases; and (4) acceptance of standardized, uniform methods for large-scale, population-based screening. She stressed that in screening initiatives in large populations, the protocols may have to be more practical (e.g., capillary blood glucose vs. drawn blood, random blood glucose instead of fasting blood glucose).

Dr. Linder also cited clinical reports from Dr. Dan Hale, Associate Professor of Pediatrics at the University of Texas Health Science Center at San Antonio, Texas. Of 669 pediatric patients seen by Dr. Hale and another practitioner between 1990 and 1998, 512 (77 percent) had type 1 diabetes; 123 (18 percent) had type 2 diabetes; and 34 (5 percent) had other types, such as unclassified, atypical, and maturity-onset diabetes of youth. During this time, there was been a steady rise in the number of Mexican American type 2 diabetes pediatric patients, from approximately 2 per year to up to 30 per year. A similar rise in type 2 incidence in the African American and, only most recently, in the white communities has occurred. For the past 3 years, about 40 percent of the new pediatric diabetes diagnoses have been type 2, a substantial increase. Dr. Hale's data also show that although 100 percent of diabetic Mexican American children aged 5 or under have type 1 diabetes, 74 percent of all new diagnoses among Mexican American children over 15 years old are for type 2 diabetes. A similar type 1/type 2

distribution is seen among African American children; a lesser trend is seen among whites.

Another small survey conducted by Dr. Hale was based on data obtained through screening of about 1,500 children at three public middle schools in San Antonio. Nearly 60 percent of children surveyed had a family history of diabetes; 40 percent of the boys and 27 percent of the girls had a BMI greater than the 95 percentile; 29 percent had fasting hyperinsulinemia; 19 percent had acanthosis nigricans; 7 percent had impaired fasting glucose; and 1 percent had undiagnosed diabetes (presumably type 2). These children also had an adverse risk profile for coronary artery disease. Approximately 50 percent had elevated total cholesterol; 29 percent had a family history of hyperlipidemia; 27 percent had elevated triglyceride levels; 11 percent had a family history of myocardial infarction under the age of 50 in a parent or grandparent; 8 percent had low HDL cholesterol; 7 percent had high LDL cholesterol; and 3 percent of the girls and 15 percent of the boys had diastolic blood pressures greater than the 95 percentile for their age.

Dr. Linder summarized findings of a study by Dr. Lawrence Dolan, of the Children's Hospital Medical Center of Cincinnati, which included data on 128 pediatric patients diagnosed with type 2 diabetes between 1992 and 1998; the study population is predominantly African American and female. As of December 1998, the overall prevalence of type 2 diabetes for the greater Cincinnati area was 0.14 per 1,000 (0.014 percent) for children up to 19 years old; the children with type 2 diabetes tend to be female, African American, and in older adolescence (aged 15 to 19). The overall incidence rate of type 2 diabetes increased greatly during 1992 and 1994; since then, the incidence rate has been relatively stable. Overall, Dr. Dolan's data show the average age for children with type 2 diabetes is 15.1 years, which does not vary much by gender or race. The average BMI is 36.3 (again no real difference by gender or race). Acanthosis nigricans is present in 71 percent of the population (African Americans, 82 percent; whites, 54 percent).

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Many of these children exhibit complications common to type 2 diabetes, including blood pressure above the 90 percentile (corrected for age and height) in a fair number of the 66 patients for whom data were available; a statistically significant relationship between systolic pressure and BMI was observed. Further, among 27 patients tested, 23 (85 percent) had at least one lipid abnormality (elevated LDL, triglycerides, or cholesterol; or low HDL): 14 among 17 of the African Americans (82 percent) and 9 among 10 (90 percent) of the non-Hispanic whites. Among the 11 children with type 2 diabetes whose albumin excretion rate was checked to screen for diabetic nephropathy, 3 (27 percent) had elevated excretion rates (greater than 20 g/min as measured by timed overnight urine collection), signaling possible incipient nephropathy. Ophthalmologic abnormalities, such as retinopathy, were not seen in this population.

Dr. Dolan reported during the July 1999 DMICC meeting that within the diabetes center at the Cincinnati Children's Hospital, there has been no change over time in the diagnostic criteria for type 2 diabetes, the ethnic pattern of referrals, or the referral patterns by the practicing physicians. However, Dr. Dolan asserted that the hospital's patient database is probably a significant underestimate of the overall type 2 pediatric diabetes disease process. Evidence for this statement included Dr. Dolan's review of the chief complaint of patients on hospitalization: only 59 percent had the classic symptoms of polyuria and polydipsia; 40 percent had nonclassic symptoms, and 13 percent presented only with a positive urinalysis for glucose, obtained during a routine physical examination.

Dr. Linder similarly highlighted results of studies conducted by Dr. Silva Arslanian, Professor of Pediatrics at Children's Hospital of Pittsburgh. In one series of experiments, a hyperglycemic clamp was used to compare the amount of insulin secreted over 120 minutes while blood glucose was clamped at a constant, hyperglycemic level of 225 mg/dL in a group of healthy African American and white adolescent volunteers. Data showed that for the

same glucose level, African Americans on average secrete significantly more insulin than do whites. From these experiments, Dr. Arslanian derived an insulin sensitivity index for each of the volunteers; insulin sensitivity was approximately 35 to 40 percent lower in the African American adolescents than in their matched white peers.

Additional experiments using CAT scans revealed that insulin sensitivity (controlling for BMI) is less in girls than in boys and is inversely proportional both to BMI and to total percent body fat. Fasting insulin levels, a marker of insulin resistance, also as expected, increase with increasing BMI, even when measured in normal nondiabetic children. Further data showed that insulin sensitivity declines (and fasting insulin levels increase) with increasing percentages of either visceral or subcutaneous fat (as a proportion of total body fat); however, the impact of excessive visceral fat was more deleterious than the impact of subcutaneous fat. Dr. Arslanian's findings suggest that the onset of puberty is associated with insulin resistance and that gender differences in insulin sensitivity need further evaluation with careful attention to body composition differences. For young children (10 years) with a family history of diabetes, insulin resistance is lower still and is seen before the onset of puberty, with peak insulin resistance occurring at 13 to 14 years of age.

Dr. Linder emphasized the collective importance of these findings, which suggest the need for accurate population-based screening among children. The key research goals identified during the July 1999 DMICC meeting included:

- Gather better population-based incidence and prevalence data in children and adolescents
- Define initial metabolic abnormalities in type 2 diabetes
- Improve our understanding of the basis for racial and ethnic disparities in diabetes
- Develop effective primary prevention and treatment regimens and strategies.

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In brief, the increasing prevalence of type 2 diabetes and related complications among young persons from childhood through their 30s, combined with the duration of the disease, signal a significant public health issue for this country that must be addressed aggressively.

### **CDC: State Programs and Tribal Peoples with Diabetes**

Dr. JoAnne Pegler, Liaison, National Diabetes Prevention Center, CDC, provided a brief overview of some of the CDC's activities that relate to diabetes in children and Tribal peoples. The CDC's primary role in health care is to take a lead in addressing public health issues. The Division of Diabetes Translation, for example, is responsible for translating diabetes research findings into practice and disseminating this information as extensively as possible. Part of the CDC's role in addressing public health issues also involves efforts to close gaps in health disparities. The CDC has a long-standing relationship with IHS and is a partner with IHS in providing health-related services, in the new Diabetes Prevention Centers (at the University of Mexico, 1 Tribal college, and other locations), and the U.S./Mexico Border Project. The agency also oversees diabetes programs in all 50 States. Dr. Pegler announced that the CDC, in conjunction with the NIH, expects to release an RFA focused on type 2 diabetes in children sometime in late summer or fall 2000. The CDC also is sponsoring a regional conference on type 2 diabetes in children in New Mexico from August 28 through 31.

### **NDEP: American Indian and Alaska Native Programs**

As Dr. Yvette Roubideaux, Clinical Assistant Professor, College of Public Health, University of Arizona, explained, the National Diabetes Education Program (NDEP) is a joint program of the CDC and NIDDK/NIH that includes public and private sector partners. The initial NDEP was challenged with developing educational messages that would reach diverse cultures. In the face of that challenge, the Program established several special work groups, including the American Indian Work Group, to assist the larger NDEP in disseminating important research findings and developing culturally appropriate diabetes education messages and products. Other work groups focus on issues unique to African Americans, Hispanic Americans, and Asian Americans/Pacific Islanders.

The NDEP American Indian Campaign has developed special messages intended for American Indians and Native Alaska populations using a broad-based media campaign that includes television, radio, print materials, community partnerships, the Internet, and toll-free telephone access. Key messages include "Control your Diabetes. For Life" and "Control your Diabetes for Future Generations." The campaign materials have been distributed to all 333 Indian health grant programs, and the program has received awards for the TV spots.

Continuing challenges include the increasing burden of diabetes in Indian populations; increasing demands for educational materials; the increasing need to reach out to children, families, and communities; continuing development of creative, informative resources, products, and messages to disseminate; and identifying resources to evaluate campaign outcomes.

More immediate future activities of the NDEP American Indian Campaign are the continued dissemination of current materials and the development and expansion of a youth focus for children aged 12 to 18 years.

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**ADA/American Indian Program—  
Awakening the Spirit: Pathways to Diabetes  
Prevention and Control**

Ms. Lorraine Valdez, Nursing Consultant, IHS National Diabetes Program, described the ADA's American Indian Program, "Awakening the Spirit—Pathways to Diabetes Prevention and Control." This program, developed by Native Americans in partnership with volunteer ADA Diabetes Educators and the ADA Native American Program Design Team, was established in 1997 and launched in 1999 with a Powwow attended by more than 200. The main messages of the program are "Strong in Body and Spirit" and hope that diabetes mellitus can be delayed or prevented. The program's primary goals and objectives include disseminating messages, providing interventions to ADA staff and Tribal communities, developing working relationships with ADA and others, and increasing awareness among Tribes of ADA as a resource and partner. Ms. Valdez noted that early stages of the program were described through a series of articles in the ADA magazine, *Diabetes Forecast*.

**Future Directions: Type 2 Diabetes in American Indian and Alaska Native Children**

Drs. Garfield and Spiegel thanked the presenters and attendees for their participation, time, and input. Dr. Spiegel then noted several upcoming NIH activities, including the July 18th meeting on the possibility of developing and implementing a National Kidney Disease Education Program (NKDEP) that would mirror the NDEP and similar programs; the upcoming release of several RFAs for research on type 2 diabetes; and NIH's development of a strategic plan to reduce health disparities, of which NIDDK's plan emphasizing diabetes and obesity is a significant component.

Mr. Buford Rolin offered concluding remarks on behalf of the Tribal Leadership Support Group. Recognizing the integral role of partnerships in improving health care, he thanked all who attended the meeting and expressed interest in continued efforts to work together to eliminate the devastating effects of diabetes.

**Adjournment**

Dr. Allen Spiegel adjourned the meeting at 4:20 p.m.



**Diabetes Mellitus Interagency Coordinating  
Committee (DMICC) Meeting**

*Federal Implementation of the Diabetes Quality  
Improvement Project (DQIP)*

January 14, 2000

8:30 am–4:00 pm

Holiday Inn–Bethesda

Bethesda, Maryland

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**PARTICIPANTS**

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Agency for Healthcare Research and Quality

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**Philip Sheridan, MD**

National Institute of Neurological  
Disorders and Stroke

**Elizabeth Warren Boulton, RN, MSN**

Hager Sharp

**SPEAKERS**

**Kelly Acton, MD, MPH**

Indian Health Services

**John Eisenberg, MD**

Agency for Healthcare Research and Quality

**Barbara Fleming, MD, PhD**

Health Care Financing Administration

**Sheldon Greenfield, MD**

New England Medical Center

**Roland Hiss, MD**

University of Michigan Medical School

**Richard Kahn, PhD**

American Diabetes Association

**Leonard Pogach, MD, MBA**

Department of Veterans Affairs

**Frances Stewart, MD**

Department of Defense

**Dorothy Tucker, MBA, MSW, MA**

National Committee for Quality Assurance

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## Welcome and Introductions

Richard Eastman, MD, Chairman, Diabetes Mellitus Interagency Coordinating Committee (DMICC), and Director, Division of Diabetes, Endocrinology, and Metabolic Diseases, National Institute of Diabetes and Digestive and Kidney Diseases (NIDDK), National Institutes of Health (NIH), welcomed all in attendance. He noted that Dr. Nancy Miller from the NIH Office of the Director and Dr. Allen Spiegel, the newly appointed NIDDK Director, were unable to attend the meeting.

## Overview of the Meeting

Barbara Fleming, MD, PhD, Senior Clinical Advisor, Health Care Financing Administration (HCFA), provided a brief history of the Diabetes Quality Improvement Project (DQIP), which has developed into a collaborative effort to improve the care of diabetes and the quality of life for patients with diabetes. DQIP's initial goals in striving to improve care include the development of a single set of comprehensive performance measures for diabetes from which national standards could be identified, the ability to compare standards of care across multiple health settings, and the identification of best practices that then could be disseminated throughout the health care community.

The three key points to understanding DQIP are that the DQIP measures (1) are not guidelines but rather performance measures that serve as indicators to assess care and provide a strategy for accountability, (2) have more rigorous criteria than do guidelines, and (3) are in wide use in a variety of health care plans and settings. Approximately 400 managed care plans in the commercial and Medicare markets will be collecting and publicly reporting DQIP measures data in the year 2000. In addition, HCFA is collecting data on three of the DQIP measures in fee-for-service plans that have contracted with Medicare for all beneficiaries in all 50 states.

In 1997, HCFA assembled a core group of producers and users of diabetes performance measures and provided funding for DQIP. The DQIP Steering Committee included HCFA, the Department of Veterans Affairs (DVA), the American Diabetes Association (ADA), the American College of Physicians (ACP), the American Academy of Family Physicians (AAFP), the Foundation for Accountability, and the National Committee for Quality Assurance (NCQA). The Steering Committee selected 15 experts in diabetes and measure methodology who, under the leadership of Dr. Sheldon Greenfield of the New England Medical Center, produced the DQIP measures for diabetes care for patients aged 18 to 75 years. These measures, developed using three major criteria—evidence to support the measure; ability to collect the measures feasibly, accurately, and reliably; and existing variability among physicians and practices in performance of the measures—include:

- Hemoglobin A1c (HbA1c) tested
- Poor control (HbA1c>9.5)
- Eye exam performed
- Lipid profile performed
- Lipids controlled (LDL <130 mg/dL)
- Kidney status monitored
- Blood pressure controlled
- Foot exam performed

More than 200 individuals or groups provided comments on this set of eight measures, which were released in August 1998. Dr. Fleming re-emphasized that the performance measures developed by the DQIP panel are just that—measures, not guidelines. They are based on both the state of evidence and the state of practice. DQIP provides a conceptual framework for the development of future measurement systems both in its approach to content and partnerships. The existence of a single set of broadly accepted performance measures allows for valid comparison of diabetes care across diverse health care settings for the first time for any disease. This strategy provides opportunities for meaningful benchmarking and accountability and enhanced quality improvement (QI) while simultaneously

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reducing burdens on physicians and providers. Growing interest in DQIP has led to the expansion of the initial DQIP partnership base, which now includes several Federal and private sector partners. Dr. Fleming noted that Health and Human Services (HHS) Secretary Dr. Donna Shalala has asked Federal agencies to commit to these measures and implement ways to collaborate on DQIP as Federal agencies. The current meeting is part of that commitment.

Six of the eight measures have been incorporated into Health Plan Employer Data and Information Set (HEDIS) 2000 and will be reported publicly for Medicare, Medicaid, and commercial plans during 2000. HCFA is using claims data to generate three measures that can be obtained for all beneficiaries in the fee-for-service setting. A variety of other organizations and agencies also are using the DQIP measures. In addition, HCFA, the ADA, and the American Association of Health Plans have developed extensive materials in support of DQIP, including standardized software and paper collection tools, a data analysis package, training materials, and QI tools.

Results of the New York State PRO Pilot Study, which is examining the performance of measures in different health care settings, found that an average of 37 percent of diabetics had their blood pressure under control, 42 percent received foot exams, 41 percent received eye exams, and 34 percent were monitored regularly for nephropathological changes. The overall results of this pilot study indicate that there are many opportunities for improvement in delivery and receipt of care and that care varies considerably across HMOs and fee-for-service vendors. The Minnesota PRO, which covers older Medicaid patients in eight plans within the state, also is monitoring DQIP measures. One interesting finding was that a relatively high proportion of diabetics (mean of 72 percent) received an A1c test during the reporting period. However, data also show that approximately 39 percent of diabetics tested had an A1c level greater than 9.5.

DQIP is an ongoing process that will continue to evolve and develop as changes and advances in evidence and practice occur. Data collected thus far show room for improvement in all measures. HCFA is funding DQIP 2.0, which includes a re-evaluation of the current DQIP measure set that will accommodate changes based on new, compelling data and the state of practice for diabetes care.

### **DQIP: A Translation of Research into Practice**

John Eisenberg, MD, Director, Agency for Healthcare Research and Quality (AHRQ, formerly the Agency for Health Care Policy and Research/AHCPR), and Operating Chair, Quality Interagency Coordination (QuIC) Task Force, opened his presentation by recognizing that historically there have been few standardized, validated performance measures for diabetes. However, DQIP has helped to address this gap by using a “bench to benchmarking” approach in developing a set of standards for practice. The DQIP program represents the translation of research into practice. Biomedical research and clinical trials sponsored by NIH led to outcomes and effectiveness research sponsored by AHCPR, including the Diabetes Patient Outcome Research Team (PORT) at New England Medical Center. These studies documented the relationship between process of care and outcomes in diabetes, and led to the design of performance measures that were tested by HCFA’s PRO program.

As stewards of public money, HCFA and other Federal agencies are using DQIP to bring together and establish new partnerships to amplify the program’s message and as leverage to move the health care system and, thus, patient care forward. The various Federal agencies involved in DQIP have different roles in this and other health care efforts. The Federal Government plays many roles in health care quality that are exemplified by DQIP—conducting and sponsoring basic and clinical research (e.g., NIH), sponsoring and conducting health services research (AHRQ), delivering services (e.g., DVA), purchasing services (e.g., HCFA, Office

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of Personnel Management, Indian Health Service [IHS], regulation (Food and Drug Administration [FDA]), and surveillance and public health (Centers for Disease Control and Prevention [CDC]). DQIP provides a mechanism to bring together these activities not only within the Federal system but also across the private sector.

The QuIC was established by President Clinton to enable Federal agencies with health care responsibilities to coordinate their activities to:

- Measure and improve quality of patient care
- Provide beneficiaries with information to assist in making choices regarding care
- Develop the infrastructure needed to improve the health care system

QuIC participants include DVA, Department of Defense (DoD), several divisions of HHS, the Department of Labor (which regulates OSHA and ERISA), OPM, the Office of Management and Budget (OMB), the Coast Guard, the Federal Bureau of Prisons, the Federal Trade Commission, the Commerce Department, and the National Highway Transportation and Safety Board (NHTSB). Interagency coordination is expected to assist in identifying and implementing evidence-based, validated performance measures, including measures for diabetes care, and eliminating redundancy and overlap across agencies. To that end, the QuIC Task Force has focused on efforts to improve quality care among patients, emphasizing performance practice measures in the following areas:

- Diabetes care (QuIC's first major project for interagency collaboration)
- Evaluation of common guidelines for care between DVA and DoD
- Conferences to identify successful strategies
- Agreement among Federal agencies to collect, compare, and report the performance of providers with respect to DQIP measures

- Depression diagnosis and care
- Reduction in medical errors
- Evaluation of the effects of working conditions on quality of care provided by health care workers

The QuIC Task Force will continue to take steps to demonstrate how DQIP improves patient care and quality of care.

### **DQIP: A History and the Measures**

Sheldon Greenfield, MD, Professor of Medicine, Tufts University School of Medicine, New England Medical Center, provided a "case study" of DQIP as a collaborative effort — involving HCFA, ADA, AAFP, DVA, CDC, NCOA, and ACP — to develop a comprehensive set of measures for diabetes. He emphasized the importance of gathering data and support for DQIP before the project was formally launched by multiple agencies and the private sector. He cited Drs. Eastman, Fleming, and Kahn as instrumental in this effort.

The primary features of DQIP measures were outlined by Dr. Greenfield. As he explained, the measures and DQIP itself:

- Are comprehensive and cover all aspects of diabetes and diabetes care
- Emphasize both process and outcome and strive to identify the optimum process to achieve the best patient outcomes
- Identify risk according to case mix and subgroups, based on both frequency of a measure within a certain population and threshold variation
- Address accountability (i.e., for what can physicians fairly be held responsible) and improvement (i.e., seek continuous improvement in patient care and status by setting goals higher)
- Are "politically" sensitive within the context of diverse clinical setting, practices, and health care delivery systems

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DQIP measures may be used as potential predictors, or as a gradient, of risk for adverse conditions associated with diabetes. Following this general background, Dr. Greenfield provided data and applications of several of the eight DQIP measures. For example, for the HbA1c test, which indicates glycemic control, providers are expected to report the percentage of patients receiving at least one test during the reporting year, the percentage of patients whose most recent HbA1c level is greater than 9.5 percent, and the mean and distribution of patients with HbA1c levels in five categories (<7.0 percent, 7.0–7.9 percent, 8.0–8.9 percent, 9.0–9.9 percent, >10 percent). The first two reporting values allow for accountability, whereas the third serves as a mechanism to track internal QI.

Another DQIP measure involves tracking the percentage of patients receiving an eye exam (as a proxy for a dilated eye exam) by an eye care professional (i.e., optometrist or ophthalmologist) in the reporting year, or in the year prior to the reporting year if the patient meets two of the following criteria: is not taking insulin, has an HbA1c less than 8.0 percent, and/or has no evidence of retinopathy in the previous year. Implementing this measure should improve patient outcome and provider accountability as well.

Monitoring serum lipids involves collecting information on the percentage of patients receiving a lipid profile test during the reporting year or prior year and the percentage of low-risk patients whose most recent LDL is less than 130 mg/dL; these measures allow for accountability.

Urine proteins are used to monitor diabetic nephropathy based on either the microalbuminuria test or medical recognition of nephropathy, which requires certain criteria to be met. These measures are designed to promote accountability among providers.

The DQIP accountability measure for blood pressure involves tracking the percentage of patients whose most recent blood pressure reading is <140/90.

Tracking foot care and foot examinations remains a challenge in large part because such aspects of care

of diabetic patients are not documented regularly by doctors in patients' charts. In addition, controlled studies of foot care in diabetics are absent. A patient survey is being field tested to evaluate the DQIP measure of a regular foot examination.

In summary, eight DQIP measures were finalized in 1998; the complement of patient-derived measures is expected to be finalized in 2000. These measures may be revised, and other measures (e.g., immunizations, education, functional status, satisfaction) may be added over time, pending new evidence and/or improved practices. The current DQIP measures are comprehensive and continued success and improved quality will require collaborations among agencies and between the public and private sectors.

### **DQIP and the Private Sector (Part 1)**

Richard Kahn, PhD, Chief Scientific and Medical Officer, ADA, highlighted the ADA's Recognition Programs, which have served as vehicles for the development and implementation of standards of care and measures for diabetes care. In the early 80's, the diabetes community began efforts to develop "National Standards for Diabetes Education." This effort received its primary support through the now-defunct National Diabetes Advisory Board. In 1986, the ADA launched its "Education Recognition Program." Over the next 1 to 2 years, the ADA began development of clinical practice recommendations, and in 1988, released the first standards of medical care for persons with diabetes.

In 1993, the Association convened a task force to determine whether diabetes quality care could be assessed in a doctor's office. The task force decided that such an assessment was possible, by reviewing medical records from physicians' offices to determine adherence to the standards of care. The task force also recommended that the ADA establish a program to recognize professionals who were meeting the medical standards.

The issue of assessing delivery of care within a practice was revisited in 1995, when the Association

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distilled the somewhat lengthy, narrative standards into a list of approximately 150 action items. The 150 bulleted items were distilled further into 12 measures, and ADA evaluated the measures by conducting a study at 29 difference practice sites around the country. An evaluation of the study data resulted in a total of 11 measures being adopted as part of a newly implemented "Provider Recognition Program." As Dr. Kahn noted, there is considerable overlap between the original 11 ADA measures and the current DQIP measures. The original 11 ADA measures (annual unless noted otherwise, depending on patient-specific criteria) include Hb1Ac (proportion of patients at <8 percent or > 9.5 percent), eye exam within the past year, annual foot exam, blood pressure (proportion < 140/90), nephropathy assessment within the past year, lipid profile (proportion with LDL <130 mg/dL) within the past year, tobacco status and counseling, self-management education, medical nutrition therapy, self-monitoring of blood glucose, and patient satisfaction. The first seven of these measures were similar to the current Diabetes Quality Improvement Project measures. All measures are weighted, for a total possible maximum score of 110 points; a score of 82 or better is needed to achieve ADA recognition. Recently, however, ADA modified its measure to be entirely consistent with DQIP's measures.

The ADA's Provider Recognition Program (PRP) was launched in February 1997. Approximately 1,400 doctors at 200 sites across the country have been recognized by ADA; about 35 percent of the physicians are generalists, and 65 percent are specialists. An additional 2,000 plus practices have requested applications for the PRP. The program is voluntary and offers no financial incentives to participate or achieve recognition. The future goal of the PRP is to provide a "carrot" for provider QI. Dr. Fleming stated that HCFA will be assessing thousands of practices based on HEDIS and DQIP measures; the PRP is an advantage for those who follow measures. HCFA is also looking to develop a reward or incentive program through Medicare. Dr. Kahn estimates that some 5,000–10,000 physicians across the country could qualify for PRP.

## **DQIP and the Private Sector (Part 2)**

Dorothy Tucker, MBA, MSW, MA, Senior Health Care Analyst, NCOA, reported on NCOA's accountability program regarding DQIP measures. As Dr. Fleming noted, NCOA has played, and continues to play, an important role in encouraging private health care vendors and providers to implement DQIP measures and to establish an accountability system using these measures to improve patient care. NCOA's partnership of managed care plans, public health professionals, patient advocates, and others also monitors and tracks improvements and problems within the health care system. The Committee is part of the Performance Measurement Coordinating Council, which is involved in collaborative efforts to reconcile clinical guidelines and recommendations. This Council includes NCOA, the Joint Commission on Accreditation of Healthcare Organizations, and the American Medical Accreditation Program and started out in the area of diabetes on the strength of DQIP. Application of DQIP in practice, in health plans, and in the acute care setting are among the Council's goals for guiding and improving diabetes care.

NCOA's two core products include accreditation, defined as an assessment of the core systems within managed care plans on which high-quality care and services depend, and HEDIS, through which NCOA uses six of the eight DQIP measures to assess actual results achieved by health plans. Accreditation includes onsite reviews and surveys of health plans based on specific criteria and expectations around standards, infrastructure, processes, and systems. Through recent initiatives and the addition of new measures, NCOA can now assign plans with commendable and excellent accreditation. Accountability, as measured, for example, through public health statistics and comparisons across health care plans, is the key foundation of NCOA's activities in its interactions with private health care providers. NCOA has found wide variations in performance and measures, often on a regional basis. The Committee currently is focusing on understanding the factors driving these differences (e.g., provider education,

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standard practice, socioeconomic issues) and identifying and developing policies that address and would reconcile such disparities.

NCQA's accreditation and accountability are integrated with HEDIS measures and statistics. Ms. Tucker pointed out the NCQA currently is the only accrediting body that incorporates performance measures and plan performance as part of the accreditation. Before implementation of the comprehensive DOIP measures, NCQA included eye examinations for diabetics, among other measures not specific to diabetes care (e.g., breast/cervical cancer screening, childhood immunization), in its accreditation process.

Ms. Tucker explained that assessment of HEDIS is a continual process in that NCQA and others examine and re-examine HEDIS data to determine the feasibility and ease in obtaining data, assess a plan's past and current performance, and identify changes in clinical practice and, where possible, patient outcome. Ms. Tucker noted that HEDIS improves accountability and makes accountability more efficient, allows health plans to track performance over time, is informative regarding health care contracting, and helps purchasers work with plans with a focus on internal OI efforts.

NCQA's scoring for accreditation includes three main factors: clinical performance (i.e., effectiveness of care/HEDIS measures) plus results of member satisfaction surveys (i.e., the "CAP" survey) account for 25 percent of the final score, and the health plan system accounts for the remaining 75 percent. Ms. Tucker noted that the contribution of the clinical care/patient satisfaction component is expected to increase in the future.

In addition to clinical evidence, feasibility studies, and data collection, NCQA conducts field tests of several health plans over a period of 12 to 18 months to assess how well specific measures actually perform. NCQA also has produced a first-year reporting measure, which serves as a beta-test of six of the DOIP measures; in brief, a measure is released in one

year, and the comprehensive diabetes care assessment is conducted as data are collected and analyzed in the following years. Using these data, NCQA then revisits and revises its own testing, outreach, and evaluation efforts. The Committee's first-year reporting measures for six DOIP were released in 1999; reporting to this point in time has been largely voluntary, Ms. Tucker pointed out.

NCQA's *State of Managed Care Quality Report* indicates that health plans that report measures publicly, that are accredited, and that report over a period of time (e.g., 3 years or more) consistently outperform plans that do not meet these specifications. These data suggest that accountability does influence outcome and performance.

For more information about NCQA, interested parties can access the Committee's Website ([www.ncqa.org](http://www.ncqa.org)) or contact its Customer Support Line (1-202-955-5697), Accreditation Status Line (1-888-275-7585), or Publications Center Line (1-800-839-6487). Ms. Tucker can be contacted directly via e-mail at <[tucker@ncqa.org](mailto:tucker@ncqa.org)>.

## **DOIP and the Public Sector**

### *DoD*

Frances Stewart, MD, CAPT, MC, USN, Program Director, Patient Advocacy and Medical Ethics, Office of the Assistant Secretary of Defense, Health Affairs, summarized how DOIP is being utilized within DoD. One of the key components in the delivery of diabetes care by DoD is the clinical practice guidelines for primary care providers, developed in collaboration with DVA. The final draft of the diabetes guidelines was released in December 1999. Guidelines for diseases that are comorbid with diabetes, such as hyperlipidemia, tobacco use, and hypertension, have been published or are nearing completion.

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Each guideline includes evidence-based metrics, and medical treatment facilities are accountable for their results on the metrics that are included in the guidelines. Dr. Stewart noted that DQIP measures serve as the metrics in the joint DoD-DVA guidelines for diabetes.

Dr. Stewart explained that medical informatics is a rapidly changing area within DoD; further, information systems are not consistent across DoD and may not be for several years. Thus, implementing the new metrics in a changing environment is a challenge for the Department, which seeks to provide timely feedback regarding new metrics to its providers and providers. The Department is moving to place all patient records on one computer system, the CHCS II; pilot testing of this system began in February 2000. The agency expects implementation of this system will improve many features of delivery of care, including provider feedback and tracking patient care and testing.

DoD has developed a Diabetes Toolkit to improve the quality of patient care. A prototype informatics/database system was developed that would allow for metrics to be included in the doctor's progress notes, patient report cards and progress, interpretation of results, and advice for improvement. DQIP would be incorporated into this system.

DoD anticipates that the entire informatics structure, with DQIP as a component of that system, will improve performance through the process of measurement and track improvement in patient care.

#### *DVA/Veterans Health Administration*

Leonard Pogach, MD, MBA, National Program Director, Diabetes, DVA, reported on use of the DQIP measures in the Veterans Health Administration. He reported on the following major areas: how DVA currently uses DQIP measures, how DVA plans to use DQIP measures, and opportunities envisioned for the Federal sector. Since FY97, the measures have been used to track performance in each of the DVA's 22 networks. Network directors are held accountable for results of all clinical performance

measures in their performance contracts. Data are collected quarterly through independent external peer review. Other data, to evaluate demographic factors and assess QI, are automatically collected and then published in electronic reports. DVA also has incorporated the measures in the Diabetes Quality Enhancement Research Initiative, funded in FY99.

DVA plans to use DQIP measures to evaluate demographic factors and racial disparities and to influence major national translational programs of research into practice. DVA also plans to continue to use the measures in its research efforts (FY00–FY02). Efforts include cross-validation of chart audits, electronic data, and surveys; additional validation of the DQIP Survey in the veteran population; longitudinal analysis of DQIP data; provider profiling; and case mix adjustment models.

Dr. Pogach reported that for the Federal sector DVA envisions a leadership role in improving clinical care through benchmarking of data, sharing of successful practices, and continuing commitment to DQIP; advancing DQIP through collaborative efforts to pilot test new measures; implementing internal and external research initiatives; and making a correlation between DQIP and outcomes in longer term longitudinal analyses.

DVA sees potential for data sharing through MOAs, collaborative QI multiagency demonstration projects, and shared research initiatives.

Dr. Pogach pointed out that using, collecting, and tracking DQIP measures have led to improvements in all DQIP domains among VHA diabetic patients, except for blood pressure.

#### *IHS*

Kelly Acton, MD, MPH, Director, IHS National Diabetes Program, opened her presentation by noting that IHS has been measuring quality indicators of diabetes care through its annual Diabetes Care and Outcome Audit since 1986. Most of the 87 measures have been tracked since 1992, and all have been included in the audit since 1994.

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Some of the results of record audits conducted between 1992 and 1998 are presented here:

- As the prevalence of diabetes has increased, the number of records audited has increased, from approximately 7,000 in 1992 to 11,518 in 1998.
- Between 20 and 27 percent of diabetic persons diagnosed with hypertension have their blood pressure under control.
- Glycemic control, measured by HbA1c, varies by age. HbA1c levels are consistently higher among younger persons; however, a downward trend in this measure over time has been reported for all age groups. Approximately 25 percent of the diabetic population have good control (< 7.5 percent). Previously, reports simply indicated good, fair, or poor glycemic control. Starting this year, detailed results will be published and presented to providers.
- Eighty percent or more of diabetic patients are tested for proteinuria annually.
- Eye exam rates have stayed consistently at 53 to 55 percent during the several years, despite a variety of interventions.

The findings of the annual audits are being benchmarked against DQIP measures to reinforce and validate the recommendations of the IHS National Diabetes Program to perform the 87 elements and to compare and validate regional differences and national data.

#### *HCFA*

In adding to her earlier presentation, Dr. Fleming noted that HCFA is focused on the areas of measurement and improvement and is also in the process of developing a rewards and incentives package. HCFA continues to work on DQIP-based QI with the plans and PROs in all 50 states. Under one scenario, a plan is directed to develop a QI program using one DQIP measure; the plan must then show significant improvement in that measure over a 3-year period to retain its contract with HCFA. PROs are directed to track three DQIP measures among their beneficiaries,

with retention of the contract tied to the QI of the measures. Comments and suggestions on DQIP activities at HCFA should be forwarded to Dr. Fleming via e-mail (bfleming@hcfa.gov) or phone (1-410-786-6863).

Dr. Stewart then asked that attendees representing other government agencies step forward and present a summary of the status or relevance of DQIP within their organizations.

#### *CDC*

Michael Engelgau, MD, MS, Division of Diabetes Translation, CDC, stated that the CDC is interested in diabetes and DQIP for several reasons, and that CDC was involved in the early versions of HEDIS as well as in DQIP 1.0 and now DQIP 2.0 and assisted the measures subcommittee in the development of eye, foot, glycemic control (HbA1c), and kidney quality indicators and DQIP measurement sets by providing a public health perspective.

CDC has been tracking self-care, education, and eye exam measures on a state-by-state basis since 1994 through its Behavioral Risk Factor Surveillance System (BRFSS).

Other CDC-related activities or collaborations include the Diabetes Control Programs, the development of model contract language that Medicaid programs can use in negotiating with managed care companies for plans to include diabetes programs, the Association of States and Territorial Chronic Disease Program Directors, the National Diabetes Education Program, and partnerships with several non-government organizations to promote diabetes awareness and QI.

In the future, the CDC, in collaboration with NIDDK and DVA, will be focusing on TRIAD (Translating Research Into Action for Diabetes), a multicenter project initiated approximately 1 year ago. This project will include at least 10 health plans, 40 provider groups, and 15,000 patients with diabetes. Findings from TRIAD are likely to contribute to the future development of DQIP.

### QuIC

Dr. Stewart explained that thus far, QuIC has focused primarily on disseminating the current DQIP-related information and bringing new partners to the table (e.g., ADA, DVA, HCFA, DoD). Funding for QuIC efforts is very limited. QuIC's five working groups—Consumer and Patient Information, Key Opportunities for Clinical Quality Improvement, Measures, Developing the Workforce, and Information Systems—meet on an as-needed basis. The Steering Committee meets every 6 weeks. Dr. Stewart noted that the QI working group has been charged with three task areas: clinical guidelines (in the areas of diabetes, depression, and substance abuse), patient safety, and formulary issues. Once clinical guidelines are approved, they will be available to the public. QuIC meetings are open but limited to Federal employees and partners; however, the group welcomes input and feedback from the private sector.

### NIH

Philip Sheridan, MD, Program Director, Developmental Neurobiology Program, NIDDK, commented briefly on NIH's role in advancing and improving health care. In just 15 years, QI and delivery of care has moved beyond the bench-to-bedside paradigm and now includes benchmarking, implementing results of clinical trials, and increasing emphasis on clinical research training. Recent years also have seen increased interactions and collaborations among agencies regarding overall research planning and setting of strategic goals, participation in consensus conferences, and development of strategic and long-range plans with input from patient advocacy and professional organizations. The importance of multidisciplinary and multiorganizational collaborations underscores these efforts.

Dr. Sheridan continued by noting that NIH has become a more active player in the QI "movement" with departmental and Presidential initiatives on quality in place. NIH has been approached by the National Center for Health Statistics and AHRQ to solicit assistance in developing data for a report on the national quality of health care, which is due to the President in 2002.

### Afternoon Session: Brainstorming

Roland Hiss, MD, Chair, Department of Medical Education, and Director, Demonstration and Education Division, Michigan Diabetes Research and Training Center, University of Michigan Medical School, facilitated this brainstorming session, during which attendees were asked to suggest issues that should be considered further with respect to DQIP collaborations. The following list includes those suggestions.

- Benchmarking.
- Symposium on "Profiling" planned for June 2000, sponsored by Federal agencies with an interest in diabetes and to occur in association with the annual convention of the ADA.
- State-level (Diabetes Control Program) collaboration with the PROs.
- The CDC publication *Diabetes Surveillance*, last published in 1997, is available at <http://www.cdc.gov/diabetes/survl/surveill.htm>. The results of the BRFSS, which assesses preventive care practices, are published periodically in MMWR. This will probably also be the case for TRIAD.
- Ongoing DCCT followup, which includes the DQIP measures.
- Translational research on DQIP implementation.
- DQIP use within Federal agencies to highlight successes and problems.
- Data sets from agencies who have them made available for study.
- CDC publication of state and regional data.
- Continuous sharing of DQIP data between Federal agencies. (The subsequent discussion suggested that this be accomplished by periodic additions to the DMICC Webpage.)
- Each agency should prepare its own "report card."

- DQIP Operating Committee continually look at the experience of DQIP implementation and change or add to the DQIP measures as indicated.
- DMICC Website posting of Federal agency DQIP data.
- QuIC continuous analyses of DQIP data.
- NCHS develop a QI model and include it in national surveys such as NHANES III or IV.
- This number was inadvertently skipped over by the facilitator (i.e., no item/activity is assigned to this number).
- Commonly shared purposes:
  - Documenting racial disparities
  - Common tools for database collection (demographics, minorities, etc.). Responsibility for conducting this activity was initially assigned to the QuIC, but subsequent discussion, noted below, assigned this to a public/private sector collaboration.
  - Reward systems that provide good care.
  - Continue to hold “best practices” conferences about every 18 months.
  - Annual submission of “best practices” to the combination of HCFA, ADA, and AAFP (as was done in association with the Millennium Conference of August 1999), with HCFA taking the lead.
  - Increase the role of other Federal agencies in the research agenda beyond the “usual suspects.”
  - Benchmark the U.S. population through NHANES III.
  - DQIP update at each DMICC meeting and integrate DQIP activities into whatever the main topic for discussion is at each meeting.

## Summary and Next Steps

### *Recommendations and Their Implementation*

#### **First-Tier (Top) Activities**

The meeting attendees were asked to place a checkmark (vote) next to four items from the discussion list that they thought were the most important. The list below contains the items that received either four or five votes and notes the subsequent discussion at the summary session concerning responsibility for followup or implementation of these activities.

- *DCCT followup* (former #5). This has been under way for some time and will continue. It is an activity of the NIDDK.
- *DMICC Website, for posting of DQIP data from Federal agencies* (former #13). The DMICC is organized and directed by the NIDDK and that agency will establish DQIP data on its Web site <http://www.niddk.nih.gov/federal/dmicc.htm>.
- *Common database tools* (former #17b). This was thought to be the most important “next step” activity, as currently each agency has its own rules and format for its database and a common merging of DQIP data, or data from any other categorical diseases, would be problematic without a common understanding of definitions, scope, format, and other relevant information. During the discussion, a public/private sector collaboration was established that would involve the DMICC, QuIC and the ADA, with the ADA taking the lead responsibility.
- *Benchmark the U.S. population during NHANES III and beyond* (former #21). Responsibility for NHANES rests with the NIDDK, CDC, and CHS.

## Second-Tier Activities

The following activities received three votes from meeting participants.

- *Translational research concerning DQIP issues* (former #6). Discussion of this item bogged down with confusion over definition as to whether this meant establishing a research agenda or funding and conducting such research. Resolution of this question was postponed to the next DMICC meeting, where it will be placed on the agenda.
- *DQIP Operating Committee followup* (former #12). This activity is already being done with recommendations made to the QUIC.
- DQIP update at each DMICC meeting and also at each QuIC meeting (former #22). Minutes of these meetings will be posted on the DMICC Website for the benefit of all interested parties.
- Documenting racial disparities (former #17a). The NIDDK indicated that data concerning hemoglobin A1c and blood pressure would be obtained through future NHANES activities. The definition of minority status and agreement on how to report racial disparity information was assigned to the “database” project to be undertaken by the public/private sector collaboration (see above).

A ranking of pertinent barriers and opportunities facing DQIP collaborations can be found below.

### Next Steps

In sum, attendees agreed that the basic overarching, guiding principle for implementing these strategies and recommendations is a basic commitment across the health care system to use DQIP measures for the assessment of diabetes care.

It was suggested that progress reports on DQIP top priorities be presented at a future DMICC meeting; data and progress reports also might be placed on the DMICC Website, possibly in spreadsheet format. Attendees also requested that DMICC-related progress reports be presented to the QuIC Executive Committee.

## Issues Concerning DQIP Collaborations

*Ranking value of:*

*1 = 3 points, 2 = 2 points, 3 = 1 point*

Points	BARRIERS
12	Insufficient staff and related resources <i>Ranking: 1+1+1+1</i>
4	Lack of single easily accessible database <i>Ranking: 3+2+3</i>
2	Concerns about value/validity of DQIP <i>Ranking: 2</i>
5	Variable support/interest within agency <i>Ranking: 2+2+3</i>  Diabetes not a high priority within agency
2	Tradition of agency independence <i>Ranking: 3+3</i>  Waiting for rest of package before implementing  Concerns re “report card” effect
4	Lack of communication mechanism between agencies <i>Ranking: 2+2</i>  Lack of communication within agency
3	Write in: Sustainable effort <i>Ranking: 1</i>
1	Write in: “Quality improvement” not traditionally within NIH mission. NIH does not deliver health care <i>Ranking: 3</i>

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**Points    OPPORTUNITIES**

- 3**    To learn of the successes/problems other agencies are experiencing  
*Ranking: 1*
- 17**    To promote better diabetes care within agency and the country  
*Ranking: 1+1+1+1+1+2*
- 5**    To define and quantify racial disparities  
*Ranking: 1+2*
- 3**    To map geographic variation  
*Ranking: 3+2*
- 1**    To collaborate on DOIP-related projects  
*Ranking: 3*
- 1**    To demonstrate agency commitment to diabetes  
*Ranking: 3*
- 1**    To acknowledge/reward exemplary care within agency  
*Ranking: 3*
- 3**    To identify need for improvements within agency  
*Ranking: 2+3*
- 5**    To work collaboratively with other federal agencies  
*Ranking: 3+2+2*

To work collaboratively with private health plans
- 2**    Write in: Develop methods  
*Ranking: 2*
- 1**    Write in: Develop information system  
*Ranking: 3*
- 2**    Write in: To understand basis of low quality, develop interaction strategy  
*Ranking: 2*
- 1**    Write in: Prioritize a research agenda  
*Ranking: 3*



# **A PROGRESS REPORT FROM THE NATIONAL DIABETES EDUCATION PROGRAM**

*Prepared for the Diabetes Mellitus Interagency Coordinating Committee*

## **INTRODUCING THE NATIONAL DIABETES EDUCATION PROGRAM**

The National Diabetes Education Program (NDEP) conducts nationwide education and awareness activities to help reduce the morbidity and mortality from diabetes and its complications. The program was launched in June 1997 in response to scientific evidence that improved management of diabetes can significantly reduce the toll of the disease.

The NDEP is cosponsored by the two leading Federal agencies with responsibilities in the area of diabetes: the National Institute of Diabetes and Digestive and Kidney Diseases (NIDDK) of the National Institutes of Health and the Division of Diabetes Translation, Centers for Disease Control and Prevention (CDC). The NDEP functions as part of the Diabetes Mellitus Interagency Coordinating Committee (DMICC), which includes representatives of other Federal Government agencies involved in diabetes-related activities.

The NDEP supports two major Federal Government initiatives: the President's Initiative on Race, which aims to eliminate racial disparities in health access and outcomes; and the Healthy People 2010 initiative, which establishes health objectives for the Nation in the 21st century. Diabetes is a priority health problem in both of these programs and NDEP strategies support their objectives.

The NDEP aims to change the way diabetes is treated—by the media, by the public, and by the health care system. Program audiences include people with diabetes and their families, health care providers, payers and purchasers of health care, health care system policy makers, and the general public. More than 200 public and private sector organizations participate as NDEP partners by helping to plan and implement diabetes education activities. In three short years since its inception, NDEP messages have reached more than 180 million people through nationwide campaigns and community awareness strategies. This report recounts the development of NDEP and highlights its many accomplishments in support of its goal.

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## WHY A NATIONAL DIABETES EDUCATION PROGRAM?

### Diabetes Is a Serious and Growing Health Problem

Diabetes is universally recognized as a major public health problem in the United States — and an emerging epidemic that threatens to worsen during the 21st century. The sixth leading cause of death by disease, diabetes exacts a severe toll as the leading cause of adult blindness, kidney failure, and non-traumatic lower limb amputations and as a major contributor to premature heart disease and stroke.<sup>1</sup> Statistics from 1998 listed below attest to diabetes' impact on the health of our Nation and the drain on our health resources.

#### Diabetes in the United States: Serious, Common, and Costly<sup>2</sup>

*Diagnosed:* 10.3 million

*Undiagnosed:* 5.4 million

*Incidence:* 800,000 year

Complications:

*Adult Blindness:* 12,000-24,000 new cases each year

*Kidney Failure:* 36.3 percent of new cases<sup>3</sup>

*Heart Disease:* 2-4 times higher

*Non-traumatic Lower Limb Amputations:*  
86,600 year<sup>4</sup>

*Cost:* \$98 billion/year (direct and indirect)

*Source:* NIDDK Diabetes Fact Sheet, March 1999

Current data show that the prevalence of diabetes has increased alarmingly in the past decade. Findings from a survey conducted by the Centers for Disease Control and Prevention point to a 33 percent increase in diabetes prevalence between 1990 and 1998. The increase occurred in both sexes and among all ages, ethnic groups, and educational levels. Persons aged 30 to 39 years and those with higher levels of education had the largest increase.<sup>5</sup>

Prevalence of diabetes is expected to increase 41% in the developed world by the year 2025. A number of trends are contributing to the rise in diabetes prevalence:

- **The growing prevalence of obesity in the United States.** Obesity is a major risk factor for type 2 diabetes, the most common form of the disease. The 1999 National Health and Nutrition Examination Survey (NHANES) found that 26 percent of adults are obese, up from 23 percent in the 1988–1994 NHANES Survey.<sup>6</sup> More alarming is the increase in obesity in children. An estimated 25 percent of children and adolescents are obese, an increase of 50 percent in the past 20 years.<sup>7</sup>
- **The higher prevalence of diabetes in racial/ethnic minority populations.** Diabetes disproportionately affects African Americans, Hispanic and Latino Americans, American Indians and Alaska Natives, and Asian Americans and Pacific Islanders. Compared to non-Hispanic whites, rates of diabetes are 1.7 times higher in African Americans, 1.9 times higher in Mexican Americans, and 2.8 times higher in American Indians and Alaska Natives.<sup>1</sup> In some American Indian tribes, notably the Pima Indians in Arizona, up to half of adults have diabetes. Ethnic minority populations also experience higher rates of complications and, often, have limited access to quality health care. Some minority populations, especially Hispanic Americans are among the fastest growing segments of our society.
- **The aging of the U.S. population.** Type 2 diabetes typically develops in people ages 40 years and older, and it is especially common in persons over 65 years. More than 18 percent of persons over age 65 (6.3 million people) have diabetes.<sup>1</sup> This population segment is expected to increase dramatically in the coming years with the aging of the baby boomers.

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- **The increasing prevalence of type 2 diabetes in children.** Normally a disease of adults, type 2 diabetes is becoming more common in children and adolescents.<sup>8</sup> The National Institutes of Health estimates that the percentage of children diagnosed with type 2 diabetes has risen from less than 5 percent prior to 1994 to 20 to 30 percent today.<sup>9</sup> Minority children, especially American Indian, African American, and Hispanic/Latino American children, appear to be at greater risk, particularly if they are overweight.<sup>10</sup>

### **Better Care Is Available and Makes a Difference**

In June 1993, the NIDDK announced the long-awaited results of the Diabetes Control and Complications Trial (DCCT). This landmark study proved conclusively that improved control of blood glucose levels reduced and delayed microvascular complications affecting the eyes, kidneys, and nerves in people with type 1 diabetes.<sup>11</sup> The United Kingdom Prospective Diabetes Study (UKPDS), completed in 1998, reported similar results for people with type 2 diabetes.<sup>12</sup> These two major studies form the scientific basis for the NDEP.

Fortunately, the means to achieve improved control of blood glucose levels is now available to people with diabetes and their health care providers. Advances in medical research and technology have produced an array of treatment and management tools to improve and monitor blood glucose control:

- **Self-monitoring of blood glucose (SMBG) and the hemoglobin A1c test (A1c).** These two tests have revolutionized diabetes management. SMBG enables people with diabetes to test their blood sugar on a daily basis and ascertain with a great deal of accuracy the current level of glucose in their blood. Likewise, the A1c test, which measures the average level of blood glucose over a 3-month period, allows health care providers and people with diabetes to evaluate the success of the treatment plan and work together to make adjustments as necessary.

- **Development of new oral drugs and new forms of insulin.** In previous years, only one class of drugs, the sulfonylureas, was available to treat type 2 diabetes. Now, physicians may choose from a variety of drugs that act in different ways to lower blood glucose and improve insulin usage.

Researchers have also developed new and purer forms of insulin that act more synergistically with the body and provide better day-to-day coverage. Insulin pumps, insulin pens, and other devices to improve insulin delivery make it easier and less painful for people with diabetes to manage the disease.

- **New and more effective diagnostic and treatment approaches for diabetes complications.** Major advances have been made in diagnosing and treating diabetic eye disease. Studies have demonstrated the value of angiotensin-converting enzyme (ACE) inhibitors, a drug used to treat hypertension, in slowing the progression of diabetic kidney disease. New drugs to treat high blood pressure and to control blood lipids allow physicians to be more aggressive in treating these conditions, both of which contribute to excess mortality from heart disease in people with diabetes. In addition, management of diabetes in pregnancy (gestational diabetes) is vastly improved. Many women with diabetes are now able to have successful pregnancies with minimum risk to themselves and their babies.
- **New guidelines for diagnosis of type 2 diabetes.** New guidelines for diagnosing diabetes, adopted in 1997, make it easier to identify people with undiagnosed diabetes and bring them into the medical system earlier. Currently, an estimated 5.4 million people have undiagnosed diabetes. Early identification and treatment of these patients will lessen the damage caused by uncontrolled high blood glucose levels.

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- **Advances in Care Are Not Being Applied.**

Unfortunately, surveys show that many of these advances in knowledge are not being applied in current diabetes care. More than half of people with diabetes have hemoglobin A1c levels above 7 percent, the level above which the risk for microvascular complications increases significantly, and more than one third have values greater than 8 percent. The hemoglobin A1c test is not widely used in clinical practice, despite its proven value in assessing the level of diabetes control.<sup>13</sup> A recent study of 345,253 Medicare patients aged 65 years and older showed that less than half of those with diabetes had annual eye examinations and less than a third had a hemoglobin A1c test every 6 months.<sup>14</sup>

A number of studies document that current care often does not meet the recommended standards for treating diabetes, screening for complications, referrals to specialists, blood glucose self-monitoring, dietary counseling, and patient education. People with diabetes themselves often neglect self-care practices because of lack of time or resources, lack of education in diabetes management, or lack of appreciation of the seriousness of diabetes.

## **PLANNING THE NATIONAL DIABETES EDUCATION PROGRAM**

The results of the Diabetes Control Complication Trial (DCCT) set the stage for a national diabetes education program. The DCCT message—good blood glucose control matters—needed to be disseminated to people with diabetes and those responsible for their care. A series of planning meetings in 1996 and 1997 laid the groundwork for the National Diabetes Education Program (NDEP).

From the outset, program planning involved a wide variety of organizations, government agencies, and professional groups with an interest in diabetes that represented each of the program's target audiences: health care professionals, payers and purchasers of health care, public health officials, and organizations and advocacy groups serving the general public and people with diabetes and their families, including a large number of organizations representing minority populations. The planning meetings resulted in the following key strategies for program implementation:

- Developing and disseminating guiding principles that promote quality diabetes care.
- Creating program partnerships with other organizations concerned about diabetes.
- Developing and implementing ongoing awareness and education activities.
- Identifying, developing, and disseminating educational tools and resources, including those that address the needs of special populations.
- Promoting policies and activities to improve the quality of and access to diabetes care.

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The National Diabetes Education Program is truly a national effort, involving both national leadership and grassroots input in all phases of planning and development. The program's sponsorship by the two major health agencies of the Federal Government, NIH and CDC, provides a firm basis of credibility, commitment, resources, links to public health agencies nationwide, and the scientific basis for the program. The program's partnerships with community and consumer groups and health-related organizations in the private sector ensure broad and meaningful input in its design, effective implementation, wide dissemination of its messages, and continued growth.

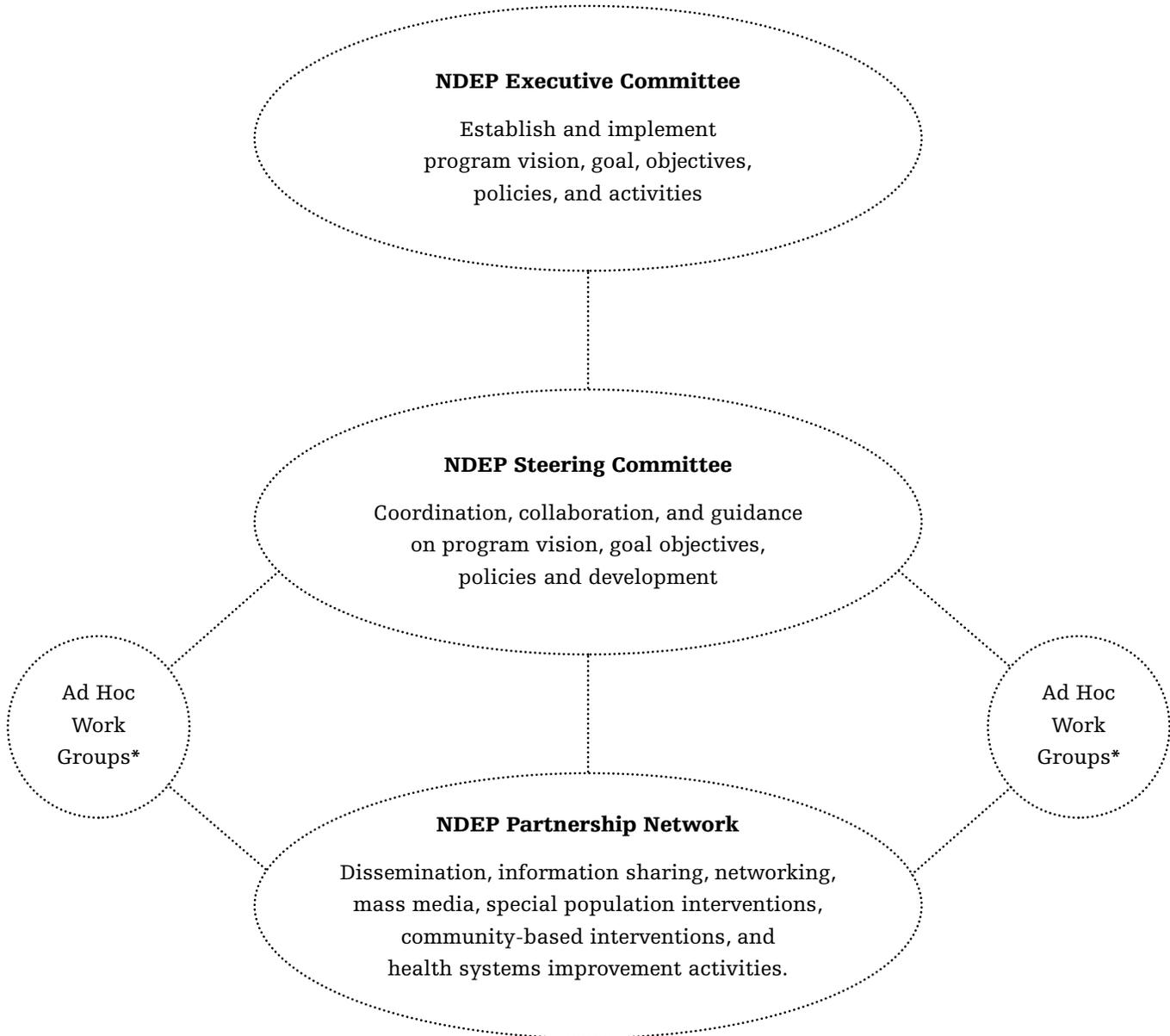
The program involves representatives from national, state, and local level organizations on its Executive and Steering Committees and on work groups that help plan and implement program strategies. (See NDEP Organizational Chart on next page.) The NDEP work groups assist in developing, implementing, and/or evaluating specific program components. Work group participants include Steering Committee members and representatives from the Partnership Network who have the necessary expertise, experience and organizational linkages to address the work group's tasks.

The NDEP Work Groups include:

- Guiding Principles of Diabetes Care Work Group
- Community Interventions Work Group, including:
  - African American Work Group
  - Hispanic/Latino American Work Group
  - American Indian Work Group
  - Asian American/Pacific Islander Work Group
- Health Care Providers Work Group
- Podiatry, Pharmacy, Optometry, and Dentistry (PPOD) Work Group
- Team Approach to Care Work Group
- Diabetes in Children and Adolescents Work Group
- Business and Managed Care Work Group
- Medicare Benefits Work Group
- Evaluation Work Group

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## THE NDEP ORGANIZATIONAL STRUCTURE



*\*Ad hoc work groups of the NDEP assist in the development, implementation, and/or evaluation of specific program components.*

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## ACCOMPLISHMENTS OF THE NDEP: 1997-2000

The NDEP was introduced to the diabetes community in June 1997 at the American Diabetes Association's Annual Scientific Meeting. In the three years since its inception, the program has:

- developed guiding principles for diabetes care;
- built a strong Partnership Network;
- reached millions with its *Control Your Diabetes. For Life.* mass media campaign messages;
- developed tools and resources for people with diabetes, health care providers, and partners;
- laid the groundwork for improving access to quality health care services.

### Guiding Principles of Diabetes Care

One of the first priorities of the new NDEP was to define broad elements of good diabetes care to meet the need for consensus in the medical and health insurance communities. The NDEP convened a work group of diabetes experts to help develop the program's *Guiding Principles of Diabetes Care*. The guiding principles were developed in English and Spanish and in two versions: a professional version for health care providers, managed care, and employers; and a lay version for people with diabetes and their families. Released in 1998, the guiding principles describe seven overarching essential components of quality diabetes care that form the basis for the NDEP's public and professional awareness program.

*The Guiding Principles for Diabetes Care* are intentionally broad. They are flexible enough to adapt to different practice settings and they accommodate the needs of individual patients. They may be used as a guide for physicians and their patients in making decisions about the diabetes management plan and they may be used by managed care organizations and employers to determine diabetes care and treatment, service options, assess quality, and establish diabetes care principles.

## Building the Partnership Network

### *The Partners*

The core of NDEP is its Partnership Network. The program's first Partnership Network meeting in March 1998 brought together about 100 potential partners, many of whom had participated in the planning meetings. Today, the network has doubled in size and is still growing. The diversity of the Partnership Network reflects the pervasive impact of diabetes and its complications on the individual with diabetes, the family, the community, the work environment, and the health care system.

### *The Role of Partners*

Partners play a crucial role in the success of the program. They help create messages and activities and disseminate them to their constituencies through local and constituent media and in community-based interventions. Partners serve on the NDEP Steering Committee and on work groups where they participate in setting priorities, identifying program needs, and developing new projects. Partners often advise program staff on special needs and are available to lend their expertise in developing materials or programs for special populations. Drawing on their contacts, they work in their communities to improve health care systems. And they seek to expand the NDEP Partnership Network by forming their own networks and encouraging others to become a part of NDEP.

### *Communicating with Partners*

Partners network with each other at partnership meetings, through work group calls, and via the electronic media, sharing information about effective approaches and new ideas. NDEP program staff communicates with partners in a number of ways:

- **Partnership Network Meetings** include technical assistance sessions, forums for exchanging information, and workshops on using new NDEP products;

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- **NDEP Program Update**, the NDEP newsletter, highlights new program and partner activities and resources; and
  - **The NDEP Website (at <http://ndep.nih.gov>)** posts up-to-date information and resources and provides links to other related organizations and programs.

#### *NDEP Resources for Partners*

NDEP has developed a variety of resources for partners such as media materials, community intervention resources, materials for businesses and employers to support diabetes control, and various tools and educational materials for health care providers and patients. All materials are copyright-free and may be duplicated as needed.

The NDEP *Campaign Guide for Partners* includes an array of media materials designed to be adapted by partner organizations for multiple purposes, depending on individual needs and situations. There are reproducible print ads and educational brochures, press releases and fact sheets, as well as ideas on how to work with the media. Partners are encouraged to add their own logos to materials and use them in creative ways.

A major resource for partners is NDEP's *Diabetes Community Partnership Guide*. The guide provides a blueprint for conducting a diabetes awareness program, with tips for enlisting potential partners, planning events, suggested activities for raising and maintaining diabetes awareness in the community, reaching goals, and evaluating the success of the program.

All NDEP materials are readily available from the National Diabetes Information Clearinghouse (NDIC) and also may be downloaded from the NDEP website. A complete list of materials and other resources produced by NDEP is included in Appendix 2.

#### *Highlights of Partner Activities*

NDEP partners have engaged in a wide range of activities to promote NDEP messages. Activities include disseminating NDEP materials through state and local health departments, placing NDEP messages on local radio and television stations, promoting NDEP at local and national health-related meetings, adapting NDEP materials into other languages, supporting a website and toll-free telephone service, helping in printing and disseminating NDEP materials, and incorporating NDEP messages and strategies into ongoing programs of their organization. Brief descriptions of partner activities are presented in Appendix 3.

To help support partner activities, six minority organizations have been awarded grants from CDC to work with the NDEP's minority work groups to help disseminate culturally appropriate diabetes education messages through community and media channels. The grantees include: the Association of American Indian Physicians, the Association of Asian Pacific Community Health Organizations, the National Asian Women's Health Organization (NAWHO), the National Council of La Raza, the National Hispanic Council on Aging, and the Urban League of Nebraska. See Appendix 3 for highlights of these organizations' activities.

#### **Raising Awareness About the Importance of Diabetes Control**

People with diabetes play a major role in controlling their disease and helping to prevent serious complications. Making people with diabetes aware of this important fact has been the key objective of the NDEP's awareness campaign. Launched in June of 1998, the *Control Your Diabetes. For Life.* awareness campaign has been designed to achieve maximum impact through targeted, efficient use of the mass media.

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The campaign has reached over 180 million Americans with radio and television public service announcements (PSAs), print ads, and newspaper stories carrying the program's messages. The ability of the campaign to achieve such national prominence within a two-year period reflects both the commitment to this effort by NDEP's many partners and the principles of effective public health education on which it is based.

- Research was conducted to assess educational needs and set priorities, and gain an understanding of the primary audiences for the campaign.
- Minority groups at high risk for developing diabetes participated in planning the campaign.
- Strategies were tailored to the intended campaign audiences.

- Campaign promotion and distribution mechanisms were selected based on their potential for reaching specific segments of the campaign's ethnically and culturally diverse audiences.

#### *Conducting Audience Research*

To help ensure the success of the awareness campaign, the NDEP sought the help of the people it hoped to reach. Focus groups were conducted around the country with diabetes patients representing the various ethnic, racial, and senior audiences for the campaign. The focus groups explored attitudes about diabetes, the language patients use to discuss diabetes, and reactions to promising educational strategies for helping patients control their disease.

#### **Milestones in the NDEP Awareness Campaign, 1998-2000**

- Campaign launch, including release of *Many Faces of Diabetes* TV PSA and first wave of Hispanic/Latino *Rayos y Truenos* PSAs, June 1998
- Launch of the African American campaign, September 1998
- Medicare Expanded Benefits campaign launched, April 1999
- Launch of Phase Two of the Hispanic/Latino *Thunder and Lightning* campaign, May 1999
- Release of TV PSAs: *Family Reunion* (African Americans), *Taking Control* (General Audience), *Future Generations* (American Indians), *Thunder and Lightning* (Hispanics/Latinos), June 1999
- Launch of the American Indian campaign, including *Future Generations* radio and print PSAs, November 1999.
- Launch of the Asian American and Pacific Islander (AAPI) campaign, including print media and radio PSAs, November 1999.
- National Association of Broadcasters disseminates TV PSAs on behalf of NDEP, June 2000

### *Minority Group Participation in Designing the Campaign*

NDEP formed Work Groups comprised of representatives of each of the race/ethnic minorities disproportionately affected by diabetes. The Work Groups' involvement was crucial to ensuring that the campaign messages were culturally sensitive and resonated with the audiences they were designed to inform and influence. The Work Groups also played a role in promoting the campaign messages to the constituencies they represent through targeted placement in local media and trusted community-based communication channels.

### *Crafting the Campaign Messages*

The use of mass media is a proven strategy for raising broad public awareness of an issue in a relatively brief period of time. Mass media campaign effectiveness depends on a number of factors, none more important than a compelling and convincing message. The message "platform" for the NDEP awareness campaign drives the development of all campaign messages: *Diabetes is serious, common, costly, yet controllable*. The hopeful element in that message platform—diabetes is controllable—has become the unifying theme for all campaign materials directed to people with diabetes: *Control Your Diabetes. For Life*. Implicit in this call to action is the recognition that people with diabetes play an important, ongoing role in managing their disease to protect their health and prevent complications.

To reach the broad, general audience of people with diabetes, the *Control Your Diabetes. For Life* campaign was launched in 1998 with "The Many Faces of Diabetes" television PSAs. These PSAs and companion posters demonstrated that diabetes affects people of every race and ethnic group. Targeted to people with diabetes over age 45, the PSAs emphasize that controlling diabetes makes a big difference in the way people feel now and in reducing their chances of complications later on.

### *Tailoring the Message for Diverse Audiences*

Based on focus group research, the central campaign message has been carefully tailored for each of the high-risk minority audiences. The result is a set of campaign materials reflecting important cultural considerations that enhance their persuasiveness with a particular audience and help motivate people with diabetes to practice good diabetes self-management.

The "Family Reunion" theme for African American audiences, for example, speaks to the importance of family support and inter-generational ties within this community. The "Future Generations" theme, designed for American Indians, emphasizes the need to protect and pass along culture and traditions. The program message to the multi-cultural Asian American/Pacific Islander audience, "Manage Your Diabetes," has been translated into eleven different languages. To reach Hispanic/Latino audiences, the NDEP developed the "Rayos Y Truenos" PSAs. These messages address the cultural barrier of fatalism and put diabetes control in context with the message that "There are certain things in life that cannot be controlled, but diabetes is not one of them."

The Balanced Budget Act of 1997 mandated new benefits for all Medicare-eligible people with diabetes. The NDEP joined forces with the Health Care Financing Administration (HCFA) to promote the new benefits and help people learn how to control diabetes. *The Medicare Benefits & Controlling Your Diabetes* campaign, launched in 1999, was developed to meet those objectives.

#### **NDEP Awareness Campaign Materials**

- Brochures for people with diabetes
- Campaign guide to encourage participation by state and local groups
- Media kits, press releases, and fact sheets
- Print ads
- Posters
- Radio and television PSAs

*Delivering the Message*

In the same way that the NDEP has tailored campaign materials to particular audiences, the Program has used targeted, highly efficient and cost-effective strategies to promote and distribute campaign messages to target audiences. Campaign dissemination strategies employ selective distribution of PSAs and print materials to media outlets most likely to reach campaign audiences. Campaigns are also timed to coincide with events of importance to key audiences.

- Campaign PSAs were distributed to media markets that have the highest concentrations of the minority audiences and the seniors for whom the PSAs were designed.
- Distribution of radio PSAs was even more targeted: stations were identified that geared their programming to specific minority groups. The “Family Reunion” radio PSA, for example, was distributed primarily to radio stations airing programs geared to the African American community.
- The American Indian campaign was kicked off in November 1999 — Native American Heritage Month as well as National Diabetes Month. “Future Generations” radio PSAs were distributed to American Indian radio stations and print public service ads were distributed to American Indian newspapers. In addition, general audience media outlets in markets with the highest concentrations of American Indians received the campaign ads.
- Latino communications firms were used to distribute the Hispanic/Latino campaign materials, ensuring that they reached appropriate media outlets such as *Univision* and *Telemundo*, two Hispanic/Latino television networks.
- The National Asian Women’s Health Organization and the Association of Asian Pacific Community Health Organizations, two community-based Asian associations, are conducting outreach to the Asian and Pacific Islander communities and distributing campaign materials to appropriate media outlets and other communication channels.

*Control Your Diabetes. For Life.* Television PSA Campaign, August 1998–May 2000

<b>Campaign Phase &amp; Coverage Period</b>	<b>Reach/ Penetration</b>	<b>Total # of Plays</b>	<b>Dollar Value</b>
Many Faces of Diabetes 8/98–7/99 (General audience PSA)	274 TV stations, 48 states, 243 cable systems	41,389	\$3,959,709
Taking Control, Family Reunion, Future Generations, Thunder & Lightning, 6/99–5/00 (4 targeted audience PSAs)	350 TV stations, 50 states, 19 cable systems	28,293	\$5,920,445
Medicare Benefits & Controlling Your Diabetes 4/99-6/99 (Senior Audience PSAs)	28 stations, 17 markets, 8 states	1,424	\$161,278
Rayos Y Truenos 9/99-10/00 (Hispanic/Latino PSA)	23 stations	4,423	\$447,779

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The success of these efforts can be measured in the numbers of materials distributed, the airplay given to the Program's PSAs, coverage in national and local print and broadcast media, and personal appearances by campaign spokespersons. Articles on the campaign, for example, have appeared in 3,360 publications with an estimated readership of over 180 million people. The campaign's achievements are also reflected in the numerous awards the NDEP has received, including the Department of Health and Human Services' (DHHS) Distinguished Program Award in May of 2000.

#### *Role of the Partnership Network in the Awareness Campaign*

The NDEP Partnership Network has contributed significantly to the success of the awareness campaign. Partners have helped identify appropriate radio stations, newspapers, and other outlets to receive campaign PSAs and other promotional materials. Many partners have become active participants in the campaign, distributing TV, radio, and print PSAs with their own local tags to broadcast stations and print media outlets. They have made presentations about the campaign to their state and local networks, obtained private sector support for reproducing campaign materials, and adapted campaign messages to reflect their communities. They also have helped translate media materials such as the news releases and print ads for the Asian American and Pacific Islander Campaign into 12 languages.

#### **Educational Tools and Resources for People with Diabetes and Health Care Providers**

Controlling diabetes is a challenge for both people with diabetes and health care providers. People with diabetes, and their support system, must assume a large part of the responsibility for managing their own care. This self-care includes following dietary and physical activity guidelines that may require major lifestyle changes, as well as monitoring blood sugar levels and taking medications, if needed, on a regular basis. The NDEP is responding to the

educational needs of people with diabetes and providers, helping to prepare them to meet their joint responsibility for diabetes control.

NDEP has developed several brochures for people with diabetes that present information and tips for controlling diabetes in simple, easy-to-understand language and in positive encouraging terms. In addition to the *Guiding Principles of Care* for health care providers, NDEP has produced a quick-reference pocket guide on current standards of care and a comprehensive kit for preventing diabetes foot problems. See Appendix 2 for a list of NDEP tools and resources.

#### **Improving Quality and Access to Diabetes Care**

Improving the quality of and access to care for people with diabetes is a major objective of the NDEP. Program strategies include disseminating information and education to health care providers, educating employers about quality diabetes care, and encouraging payers and purchasers to provide reimbursement for team care approaches that may improve the quality of diabetes care. NDEP Work Groups are playing a major role in implementing these strategies.

#### **Reaching Out to Health Care Providers**

One of the keys to improving the quality of diabetes care is ensuring that health care providers understand how to manage the disease and are aware of its implications for a variety of other conditions. Provider education and training is needed to improve diabetes outcomes.

In addition to developing educational resources such as the *Diabetes Numbers At a Glance* card and the *Feet Can Last a Lifetime* kit, the NDEP conducts a variety of other provider awareness-building and educational activities. The program has presented or exhibited at meetings of key primary care provider groups such as the American College of Physicians

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and the American Association of Family Physicians, as well as at meetings of diabetes specialists, diabetes educators, and dietitians. The response from these groups has resulted in broad support for NDEP educational initiatives.

Articles in professional journals and newsletters have also proven a highly effective way of promoting the problem of diabetes to health care providers. The most prominent example appeared in the *Journal of the American Medical Association (JAMA)* in July of 2000. Entitled "Promoting Early Diagnosis and Treatment of Type 2 Diabetes," this NDEP commentary argued persuasively for making diabetes care a national health care priority. Not only did this article reach the readers of JAMA, but it also resulted in an Associated Press wire service story that reached over 40 million newspaper readers.

### **Business and Managed Care**

Business and managed care organizations are essential partners in NDEP efforts to address issues of access and quality of care for people with diabetes. The NDEP Business and Managed Care (BMC) Work Group seeks to increase awareness of the clinical and economic benefits of quality diabetes care among employers, benefits managers, and managed care decision makers. It also promotes worksite strategies for diabetes-related health promotion and disease prevention.

As its first project, the BMC Work Group developed *Making a Difference: The Business Community Takes on Diabetes*, an NDEP publication designed to build awareness of the economic and health consequences of diabetes, and the benefits of worksite interventions to prevent diabetes-related problems. This booklet also outlines specific goals and action steps that businesses can take to support employees who have diabetes and to encourage health-promoting lifestyles among all employees. *Making a Difference* has been widely distributed among business groups, corporations and occupa-

tional health organizations, including the Association for Worksite Health Promotion and the American College of Occupational and Environmental Medicine.

### **Team Care Approach**

People with diabetes need continuous, proactive, and carefully planned care. The most realistic way of achieving such care is through the use of interdisciplinary health care teams trained in diabetes management. Team care integrates the skills of different health care professionals with those of people with diabetes and family members into a comprehensive lifetime diabetes management program.

The NDEP Team Care Work Group has generated a report, *Team Care: Comprehensive Lifetime Management for Diabetes*, which focuses on the importance of team care and the requirements for achieving it. Intended for organizational leaders in health care systems and purchasers of health care, the report provides guidelines for team care policies that will improve outcomes for people with diabetes while minimizing expensive procedures and hospitalizations.

### **Comprehensive Diabetes Care Campaign**

A new initiative to promote comprehensive diabetes care is being developed by the NDEP Health Care Providers Work Group. The initiative will focus on helping primary care providers improve their diabetes management skills to attain improved blood glucose control as well as better management of cardiovascular risk factors such as blood pressure and blood lipids. Primary care physicians, nurse practitioners, and physician assistants will be targeted by the initiative. Complementary messages will be developed for people with diabetes.

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The comprehensive care initiative will be launched in Spring 2001. In preparation for that launch, NDEP has enlisted the support and participation of key diabetes and other health care provider organizations represented on the NDEP Steering Committee. Campaign strategies include an educational campaign to promote awareness of the importance of comprehensive care and development of tools and resources to facilitate provider implementation of recommended clinical practices.

### **Pharmacy, Podiatry, Optometry and Dentistry (PPOD)**

Pharmacy, podiatry, optometry, and dentistry are areas of health care with special importance for people with diabetes. The NDEP Pharmacy, Podiatry, Optometry and Dental (PPOD) Work Group was formed in the spring of 2000 and has moved rapidly to develop a new NDEP initiative targeting providers in these areas. A plan is now in place to accomplish the following:

- Utilize PPOD delivery channels to disseminate information to increase the awareness of people with diabetes and their families about the importance of glucose control and prevention of complications.
- Increase access to and awareness of quality diabetes care for the prevention and control of complications through collaboration between PPOD and other health care providers.

PPOD providers, other primary care providers, and health service delivery systems will work collaboratively to implement the plan.

### **Children and Adolescents with Diabetes**

Under the leadership of the Children and Adolescents with Diabetes Work Group, NDEP is developing a campaign to decrease morbidity and mortality related to diabetes among these younger age groups. Directed to health care providers, the campaign has a number of objectives:

- To increase health care provider awareness of the increasing incidence of type 2 diabetes in the younger population, and disproportionate increases among special populations.
- To increase health care provider knowledge of the risk factors for type 2 diabetes in children and youth.
- To change health care provider behavior to include testing for type 2 diabetes in high-risk youth.
- To increase early diagnosis of diabetes among children and adolescents.

NDEP will partner with a number of health care provider organizations to disseminate the targeted messages and materials being developed for the campaign. The Work Group is also creating educational materials for schools and day care centers to assist them in managing children with diabetes.

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## **PRIORITIES FOR THE FUTURE**

In the coming years, the NDEP will continue to work to support the objectives of the President's Initiative on Race and Healthy People 2010. To increase awareness about diabetes, the program will continue to promote and reinforce its message that "Diabetes is serious, common, costly, yet controllable." Awareness campaigns are being planned that focus on offering social support for people with diabetes, providing healthy eating tips to Hispanics/Latinos to help control the disease, renewing efforts to reach seniors with messages about Medicare's benefits for people with diabetes, and promoting the importance of healthy eating and regular physical activity to American Indian children to help reduce their risk of diabetes.

NDEP will continue to support its Partnership Network with technical assistance tools and training sessions, meetings, and a new interactive website designed to promote information sharing. Greater emphasis will be placed on developing NDEP activities with partners and fostering mutually beneficial relationships.

As new biomedical research on management of diabetes emerges, the NDEP will translate that science for primary care providers and people with diabetes alike. An immediate priority is to expand the program's blood glucose control message to include rigorous control of the key cardiovascular risk factors of blood lipids and blood pressure, as demonstrated by the UKPDS and other recent studies. In addition, the program will implement its plans for disseminating important new information about the emerging problems of type 2 diabetes in children and adolescents. Data from ongoing NIDDK clinical trials and research will need to be released in the near future and will be promoted by NDEP to the scientific, health professional, and lay public communities.

To change the way diabetes is treated, the NDEP will expand its efforts to change the health care system. Plans are in the offing to promote the team approach to care to the people who make decisions about health care plans. Similarly, the program will offer worksite-based diabetes control program tools to employers, and the people who purchase health care.

Finally, the NDEP plans to begin implementing evaluation of the program. The program will gather measures of partner activities and examine the minority work group component of the Partnership Network. In addition, plans will be developed for measuring the NDEP's impact on target audience, knowledge, attitudes practices, and outcomes related to diabetes care.

The National Diabetes Education Program has made its mark as a strong, flexible organization that responds rapidly to public health needs and to the needs of its constituents. The program envisions a promising future that will continue to be shaped by its strong leadership and the many partners who have worked steadfastly to spread the word about the program and the importance of diabetes control.

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## NDEP Publications

### Materials for People with Diabetes

Single copies free. See each item for pricing of additional copies and limits.

*Take Care of Your Feet for a Lifetime* (NDEP-4) ★

This illustrated patient booklet provides step-by-step instructions for proper foot care.

Includes a tear-off reminder card and a patient "To Do" list. Package of 25, \$5. Limit 2 packages.

*Control Your Diabetes. For Life. Tips for Feeling Better and Staying Healthy* (NDEP-8) ★

This 2-color patient education booklet provides an action plan for diabetes control that includes tips on knowing blood sugar levels, reaching blood sugar goals, and maintaining blood sugar control.

Package of 50, \$5. Limit 2 packages.

*Control Your Diabetes. For Life. Tips for Feeling Better and Staying Healthy, Photocopy Master* (NDEP-8PM)

Camera-ready version of NDEP-8. Limit 1 copy.

*Tome su diabetes en serio, para que no se vuelva cosa seria.*

*Recomendaciones para sentirse mejor y estar mas saludable* (NDEP-9) ★

Spanish version of *Control Your Diabetes. For Life. Tips for Feeling Better and Staying Healthy*.

Package of 50, \$5. Limit 2 packages.

*If You Have Diabetes, Know Your Blood Sugar Numbers* (NDEP-10) ★

This reproducible, black-and-white patient education brochure provides information on measuring blood sugar levels using the hemoglobin A1C test and the finger-stick test (with a blood glucose monitor).

Package of 50, \$5. Limit 1 package.

*Sepa cuánta azúcar tiene en la sangre: Hágase la prueba para controlar el azúcar sanguíneo* (NDEP-11) ★

Spanish version of *Know Your Blood Sugar Numbers: The ABCs of Testing for Blood Sugar Control*.

Package of 50, \$5. Limit 1 package.

*7 Principles for Controlling Your Diabetes for Life* (NDEP-17) ★

This easy-to-read brochure for people with diabetes describes the essential components of quality diabetes care in a checklist form. Package of 50, \$5. Limit 1 package.

*7 Principios para controlar la diabetes para toda la vida* (NDEP-18) ■

Spanish version of *7 Principles for Controlling Your Diabetes for Life*. Package of 50, \$5. Limit 1 package.

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*Expanded Coverage for Diabetes—Medicare and You* (NDEP-19) ★

This brochure provides Medicare beneficiaries who have diabetes with information on expanded benefits for diabetes equipment and supplies. Limit 1 copy.

*Expanded Coverage for Diabetes—Medicare and You, Photocopy Master* (NDEP-19PM)

Camera-ready version of NDEP-19. Limit 1 copy.

*Medicare tiene más que ofrecer. Beneficios adicionales para la diabetes* (NDEP-30) ★

Spanish version of *Expanded Coverage for Diabetes—Medicare and You*. Limit 1 copy.

*Medicare tiene más que ofrecer. Beneficios adicionales para la diabetes, Photocopy Master*

(NDEP-30PM) Camera-ready version of NDEP-30. Limit 1 copy.

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Visit our home page at <http://ndep.nih.gov> to preview or download these publications.

## **Materials for Health Care Providers**

Single copies free. See each item for pricing of additional copies and limits.

*Feet Can Last a Lifetime Kit* (NDEP-2) ★

This comprehensive kit for health care providers contains ready-to-use foot exam forms, Medicare certification forms for therapeutic footwear, a sample disposable sensory testing monofilament, reproducible patient education materials, and current resource and reference materials. Single kit free. Each additional kit, \$3. Limit 6 kits.

*Feet Can Last a Lifetime Videotape* (VHS) (NDEP-6)

This two-part video is designed for both patients and health care providers. Part 1, dedicated to patient education, is a comprehensive guide to proper foot care including a sensory foot examination by a health care provider, self-examination of the foot, daily foot and skin care, footwear selections, and the role of the podiatrist. Part 2, for health care providers, reviews steps for conducting foot exams, assessing patients' risk category, and counseling patients on proper foot care (approximately 22 minutes). (\$7)

*Diabetes Numbers at-a-Glance* (NDEP-12) ★

This quick-reference pocket guide for health care providers lists criteria for diagnosing diabetes and treating people with diabetes. Package of 10, \$5. Limit 5 packages.

*Guiding Principles of Diabetes Care* (NDEP-16) ★

This booklet describes the essential components of quality diabetes care for people with diabetes, their families, health care providers, and insurers. Package of 50, \$5. Limit 1 package.

*Guía de Principios para el Cuidado de la Diabetes* (NDEP-20) ★

Spanish version of *Guiding Principles of Diabetes Care*. Package of 50, \$5. Limit 1 package.

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## Materials for Organizations

The following items are intended for use in public education campaigns, not for individual patients. See each item for pricing of additional copies and limits.

### *Control Your Diabetes. For Life. Campaign Guide for Partners* (NDEP-15) ★

This 58-page how-to guide is designed to help partner organizations disseminate the Control Your Diabetes. For Life. campaign messages. Single copy free. Each additional copy, \$3. Limit 2 copies.

### *Control Your Diabetes. For Life. Campaign Videotape 1999 Edition* (VHS) (NDEP-23)

Includes: A message to Partners from Miss America; "Taking Control," 30-second general audience PSA; "Family Reunion," 30-second African-American PSA; "Future Generations," 30-second American Indian PSA; "Medicare Benefits," 30-second Older American PSA (English); "Medicare Benefits," 30-second Older American PSA (Spanish); "Thunder & Lightning," 30-second Hispanic/Latino PSA (English); "Rayos y Truenos," 30-second Hispanic/Latino PSA (Spanish); "Couple in the Rain," 15-second Hispanic/Latino PSA (Spanish); "Snowstorm," 15-second Hispanic/Latino PSA (Spanish). (\$10)

### *Control Your Diabetes. For Life. Campaign Videotape 1998 Edition* (VHS) (NDEP-14) Includes:

*Many Faces of Diabetes*, 60-, 30-, and 15-second general audience PSAs; *Rayos y Truenos*, 30-second PSA in Spanish; a message from U.S. Surgeon General Dr. David Satcher; and campaign launch video news release. (\$10)

### *Changing the Way Diabetes Is Treated (The NDEP Program Video)* (NDEP-24)

This video introduces the National Diabetes Education Program and its purpose, goals, and objectives. It presents information on the devastating effects of diabetes and reasons why organizations should participate in the program. (\$10)

★ Commercial printer-ready Zip cartridges available. Call (301) 654-3327

Visit our home page at <http://ndep.nih.gov> to preview or download these publications.

### *Diabetes Community Partnership Guide* (NDEP-21)

A how-to kit that includes ideas, tools, and guidelines for community partnerships and diabetes activities. Single copy free. Each additional copy, \$3. Limit 2 copies.

### *Medicare Benefits and Controlling Your Diabetes Community Kit* (NDEP-22)

This kit provides organizations with tools to promote the expanded benefits for Medicare recipients for diabetes equipment and supplies. Single copy free. Each additional copy, \$2. Limit 2 copies.

### *How Can Medicare Help You Control Your Diabetes?* Poster (NDEP-31)

This poster provides information about Medicare's expanded coverage for diabetes equipment and monitoring supplies. Single copy free. Each additional copy, \$1. (Limited quantity available.)

### *Making a Difference: The Business Community Takes on Diabetes* (NDEP-33) ★

This white paper is a call-to-action for business leaders to become involved in workplace and community activities to control diabetes-related complications. It provides information on the human and economic impact of diabetes and gives suggestions on how businesses can help employees with diabetes achieve improved glycemic control. Single copy free. Each additional copy, \$1.

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## Media Kits

Single copy free. Limit 1 copy each. Reproducible.

### *General Audience Campaign Media Kit (NDEP-25)*

Focuses on the seriousness of diabetes and the importance of controlling blood sugar levels. Includes a sample news release, diabetes statistics, resources, educational materials for people with diabetes, print public service ads, and live-read radio scripts.

### *African-American Media Kit (NDEP-26)*

Focuses on the seriousness of diabetes in the African-American population with a “Family Reunion” theme. Includes a sample news release, diabetes statistics, resources, educational materials for patients, print public service ads, and live-read radio scripts.

### *American Indian Media Kit (NDEP-27)*

Focuses on the seriousness of diabetes in the American Indian population. Includes a sample news release, diabetes statistics, resources, educational materials for patients, print public service ads, and live-read radio scripts.

### *Asian American and Pacific Islander Media Kit—English Version (NDEP-28)*

Focuses on the seriousness of diabetes in Asian Americans and Pacific Islanders. Includes a sample news release, diabetes statistics, resources, educational materials for patients, print public service ads, and live-read radio scripts.

### *Asian American and Pacific Islander Media Kit—Translated Versions*

The sample news release, diabetes statistics, live-read radio scripts, and print ads from the English kit have been translated into 11 Asian American and Pacific Islander languages.

*Cambodian (NDEP-28CA)*

*Chinese (NDEP-28CH)*

*English (for Asian Indians) (NDEP-28EI)*

*Gujarati (for Asian Indians)(NDEP-28GU)*

*Hindi (for Asian Indians) (NDEP-28HI)*

*Hmong (NDEP-28HM)*

*Ilokano (for Filipinos) (NDEP-28IIL)*

*Korean (NDEP-28KO)*

*Laotian (NDEP-28LO)*

*Samoan (NDEP-28SM)*

*Tagalog (for Filipinos) (NDEP-28PI)*

*Vietnamese (NDEP-28VI)*

### *Hispanic and Latino Media Kit (NDEP-29)*

Focuses on the seriousness of diabetes in the Hispanic and Latino population. Includes a sample news release, diabetes statistics, resources, educational materials for patients, print public service ads, and live-read radio scripts.

★ Commercial printer-ready Zip cartridges available. Call (301) 654-3327

Visit our home page at <http://ndep.nih.gov> to preview or download these publications.

## Highlights of NDEP Partner Activities

NDEP partners include State Diabetes Control Programs, minority-focused organizations and agencies, voluntary and professional groups, and business and media-related groups. Following are highlights of NDEP activities implemented by partner organizations.

### STATE DIABETES CONTROL PROGRAMS

The CDC supports Diabetes Control Programs (DCPs) in state health departments in all 50 states and U.S. territories. Their mission is to lessen the burden of diabetes in their states. The DCPs are active partners in NDEP, promoting the program through their networks. Examples of DCP activities include the following:

**Arkansas Diabetes Control Program:** Converted the NDEP’s “Family Reunion” print ads into a public transit ad, which is being displayed on public transportation vehicles throughout the state; transferred the “Family Reunion” TV PSA to 35mm format for showing in movie theaters; placed NDEP news releases and public service ads in Arkansas media outlets; and distributed materials to health care providers and at community events.

**California Diabetes Control Program:** Contracted with the California Broadcasters Association to add a local tag to the *Control Your Diabetes. For Life.* and Spanish-language radio PSAs, which were broadcast throughout the state.

**Connecticut Diabetes Control Program:** Worked with the Connecticut Department of Public Health Refugee Health Program to promote the NDEP’s Asian American and Pacific Islander campaign materials.

**Delaware Diabetes Control Program:** With the American Diabetes Association (ADA), conducted five community presentations to promote diabetes and NDEP awareness and distributed NDEP materials to 35 churches that participate in ADA’s Diabetes Sunday Program.

**Idaho Diabetes Control Program:** Incorporated NDEP messages and logo on its fact sheet, “Diabetes in Idaho and the U.S.: Reducing the Burden of Diabetes,” which is being distributed throughout the state at local health professional events and to members of the Diabetes Alliance of Idaho; distributes NDEP materials to rural health clinics; and developed partnerships with four American Indian tribes and is working with tribal leaders to disseminate NDEP’s American Indian campaign.

**Indiana Diabetes Control Program:** Placed the Control Your Diabetes. For Life. logo on the Indiana State Department of Health’s diabetes web page and has linked this page to the NDEP web site; the department’s web page was highlighted during March, Diabetes Awareness Month, and on a video produced by the department.

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**Kentucky Diabetes Control Program:** Trained over 100 members of the Kentucky Diabetes Network and 45 local health departments, nurses, dietitians, and health educators in using the Community Partnership Guide and widely distributed the NDEP Numbers-at-a-Glance cards to health care providers.

**Maryland Diabetes Control Program:** Held a statewide diabetes partnership meeting based on the NDEP partnership model and showcased NDEP campaign messages.

**Michigan Diabetes Control Program:** Incorporated NDEP messages and materials into presentations to the Michigan Diabetes Outreach Network (NDON), which reaches people with diabetes and health care professionals throughout the state.

**Mississippi Diabetes Control Program:** Developed diabetes information pages for telephone directories in three cities with large African-American populations, using NDEP African American campaign materials; also contracted with the Southern Urban Network, a consortium of 25 African American radio stations across the state to broadcast the NDEP campaign PSAs.

**New York Diabetes Control Program:** Promotes NDEP on state health websites and distributes NDEP materials through three Diabetes Centers of Excellence and at the state fair, the Senior Games, and the La Salud Hispanic Health Fair; adapts NDEP material for use by the state's 14 Community Diabetes Coalitions.

**North Carolina Diabetes Control Program:** Developed partnerships with rural health centers and hospitals, HMOs, and veterans hospitals and shared NDEP campaign materials with the state's 87 local health departments; distributed NDEP African American campaign materials via the *Baptist Informer*, a monthly newsletter that goes to more than 15,000 African American churches in the state; NDEP general audience and American Indian campaign print ads also have appeared in *Making a Difference in Diabetes*, a magazine published by the *Durham Herald Sun* newspapers.

**North Dakota Diabetes Control Program:** Developed a *Leader's Guide* for service organizations to promote diabetes education in their communities that lists NDEP materials as resources and is used by nearly 400 service organizations; also lists NDEP materials on its Department of Health website.

**Ohio Diabetes Control Program:** In partnership with the Ohio Association of Broadcasters, arranged for broadcast of NDEP TV PSA campaign messages throughout the state.

**Oregon Diabetes Control Program:** Partnered with the horticultural nursery industry to place diabetes print ads and articles in *The Digger Magazine*, which reaches growers in Oregon, Washington, Idaho, and British Columbia; also maintains a web page, including a Spanish version, that has a link to the NDEP web page.

**Tennessee Diabetes Control Program:** In partnership with the University of Tennessee Extension Service, included NDEP messages in its statewide health education program and the University's Center for Community-based Health Initiatives; also using NDEP African American campaign materials in community-based interventions with 18 county health councils and in State Extension Service diabetes cooking schools; promoted NDEP PSAs on local radio stations, and disseminated the NDEP Community Partnership Guide to regional offices and coalitions, primary care providers, insurers, public health workers, and diabetes educators.

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**Texas Diabetes Control Program:** Through its partnership with the Texas Association of Broadcasters, the Texas DCP distributed NDEP PSAs to 143 television stations and 723 radio stations; the DCP also is encouraging its 18 community-based organization grantees to become involved in NDEP.

**Utah Diabetes Control Program:** Distributed the “Guiding Principles of Diabetes Care” to health plan medical directors and quality assurance staff throughout the state; incorporated NDEP campaign messages into a statewide media campaign; distributed NDEP materials, using own logo, to health plans, community health centers, quality improvement clinics, hospital administrators, diabetes educators, community partners, Indian tribes, resource line callers, and state Extension Services; used NDEP radio and television PSAs, as well as its own, in diabetes awareness campaigns directed to American Indians, Hispanics, and older Americans.

**Washington Diabetes Control Program:** Convened a meeting with representatives of 30 organizations serving the state’s Asian and Pacific Islander communities to promote NDEP; distributed NDEP information and diabetes care wallet cards in English and Spanish to more than 7,000 primary care providers in the state and distributed 70,000 diabetes care wallet cards with the NDEP logo to retail pharmacies; shared its *Control Your Diabetes. For Life.* wallet cards with DCP programs in Connecticut, Idaho, Mississippi and Montana; sponsors a website to communicate with other NDEP partners and health care professionals; provided NDEP materials at healthy eating classes and at Asian American/Pacific Islander and community-wide health fairs; presented NDEP PSAs to the Washington State Diabetes Collaborative.

**West Virginia Diabetes Control Program:** In partnership with West Virginia Medical Institute and the West Virginia Hospital Association, developed a *Year 2000 Diabetes Toolkit*, featuring the *Control Your Diabetes. For Life* theme, which was mailed to more than 800 physicians in the state; also has developed radio and television PSAs that feature the NDEP campaign theme.

**Wisconsin Diabetes Control Program:** Developed the *Personal Diabetes Care Record Card* for patients, which includes the NDEP campaign logo and is available in English, Spanish, and Hmong; the cards have been widely distributed throughout the state; also has distributed the NDEP’s press release, “Nation’s Health Report Shows Widespread Increase in Diabetes,” to all media outlets in the state in conjunction with the launch of Healthy People 2010.

**Wyoming Diabetes Control Program:** The DCP held a NDEP campaign launch event in the state capitol and is promoting NDEP messages in media outlets throughout the state.

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## Minority-Focused Organizations and Agencies

NDEP has strong support from the many minority organizations that participate as partners in the program. Representatives from a number of these groups serve on the Steering Committee and on the Work Groups, including the four Work Groups concerned with minority populations, the African American Work Group, the Hispanic/Latino Work Group, the Asian American and Pacific Islander Work Group, and the American Indian Work Group.

Minority organizations are actively working with NDEP to develop culturally and linguistically appropriate campaign and educational materials and disseminate NDEP messages among their constituencies and health care professionals who provide services to minority patients. Some examples of activities are:

**African-American Work Group Members:** Participated in a panel on diabetes in the African American community at the Lonnie Mitchell Historically Black Colleges and Universities Substance Abuse Conference and displayed and distributed NDEP materials.

**Association of American Indian Physicians (AAIP):** Promotes NDEP on its website, through its toll-free telephone service, at meetings, through a speakers bureau; networks with local and tribal health units; participated in the NDEP American Indian campaign launch; monitors and evaluates use of NDEP materials; promotes NDEP through its network of regional partners and to allied organizations and programs such as the Association of Native American Students and Strategies for the Prevention and Control of Diabetes Project; added the AAIP logo to the NDEP American Indian radio, print, and television PSAs and distributed them to American Indian media; developed an American Indian *Control Your Diabetes. For Life.* campaign poster/calendar that is distributed at conferences, events, and workshops attended by AAIP; distributed *Things You Can Do to Make a Difference in Diabetes in Your Community* to promote the campaign and encourage diabetes awareness activities for American Indians throughout the United States; disseminates NDEP patient education brochures with the AAIP logo at American Indian events and conferences; developed a media kit for distribution at Native American events and meetings.

**Association of Asian Pacific Community Health Organizations:** The organization's BALANCE Program for Diabetes funded centers in California, Hawaii, Massachusetts, and New York using NDEP resources; held community discussion groups to profile Asian Americans' and Pacific Islanders' knowledge, attitudes, and beliefs about diabetes; coordinated a review of 150 existing diabetes education materials in Asian and Pacific Island languages; and trains media spokespersons for the NDEP's media campaign.

**Black Women's Agenda (Washington, DC):** Showcased the NDEP television PSA, "Family Reunion," at its Annual Luncheon and Workshop held at the Congressional Black Caucus Meeting and made a presentation on NDEP.

**Center for Substance Abuse Treatment (Washington, DC):** Distributed NDEP materials at the "Targeted Capacity Expansion Conference," held in Washington, DC, reaching more than 530 SAMHSA grantees and others; also sponsored a workshop on diabetes in the American Indian community during the conference.

**Connecticut Department of Public Health Refugee Health Program:** Presented the NDEP message to Cambodian groups in Western Massachusetts and Connecticut and networked with the Connecticut DCP to promote NDEP Asian American and Pacific Islander materials.

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**Diabeticos Hispanos (Millville, NJ):** Produces a segment for Perfil Latino, a weekly bilingual cable television program that airs in New Jersey and reaches more than 14 Hispanic communities.

**Indian Health Service:** Presented NDEP's American Indian campaign at meetings with the New Mexico Diabetes Advisory Council, Navajo Area Indian Health Service Diabetes Coordinators, and the National Diabetes Prevention Center; mailed NDEP campaign materials and educational materials to all IHS diabetes grantees; and included information about NDEP its newsletter Diabetes News.

**Japanese American Community Diabetes Study (JACDS) at the University of Washington:** Included an article on the NDEP's importance to Asian Americans and Pacific Islanders on its Spotlight Feature website and created a link with the NDEP website.

**La Voz del Anciano (Dallas, TX):** Holds diabetes awareness programs in Spanish at senior centers and churches and distributes NDEP materials to health care providers, at community events, and in organization mailings.

**The Links, Inc:** Distributed NDEP's "Family Reunion" PSA to 240 chapters throughout the country to use in community outreach activities; included NDEP materials in the National Eye Institute's Diabetes Month mailing to Links chapters throughout the country; and co-authored an editorial with NDEP on African Americans and diabetes that was placed in African American newspapers across the country.

**National Asian Women's Health Organization:** Disseminated the NDEP Asian American and Pacific Islander media kit to print and media outlets throughout the country serving this population, reaching more than 750,000 persons; holds regional conferences to distribute diabetes educational materials and NDEP Asian-language media kits, which have been translated into 11 different Asian languages; included the NDEP print ad, editorial, and feature story on the NDEP's AAPI awareness campaign in the organization's Diabetes Program newsletter, which is distributed to more than 5,000 individuals; developed the NAWHO Diabetes Program Brochure, which includes information on NDEP and the program's logo.

**National Caucus and Center on Black Aged (Washington, DC):** Sponsored a diabetes education workshop with the NDEP at the caucus' "Circle of Friends: Partnerships for Health" program during Older Americans Month and distributed NDEP materials at the meeting.

**National Coalition of Hispanic Health & Human Service Organizations:** Incorporated an article about the new Medicare benefits for people with diabetes in its newsletter and included a presentation on the NDEP's "Rayos Y Truenos" campaign on its annual meeting agenda.

**National Council of La Raza:** With NDEP funding, established a National Latino Diabetes Initiative that supports four community-based organizations that are promoting diabetes education and awareness and incorporating NDEP principles; launched a bilingual web site dedicated to providing the latest news and information about diabetes for the Latino community; produces and distributes *The Diabetes Alert* on a quarterly basis to NCLR affiliates; produced a children's storybook about diabetes titled *Dia a Dia con la Tia Betes*; sponsored a diabetes awareness campaign called *A Su Salud: Viva Mas, Viva Mejor!*, that reached nearly 37 million people through print, broadcast, radio, and Internet locally and nationally.

**National Hispanic Council on Aging:** Supports a diabetes awareness project that targets midlife and older Mexican Americans and Puerto Ricans at risk for or who have diabetes.

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**North East Medical Services (NEMS) (San Francisco, CA):** Distributed resource and education materials to 1,000 NEMS patients and 7,000 attendees of San Francisco's Chinese New Year's Fair; placed monthly diabetes PSAs in major San Francisco Bay area Chinese newspapers; developed a press release on diabetes and cardiovascular disease and distributed it to a Chinese newspaper published in several major cities; translated the *Control Your Diabetes. For Life.* campaign brochure and Diabetes Numbers at-a-Glance card and distributed them to patients and health care providers; distributed translated NDEP materials through Chinese herbalists, acupuncturists, and Chinese-owned businesses.

**Office of Minority Health:** Devoted an entire issue of its Closing the Gap newsletter, which reaches more than 7,000 individuals and organizations, to the NDEP and exhibited NDEP materials at its Partnership Summit.

**Tennessee African American NDEP Work Group:** Promoted diabetes awareness and presented NDEP goals to 350 participants at the Fourth Annual Minority Health Summit and partnered with the Tennessee Minority Health Coalition to exhibit NDEP materials at the meeting.

**Urban League of Nebraska Inc.:** Spearheading the National Urban League's program called *Lift Every Voice: A Community-Based National Diabetes Education and Prevention Program.* The League is replicating and enhancing an effective community organization/education strategy and apply it to diabetes education and prevention and is providing technical assistance resources and training in 16 targeted African American communities to implement a series of culturally appropriate community intervention strategies.

**Urban League of Wichita:** Conducts the Urban League's "Lift Every Voice" diabetes education and awareness program in Kansas and partners with local organizations to distribute NDEP materials.

**Vietnamese American Health Care Association (Madison, WI):** Promotes the NDEP campaign to Vietnamese media in Orange County, San Jose, Houston, Washington, DC, Chicago, and St. Paul; also distributes NDEP materials to the Vietnamese Physician Association and 120 community-based organizations.

### **Voluntary and Professional Groups**

A number of voluntary and professional groups are active in NDEP as members of the NDEP Steering Committee and as members of NDEP Work Groups. As such, they are invaluable partners in developing messages and materials designed to reach a wide audience of the general public, patients, health care community, and insurance and business industries. Examples of NDEP-related activities carried out by these groups include:

**American Academy of Family Physicians:** Published news about NDEP and the program's Guiding Principles for Diabetes Care in its journal, *American Family Physician*, and has linked its website to the NDEP's "Guiding Principles."

**American Academy of Nurse Practitioners:** Publishes news of NDEP in its newsletter and invited NDEP to exhibit at its annual meeting.

**American Association of Clinical Endocrinologists:** Announced support for NDEP in a news release about its "Patients First" campaign.

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**American Association of Diabetes Educators:** Distributes NDEP materials at annual meetings; includes NDEP presentations at annual meetings; and features news of NDEP in its publications.

**American Diabetes Association:** ADA affiliates have partnered with DCPs and other groups to disseminate NDEP messages; included the NDEP's "Numbers At-a-Glance" reference cards in a mailing to 15,000 health care professionals; added the ADA tag to NDEP's "Family Reunion" and "Future Generations" TV PSAs and distributed them to TV stations across the country; features NDEP presentations at meetings; and has representatives on the NDEP Steering Committee and on Work Groups.

**American Dietetic Association:** Featured presentations on NDEP initiatives at every annual meeting since 1997; devoted an entire issue of *On the Cutting Edge*, a monthly newsletter of the association's Diabetes Care and Education (DCE) Practice Group to NDEP; and runs a regular column on NDEP in *Newsflash*, another DCE practice group publication.

**Delmarva Foundation for Medical Care (Easton, MD):** Distributed a diabetes toolkit containing NDEP messages and information to nearly 3,000 providers.

**La Joya Senior Citizen Center (La Joya, TX):** Gives presentations on diabetes at senior citizen centers and distributes NDEP materials in church bulletins and at senior centers, health fairs, community events, post offices, and stores.

**Lions Clubs International:** Mailed NDEP kits to district Diabetes Awareness Chairmen across the country; linked its website to NDEP's website; promotes NDEP activities and materials in its publications and through its CORE 4 Grant Program initiative.

**Mt. Sinai Medical Center (Cleveland, OH):** Included information on NDEP in presentations at community events in the Cleveland, Ohio, area.

**National Medical Association (NMA):** Announced support for NDEP at the African American campaign press briefing in 1998 in Washington, DC.

**Northeast Cluster of the Bureau of Primary Health Care Diabetes Collaborative (Staten Island, NY):** Sponsored presentations on NDEP at 20 community health centers and trained health team members in using the Community Partnership and Campaign guides.

**Southern New Jersey Family Medical Center:** Features the NDEP's *Control Your Diabetes. For Life.* campaign theme in print ads distributed to local newspapers and advertising books; included diabetes information in *The Atlantic County Minority Health Guide*; participated in a diabetes telethon on local television in Atlantic City, NJ.

**U.S. Department of Veterans Affairs:** Worked with community leaders in Los Angeles to display the translated Asian Indian print ads at the festival of Garba, which attracts 3,000 people; also displayed the ads on the bulletin board of a Los Angeles temple during the Indian New Year's festival. In addition, the VA has partnered with the NDEP on the "Feet Can Last a Lifetime" kit, promoted NDEP materials throughout the VA, linked its website to the NDEP site, and invited the NDEP to present at their annual meeting.

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## **Business and Media Partners**

NDEP partners in the business and media communities are important allies in producing and disseminating NDEP messages and materials. A number of companies have helped the program and its partners in printing materials, helping to support meetings, distributing NDEP materials in direct mailings and through their sales teams, and cosponsoring campaigns. For example:

**Bayer Pharmaceuticals:** Reprinted 1,000 NDEP American Indian posters for distribution at the National Indian Health Board meeting in Anchorage, Alaska; sponsored a luncheon and distributed NDEP materials at AAIP's mid-year diabetes conference.

**Bristol Meyers Squibb:** Sponsored professional golfer Lee Elder's appearances at NDEP campaign launches.

**Eli Lilly and Company:** Sponsored a luncheon following the NDEP campaign launch in June 1998; provided funding support for NDEP to exhibit the African American campaign at the National Council of Negro Women's Black Family Reunion Celebration in Washington DC in 1999.

**HealthQuest Magazine:** Publishes NDEP print PSAs to promote diabetes control and features articles about diabetes and African Americans in the magazine.

**Lifescan:** Reprinted and distributed over one million copies of the Diabetes at-a-Glance card to health care providers and patients.

**Merck-Medco:** Printed and distributed copies of the Diabetes Numbers At-a-Glance card to 40,000 physicians in its diabetes prescription program.

**Mutual of Omaha:** Teamed up with 100 Black Men of Omaha to initiate a campaign targeted to African Americans with diabetes in Nebraska using NDEP campaign messages.

**National Association of Broadcasters:** Transmitted NDEP PSAs on its monthly satellite feed of programming and PSA messages to its 1,300 member TV stations.

**Parke-Davis:** Sponsored printing of 70,000 diabetes care wallet cards with the NDEP logo and slogan distributed by the Washington Diabetes Control Program to all retail pharmacies in the state.

**Pfizer, Inc.:** Supported the Wyoming Diabetes Control Program's efforts to promote NDEP activities across the state.

**WJLA-TV/Parke Davis/Safeway:** In partnership with NDEP, the Health Care Financing Administration, Parke Davis, and pharmacies in local Safeway stores, the ABC affiliate in Washington, DC, promoted diabetes awareness and Medicare benefits in the metropolitan Washington, DC, area during Diabetes Month in 1998.

**Interagency Coordinating Committees**

Sec.429. [285c—3] (a) For the purpose of—

- (1) better coordination of the research activities of all the national research institutes relating to diabetes mellitus, digestive diseases, and kidney, urologic, and hematologic diseases; and
- (2) coordinating those aspects of all Federal health programs and activities relating to such diseases to assure the adequacy and technical soundness of such programs and activities and to provide for the full communication and exchange of information necessary to maintain adequate coordination of such programs and activities;

the secretary shall establish a Diabetes Mellitus Interagency Coordinating Committee, a Digestive Diseases Interagency Coordinating Committee, and a Kidney, Urologic, and Hematologic Diseases Coordinating Committee (hereafter in this section individually referred to as a “Committee”).

- (a) Each committee shall be composed of the Directors of each of the national research institutes and divisions involved in research with respect to the diseases for which the Committee is established, the Division Director of the Institute for the diseases for which the Committee is established, the Chief Medical Director of the Veterans’ Administration,<sup>1</sup> and the Assistant Secretary of Defense for Health Affairs (or the designees of such officers) and shall include representation from all other Federal departments and agencies whose programs involve health functions or responsibilities relevant to such diseases, as determined by the Secretary. Each Committee shall be chaired by the Director of NIH (or the designee of the Director). Each committee shall meet at the call of the chairman, but not less often than four times a year.
- (b) each Committee shall prepare an annual report for—
  - (1) the Secretary;
  - (2) the Director of NIH; and
  - (3) the Advisory Board established under section 430 for the diseases for which the Committee was established, detailing the work of the Committee in carrying out paragraphs (1) and (2) of subsection (a) in the fiscal year for which the report was prepared. Such report shall be submitted not later than 120 days after the end of each fiscal year.

<sup>1</sup> The reference is deemed to be a reference to the Under Secretary for Health of the Department of Veteran Affairs. See section 302 (e)(1) of Public Law 102-405(106) Stat. 1985 and section 10(4) of Public Law 100-527 (102 Stat.2641)



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