APPENDIX D

TYPE 1 DIABETES CONSORTIA COORDINATION

This Appendix provides an overview of the numerous collaborative efforts among the type 1 diabetes research consortia and networks.

PROMOTING COORDINATION AMONG TYPE 1 DIABETES RESEARCH CONSORTIA AND NETWORKS

The research efforts supported by the Special Statutory Funding Program for Type 1 Diabetes Research span a wide range of scientific areas. However, many of the large-scale research efforts have elements in common. For example, several research consortia are studying the genetics of type 1 diabetes or of specific complications; multiple consortia are enrolling newborns in studies and following them to examine different environmental triggers; and clinical trials networks are testing different strategies to slow disease progression in newly diagnosed patients. Coordination helps to prevent duplicative work by promoting the sharing of resources and methodology as well as by facilitating cross-disciplinary research approaches. Furthermore, collaboration between researchers with distinct interests facilitates the pursuit of novel research directions.

Panels of external scientific and lay experts convened by NIH to provide input on progress and future directions have strongly encouraged NIH to capitalize on existing research efforts by maximizing connections among research groups with both related and distinct interests. The panels encouraged NIH to enhance strong existing coordination across consortia to synergize research efforts. Based on this input and in order to maximize research progress, NIH has facilitated and enhanced coordination among research consortia with both overlapping and distinct interests. The NIH has organized meetings to facilitate broad coordination efforts as well as focused meetings of consortia that share common interests. For example, research consortia studying newborns (TEDDY, TRIGR, TrialNet) have met to discuss opportunities for collaboration, and have also coordinated patient recruitment to ensure that they are not adversely competing for patient participants in their studies. This helps all studies achieve their goals in the most streamlined and cost-efficient manner. In another example, a research consortium studying continuous glucose monitoring in children (DirecNet) and a clinical trials network testing strategies for treating newly diagnosed patients (TrialNet) are collaborating on a clinical trial testing early intensive blood glucose control using a closedloop system in new-onset patients. Thus, the strengths and expertise of both networks are being utilized to conduct this joint trial.

ENHANCING INFORMATION SHARING

To enhance information sharing, NIDDK, with input from external experts, spearheaded the development of Web sites for people with or at risk for type 1 diabetes and their family members (www.T1Diabetes.nih.gov/patient) and researchers (www.T1Diabetes.nih.gov/investigator). The Web site for patients describes clinical research studies recruiting patients and has contact information for the studies if patients are interested in enrolling. The Web site for investigators includes information on research consortia and clinical trial networks; research resources available to the broad scientific community; and information on research funding opportunities. These Web sites not only enhance patient recruitment efforts, but also provide researchers with access to information, data, and protocols generated by the type 1 diabetes research consortia, thereby facilitating resource sharing and coordination.

The NIDDK is also spearheading a new Web site to advertise the availability of biosamples and data from type 1 diabetes research consortia. Through consortia Web sites, the NIH Guide for Grants and Contracts, and other methods, NIH has already advertised the availability of samples and data. However, the new Web site will serve as a "one stop shop" for information on research resources that are currently available, as well as resources that are expected to be available in the future.

HIGHLIGHTS OF TYPE 1 DIABETES CONSORTIA COLLABORATION AND COORDINATION

A summary of interactions between research consortia is presented in Table D1. The "at a glance" matrix shows consortia that have ongoing or past collaborative activities. For a description of the collaborative activities, please see sections in each consortium's evaluation called "Coordination with Other Research Efforts" in Appendix C.

Table D1: "At a Glance" Matrix of Past and Ongoing Type 1 Diabetes Consortia Coordination Activities

