



Directory of Digestive Diseases Organizations

This directory lists Government agencies and professional and voluntary associations that provide information and resources related to digestive diseases. Some of these organizations offer educational materials and other services to patients and the general public, while others primarily serve health care providers.

NIDDK-funded Digestive Diseases Research Core Centers (DDRCCs) and Digestive Diseases Research Development Centers (DDRDCs)

Center for Gastrointestinal Biology and Disease (CGIBD)

Robert Sandler, M.D., M.P.H., Principal Investigator

CB #7555

Bioinformatics Building

130 Mason Farm Road

Chapel Hill, NC 27599-7555

Phone: 919-966-1757

Fax: 919-966-7592

Email: cgibd@med.unc.edu

Internet: <http://cgibd.med.unc.edu/index.php>

Center for Molecular Studies in Digestive and Liver Diseases

Anil K. Rustgi, M.D., Director

University of Pennsylvania Perelman School of Medicine

950 Biomedical Research Building

421 Curie Boulevard

Philadelphia, PA 19104

Phone: 215-898-0850

Fax: 215-898-0573

Internet: www.med.upenn.edu/molecular/

Center for the Study of Inflammatory Bowel Disease (CSIBD)

Ramnik Xavier, M.D., Ph.D., Director

Phone: 617-726-3767

Internet: www.massgeneral.org/csibd/

CURE: DDRCC

Enrique Rozengurt, D.V.M., Ph.D., Director
University of California, Los Angeles
Phone: 301-312-9284
Email: CUREadm@Mednet.ucla.edu
Internet: <http://cure.med.ucla.edu/>

Harvard Digestive Diseases Center

Richard S. Blumberg, M.D., and Wayne I. Lencer, M.D., Co-Directors
300 Longwood Avenue
Enders 720
Boston, MA 02115
Email: hddc@childrens.harvard.edu
Internet: www.hms.harvard.edu/hddc/index.html

Hopkins Digestive Diseases Basic and Translational Research Core Center (DDBTRCC)

Mark Donowitz, M.D., Director
720 Rutland Avenue
925 Ross Research Building
Baltimore, MD 21205
Phone: 410-955-9675 or 410-955-9677
Email: mtonowitz@jhmi.edu
Internet: www.jhugicc.org

Marion Bessin Liver Research Center

Allan W. Wolkoff, M.D., Director
Albert Einstein College of Medicine
625 Ullman Building
1300 Morris Park Avenue
Bronx, NY 10461
Phone: 718-430-2098
Internet: www.einstein.yu.edu/centers/liver-research/

Mayo Clinic Center for Cell Signaling in Gastroenterology (C-SiG)

Nicholas F. LaRusso, M.D., Director
200 First Street SW
Rochester, MN 55905
Phone: 507-293-1449
Internet: <http://mayoresearch.mayo.edu/gastro-cell-signaling-center/>

Michigan Gastrointestinal Peptide Research Center

Chung Owyang, M.D., Director
U-M Health System
6520 MSRB1
1150 West Medical Center
Ann Arbor, MI 48109
Email: GutPeptide@umich.edu
Internet: www.med.umich.edu/mgpc/

Texas Medical Center Digestive Diseases Center (DDC)

Mary K. Estes, Ph.D., Director
Baylor College of Medicine
One Baylor Plaza, Room 920E
Houston, TX 77030
Phone: 713-798-3481
Email: dfox@bcm.edu
Internet: www.bcm.edu/gastro/DDC/

University of California, San Diego DDRDC

Lars Eckmann, M.D., Director
University of California, San Diego
Division of Gastroenterology
9500 Gilman Drive
La Jolla, CA 92093-0063
Phone: 858-534-3320
Email: kkasser@ucsd.edu
Internet: <http://gicenter.ucsd.edu/index.shtml>

University of California, San Francisco Liver Center

Jacquelyn J. Maher, M.D., Director
San Francisco General Hospital
1001 Potrero Avenue, Building 40, Room 4102
San Francisco, CA 94110
Phone: 415-206-4805
Fax: 415-641-0517
Email: jmaher@medsfgh.ucsf.edu
Internet: <http://livercenter.ucsf.edu/>

University of Chicago DDRCC

Eugene B. Chang, M.D., Director
University of Chicago Medical Center
5841 South Maryland Avenue, MC 4076
Chicago, IL 60637
Phone: 773-702-6458
Internet: www.uchicagoddrrcc.org/

Vanderbilt Digestive Disease Research Center (VDDRC)

Richard M. Peek, M.D., Director
2215 Garland Avenue
1030C Medical Research Building IV
Nashville, TN 37232-0252
Phone: 615-322-5200
Fax: 615-343-6229
Email: richard.peek@vanderbilt.edu
Internet: www.mc.vanderbilt.edu/root/vumc.php?site=ddrc

Washington University in St. Louis School of Medicine DDRCC

DDRCC Administrator

Internal Medicine—Gastroenterology

660 South Euclid, Campus Box 8124

St. Louis, MO 63110

Phone: 314-362-0799

Fax: 314-362-2505

Email: ddrcc@dom.wustl.edu

Internet: <http://ddrcc.wustl.edu/>

Yale Liver Center

Michael H. Nathanson, M.D., Ph.D., Director

The Anlyan Center for Medical Research & Education

300 Cedar Street, Room S241

New Haven, CT 06520

Phone: 203-785-5279

Fax: 203-785-7273

Internet: <http://livercenter.yale.edu/index.aspx>

Government Agencies and Professional and Voluntary Organizations

Academy of Nutrition and Dietetics (*Formerly the American Dietetic Association*)

120 South Riverside Plaza, Suite 2000
Chicago, IL 60606–6995
Internet: www.eatright.org

Mission: To empower members to be the nation’s food and nutrition leaders.

Services provided:

Accreditation standards
Educational programs and meetings for health care providers
Information for the media
Publications for health care providers and patients
Registered dietitian locator

Alagille Syndrome Alliance

10500 SW Starr Drive
Tualatin, OR 97062
Phone: 503–885–0455
Email: alagille@alagille.org
Internet: www.alagille.org

Mission: To serve as the main networking resource and source of information for people with Alagille Syndrome (AGS), their families, friends, and health care providers. The Alliance is also dedicated to increasing public awareness of AGS and supporting research efforts on behalf of the AGS community.

Services provided:

Events for health care providers and patients
Publications for patients
Support groups

Alpha-1 Foundation

3300 Ponce de Leon Boulevard
Coral Gables, FL 33134
Phone: 1–877–2–CURE–A1 (1–877–228–7321) or 305–567–9888
Fax: 305–567–1317
Email: info@alpha-1foundation.org
Internet: www.alpha-1foundation.org

Mission: To provide leadership and resources that will result in increased research, improved health, worldwide detection, and a cure for Alpha-1—antitrypsin deficiency—a genetically inherited disease affecting either the liver or lungs in children and adults.

Services provided:

Advocacy and public policy
Clinical resource center locator
Continuing medical education (CME) and continuing respiratory care education (CRCE) programs
Educational programs and meetings and events for health care providers, patients, and their families
Publications for health care providers and patients
Resources
Support groups

American Association for the Study of Liver Diseases (AASLD)

1001 North Fairfax Street, Suite 400
Alexandria, VA 22314
Phone: 703–299–9766
Fax: 703–299–9622
Email: aasld@aasld.org
Internet: www.aasld.org

Mission: To advance the science and practice of hepatology, liver transplantation, and hepatobiliary surgery, thereby promoting liver health and optimal care of patients with liver and biliary tract diseases.

Services provided:

Advocacy and public policy
Certification activities
Educational programs and meetings for health care providers
Physician locator
Practice guidelines
Publications for health care providers and patients
Resources

American Celiac Disease Alliance (ACDA)

2504 Duxbury Place
Alexandria, VA 22308
Phone: 703–622–3331
Email: info@americanceliac.org
Internet: www.americanceliac.org

Mission: To represent and advocate on behalf of the entire celiac community—patients, physicians, researchers, food manufacturers, and other service providers.

Services provided:

Advocacy and public policy
Resources

American College of Gastroenterology (ACG)

6400 Goldsboro Road, Suite 200
Bethesda, MD 20817
Phone: 301-263-9000
Fax: 301-263-9025
Email: info@acg.gi.org
Internet: www.gi.org

Mission: To advance the medical treatment and scientific study of gastrointestinal disorders and strive to serve the evolving needs of physicians in the delivery of high-quality scientific, humanistic, clinical, ethical, and cost-effective health care to gastroenterology patients.

Services provided:

Advocacy and public policy
Certification activities
Continuing medical education (CME)
Educational programs and meetings for health care providers
Gastroenterologist physician locator
Information for the media
Liver disease expert locator
Practice guidelines and clinical updates
Publications for health care providers and patients

American Gastroenterological Association (AGA)

4930 Del Ray Avenue
Bethesda, MD 20814
Phone: 301-654-2055
Fax: 301-654-5920
Email: member@gastro.org
Internet: www.gastro.org

Mission: To advance the science and practice of gastroenterology.

Services provided:

Advocacy and public policy
Certification activities
Continuing medical education (CME)
Educational programs and meetings for health care providers
Gastroenterologist locator service
Information for the media
Publications for health care providers and patients

American Hemochromatosis Society, Inc. (AHS)

P.O. Box 950871
Lake Mary, FL 32795-0871
Phone: 1-888-655-IRON (1-888-655-4766) or 407-829-4488
Fax: 407-333-1284
Email: mail@americanhs.org
Internet: www.americanhs.org

Mission: To educate and support people with HFE-associated hereditary hemochromatosis—genetic iron overload—and their families, to educate the medical community about the latest research on the disease, and to identify through genetic testing the more than 43 million Americans who unknowingly carry the single or double gene mutations for hereditary hemochromatosis, which puts them at risk for loading excess iron.

Services provided:

Information for the media
Physician referral program
Resources

American Liver Foundation (ALF)

39 Broadway, Suite 2700
New York, NY 10006
Phone: 1-800-GO-LIVER (1-800-465-4837) or 212-668-1000
Fax: 212-483-8179
Internet: www.liverfoundation.org

Mission: To facilitate, advocate, and promote education, support, and research for the prevention, treatment, and cure of liver disease.

Services provided:

Advocacy and public policy
Chapter locator
Educational programs, meetings, and events for health care providers
Publications for health care providers, patients, and caregivers
Research
Resources
Support groups

American Neurogastroenterology and Motility Society (ANMS) (Formerly American Motility Society)

45685 Harmony Lane
Belleville, MI 48111
Phone: 734-699-1130
Fax: 734-699-1136
Email: admin@motilitysociety.org
Internet: www.motilitysociety.org

Mission: To advance the study of neurogastroenterology and gastrointestinal motility, to translate the scientific advances to patient care, and to disseminate the knowledge to patients and caregivers in order to improve the diagnosis and treatment of patients with neurogastroenterology and GI motility disorders.

Services provided:

Educational programs and meetings for health care providers
Publications for patients
Research
Resources

American Pancreatic Association (APA)

P.O. Box 14906
Minneapolis, MN 55414
Phone: 612-626-9797
Fax: 612-625-7700
Email: apa@umn.edu
Internet: www.american-pancreatic-association.org

Mission: To foster clinical and basic science research needed to cure diseases of the pancreas and strive to advance the field of research while training the next generation of researchers devoted to finding a cure for these deadly diseases.

Services provided:

Educational meetings for health care providers
Publications for health care providers
Resources

American Porphyria Foundation (APF)

4900 Woodway, Suite 780
Houston, TX 77056-1837
Phone: 1-866-APF-3635 (1-866-273-3635) or 713-266-9617
Fax: 713-840-9552
Email: porphyrus@aol.com
Internet: www.porphyrifoundation.com

Mission: To improve the health and well-being of individuals and families affected by porphyria by enhancing public awareness about porphyria, developing educational programs and distributing educational materials about porphyria, and supporting research to improve treatment and lead to a cure. The APF also serves as an advocate to other public, private, and Government agencies interested in funding research and educational programs.

Services provided:

Continuing medical education (CME)
Information for the media
National Porphyria Registry
Publications for health care providers
Research
Resources

American Society for Gastrointestinal Endoscopy (ASGE)

3300 Woodcreek Drive
Downers Grove, IL 60515
Phone: 1-866-353-ASGE (1-866-353-2743) or 630-573-0600
Fax: 630-963-8332
Email: info@asge.org
Internet: www.asge.org

Mission: To be the leader in advancing patient care and digestive health by promoting excellence in endoscopy.

Services provided:

Advocacy and public policy
Continuing medical education (CME)
Educational programs and meetings for health care providers
Information for the media
Practice guidelines and technology reviews
Publications for health care providers and patients

American Society for Parenteral and Enteral Nutrition (ASPEN)

8630 Fenton Street, Suite 412
Silver Spring, MD 20910
Phone: 1-800-727-4567 or 301-587-6315
Fax: 301-587-2365
Email: aspen@nutr.org
Internet: www.nutritioncare.org

Mission: To improve patient care by advancing the science and practice of clinical nutrition and metabolism.

Services provided:

Certification activities
Clinical guidelines
Continuing medical education (CME)
Publications for health care providers, patients, and caregivers
Standards of practice

American Society of Abdominal Surgeons (ASAS)

824 Main Street, 2nd floor, Suite 1
Melrose, MA 02176
Phone: 781-665-6102
Fax: 781-665-4127
Email: office@abdominalsurg.org
Internet: www.abdominalsurg.org

Mission: To sponsor an extensive continuing education program for physicians in the field of abdominal surgery.

Services provided:

Educational meetings for health care providers
Publications for health care providers

American Society of Colon and Rectal Surgeons (ASCRS)

85 West Algonquin Road, Suite 550
Arlington Heights, IL 60005
Phone: 847-290-9184
Fax: 847-290-9203
Email: ascrs@fascrs.org
Internet: www.fascrs.org

Mission: To assure high-quality patient care by advancing the science through research and education for the prevention and management of disorders of the colon, rectum, and anus.

Services provided:

Educational programs and meetings for health care providers
Certification activities
Colorectal surgeon locator
Position statements
Publications for health care providers and patients

Association of Gastrointestinal Motility Disorders, Inc. (AGMD)

12 Roberts Drive
Bedford, MA 01730
Phone: 781-275-1300
Fax: 781-275-1304
Email: digestive.motility@gmail.com
Internet: www.agmd-gimotility.org

Mission: To serve as an integral educational resource concerning digestive motility diseases and disorders and function as an information base for members of the medical and scientific communities; to provide a forum for patients suffering from digestive motility diseases and disorders as well as their families and members of the medical, scientific, and nutritional communities.

Services provided:

Educational meetings for health care providers
Resources
Support groups

Autosomal Recessive Polycystic Kidney Disease & Congenital Hepatic Fibrosis (ARPKD/CHF) Alliance

P.O. Box 70
Kirkwood, PA 17536
Phone: 1-800-708-8892 or 717-529-5555
Fax: 1-800-807-9110
Email: info@arpkdchf.org
Internet: www.arpkd.org or www.arpkdchf.org

Mission: To educate, advocate, support, and advance research specific to ARPKD/CHF and improve the lives of those affected.

Services provided:

Educational programs and events for health care providers
Public service announcements (PSAs)
Resources
Support groups

Celiac Disease Foundation (CDF)

20350 Ventura Boulevard, Suite 240
Woodland Hills, CA 91364
Phone: 818-716-1513
Fax: 818-267-5577
Email: info@celiac.org
Internet: www.celiac.org

Mission: To provide services and support regarding celiac disease and dermatitis herpetiformis through programs of awareness, education, advocacy, and research.

Services provided:

Educational events for health care providers and patients
Public service announcements (PSAs)
Publications for health care providers and patients
Resources
Support groups

Celiac Support Association (CSA) *(Formerly the Celiac Sprue Association/USA, Inc.)*

P.O. Box 31700
Omaha, NE 68131-0700
Phone: 1-877-CSA-4-CSA (1-877-272-4272) or 402-558-0600
Fax: 402-643-4108
Email: celiacs@csaceliacs.org
Internet: www.csaceliacs.org

Mission: To help individuals with celiac disease and dermatitis herpetiformis worldwide through research, education, and support.

Services provided:

Educational programs and meetings for health care providers
Publications for patients and family members
Resources

Centers for Disease Control and Prevention (CDC), Division of Viral Hepatitis

1600 Clifton Road
Mail Stop G-37
Atlanta, GA 30333
Phone: 1-800-CDC-INFO (1-800-232-4636)
TTY: 1-888-232-6348
Internet: www.cdc.gov/hepatitis

Mission: To provide the scientific and programmatic foundation for the prevention, control, and elimination of viral hepatitis infections.

Services provided:

Educational programs, meetings, and events for health care providers
Publications for health care providers and patients
Resources

Children's Liver Association for Support Services (C.L.A.S.S.)

25379 Wayne Mills Place, Suite 143
Valencia, CA 91355
Phone: 1-877-679-8256
Fax: 661-263-9099
Email: info@classkids.org
Internet: www.classkids.org

Mission: To address the emotional, educational, and financial needs of families with children affected by liver disease and transplantation.

Services provided:

Community forum
Publications for health care providers, patients, and families

Crohn's & Colitis Foundation of America (CCFA)

733 Third Avenue, Suite 510
New York, NY 10017
Phone: 1-800-932-2423
Email: info@ccfa.org
Internet: www.ccfa.org

Mission: To cure Crohn's disease and ulcerative colitis and to improve the quality of life of children and adults affected by these diseases.

Services provided:

Advocacy and public policy
Chapter locator
Educational programs, meetings, and events for health care providers
Physician locator
Publications for health care providers, patients, and families
Research
Support groups

Cyclic Vomiting Syndrome Association (CVSA)

10520 West Bluemound Road, Suite 106
Milwaukee, WI 53226
Phone: 414-342-7880
Fax: 414-342-8980
Email: cvsa@cvsaonline.org
Internet: www.cvsaonline.org

Mission: To serve the needs of cyclic vomiting syndrome sufferers, their families, and professional care givers by raising awareness and providing education and support to those affected by cyclic vomiting, abdominal migraine, and related disorders while advocating for and funding research.

Services provided:

Educational meetings and events for health care providers
Publications for patients
Resources
Support groups

Digestive Disease National Coalition (DDNC)

507 Capitol Court NE, Suite 200
Washington, D.C. 20002
Phone: 202-544-7497
Fax: 202-546-7105
Internet: www.ddnc.org

Mission: To work cooperatively to improve access to and the quality of digestive disease health care to promote the best possible medical outcome and quality of life for current and future patients with digestive diseases.

Services provided:

Advocacy and public policy
Educational meetings and events for health care providers and patients

Food Allergy Research & Education (FARE) (*Formerly the Food Allergy & Anaphylaxis Network*)

7925 Jones Branch Drive, Suite 1100
McLean, VA 22102
Phone: 1-800-929-4040 or 703-691-3179
Fax: 703-691-2713
Internet: www.foodallergy.org

Mission: To ensure the safety and inclusion of individuals with food allergies while relentlessly seeking a cure.

Services provided:

Educational meetings for health care providers, patients, and families
Publications for health care providers and school, restaurant, and food industry professionals
Research
Resources
Support groups

Gastro-Intestinal Research Foundation (GIRF)

70 East Lake Street, Suite 1015
Chicago, IL 60601
Phone: 312-332-1350
Fax: 312-332-4757
Email: info@girf.org
Internet: www.girf.org

Mission: To raise funds for clinical and laboratory research in digestive diseases in the Gastroenterology Section at the University of Chicago Medical Center, and promote the education of the public regarding issues of digestive health.

Services provided:

Research

Gluten Intolerance Group (GIG)

31214 124th Avenue SE
Auburn, WA 98092
Phone: 253-833-6655
Fax: 253-833-6675
Email: CustomerService@gluten.net
Internet: www.gluten.net

Mission: To provide support to people with gluten intolerances, including celiac disease, dermatitis herpetiformis, and other gluten sensitivities, so they can live healthy lives.

Services provided:

Advocacy
Gluten-free restaurant database
Product certification and accreditation
Publications for patients

Hepatitis B Foundation

3805 Old Easton Road
Doylestown, PA 18902
Phone: 215-489-4900
Fax: 215-489-4920
Email: contact@hepb.org
Internet: www.hepb.org

Mission: To find a cure and improve the quality of life for those affected by hepatitis B worldwide, fund focused research, promote disease awareness, support immunization and treatment initiatives, and serve as the primary source of information for patients and their families, the medical and scientific community, and the general public.

Services provided:

Advocacy and public policy
Educational programs for health care providers
Liver specialist locator
Publications for patients
Resources
Support groups

Hepatitis Foundation International (HFI)

1955 Briggs Chaney Road
Silver Spring, MD 20905
Phone: 1-800-891-0707 or 301-879-6891
Fax: 301-879-6890
Email: info@hepatitisfoundation.org
Internet: www.hepfi.org

Mission: To educate the public, patients, and professionals about the prevention, diagnosis, and treatment of viral hepatitis; to promote healthful lifestyles; to serve as advocates for patients and the medical community worldwide; and to support research into prevention, treatment, and cures.

Services provided:

Educational programs and meetings for health care providers
Publications for patients
Support groups

Immunization Action Coalition

1573 Selby Avenue, Suite 234
St. Paul, MN 55104
Phone: 651-647-9009
Fax: 651-647-9131
Email: admin@immunize.org
Internet: www.immunize.org and www.vaccineinformation.org

Mission: To increase immunization rates and prevent disease by creating and distributing educational materials for health professionals and the public that enhance the delivery of safe and effective immunization services. The Coalition also facilitates communication about the safety, efficacy, and use of vaccines within the broad immunization community of patients, parents, health care organizations, and government health agencies.

Services provided:

Publications for health care providers and patients
Resources

International Foundation for Functional Gastrointestinal Disorders (IFFGD)

700 West Virginia Street, Suite 201
Milwaukee, WI 53204
Phone: 1-888-964-2001 or 414-964-1799
Fax: 414-964-7176
Email: iffgd@iffgd.org
Internet: www.iffgd.org

Mission: To inform, assist, and support people affected by gastrointestinal disorders.

Services provided:

Advocacy and public policy
Information for the media
Publications for health care providers and patients
Support group locator

Iron Disorders Institute (IDI)

P.O. Box 675
Taylors, SC 29687
Phone: 1-888-565-IRON (1-888-565-4766) or 864-292-1175
Email: info@irondisorders.org or cgarrison@irondisorders.org
Internet: www.irondisorders.org

Mission: To help people with iron disorders receive early, accurate, and complete diagnosis; appropriate treatment; and the equipment to live in good health.

Services provided:

Publications for patients
Resources

NASPGHAN Foundation for Children's Digestive Health & Nutrition

1501 Bethlehem Pike
P.O. Box 6
Flourtown, PA 19031
Phone: 215-233-0808
Email: naspghan@naspghan.org
Internet: www.naspghan.org or www.gikids.org

Mission: To advance understanding of normal development, physiology, and pathophysiology of diseases of the gastrointestinal tract and liver in children; improve quality of care by fostering the dissemination of this knowledge through scientific meetings, professional and public education, and policy development; and serve as an effective voice for members and the profession.

Services provided:

Advocacy and public policy
Educational programs, meetings, and events for health care providers
Pediatric gastroenterologist locator
Publications for health care providers and patients

National Association For Continence (NAFC)

P.O. Box 1019
Charleston, SC 29402-1019
Phone: 1-800-BLADDER (1-800-252-3337) or 843-377-0900
Fax: 843-377-0905
Email: memberservices@nafc.org
Internet: www.nafc.org

Mission: To improve the quality of life of people with incontinence, voiding dysfunction, and related pelvic floor disorders by being a leading source for public education and advocacy about the causes, prevention, diagnosis, treatments, and management alternatives for incontinence.

Services provided:

Advocacy and public policy
Publications for patients
Support groups

National Diabetes Education Program (NDEP)

1 Diabetes Way
Bethesda, MD 20814-9692
Phone: 1-888-693-NDEP (1-888-693-6337)
TTY: 1-866-569-1162
Fax: 703-738-4929
Email: ndep@mail.nih.gov
Internet: www.ndep.nih.gov or www.yourdiabetesinfo.org

Mission: To improve the treatment and outcomes for people with diabetes, promote early diagnosis, and prevent or delay the onset of type 2 diabetes.

Services provided:

Community outreach programs
Information for the media
Publications for health care providers and patients
Public service campaign materials

National Diabetes Information Clearinghouse (NDIC)

1 Information Way
Bethesda, MD 20892-3560
Phone: 1-800-860-8747
TTY: 1-866-569-1162
Fax: 703-738-4929
Email: ndic@info.niddk.nih.gov
Internet: www.diabetes.niddk.nih.gov

Mission: To increase knowledge and understanding about diabetes among patients, health care professionals, and the general public. To carry out this mission, the NDIC works closely with the NIDDK's Diabetes Research Centers; the National Diabetes Education Program; professional, patient, and voluntary associations; Government agencies; and state health departments to identify and respond to informational needs about diabetes and its management.

Services provided:

Publications for health care providers and patients
Resources

National Foundation for Celiac Awareness (NFCA)

P.O. Box 544
Ambler, PA 19002-0544
Phone: 215-325-1306
Fax: 215-643-1707
Email: info@celiaccentral.org
Internet: www.celiaccentral.org

Mission: To drive diagnoses of celiac disease and other gluten-related disorders and improve the quality of life for those on a lifelong gluten-free diet through empowerment, education, and advocacy.

Services provided:

Advocacy and public policy
Continuing medical education (CME)
Educational meetings and events for health care providers
Publications for health care providers and patients
Resources

National Organization for Rare Disorders (NORD)

55 Kenosia Avenue
Danbury, CT 06810
Phone: 1-800-999-6673 or 203-744-0100
Fax: 203-798-2291
Internet: www.rarediseases.org

Mission: To help people with rare “orphan” diseases and assist the organizations that serve them. The NORD is committed to the identification, treatment, and cure of rare disorders through programs of education, advocacy, research, and service.

Services provided:

Advocacy and public policy
Publications for health care providers and patients
Rare disease database

National Pancreas Foundation (NPF)

3 Bethesda Metro Center, Suite 700
Bethesda, MD 20814
Phone: 1-866-726-2737 or 301-961-1508
Fax: 301-657-9776
Email: info@pancreasfoundation.org
Internet: www.pancreasfoundation.org

Mission: To support the research of diseases of the pancreas and to provide information and humanitarian services to those people who are suffering from such illnesses.

Services provided:

Educational meetings and events for health care providers
Physician locator
Publications for health care providers, patients, and families
Resources

North American Society for Pediatric Gastroenterology, Hepatology and Nutrition (NASPGHAN)

P.O. Box 6
Flourtown, PA 19031
Phone: 215-233-0808
Fax: 215-233-3918
Email: naspghan@naspghan.org
Internet: www.naspghan.org

Mission: To advance understanding of normal development, physiology, and pathophysiology of diseases of the gastrointestinal tract and liver in children; improve quality of care by fostering the dissemination of this knowledge through scientific meetings, professional and public education, and policy development; and serve as an effective voice for members and the profession.

Services provided:

Advocacy and public policy
Educational programs, meetings, and events for health care providers
Pediatric gastroenterologist locator
Publications for health care providers and patients

The Oley Foundation

43 New Scotland Avenue, MC-28
Albany Medical Center
Albany, NY 12208-3478
Phone: 1-800-776-OLEY (1-800-776-6539) or 518-262-5079 (outside U.S.)
Fax: 518-262-5528
Email: bishopj@mail.amc.edu
Internet: www.oley.org

Mission: To provide information and psychosocial support to consumers of home parenteral (intravenous) and enteral (tube-fed) nutrition (homePEN), helping them live fuller, richer lives. To serve as a resource for consumers' families, homePEN clinicians and industry representatives, and other interested parties.

Services provided:

Educational programs and meetings for health care providers and patients
Publications for health care providers and patients
Resources
Support groups

Pediatric/Adolescent Gastroesophageal Reflux Association (PAGER)

404 Wheaton Place, Suite C
Catonsville, MD 21228
Phone: 301-601-9541
Email: gergroup@aol.com
Internet: www.reflux.org

Mission: To gather and disseminate information on pediatric gastroesophageal reflux (GER) and related disorders; provide educational and emotional support to patients with GER, their families, and professionals; promote greater awareness of GER within both the medical community and the general public; and promote research into the causes, treatments, and eventual cure for pediatric GER.

Services provided:

Resources

Pull-thru Network (PTN)

1705 Wintergreen Parkway
Normal, IL 61761
Phone: 309-262-0786
Email: PullthruNetwork@gmail.com
Internet: www.pullthrunetwork.org

Mission: To provide information, education, support, and advocacy for children and adults living with congenital anorectal, colorectal, or urogenital disorders.

Services provided:

Educational programs and events for patients
Support groups

Rome Foundation, Inc.

P.O Box 6524
Raleigh, NC 27628
Phone: 919-539-3051
Fax: 919-900-7646
Email: mpickard@theromefoundation.org
Internet: www.romecriteria.org

Mission: To improve the lives of people with functional GI disorders.

Services provided:

Educational programs for health care providers
Publications for health care providers
Sponsor research programs

The Simon Foundation for Continence

P.O. Box 815
Wilmette, IL 60091
Phone: 1-800-23-SIMON (1-800-237-4666) or 847-864-3913
Fax: 847-864-9758
Email: info@simonfoundation.org
Internet: www.simonfoundation.org

Mission: To bring the topic of incontinence out into the open, remove the stigma surrounding incontinence, and provide help and hope to people with incontinence, their families, and the health professionals who provide their care.

Services provided:

Educational programs, meetings, and events for health care providers
Publications for health care providers and patients

The Society for Surgery of the Alimentary Tract (SSAT)

500 Cummings Center, Suite 4550
Beverly, MA 01915
Phone: 978-927-8330
Fax: 978-524-8890
Internet: www.ssat.com

Mission: To stimulate, foster, and provide surgical leadership in the art and science of patient care; to teach and research the diseases and functions of the alimentary tract; to provide a forum for the presentation of such knowledge; and to encourage training opportunities, funding, and scientific publications supporting the foregoing activities.

Services provided:

Continuing medical education (CME)
Educational programs and meetings for health care providers
Patient care guidelines
Publications for health care providers

Society of American Gastrointestinal and Endoscopic Surgeons (SAGES)

11300 West Olympic Boulevard, Suite 600
Los Angeles, CA 90064
Phone: 310-437-0544
Email: webmaster@sages.org
Internet: www.sages.org

Mission: To provide leadership in surgery, particularly gastrointestinal and endoscopic surgery, and to optimize patient care through education, research, and innovation.

Services provided:

Continuing medical education (CME)
Educational programs and meetings for health care providers
Practice and clinical guidelines
Publications for health care providers and patients

Society of Gastroenterology Nurses and Associates, Inc. (SGNA)

330 North Wabash Avenue, Suite 2000
Chicago, IL 60611-7261
Phone: 1-800-245-SGNA (1-800-245-7462) or 312-321-5165
Fax: 312-673-6694
Email: sgna@smithbucklin.com
Internet: www.sgna.org

Mission: To advance the science and practice of gastroenterology and endoscopy nursing through education, research, advocacy, and collaboration and by promoting the professional development of its members in an atmosphere of mutual support.

Services provided:

Advocacy and public policy
Certification activities
Continuing medical education (CME)
Educational programs and events for health care providers
Position statements, standards, and practice guidelines

TEF/VATER International

Phone: 301-952-6837
Fax: 301-952-9152
Email: info@tefvater.org
Internet: www.tefvater.org

Mission: To provide support for adults seeking information about babies with VATER (vertebral defects, imperforate anus, tracheoesophageal fistula, renal defects), esophageal atresia, and tracheoesophageal fistula.

Services provided:

Resources

United Network for Organ Sharing (UNOS)

P.O. Box 2484
Richmond, VA 23218
Phone: 1-888-894-6361 or 804-782-4800
Fax: 804-782-4817
Internet: www.unos.org

Mission: To advance organ availability and transplantation by uniting and supporting its communities for the benefit of patients through education, technology, and policy development.

Services provided:

Advocacy and public policy
Educational meetings and events for health care providers
Publications for health care providers and patients
Resources
Support groups

United Ostomy Associations of America, Inc. (UOAA)

2489 Rice Street, Suite 275
Roseville, MN 55113-3797
Phone: 1-800-826-0826
Email: info@ostomy.org
Internet: www.ostomy.org

Mission: To improve of the quality of life of people who have, or will have, an intestinal or urinary diversion; to provide information, advocacy, and service to, and for, its affiliated support groups, their members, and the intestinal/urinary diversion community at large.

Services provided:

Advocacy and public policy
Educational programs for health care providers
Publications for patients
Resources
Support group locator

Weight-control Information Network (WIN)

1 WIN Way
Bethesda, MD 20892-3665
Phone: 1-877-946-4627
Fax: 202-828-1028
Email: win@info.niddk.nih.gov
Internet: www.win.niddk.nih.gov

Mission: To provide the general public, health professionals, the media, and Congress with up-to-date, science-based information about obesity, weight control, physical activity, and related nutritional issues.

Services provided:

Publications for health care providers and patients
Resources

Wilson Disease Association (WDA)

5572 North Diversey Boulevard
Milwaukee, WI 53217
Phone: 1-866-961-0533 or 414-961-0533
Email: info@wilsonsdisease.org
Internet: www.wilsonsdisease.org

Mission: To fund research and facilitate and promote the identification, education, treatment, and support of patients and other individuals affected by Wilson disease.

Services provided:

Advocacy and public policy
Physician locator
Publications for health care providers and patients
Resources
Support group locator

Wound, Ostomy and Continence Nurses Society (WOCN)

15000 Commerce Parkway, Suite C
Mt. Laurel, NJ 08054
Phone: 1-888-224-WOCN (1-888-224-9626)
Fax: 856-439-0525
Email: wocn_info@wocn.org
Internet: www.wocn.org

Mission: To promote educational, clinical, and research opportunities to advance the practice and guide the delivery of expert health care to individuals with wounds, ostomies, and incontinence.

Services provided:

Accreditation programs
Advocacy and public policy
Certification activities
Continuing medical education (CME)
Publications for health care providers and patients

National Digestive Diseases Information Clearinghouse

2 Information Way
Bethesda, MD 20892-3570
Phone: 1-800-891-5389
TTY: 1-866-569-1162
Fax: 703-738-4929
Email: nddic@info.niddk.nih.gov
Internet: www.digestive.niddk.nih.gov

The National Digestive Diseases Information Clearinghouse (NDDIC) is a service of the National Institute of Diabetes and Digestive and Kidney Diseases (NIDDK). The NIDDK is part of the National Institutes of Health of the U.S. Department of Health and Human Services. Established in 1980, the Clearinghouse provides information about digestive diseases to people with digestive disorders and to their families, health care professionals, and the public. The NDDIC answers inquiries, develops and distributes publications, and works closely with professional and patient organizations and Government agencies to coordinate resources about digestive diseases.

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