



## **Directory of Digestive Diseases Organizations**

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

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

120 South Riverside Plaza, Suite 2000  
Chicago, IL 60606–6995  
Fax: 312–899–0008  
Internet: [www.eatright.org](http://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](mailto:alagille@alagille.org)  
Internet: [www.alagille.org](http://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**

2937 Southwest 27th Avenue, Suite 302

Miami, FL 33133

Phone: 1-877-2-CURE-A1 (1-877-228-7321) or 305-567-9888

Fax: 305-567-1317

Email: [info@alphaone.org](mailto:info@alphaone.org)

Internet: [www.alphaone.org](http://www.alphaone.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](mailto:aasld@aasld.org)

Internet: [www.aasld.org](http://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](mailto:info@americanceliac.org)  
 Internet: [www.americanceliac.org](http://www.americanceliac.org)

**Mission:** To represent and advocate on behalf of the entire celiac community—patients, physicians, researchers, and 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 20817-5846  
 Phone: 301-263-9000  
 Email: [info@acg.gi.org](mailto:info@acg.gi.org)  
 Internet: [www.acg.gi.org](http://www.acg.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
- Continued 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)**

4044 West Lake Mary Boulevard, #104, PMB 416  
Lake Mary, FL 32746-2012  
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

Email: [info@liverfoundation.org](mailto:info@liverfoundation.org)  
Internet: [www.liverfoundation.org](http://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](mailto:admin@motilitysociety.org)  
Internet: [www.motilitysociety.org](http://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](mailto:apa@umn.edu)  
Internet: [www.american-pancreatic-association.org](http://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)**

1520 Kensington Road, Suite 202  
Oak Brook, IL 60523  
Phone: 1-866-353-ASGE (1-866-353-2743) or 630-573-0600  
Fax: 630-573-0691  
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 20910-3805  
Phone: 1-800-727-4567 or 301-587-6315  
Fax: 301-587-2365  
Email: [aspen@nutr.org](mailto:aspen@nutr.org)  
Internet: [www.nutritioncare.org](http://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](mailto:office@abdominalsurg.org)  
Internet: [www.abdominalsurg.org](http://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](mailto:ascrs@fascrs.org)  
Internet: [www.fascrs.org](http://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](mailto:digestive.motility@gmail.com)  
Internet: [www.agmd-gimotility.org](http://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](mailto:info@arpkdchf.org)  
Internet: [www.arpkd.org](http://www.arpkd.org) or [www.arpkdchf.org](http://www.arpkdchf.org)

**Mission:** To educate, advocate, support, and advance research specific to ARPK/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: [cdf@celiac.org](mailto:cdf@celiac.org)  
Internet: [www.celiac.org](http://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 Sprue Association/USA, Inc. (CSA)**

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](mailto:celiacs@csaceliacs.org)  
Internet: [www.csaceliacs.org](http://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) or 404-718-8596  
TTY: 1-888-232-6348  
Fax: 404-781-8588  
Email: [cdcinfo@cdc.gov](mailto:cdcinfo@cdc.gov)  
Internet: [www.cdc.gov/hepatitis](http://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

### **Crohn's & Colitis Foundation of America (CCFA)**

386 Park Avenue South, 17th floor  
New York, NY 10016  
Phone: 1-800-932-2423 or 212-685-3440  
Fax: 212-779-4098  
Email: [info@ccfa.org](mailto:info@ccfa.org)  
Internet: [www.ccfa.org](http://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](mailto:cvsa@cvsaonline.org)  
Internet: [www.cvsaonline.org](http://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  
Email: [ddnc@hmcw.org](mailto:ddnc@hmcw.org)  
Internet: [www.ddnc.org](http://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

**The Food Allergy & Anaphylaxis Network**

11781 Lee Highway, Suite 160  
Fairfax, VA 22033-3309  
Phone: 1-800-929-4040  
Fax: 703-691-2713  
Email: [faan@foodallergy.org](mailto:faan@foodallergy.org)  
Internet: [www.foodallergy.org](http://www.foodallergy.org)

**Mission:** To raise public awareness, provide advocacy and education, and advance research on behalf of all those affected by food allergies and anaphylaxis.

**Services provided:**

- Educational meetings for health care providers, patients, and families

- Information for the media
- 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: info@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: [info@hepb.org](mailto:info@hepb.org)  
Internet: [www.hepb.org](http://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, 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)**

504 Blick Drive  
Silver Spring, MD 20904  
Phone: 1-800-891-0707 or 301-622-4200  
Fax: 301-622-4702  
Email: [info@hepatitisfoundation.org](mailto:info@hepatitisfoundation.org)  
Internet: [www.hepfi.org](http://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](mailto:admin@immunize.org)  
Internet: [www.immunize.org](http://www.immunize.org) and [www.vaccineinformation.org](http://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)**

P.O. Box 170864  
Milwaukee, WI 53217-8076  
Phone: 1-888-964-2001 or 414-964-1799  
Fax: 414-964-7176  
Email: [iffgd@iffgd.org](mailto:iffgd@iffgd.org)  
Internet: [www.iffgd.org](http://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  
Fax: 864-292-1878  
Email: [info@irondisorders.org](mailto:info@irondisorders.org)  
Internet: [www.irondisorders.org](http://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

## **Iron Overload Diseases Association (IOD)**

525 Mayflower Road  
West Palm Beach, FL 33405  
Phone: 561-586-8246  
Email: [iod@ironoverload.org](mailto:iod@ironoverload.org)  
Internet: [www.ironoverload.org](http://www.ironoverload.org)

**Mission:** To lead the search for the millions of Americans and other nationals who have undiagnosed iron overload; to promote adequate treatment and to prevent the severe health problems and avoidable deaths that results from neglect of iron overload.

### **Services provided:**

- Resources

## **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](mailto:memberservices@nafc.org)  
Internet: [www.nafc.org](http://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](mailto:ndep@mail.nih.gov)  
Internet: [www.ndep.nih.gov](http://www.ndep.nih.gov) or [www.yourdiabetesinfo.org](http://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](mailto:ndic@info.niddk.nih.gov)  
Internet: [www.diabetes.niddk.nih.gov](http://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, NDIC works closely with NIDDK's Diabetes Research and Training Centers; the National Diabetes Education Program (NDEP); 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](mailto:info@celiaccentral.org)  
Internet: [www.celiaccentral.org](http://www.celiaccentral.org)

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

***Services provided:***

- Advocacy and public policy
- Continued 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  
P.O. Box 1968  
Danbury, CT 06813-1968  
Phone: 1-800-999-6673 or 203-744-0100  
TDD: 203-797-9590  
Fax: 203-798-2291  
Email: orphan@rarediseases.org  
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)**

101 Federal Street, Suite 1900  
Boston, MA 02110  
Phone: 1-866-726-2737 or 617-342-7019  
Fax: 617-342-7080  
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](mailto:naspghan@naspghan.org)  
Internet: [www.naspghan.org](http://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

**Pediatric/Adolescent Gastroesophageal Reflux Association (PAGER)**

P.O. Box 7728  
Silver Spring, MD 20907  
Phone: 301-601-9541  
Email: [gergroup@aol.com](mailto:gergroup@aol.com)  
Internet: [www.reflux.org](http://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)**

2312 Savoy Street  
Hoover, AL 35226-1528  
Phone: 205-978-2930  
Email: [PullThruNetwork@gmail.com](mailto:PullThruNetwork@gmail.com)  
Internet: [www.pullthrunetwork.org](http://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

### **Reach Out for Youth with Ileitis and Colitis, Inc. (ROFY)**

P.O. Box 857  
Bellmore, NY 11710  
Phone: 631-293-3102  
Email: [info@reachoutforyouth.org](mailto:info@reachoutforyouth.org)  
Internet: [www.reachoutforyouth.org](http://www.reachoutforyouth.org)

**Mission:** To provide support and education for families raising children with Crohn's and related diseases.

#### **Services provided:**

- Resources

### **Rome Foundation, Inc.**

P.O. Box 6524  
Raleigh, NC 27628  
Phone: 919-345-3927  
Fax: 919-900-7646  
Email: [mpickard@theromefoundation.org](mailto:mpickard@theromefoundation.org)  
Internet: [www.romecriteria.org](http://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

### **Society of American Gastrointestinal and Endoscopic Surgeons (SAGES)**

11300 West Olympic Boulevard, Suite 600  
Los Angeles, CA 90064  
Phone: 310-437-0544  
Fax: 310-437-0585  
Email: [webmaster@sages.org](mailto:webmaster@sages.org)  
Internet: [www.sages.org](http://www.sages.org)

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

#### **Services provided:**

- Continued 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)**

401 North Michigan Avenue  
Chicago, IL 60611-4267  
Phone: 1-800-245-SGNA (1-800-245-7462) or 312-321-5165  
Fax: 312-673-6694  
Email: [sgna@smithbucklin.com](mailto:sgna@smithbucklin.com)  
Internet: [www.sgna.org](http://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
- Continued medical education (CME)
- Educational programs and events for health care providers
- Position statements, standards, and practice guidelines

## **The Oley Foundation**

214 Hun Memorial, 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: [bishop@mail.amc.edu](mailto:bishop@mail.amc.edu)  
Internet: [www.oley.org](http://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

## **The Society for Surgery of the Alimentary Tract (SSAT)**

900 Cummings Center, Suite 4550  
Beverly, MA 01915  
Phone: 978-927-8330  
Fax: 978-524-8890

Email: [ssat@prri.com](mailto:ssat@prri.com)  
Internet: [www.ssat.com](http://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:**

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

**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](mailto:info@simonfoundation.org)  
Internet: [www.simonfoundation.org](http://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

**TEF/VATER International**

15301 Grey Fox Road  
Upper Marlboro, MD 20772  
Phone: 301-952-6837  
Fax: 301-952-9152  
Email: [info@tefvater.org](mailto:info@tefvater.org)  
Internet: [www.tefvater.org](http://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](http://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)**

P.O. Box 512  
Northfield, MN 55057-0512  
Phone: 1-800-826-0826  
Email: [info@ostomy.org](mailto:info@ostomy.org)  
Internet: [www.ostomy.org](http://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 or 202-828-1025  
Fax: 202-828-1028  
Email: [win@info.niddk.nih.gov](mailto:win@info.niddk.nih.gov)  
Internet: [www.win.niddk.nih.gov](http://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](mailto:info@wilsonsdisease.org)  
Internet: [www.wilsonsdisease.org](http://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](mailto:wocn_info@wocn.org)  
Internet: [www.wocn.org](http://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
- Continued medical education (CME)
- Publications for health care providers and patients

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## **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](mailto:nddic@info.niddk.nih.gov)  
Internet: [www.digestive.niddk.nih.gov](http://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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October 2012