



National Digestive Diseases Information Clearinghouse (NDDIC)

Directory of Digestive Diseases Organizations for Patients

This directory lists voluntary and private organizations involved in digestive diseases-related activities for patients. The organizations offer educational materials and other services.

Alagille Syndrome Alliance

Cindy L. Hahn, Director
10500 SW Starr Drive
Tualatin, OR 97062
Phone: 503-885-6455
Email: alagille@alagille.org
Internet: www.alagille.org

Mission: To provide a support network for children, their parents, and others with Alagille syndrome (AGS). The purpose of the Alliance is to serve as the main networking resource and source of information for people with AGS and their family, friends, and health care providers. The Alliance also is dedicated to increasing public awareness of AGS and supporting research efforts on behalf of the AGS community.

Materials: Newsletter—*LiverLink*; booklet—*Alagille Syndrome in the Classroom*; brochure—*Allagille Syndrome* (published by the American Liver Foundation).

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American Celiac Society—Dietary Support Coalition

Annette & James Bentley
P.O. Box 23455
New Orleans, LA 70183-0455
Phone: 504-737-3293
Email: info@americanceleacsociety.org
Internet: www.americanceleacsociety.org

Mission: To provide practical assistance to members and individuals with celiac disease and information about the disease to the public.

Materials: Newsletter—*Whooo's Report. Call A Friend With Celiac Sprue*.

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American Dietetic Association (ADA)

120 South Riverside Plaza, Suite 2000
Chicago, IL 60606-6995
Phone: 1-800-877-1600 or 312-899-0040
Fax: 312-899-4739
Email: hotline@eatright.org
Internet: www.eatright.org

Mission: Leading the future of dietetics.

Materials: Monthly professional journal—*The Journal of the American Dietetic Association*; monthly newsletter—*ADA Courier*; books and other resources for consumers and professionals.

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American Hemochromatosis Society Inc. (AHS)

4044 West Lake Mary Boulevard, #104, PMB 416
Lake Mary, FL 32746–2012
Phone: 1–888–655–IRON (4766) or 407–829–4488
Fax: 407–333–1284
Email: mail@americanhs.org
Internet: www.americanhs.org

Mission: To educate and support hemochromatosis (genetic iron overload) patients and to educate the medical community on the latest research on the disease.

Materials: Free educational materials and email/telephone patient support, as well as physician referral services and online support groups.

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American Liver Foundation (ALF)

75 Maiden Lane, Suite 603
New York, NY 10038–4810
Phone: 1–800–GO–LIVER (465–4837),
1–888–4HEP–USA (443–7872), or 212–668–1000
Fax: 212–483–8179
Email: info@liverfoundation.org
Internet: www.liverfoundation.org

Mission: To promote liver health and liver disease prevention. ALF provides research, education, and advocacy for those affected by liver-related diseases, including hepatitis.

Materials: Member newsletters; pamphlets, fact sheets, and videos about liver diseases, transplantation, organ donation, and prevention of liver diseases.

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American Porphyria Foundation

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

Mission: To enhance public awareness about porphyria, develop and distribute educational materials for patients and physicians, and support research to improve treatment and lead to a cure.

Materials: Informational brochures—*Acute Intermittent Porphyria*, *Porphyria Cutanea Tarda (PCT)*, *ALAD Porphyria (ADP)*, *Hepatoerythropoietic Porphyria (HEP)*, *Hereditary Coproporphyrinuria (HCP)*, *Variante Porphyria (VP)*, and *Erythropoietic Protoporphyrinuria (EPP)*; newsletter.

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

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

Mission: To educate, advocate, support, and advance research specific to autosomal recessive polycystic kidney disease (ARPKD) and congenital hepatic fibrosis (CHF).

Materials: Free ARPKD/CHF Alliance newsletters and educational materials, email listserv, bereavement information and resources, "Clinical Care Considerations"—managed care guidelines for "informed individualized decision making"; "CARPKD/CHF Alliance Repository"—a blood and data bank of affected persons.

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Association of Gastrointestinal Motility Disorders, Inc. (AGMD) (formerly American Society of Adults with Pseudo-Obstruction, Inc.)

AGMD International Corporate Headquarters
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 on digestive motility disorders and function as an information base for members of the medical community. Formerly known as the American Society of Adults with Pseudo-Obstruction, Inc. (ASAP), this nonprofit international organization changed its name and broadened its mission in 1999.

Materials: Member publications—*AGMD Beacon* and *AGMD Search and Research*; physician listings and referrals; medical references; educational materials; publication listings and order form; patient information.

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Celiac Disease Foundation (CDF)

13251 Ventura Boulevard, #1
Studio City, CA 91604
Phone: 818-990-2354
Fax: 818-990-2379
Email: cdf@celiac.org
Internet: www.celiac.org

Mission: To develop awareness and improve the quality of medical and self-care for celiac disease/dermatitis herpetiformis; provide telephone information and referral services, free information, medical advisory board, and special educational seminars and general meetings. Annual dues: \$35.

Materials: Quarterly newsletter—*Guidelines for a Gluten-Free Lifestyle*; brochures.

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Celiac Sprue Association/USA Inc.

P.O. Box 31700
Omaha, NE 68131-0700
Phone: 1-877-CSA-4CSA
Fax: 402-558-1347

Email: celiacs@csaceliacs.org
Internet: www.csaceliacs.org

Mission: To provide information and educational materials for persons with celiac sprue and dermatitis herpetiformis and for parents of children with celiac disease. Made up of six regions with chapters and resource units across the United States.

Materials: Information sheets—*Celiac Sprue, Basics for the Gluten-free Diet, Gluten-free Commercial Products*; new-patient packet; handbook—*On the Celiac Condition*; quarterly newsletter for people with celiac disease—*Lifeline*; membership forms; chapter information; resource unit information; promotional brochure.

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Crohn's & Colitis Foundation of America Inc. (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
Internet: www.ccfa.org

Mission: To cure and prevent Crohn's disease and ulcerative colitis through research, and to improve the quality of life of children and adults affected by these digestive diseases through education and support.

Materials: Patient education and instructional materials about all aspects of Crohn's disease and ulcerative colitis, including emotional factors and issues specific to women and children; resource guides; three full-length books; a magazine for foundation supporters—*Foundation Focus*; extensive website at www.ccfa.org.

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Cyclic Vomiting Syndrome Association (CVSA)

CVSA USA/Canada
3585 Cedar Hill Road, NW
Canal Winchester, OH 43110
Phone: 614-837-2586
Fax: 614-837-2586
Email: waitesd@cvsaonline.org
Internet: www.cvsaonline.org

Mission: To provide opportunities for patients, families, and professionals to offer and receive support and share knowledge about cyclic vomiting syndrome; actively promote and facilitate medical research about nausea and vomiting; increase worldwide public and professional awareness; serve as a resource center for information.

Materials: Member newsletter—*Code V*; patient education publications.

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Digestive Disease National Coalition

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

Mission: To inform the public and the health care community about digestive diseases; seek Federal funding for research, education, and training; represent members' interests regarding Federal and state

legislation that affects digestive diseases research, health care, and education.

Materials: Brochures; patient education materials.

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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
Internet: www.foodallergy.org

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

Materials: Bimonthly member newsletter—*Food Allergy News*; booklets; videos; cookbooks; special-alert mailings informing members of product information, including ingredient changes, recalls, or packaging mishaps.

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Gastro-Intestinal Research Foundation

70 East Lake Street, Suite 1015
Chicago, IL 60601-5907
Phone: 312-332-1350
Fax: 312-332-4757
Email: girf@girf.org
Internet: www.girf.org

Mission: To support research and training programs at the University of Chicago Medical Center, Section of Gastroenterology, and sponsor educational activities for the public.

Materials: Several newsletters; patient education pamphlet—*Issues in Women's Gastrointestinal Health*.

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Gluten Intolerance Group of North America (GIG)

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

Mission: To provide education and support to persons with gluten intolerances, including celiac disease, dermatitis herpetiformis, and other gluten sensitivities, in order to live healthy lives.

Materials: Cookbooks and general dietary recommendations; fact sheets; member newsletter—*GIG Newsletter*; videotapes; patient packets for celiac disease and dermatitis herpetiformis; dietary guidelines for hospitalized persons with celiac disease and dermatitis herpetiformis.

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Hepatitis B Coalition

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 promote hepatitis B vaccination for all children 0–18 years, HBSAg screening for all pregnant women, testing and vaccination for high-risk groups, and education and treatment for people who are chronically infected with hepatitis B. The Immunization Action Coalition seeks to boost immunization rates and prevent disease by promoting physician, community, and family awareness of and responsibility for appropriate immunization of all children and adults against all vaccine-preventable diseases.

Materials: Semiannual publications—*NEEDLE TIPS*, *Vaccinate Adults*, and *Vaccinate Women*; a free email news service—IAC Express and HEP Express; other materials—brochures for patients in a number of languages, print materials for clinic staff, videotapes, posters, materials for various ethnic populations, adult immunization record card with or without smallpox.

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Hepatitis B Foundation

3805 Old Easton Road
Doylestown, PA 18902
Phone: 215-489-4900
Fax: 215-489-4313
Email: info@hepb.org
Internet: www.hepb.org

Mission: To raise public awareness, provide information and support, and fund cure-focused research on hepatitis B, and to promote prevention. The Hepatitis B Foundation is a voluntary nonprofit organization.

Materials: Newsletters—*B Informed*, *B Connected*, and *B News You Can Use*; brochures—*The Hepatitis B Foundation Cause for a Cure*, *Someone You Know Has Hepatitis B*, *Protect Yourself and Those You Love Against HBV*, *What Hepatitis B Carriers Should Know*, and *The First Loving Act—Vaccination*; fact sheets—*Advice to Parents of Children With HBV* and *Hot Sheet* with current hepatitis B virus research, telephone numbers, and a medical glossary; directory—*National Directory of Liver Specialists*; video—*Someone You Know*.

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Hepatitis Foundation International (HFI)

504 Blick Drive
Silver Spring, MD 20904-2901
Phone: 1-800-891-0707 or 301-622-4200
Fax: 301-622-4702
Email: hfi@comcast.net
Internet: www.hepfi.org

Mission: To provide education, training programs, and materials for the public, patients, educators, and medical professionals about the diagnosis, treatment, and prevention of viral hepatitis; support research to find cures; provide a telephone support network for patients, a listing of physician referrals, a toll-free hotline in the United States and Canada, a database of hepatitis support groups, and a website with information in multiple languages.

Materials: Information sheets—*Caring for Your Liver*; *Diagnosis and Treatment of Viral Hepatitis*; *Hepatitis A, B, and C*; *Hepatitis A and B Vaccination*; *Caution! Treating Children With Acetaminophen*; *Health Insurance*; *Helpful Tips for Carriers of HBV*; *Living With Hepatitis C—Self-Help Tips*; *Tips on Coping With Chronic Hepatitis*; additional educational materials; poster—*Take Care of Your Liver*; brochure—*Is Your Liver Giving You the Silent Treatment?*; primers for teachers and parents; workbook about the liver for children; audio tutorial CD-ROM; videos and books; newsletters—*Hepatitis Alert* and

Patient Advocacy Council newsletter.

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International Foundation for Functional Gastrointestinal Disorders (IFFGD) Inc.

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
Internet: www.iffgd.org

Mission: To inform, assist, and support people affected by gastrointestinal disorders. The IFFGD is a nonprofit education and research organization.

Materials: Quarterly newsletters—*Participate*, *Digestive Health Matters*, and *Digestive Health in Children*; educational pamphlets; fact sheets.

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Iron Disorders Institute

2722 Wade Hampton Boulevard, Suite A
Greenville, SC 29615
Phone: 864-292-1175
Fax: 864-292-1878
Email: ironstore@irondisorders.org
Internet: www.irondisorders.org

Mission: To reduce pain, suffering, and unnecessary death due to disorders of iron through education, awareness, and facilitating research.

Materials: Newsletters—*idIntouch* and *Iron Bytes*; books—*Guide to Hemochromatosis*, *Guide to Anemia*, *Cooking With Less Iron*, *Exposing the Hidden Dangers of Iron*; forms—Personal Health Profile and Physician's Reference Chart; e-publication—*idInsight*.

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Iron Overload Diseases Association Inc.

P.O. Box 15857
West Palm Beach, FL 33416-5857
Phone: 561-586-8246
Fax: 561-586-8248
Email: iod@ironoverload.org
Internet: www.ironoverload.org

Mission: To conduct professional education symposiums and exhibits at medical meetings; serve and counsel patients with hemochromatosis and their families; offer doctor referrals; promote patient advocacy concerning insurance, Medicare, blood banks, and the Food and Drug Administration; encourage research; maintain an international clearinghouse; offer public information through the media; develop chapters and self-help groups; sponsor annual symposiums and annual IOD Awareness Week.

Materials: Booklet—*Overload: An Ironic Disease*; bimonthly newsletter—*Ironic Blood*; information brochure—*Iron Overload Alert*; fact sheet.

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National Association For Continence (NAFC) (formerly Help for Incontinent People [HIP])

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

Mission: To serve as a leading source of education, advocacy, and support to the public and to the health profession about the causes, prevention, diagnosis, treatments, and management alternatives for incontinence.

Materials: Quarterly newsletter—*Quality Care; Annual Resource Guide of Continence Products and Services*; other educational materials, including books and audiovisuals.

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National Diabetes Education Program (NDEP)

1 Diabetes Way
Bethesda, MD 20892-3560
Phone: 1-800-438-5383
Fax: 703-738-4929
Email: ndep@mail.nih.gov
Internet: www.ndep.nih.gov

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

Materials: Diabetes education materials are available free or at little cost.

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National Diabetes Information Clearinghouse (NDIC)

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

Mission: To serve as a diabetes informational, educational, and referral resource for health professionals and the public. NDIC is a service of the NIDDK.

Materials: Diabetes education materials are available free or at little cost. Literature searches on a myriad of subjects related to diabetes are provided. NDIC publishes [Diabetes Dateline](#), a quarterly newsletter.

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National Foundation for Celiac Awareness

P.O. Box 544
Ambler, PA 19002
Phone: 215-325-1306
Fax: 215-283-2335
Email: info@celiaccentral.org
Internet: www.celiaccentral.org

Mission: The Foundation's mission is to raise awareness and funding for celiac disease that will advance research, education and screening, and improve the quality of life of children and adults affected by this autoimmune disease through grant making and direct programming.

Materials: Books—*Celiac Sprue, A Guide Through the Medicine Cabinet*; *Gluten-Free Diet: A Comprehensive Resource Guide*; *Triumph Dining*; *NFCA Gluten-Free Resource Guide*.

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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
Fax: 203–798–2291
Email: orphan@rarediseases.org or RN@rarediseases.org
Internet: www.rarediseases.org

Mission: A unique federation of voluntary health organizations dedicated to helping people with rare “orphan” diseases and assisting the organizations that serve them; committed to the identification, treatment, and cure of rare disorders through education, advocacy, research, and service programs.

Materials: Member newsletter—*Orphan Disease Update (ODU)*; *NORD Resource Guide*; *Physicians Guide for Rare Disorders*; booklets—free guides for physicians about several rare disorders.

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Oley Foundation for Home Parenteral and Enteral Nutrition (HomePEN)

214 Hun Memorial, MC–28
Albany Medical Center
Albany, NY 12208–3478
Phone: 1–800–776–OLEY (6539) or 518–262–5079 (outside U.S.)
Fax: 518–262–5528
Email: info@oley.org
Internet: www.oley.org

Mission: To enrich the lives of those requiring home nutrition support.

Materials: Bimonthly newsletter—*LifelineLetter*; charts—*Home Parenteral Nutrition Complication Chart* and *Home Enteral Nutrition (HEN) Complication Chart*; video library of annual conference presentations; video—*Choices in Nutrition: Understanding HPN Therapy Options*; HomePEN Family Network; toll-free consumer networking.

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Pediatric/Adolescent Gastroesophageal Reflux Association Inc. (PAGER)

P.O. Box 486
Buckeystown, MD 21717–0486
Phone: 301–601–9541
Fax: 630–982–6418
Email: gergroup@aol.com
Internet: www.reflux.org

Mission: To gather and disseminate information on pediatric gastroesophageal reflux and related disorders; provide support and education to patients, their families, and the public; promote the general welfare of patients with gastroesophageal reflux and their families; promote public awareness of the condition as well as promote research into the causes, treatments, and eventual cure for reflux. Provide trained, experienced volunteer speakers and parent-to-parent sharing via meetings and electronic message boards.

Materials: Literature on gastroesophageal reflux and related disorders with descriptions of tests, procedures, medications, and parent-tested home care techniques; quarterly newsletter; brochure on breastfeeding a baby with reflux; reprint from *JAMA*—*Mapping a Gene for Severe Pediatric GER to Chromosome 13q14*; booklets on going to school with GERD, dental care for children with GERD, and feeding disorders and GERD.

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Pull-thru Network

2312 Savoy Street
Hoover, AL 35226-1528
Phone: 205-978-2930
Email: info@pullthrough.org
Internet: www.pullthrough.org

Mission: To provide emotional support and information to patients and families of children who have had or will have pull-through surgery to correct an imperforate anus or associated malformation, Hirschsprung's disease, or other fecal incontinence problems; sponsor online discussion groups; maintains a lending library and an article reprint service; and sponsors regional meetings. A chapter of the United Ostomy Association.

Materials: Quarterly publication—*Pull-thru Network News*; free brochure—*Anorectal Malformations—A Parent's Guide*.

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Reach Out for Youth with Ileitis and Colitis Inc.

84 Northgate Circle
Melville, NY 11747
Phone: 631-293-3102
Fax: 631-293-3102
Email: reachoutforyouth@reachoutforyouth.org
Internet: www.reachoutforyouth.org

Mission: Reach Out for Youth with Ileitis and Colitis is a nonprofit support group for families of youngsters with IBD. Founded in 1979, the organization has helped hundreds of families cope with the effects of IBD. The self-help group's goals include providing educational and emotional support to patients and their families and organizing fundraising efforts to promote research into the causes and treatment of IBD.

Materials: Newsletter—*The Inner Circle*; educational brochure—*The Inside Story*; educational plans—information on accessing services under Section 504 for children with special health care needs.

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The Simon Foundation for Continence

P.O. Box 815
Wilmette, IL 60091
Phone: 1-800-23-SIMON or 847-864-3913
Fax: 847-864-9758
Internet: www.simonfoundation.org

Mission: To bring the topic of incontinence out of the closet and remove the associated stigma; provide educational materials to patients, their families, and the health care professionals who provide patient care.

Materials: Quarterly newsletter—*The Informer*; hardbound 122-page book—*Managing Incontinence: A Guide to Living With Loss of Bladder Control*; additional patient education materials.

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TEF-VATER International

15301 Grey Fox Road

Upper Marlboro, MD 20772
Phone: 301-952-6837
Fax: 301-952-9152
Email: info@tefvater.org
Internet: www.tefvater.org

Mission: To provide support to children and adults born with esophageal atresia (EA), tracheoesophageal fistula (TEF), or VACTERL (V—vertebral, A—anal, C—cardial, TE—tracheo-esophageal, R—renal, L—limb).

Materials: Newsletter—*Inside Connections*; general information; books—several books concerning coping, working with medical practitioners, and personal stories and accounts of parents who have children with birth defects.

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United Ostomy Associations of America, Inc.

P.O. Box 66
Fairview, TN 37062-0066
Phone: 1-800-826-0826 or 949-660-8624
Fax: 949-660-9262
Email: info@uoaa.org
Internet: www.uoaa.org

Mission: To produce and distribute materials about ostomy care and management; through trained UOA members, offer practical assistance and emotional support to ostomy patients; sponsor annual youth rally and state and regional conferences for local affiliates. UOA has 500 chapters to serve people locally.

Materials: Journal—*Ostomy Quarterly*; patient education pamphlets; self-care handbooks; audiovisual program; magazine—*The Phoenix*.

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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
Internet: www.win.niddk.nih.gov

Mission: To produce and disseminate up-to-date, science-based materials on weight control, obesity, physical activity, and related nutritional issues; develop communication and promotional strategies that encourage individuals to engage in regular physical activity and eat healthy foods.

Materials: Fact sheets, pamphlets, reprints, consensus statements, reports, and literature searches on weight control, obesity, and weight-related nutritional disorders; quarterly newsletter—*WIN Notes*.

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Wilson's Disease Association International

1802 Brookside Drive
Wooster, OH 44691
Phone: 1-888-264-1450 or 330-264-1450
Fax: 330-264-0974
Email: info@wilsonsdisease.org
Internet: www.wilsonsdisease.org

Mission: To find research and facilitate and promote the identification, education, treatment, and

support of patients and other individuals affected by Wilson disease.

Materials: *The Copper Connection* (newsletter) and international brochures.

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National Digestive Diseases Information Clearinghouse

2 Information Way
Bethesda, MD 20892-3570
Phone: 1-800-891-5389
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.

Publications produced by the Clearinghouse are carefully reviewed by both NIDDK scientists and outside experts.

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National Digestive Diseases Information Clearinghouse
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