Associations Providing Support for Patients with Digestive Diseases

Compiled by Stacey McCray, R.D. and Carol Rees Parrish, M.S., R.D., Nutrition Support Specialists at the University of Virginia Health Science Center

GENERAL GI

American Gastroenterological Association
4930 Del Ray Avenue
Bethesda, MD 20814
301-654-2055
www.gastro.org
E-mail: member@gastro.org
The oldest medical-specialty society in the U.S. Dedicated to the mission of advancing the science and practice of gastroenterology; publishes two highly respected journals each month; has a patient center through which patients can learn more about their digestive health and GI disorders and locate a doctor in their area.

Digestive Disease National Coalition
507 Capitol Court, N.E.
Suite 200
Washington, D.C. 20002
202-544-7497
www.ddnc.org
An advocacy organization focused on improving public policy related to digestive diseases and increasing public awareness of diseases of the digestive system. Very good site for other links.

National Digestive Diseases Information Clearinghouse
Information Clearinghouse
2 Information Way
Bethesda, MD 20892-3570
800-891-5389
301-654-3810
www.niddk.nih.gov/health/digest/nddic.htm
An information dissemination service; goal is to increase knowledge and understanding about digestive diseases among people with these conditions, health care professionals, and the general public.

National Institute of Diabetes and Digestive and Kidney Disease (NIDDK)
Building 31, Room 9A-04
31 Center Drive, MSC 2560
Bethesda, MD 20892-2560
301-496-3583
www.niddk.nih.gov
Conducts and supports research on many of the most serious diseases affecting public health.

NUTRITION SUPPORT

American Society for Parenteral and Enteral Nutrition (ASPEN)
8630 Fenton Street, Suite 412
Silver Spring, MD 20910
800-727-4567; 301-587-6315
www.nutritioncare.org
E-Mail: aspen@nutr.org
Promotes communication between professionals involved in the area of nutrition support, promotes proper application of nutrition support, and encourages professional competence in the field of nutrition support.

The Oley Foundation, Inc.
214 Hun Memorial A-28
Albany Medical Center
Albany, NY 12208-3478
800-776-OLEY; 518-262-5079
www.oley.org
E-Mail: bishopj@mail.amc.edu
Devoted to enhancing the lives of those requiring home nutrition support by coordinating a newsletter, an informational web site, regional and national patient-focused conferences, and networking opportunities.

MOTILITY DISORDERS

American Motility Society
45685 Harmony Lane
Belleville, MI 48111
734-699-1130
www.motilitysociety.org
Email: admin@motilitysociety.org
The group's mission is to advance the study of neurogastroenterology and GI motility, to translate the scientific advances to patient care, and to disseminate the knowledge to patients and care-givers in order to improve the diagnosis and treatment of patients with neurogastroenterology and GI motility disorders.

Association of Gastrointestinal Motility Disorders, Inc. (AGMD)
12 Roberts Drive
Bedford, MA 01730
781-275-1300
www.agmd-gimotility.org
E-Mail: gimotility@msn.com
Non-profit international organization which serves as an educational resource concerning digestive motility diseases and disorders, functions as an important information base for members of the medical and scientific communities, and provides a forum for patients suf-

fering from digestive motility diseases and disorders, their families, and members of the medical community.

Carcinoid Cancer Foundation, Inc.
The Carcinoid Cancer Foundation, Inc.
333 Mamaroneck Avenue # 492
White Plains, NY 10605
888-722-3132; 914-683-1001
www.carcinoid.org
Non-profit organization encouraging and supporting research and education regarding carcinoid and related neuroendocrine tumors.

Gastroparesis and Dysmotilities Association (GDPA)
5520 Dalhart Hill, N.W.
Calgary AB Canada T3A 1S9

GPDA-USA
300 Remington Drive
Brandon, MS 39042
403-247-3215
www.digestivedistress.com/index.htm
E-Mail: mek@gpda.net (GDPA-USA); jkf@gpda.net (GDPA)
A North American-wide non-profit group focused on education, awareness, advocacy, and support for research into digestive motility problems, providing an on-line forum and patient educational booklets.

Cyclic Vomiting Syndrome Association (CVSA)
CVSA USA/Canada
3585 Cedar Hill Road, N.W.
Canal Winchester, OH 43110
614-837-2586 (phone/fax)
www.CVSAonline.org
E-Mail: waitesd@cvsaonline.org
Raises awareness and provides education and support to those affected by cyclic vomiting, abdominal migraine and related disorders while advocating for and funding research.

International Foundation for Functional Gastrointestinal Disorders (IFFGD)
Formerly: International Foundation for Bowel Dysfunction
P.O.Box 170864
Milwaukee, WI 53217-8076
1-888-964-2001; 414-964-1799
www.IFFGD.org
E-Mail: iffgd@iffgd.org
Nonprofit education and research organization addressing the issues surrounding life with gastrointestinal functional and motility disorders and increasing the awareness about these disorders among the general public, researchers, regulators, and the clinical care community; mission is to inform, assist, and support people affected by gastrointestinal disorders.

PANCREAS

The National Pancreas Foundation
364 Boylston Street, 4th Floor
Boston, MA 02116
866-726-2737
www.pancreasfoundation.org
Supports the research of diseases of the pancreas and provides information and humanitarian services to those people who are suffering from such illnesses.

LIVER

Children's Liver Disease Foundation
36 Great Charles Street,
Birmingham, B3 3JY, United Kingdom
+44 (0) 121 212 3839
www.childliverdisease.org/
E-Mail: info@childliverdisease.org
The group's mission is to fight childhood liver disease through funding pioneering medical research, providing effective education and giving professional and caring support to families and young people with liver disease.

American Liver Foundation's (ALF)
75 Maiden Lane, Suite 603
New York, NY 10038
800-GO-LIVER (465-4837); 888-4HEP USA (443-7872)
www.liverfoundation.org
E-Mail: info@liverfoundation.org
The nation's leading nonprofit organization promoting liver health and disease prevention; provides research, education and advocacy for those affected by liver-related diseases including hepatitis.

Canadian Liver Foundation
2235 Sheppard Avenue East, Suite 1500
Toronto, ON M2J 5B5
800-563-5483; 416-491-3353
www.liver.ca/Home.aspx; E-Mail: clf@liver.ca
Group's mandate is to promote liver health and to reduce the incidence and impact of all liver disease; works through volunteer chapters across the country to improve public awareness and understanding of liver health and liver disease, raise funds for research, and reach out to liver disease patients and their families.

Primary Biliary Cirrhosis (PBCers) PBCers Organization
www.pbcers.org
E-mail: PBCersOrg@aol.com
1430 Garden Rd.
Pearland, TX 77581
Support and education system for Primary Biliary Cirrhosis (PBC) patients, family members and friends.

OTHER GI ORGANIZATIONS

American Partnership for Eosinpohilic Disorders
3419 Whispering Way Drive
Richmond, Texas 77469
713-498-8216
www.apfed.org
E-Mail: mail@apfed.org
Non-profit organization working to improve awareness, education and research funding for eosinophil associated disorders and support families living with eosinophil associated disorders including eosinophilic esophagitis, eosinophilic gastroenteritis, hypereosinophilic syndrome and others.

United Ostomy Associations of America, Inc
P.O. Box 66
Fairview, TN 37062-0066
800-826-0826
www.uoaa.org
E-Mail: info@uoaa.org
Association of affiliated, volunteer managed, non-profit support groups committed to the improvement of the quality of life of people who have, or will have, a bowel or urinary diversion and dedicated to the provision of information, advocacy and service to its affiliated support groups, their members and the bowel/urinary diversion community.

CELIAC

Gluten Intolerance Group (GIG)
15110 10th Ave, S.W., Suite A
Seattle, WA 98166
206-246-6652
www.gluten.net
E-Mail: info@gluten.net
Provides support to persons with gluten intolerances, including celiac disease, dermatitis herpetiformis, and other gluten sensitivities, in order to live healthy lives.

American Celiac Society
PO Box 23455
New Orleans, LA 70183-0455
504-737-3293
www.americanceliacsociety.org
E-Mail: americanceliacsociety@yahoo.com
Non-profit tax exempt organization providing counseling and education to individuals with Celic Disease, Dermatitis Herpetiformis, Crohn's disease, Lactose Intolerance, Wheat Intolerance and other dietary disorders. Information is also provided to the medical community with limited information in Spanish and Italian.

Celiac Disease Foundation (CDF)
13251 Ventura Blvd. #1
Studio City, CA 91604
818-990-2354 ; Fax: 818-990-2379
www.celiac.org
E-Mail: cdf@celiac.org
Non-profit, public benefit corporation dedicated to providing services and support regarding Celiac Disease and Dermititis Herpetiformis through programs of awareness, education, advocacy and research.

Canadian Celiac Association
5170 Dixie Rd, Suite 204
Mississauga, ON L4W 1E3
800-363-7296
www.celiac.ca/
E-Mail: info@celiac.ca
National organization providing services and support to persons with Celiac Disease and Dermatitis Herpetiformis through programs of Awareness, Advocacy, Education, and Research.

Celiac Sprue Association/USA, Inc.
P.O. Box 31700
Omaha, NE 68131-0700
877-CSA-4-CSA; 402-558-0600
www.csaceliacs.org
E-Mail: celiacs@csaceliacs.org
Member based non-profit organization dedicated to helping individuals with celiac disease and dermatitis herpetiformis worldwide through education, research and support.

CROHN'S AND COLITIS

Crohn's and Colitis Foundation of America, Inc
386 Park Avenue South, 17th floor
New York, NY 10016-8804
800-932-2423
www.ccfa.org
E-Mail: info@ccfa.org
Non-profit, volunteer-driven organization dedicated to finding the cure for Crohn's disease and ulcerative colitis and to improving the quality of life of children and adults affected by these digestive diseases through education and support.

Reach Out for Youth with Ileitis and Colitis, Inc.
84 Northgate Circle
Melville, NY 11747
631-293-3102
www.reachoutforyouth.org
E-Mail: info@reachoutforyouth.org
Helps children with Crohn's disease, ulcerative colitis and other gastrointestinal diseases and their families through personal support and education.