

**PATIENT SUPPORT GROUPS
GASTROENTEROLOGY AND RARE DISEASE
UNITED STATES AND CANADA**

Alagille Syndrome Alliance

10500 SW Starr Drive
Tualatin, OR 97062
Telephone: (503) 885-0455
Email: alagille@alagille.org
Web: www.alagille.org

The Alagille Syndrome Alliance is a not-for-profit organization that's mission is to be 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. The Alliance is supporting AGS families, celebrating the AGS community, and building a better life with AGS through education, collaboration, and research.

Alpha-1 Association

2937 SW 27th Avenue, Suite 106
Miami, FL 33133
Telephone: (305) 648-0088 or (800) 521-3025
Fax: (305) 648-0089
Email: info@alpha1.org
Web: www.alpha1.org

The Alpha-1 Association is a member-based nonprofit organization dedicated to identifying those affected by Alpha-1 Antitrypsin Deficiency (Alpha-1), improving the quality of their lives through support, education, and advocacy, and encouraging participation in research.

Alphanet

2937 SW 27th Avenue, Suite 305
Miami, FL 33133
Telephone: (800) 577-ANET (577-2638)
Email: info@alphanet.org
Web: www.alphanet.org

Alphanet, a not-for-profit disease management company, provides a wide range of support services to Bayer Direct subscribers, oversees clinical trials involving Alpha-1 therapies, and is developing a comprehensive disease management program to improve the quality of life for those affected by Alpha-1. Since its start in 1995, Alphanet has contributed over \$4 million to support Alpha-1 Antitrypsin Deficiency and Alpha-1 Community programs.

Alpha-1 Foundation

2937 SW 27th Avenue, Suite 302
Miami, FL, 33133
Telephone: (305) 567-9888 or (877) 2-CURE-A1 (228-7321)
Fax: (305) 567-1317
Email: jwwalsh@alphaone.org
Web: www.alphaone.org

The Alpha-1 Foundation is a not-for-profit corporation founded in 1995 that is dedicated to providing the leadership and resources that will result in increased research, improved health, worldwide detection, and a cure for Alpha-1. The majority of the Board of Directors has either been diagnosed with Alpha-1 or has a family member diagnosed with Alpha-1.

American Hemochromatosis Society

4044 W. Lake Mary Boulevard, Unit #104, PMB 416
Lake Mary, FL 32746
Telephone: (407) 829-4488 or (888) 655-IRON (4766)
Fax: (407) 333-1284

The mission of the American Hemochromatosis Society (AHS) is to educate and support the victims of HFE-associated hereditary hemochromatosis (genetic iron overload) and their families as well as educate the medical community on the latest research on Hereditary Hemochromatosis (HH). AHS' aim is to identify through genetic testing, the 43 million+ Americans who unknowingly carry the single or double gene mutations for HH which puts them at risk for loading excess iron.

American Liver Foundation

75 Maiden Lane, Suite 603
New York, NY 10038
Telephone: (212) 668-1000 or 1-800-Go-Liver(465-4837)
Fax: (212) 483-8179
Web: www.liverfoundation.org

The mission of the American Liver Foundation is to facilitate, advocate and promote education, support and research for the prevention, treatment and cure of liver disease. The ALF is a national, voluntary not-for-profit organization. It has been dedicated to the prevention, treatment, and cure of hepatitis and other liver diseases through research, education and advocacy since 1976.

Association of Gastrointestinal Motility Disorders, Inc. (AGMD)

12 Roberts Drive
Bedford, Massachusetts 01730
Telephone: (781) 275-1300
Facsimile: (781) 275-1304
Email: gimotility@gmx.com
Web: www.agmd-gimotility.org

AGMD is a non-profit international organization which serves as an integral educational resource concerning digestive motility diseases and disorders. It also functions as an important information base for members of the medical and scientific communities. In addition, AGMD provides a forum for patients suffering from digestive motility diseases and disorders as well as their families and members of the medical and scientific communities.

Association for Glycogen Storage Disease - AGSD

P.O. Box 896
Durant, IA 52747
Telephone: (563)785-6038 (Voice)
Fax: (563) 785-6038 (FAX)
Web: www.agsdus.org

The Association for Glycogen Storage Disease (AGSD) is a nonprofit support group, established in 1979, for families and persons affected by glycogen storage disease (GSD). AGSD was organized to promote and protect the interests of all persons affected by GSD; to coordinate scientific, educational, and charitable activities related to GSD; to act as a clearinghouse on GSD-related matters; and to publish and distribute material to doctors and other interested persons. AGSD holds a yearly conference focusing on the latest research, care, and treatments available to affected persons.

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

P.O. Box 70
Kirkwood, PA 17536
Colleen Zak, Coordinator
Telephone: (717) 529-5555 or (800) 708-8892
Fax: (800) 807-9110
Email: info@arpkdchf.org
Web: www.arpkdchf.org

Patient population needs guide the ARPKD/CHF Alliance's direction. Their mission is to educate, advocate, support and advance research specific to ARPKD/CHF. Their purpose is to improve the lives of those affected.

Canadian Liver Foundation

Suite 1500-2235 Sheppard Avenue East
Toronto, Ontario M2J 5B5
Canada
Telephone: (416) 491-3353 or (800) 563-5483 (Toll free from Canada only)
Fax: (416) 491-4952
Email: clf@liver.ca
Web: www.liver.ca

Founded in 1969 by a group of doctors and business leaders concerned about the increasing incidence of liver disease, the Canadian Liver Foundation (CLF) was the first organization in the world devoted to providing support for research and education into the causes, diagnoses, prevention and treatment of all liver disease. The CLF's mandate is to promote liver health and to reduce the incidence and impact of all liver disease. To achieve this goal, the CLF works through its volunteer chapters across Canada 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.

Canadian Cystic Fibrosis Foundation

2221 Yonge Street, Suite 601
Toronto, Ontario, M4S 2B4
Canada
Telephone: (416)485-9149 or (800) 378-2233 (Toll free from Canada only)
Fax: (416)485-0960 or (416) 485-5707
Email: info@cysticfibrosis.ca
Web: www.cysticfibrosis.ca

For 50 years, the Canadian Cystic Fibrosis Foundation has been a strong voice and champion for people with cystic fibrosis, their caregivers, and families. They build awareness and advocate for change, work with governments to provide essential programs to enhance the quality of life for people with CF, partner with community groups to improve access to support services, and help create policy, effect change, raise funds and promote CF research.

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

26444 Emerald Dove Drive
Valencia, CA 91355
Telephone: (661) 263-9099 or (877) 679-8256
Email: info@classkids.org
Web: www.classkids.org

C.L.A.S.S. was founded out of the recognized need for an organization dedicated to addressing the emotional, educational and financial needs of families with children affected by liver disease and transplantation. C.L.A.S.S. offers a variety of ways to be both a source of support to families and a valuable resource to all affected by liver disease and transplantation.

Crohn's and Colitis Foundation of America

386 Park Avenue South, 17th Floor
New York, NY 10016
Telephone: (800) 932-2423
Email: info@ccfa.org
Web: www.ccfa.org

The Crohn's and Colitis Foundation of America is a non-profit, volunteer-driven organization dedicated to finding the cure for Crohn's disease and ulcerative colitis. Founded in 1967, the Foundation funds cutting-edge studies at major medical institutions, nurtures investigators at the early stages of their careers, and finances underdeveloped areas of research. Educational workshops and symposia, together with the scientific journal, *Inflammatory Bowel Diseases*, enable medical professionals to keep pace with this rapidly growing field.

Crigler-Najjar Syndrome Association

CNA / King's Way Foundation
c/o Cory Mauck
3134 Bayberry Street
Wichita, Kansas 67226
Email: mauckc@msn.com
Web: www.criglenajjar.com

The Crigler-Najjar Association was established as a support group for and by patients and families with Crigler-Najjar Syndrome (Types I and II). Anyone is welcome to participate and assist in the activities of the association.

Crohn's and Colitis Foundation of Canada

600-60 St. Clair Avenue East
Toronto, Ontario M4T 1N5
Canada
Telephone: (416) 920-5035 or (800) 387-1479
Fax: (416) 929-0364
Email: ccfc@ccfc.ca
Web: www.ccfc.ca

The Crohn's and Colitis Foundation of Canada (CCFC) is a national not-for-profit voluntary medical research Foundation. Its mission is to find the cure for inflammatory bowel disease. To achieve its mission, the Foundation is committed to raising increasing funds for medical research. The CCFC is one of the world's leaders in non-governmental, per capita funding of IBD research.

Cystic Fibrosis Foundation

6931 Arlington Road, 2nd floor
Bethesda, Maryland 20814
Telephone: (301) 951-4422 or (800) FIGHT CF (344-4823)
Email: info@cff.org
Web: www.cff.org

The mission of the Cystic Fibrosis Foundation, a nonprofit donor-supported organization, is to assure the development of the means to cure and control cystic fibrosis and to improve the quality of life for those with the disease. The CF Foundation is the leading organization in the United States devoted to cystic fibrosis. It funds and accredits more than 115 CF care centers, 95 adult care programs and 50 affiliate programs, and more than 75 chapters and branch offices nationwide.

Genetic Alliance

4301 Connecticut Avenue, NW Suite 404
Washington, DC 20008
Telephone: (202) 966-5557 or (800) 336-4363
Fax: (202) 966-8553
Email: info@geneticalliance.org
Web: www.geneticalliance.org

Genetic Alliance is the world's leading nonprofit health advocacy organization committed to transforming health through genetics and promoting an environment of openness centered on the health of individuals, families, and communities. Genetic Alliance's network includes more than 1,000 disease-specific advocacy organizations, as well as thousands of universities, private companies, government agencies, and public policy organizations. The network is a dynamic and growing open space for shared resources, creative tools, and innovative programs.

The Hemochromatosis Information Center

See Iron Disorders Institute

Hepatitis Foundation International

504 Blick Drive
Silver Spring, MD 20904
Telephone: (301) 622-4200 or (800) 891-0707
Fax: (301) 622-4702
Email: info@hepatitisfoundation.org
Web: www.hepfi.org

The Hepatitis Foundation International (HFI) is dedicated to the eradication of viral hepatitis, a disease affecting over 500 million people around the world. The HFI seeks to raise awareness of this enormous worldwide problem and to motivate people to support this important – and winnable – battle.

Hepatitis B Foundation

3805 Old Easton Road
Doylestown, PA 18902
Telephone: (215) 489-4900
Fax: (215) 489-4313
Email: info@hepb.org
Web: www.hepb.org

The Hepatitis B Foundation is the only national non-profit organization solely dedicated to the global problem of hepatitis B. The Hepatitis B Foundation is dedicated to finding a cure and improving the quality of life for those affected by hepatitis B worldwide. The Foundation's commitment includes funding focused research, promoting disease awareness, supporting immunization and treatment initiatives, and serving as the primary source of information for patients and their families, the medical and scientific community, and the general public.

Iron Disorders Institute

PO Box 675

Taylors, SC 29687

Telephone: (864) 292-1175 or (888) 565-IRON (4766)

Fax: (864) 292-1878

Email: info@irondisorders.org

Web: www.irondisorders.org

Iron Disorders Institute (IDI) is a 501(c)3 national organization that received its non-profit status in 1998. IDI's vision is that no one should suffer or die prematurely because of Iron-Out-of-Balance™. IDI exists so that people with iron disorders receive early, accurate (complete) diagnosis, appropriate treatment and are equipped to live in good health.

Iron Overload Diseases Association, Inc.

525 Mayflower Rd.

West Palm Beach, FL 33405

Telephone: (561) 586-8246

Email: iod@ironoverload.org

Web: <http://www.ironoverload.org>

The IOD's mission is 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.

Liver Families

23974 Aliso Creek Road #242

Laguna Niguel, CA 92677

Web: www.liverfamilies.net

Liver Families is dedicated to providing an active, international, online community to families whose lives have been touched by pediatric liver disease and transplant. Through this community Liver Families seeks to offer support, knowledge and hope to liver families around the world.

National Organization for Rare Disorders (NORD)

55 Kenosia Avenue

PO Box 1968

Danbury, CT 06813-1968

Telephone: (203) 744-0100 or (800) 999-6673 (voicemail only)

Fax: (203)798-2291

Email: orphan@rarediseases.org

Web: www.rarediseases.org

NORD is a unique federation of voluntary health organizations dedicated to helping people with rare "orphan" diseases and assisting the organizations that serve them. NORD is committed to the identification, treatment, and cure of rare disorders through programs of education, advocacy, research, and service.

National Reye's Syndrome Foundation

426 North Lewis
P.O. Box 829
Bryan, OH 43506
Telephone: (419) 636-2679 or (800) 233-7393
Fax: (419) 636-9897
Email: nrsf@reyessyndrome.org
Web: www.reyessyndrome.org

The National Reye's Syndrome Foundation is a 501(c)3 charity is the only citizen group generating a concerted, organized lay movement to eradicate Reye's Syndrome. The Foundation is committed to the health and well-being of those who are most at risk; children. The Foundation has made great gains toward our ultimate goal of eradicating Reye's Syndrome. Their public awareness programs have resulted in a decrease in the number of cases reported in recent years. It is hoped that research will bring the Foundation closer to its goal.

National Urea Cycle Disorders Foundation

75 South Grand Avenue
Pasadena, CA 91105
Telephone: (626) 578-0833 or (800) 38-NUCDF (386-8233)
Fax: (626) 578-0823
Email: info@nucdf.org
Web: www.nucdf.org

The National Urea Cycle Disorders Foundation is a non-profit organization dedicated to the identification, treatment and cure of urea cycle disorders. NUCDF is a nationally-recognized resource of information and education for families and healthcare professionals.

Office of Rare Diseases Research (ORD) – at the National Institutes of Health (NIH)

6100 Executive Boulevard
Room 3A07, MSC 7518
Bethesda, MD 20892-7518
Telephone: (301) 402-4336
Fax: (301) 480-9655
Email: ordr@od.nih.gov
Web: rarediseases.info.nih.gov

The Office of Rare Diseases Research (ORDR) was established in 1993 within the Office of the Director of the National Institutes of Health (NIH). ORDR coordinates and supports rare diseases research, responds to research opportunities for rare diseases, and provides information on rare diseases. Public Law 107-280, the Rare Diseases Act of 2002, established the ORDR by statute. The goals of ORDR are to stimulate and coordinate research on rare diseases and to support research to respond to the needs of patients who have any one of the more than 6,800 rare diseases known today.

Parents of Galactosemic Children, Inc.

P.O. Box 2401
Mandeville, LA 70470-2401
Web: www.galactosemia.org

Parents of Galactosemic Children, Inc is a non-profit charitable organization. Founded in February 1985 by a small group of mothers in New York, PGC realizes the need for further information and networking between affected families and professionals. Metabolic Clinics across the nation continue to assist PGC in researching families and information. Today the PGC mailing list includes over 1000 families and extended families, professionals and clinics, media groups, donors, and numerous international contacts.

PKD (Polycystic Kidney Disease) Foundation

8330 Ward Parkway, Suite 510
Kansas City, MO 64114-2000
Telephone: (816) 931-2600 or (800) PKD-CURE
Fax: (816) 931-8655
Email: pkdcure@pkdcure.org
Web: www.pkdcure.org

The PKD Foundation is the only organization worldwide dedicated to fighting PKD through research, education, advocacy, support and awareness. The Foundation's goal is simple - to discover and deliver treatments and a cure for PKD.

PKIDS (Parents of Kids with Infectious Diseases)

P.O. Box 5666
Vancouver, WA 98668
Telephone: (360) 695-0293 or (877) 55-PKIDS
Fax: (360) 695-6941
Email: pkids@pkids.org
Web: www.pkids.org

PKIDS' mission is to educate the public about infectious diseases, the methods of prevention and transmission, the latest advances in medicine, and the elimination of social stigma borne by the infected; and to assist the families of the children living with hepatitis, HIV/AIDS, or other chronic, viral infectious diseases with emotional, financial and informational support."

Progressive Familial Intrahepatic Cholestasis (PFIC) – Resource for Pediatric Liver Disease

Email: PFICII@pfic.org
Web: www.pfic.org

PFIC.org is a website that was built by and for PFIC patients and families. It was established to provide a resource for those with new diagnoses and for those continuing to search for treatments and solutions to the challenges of PFIC. The mission of PFIC.org is to improve the lives of patients and families worldwide affected by this disease. The organization supports research programs, provides educational materials, matches families for peer support, and participates in advocacy opportunities.

PSC Partners Seeking a Cure Foundation

5237 South Kenton Way
Englewood, CO 80111
Telephone: (303) 771-5227
Email: contactus@pscpartners.org
Web: www.pscpartners.org

PSC Partners Seeking a Cure is a grassroots volunteer organization that was formed in 2005 to provide primary sclerosing cholangitis (PSC) patients and their caregivers education and support and to raise funds to research the origins and a cure for the disease.

United Mitochondrial Disease Foundation

8085 Saltsburg Road, Suite 201
Pittsburgh, PA 15239
Telephone: (412) 793-8077 or (888) 317-UMDF (8633)
Fax: (412) 793-6477
Email: info@umdf.org
Web: www.umdf.org

The UMDF's mission is to promote research and education for the diagnosis, treatment and cure of mitochondrial disorders and to provide support to affected individuals and families. UMDF supports scientific collaboration and family networking through international symposia and is building an endowment to sustain research through the millennium.

Wilson's Disease Association

5572 North Diversey Boulevard
Milwaukee, WI 53217
Telephone: (414) 961-0533 or (866) 961-0533
Email: info@wilsonsdisease.org
Web: www.wilsonsdisease.org

The Wilson Disease Association is dedicated to providing the leadership and resources that will result in increased research, improved health, worldwide detection, and a cure for Wilson disease. WDA's website is designed to give patients, family members, and healthcare professionals the most up-to-date information on treatment, legislation, support groups, research, fundraising, and patient stories.

YES

791 Arnold Paul Road
Canton, TX 75103
Telephone: (877) 937-7478
Fax: (903) 567-3509
Email: info@beatlivercancers.org
Web: www.beatlivercancers.org

YES's mission is to provide information, education, support, options, and hope for those affected by liver tumors. YES is committed to raising awareness to this often forgotten patient population.