



Directory of Hematologic Diseases Organizations

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

NIDDK-funded Centers of Excellence in Molecular Hematology

Cincinnati Center of Excellence in Molecular Hematology (CCEMH)

Yi Zheng, Ph.D., Director

Cincinnati Children's Hospital Medical Center

3333 Burnet Avenue

Cincinnati, OH 45229-3026

Phone: 1-800-344-2462 or 1-877-881-8479 (outside tri-state area)

TTY: 513-636-4900

Email: yi.zheng@cchmc.org

Internet: www.cincinnatichildrens.org/research/divisions/e/ex-hem/center-of-excellence-in-molecular-hematology/

Core Center for Excellence in Hematology (CCEH)

Beverly J. Torok-Storb, Principal Investigator

1100 Fairview Avenue North, D1-100

P.O. Box 19024

Seattle, WA 98109

Phone: 206-667-4549

Fax: 206-667-5978

Email: btorokst@fhcrc.org

Internet: <http://cceh.fhrc.org/>

Government Agencies and Professional and Voluntary Organizations

AABB

8101 Glenbrook Road
Bethesda, MD 20814–2749
Phone: 301–907–6977
Fax: 301–907–6895
Email: aabb@aabb.org
Internet: www.aabb.org

Mission: To advance the practice and standards of transfusion medicine and cellular therapies to optimize patient and donor care and safety.

Services provided:

Accreditation programs and standards of practice
Blood bank locator
Educational programs, meetings, and events for health care providers
Information for the media
Publications for health care providers
Resources

American Hemochromatosis Society, Inc. (AHS)

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

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

Services provided:

Information for the media
Physician referral program
Resources

American 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
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
Resources

American Red Cross

2025 E Street NW
Washington, D.C. 20006
Phone: 1-800-RED-CROSS (1-800-733-2767) or 202-303-5214
Internet: www.redcross.org

Mission: To provide relief to victims of disaster and help people prevent, prepare for, and respond to emergencies. Red Cross services include community services that help the needy; collection, processing, and distribution of lifesaving blood and blood products; educational programs that promote health and safety; and international relief and development aid.

Services provided:

Blood donation
Information for the media
Local Red Cross locator
Resources

American Society for Apheresis (ASFA)

201–375 West 5th Avenue
Vancouver, BC, Canada V5Y 1J6
Phone: 604–484–2851
Fax: 604–874–4378
Email: asfa@apheresis.org
Internet: www.apheresis.org

Mission: To advance apheresis medicine for patients, donors, and practitioners through education, evidence-based practice, research, and advocacy.

Services provided:

Clinical practice guidelines
Educational programs and meetings for health care providers
Publications for health care providers and patients

American Society of Clinical Oncology (ASCO)

2318 Mill Road, Suite 800
Alexandria, VA 22314
Phone: 571–483–1300
Internet: www.asco.org

Mission: To conquer cancer through research, education, prevention, and delivery of high-quality patient care.

Services provided:

Advocacy and public policy
Clinical practice guidelines
Continuing medical education (CME)
Educational programs and meetings for health care providers
Publications for health care providers
Resources

American Society of Gene & Cell Therapy (ASGCT)

555 East Wells Street, Suite 1100
Milwaukee, WI 53202
Phone: 414–278–1341
Fax: 414–276–3349
Email: info@asgct.org
Internet: www.asgct.org

Mission: To advance knowledge, awareness, and education leading to the discovery and clinical application of genetic and cellular therapies to alleviate human disease.

Services provided:

Educational programs and meetings for health care providers
Information for the media
Publications for health care providers
Resources

American Society of Hematology (ASH)

2021 L Street, NW, Suite 900
Washington, D.C. 20036
Phone: 202-776-0544
Fax: 202-776-0545
Internet: www.hematology.org

Mission: To further the understanding, diagnosis, treatment, and prevention of disorders affecting the blood, bone marrow, and the immunologic, hemostatic, and vascular systems by promoting research, clinical care, education, training, and advocacy in hematology.

Services provided:

Advocacy and public policy
Certification activities
Clinical practice guidelines
Continuing medical education (CME)
Educational programs and meetings for health care providers
Hematologist locator
Publications for health care providers and patients
Research

American Society of Pediatric Hematology/Oncology (ASPHO)

8735 West Higgins Road, Suite 300
Chicago, IL 60631
Phone: 847-375-4716
Fax: 847-375-6483
Email: info@aspho.org
Internet: www.aspho.org

Mission: To promote optimal care of children and adolescents with blood disorders and cancer by advancing research, education, treatment, and professional practice.

Services provided:

Certification activities
Continuing medical education (CME)
Educational programs and meetings for health care providers

America's Blood Centers (ABC)

725 15th Street NW, Suite 700
Washington, D.C. 20005
Phone: 1-888-USBLOOD (1-888-872-5663) or 202-393-5725
Fax: 202-393-1282
Internet: www.americasblood.org

Mission: To help member blood centers serve their communities.

Services provided:

Advocacy and public policy
Blood donor registry
Publications for health care providers, patients, and students
Resources

Aplastic Anemia & MDS International Foundation

100 Park Avenue, Suite 108
Rockville, MD 20850
Phone: 1-800-747-2820 or 301-279-7202
Fax: 301-279-7205
Email: help@aamds.org
Internet: www.aamds.org

Mission: To support patients and families living with aplastic anemia, myelodysplastic syndromes, paroxysmal nocturnal hemoglobinuria, and related bone marrow failure diseases.

Services provided:

Advocacy and public policy
Continuing medical education (CME)
Educational programs for health care providers
Information for the media
Patient and family conferences
Resources
Support groups

Be The Match (*Operated by the National Marrow Donor Program [NMDP]*)

National Marrow Donor Program
3001 Broadway Street NE, Suite 100
Minneapolis, MN 55413-1753
Phone: 1-800-MARROW2 (1-800-627-7692) or 612-627-5800 (Outside the U.S.)
Internet: www.marrow.org or www.bethematch.org

Mission: To help people diagnosed with leukemia and other life-threatening diseases get a bone marrow or cord blood transplant from a matching donor.

Services provided:

Clinical guidelines
Continuing medical education (CME)
Donor match registry
Educational programs and events for health care providers and patients
Publications for health care providers and patients
Research
Resources

Children's Cancer & Blood Foundation (CCBF)

333 East 38th Street, Suite 830
New York, NY 10016
Phone: 212-297-4336
Fax: 212-297-4340
Email: info@childrenscbf.org
Internet: www.childrenscbf.org

Mission: To support the comprehensive clinical care of children living with blood disorders, foster research to help understand the causes of childhood blood disorders, and sponsor the fellowship training of pediatricians in the subspecialty of pediatric hematology and oncology.

Services provided:

Resources

Cooley's Anemia Foundation (CAF)

330 Seventh Avenue, Suite 200
New York, NY 10001
Phone: 212-279-8090 or 1-800-522-7222
Fax: 212-279-5999
Internet: www.thalassemia.org

Mission: To advance the treatment and cure for Cooley's anemia/thalassemia major, enhance the quality of life of patients, and educate the medical community, trait carriers, and the public about Cooley's anemia/thalassemia major.

Services provided:

Clinical trials
Patient-family conferences
Resources

Diamond Blackfan Anemia Foundation, Inc. (DBAF)

P.O. Box 1092
West Seneca, NY 14224
Phone: 716-674-2818
Email: dbafoundation@juno.com
Internet: www.dbafoundation.org

Mission: To collectively and actively generate funds for the charitable and scientific purpose of furthering, by clinical study, laboratory research, publication, and teaching, the knowledge of the disorder known as Diamond Blackfan Anemia (DBA); and to share this knowledge, to inform, to lend support, and to communicate with all families of DBA patients.

Services provided:

Patient registry
Publications for health care providers and patients
Support groups

Fanconi Anemia Research Fund, Inc.

1801 Willamette Street, Suite 200
Eugene, OR 97401
Phone: 1-888-FANCONI (1-888-326-2664) or 541-687-4658
Fax: 541-687-0548
Email: info@fanconi.org
Internet: www.fanconi.org

Mission: To find effective treatments and a cure for Fanconi anemia and to provide education and support services to affected families worldwide.

Services provided:

Meetings and events for health care providers and patients
Publications for health care providers and patients
Support groups

Hemochromatosis.org (Formerly known as *The Hemochromatosis Information Center*)

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

Mission: To increase awareness of the disorder and related issues among the public, professionals, and government agencies; encourage routine screenings; and promote research.

Services provided:

Publications for patients
Resources

Hemophilia Federation of America (HFA)

820 First Street NE, Suite 720
Washington, D.C. 20002
Phone: 1-800-230-9797 or 202-675-6984
Fax: 972-616-6211
Email: info@hemophiliafed.org
Internet: www.hemophiliafed.org

Mission: To assist and advocate for the bleeding disorders community.

Services provided:

Advocacy and public policy
Support groups

HHT Foundation International, Inc.

P.O. Box 329
Monkton, MD 21111
Phone: 410-357-9932
Fax: 410-357-0655
Email: hhtinfo@hht.org
Internet: www.hht.org

Mission: To find a cure for HHT while saving the lives and improving the well-being of individuals and families affected by HHT.

Services provided:

Resources

Histiocytosis Association (Formerly known as Histiocytosis Association of America)

332 North Broadway
Pitman, NJ 08071
Phone: 856-589-6606
Fax: 856-589-6614
Email: info@histio.org
Internet: www.histio.org

Mission: To raise awareness about histiocytic disorders, provide educational and emotional support, and fund research leading to better treatments and a cure.

Services provided:

Educational programs, meetings, and events for patients and their families
Resources
Support groups

International Myeloma Foundation (IMF)

12650 Riverside Drive, Suite 206
North Hollywood, CA 91607-3421
Phone: 1-800-452-CURE (1-800-452-2873) or 818-487-7455
Fax: 818-487-7454
Email: TheIMF@myeloma.org
Internet: www.myeloma.org

Mission: To educate patients, meet their emotional needs, and support myeloma research.

Services provided:

Advocacy and public policy
Educational programs and meetings for health care providers and patients
Information for the media
Research
Resources
Support groups

International Society on Thrombosis and Haemostasis (ISTH)

610 Jones Ferry Road, Suite 205
Carrboro, NC 27510
Phone: 919-929-3807
Fax: 919-929-3935
Internet: www.isth.org

Mission: To advance education and stimulation of research into thrombosis and hemostasis through meetings, peer-reviewed publications, and expert committees on practical issues related to research methods and standards.

Services provided:

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

Iron Disorders Institute (IDI)

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

The Leukemia & Lymphoma Society (LLS)

1311 Mamaroneck Avenue, Suite 310
White Plains, NY 10605
Phone: 1-800-955-4572 or 914-949-5213
Fax: 914-949-6691
Email: infocenter@lls.org
Internet: www.lls.org

Mission: To cure leukemia, lymphoma, Hodgkin's disease, and myeloma and improve the quality of life of patients and their families.

Services provided:

Advocacy and public policy
Chapter locator
Continuing medical education (CME)
Educational programs for patients
Publications for patients
Support groups

Lymphoma Research Foundation (LRF)

115 Broadway, Suite 1301
New York, NY 10006
Phone: 212-349-2910 or 1-800-500-9976
Fax: 212-349-2886
Email: lrf@lymphoma.org or helpline@lymphoma.org
Internet: www.lymphoma.org

Mission: To fund innovative lymphoma research, provide people with lymphoma and health care professionals with up-to-date information about this type of cancer, and eradicate lymphoma and serve those touched by this disease.

Services provided:

Advocacy and public policy
Chapter locator
Educational programs and meetings for health care providers
Publications for patients
Support groups

March of Dimes

1275 Mamaroneck Avenue
White Plains, NY 10605
Phone: 1-888-MODIMES (1-888-663-4637) or 914-997-4488
Fax: 914-428-8203
Email: askus@marchofdimes.com
Internet: www.marchofdimes.com

Mission: To help moms have full-term pregnancies and research the problems that threaten the health of babies.

Services provided:

Advocacy and public policy
Chapter locator
Continuing nursing education (CNE)
Publications for health care providers and patients
Research
Resources

National Hemophilia Foundation (NHF)

116 West 32nd Street, 11th Floor
New York, NY 10001
Phone: 1-800-42-HANDI (1-800-424-2634)* or 212-328-3700
Fax: 212-328-3799* or 212-328-3777
Email: handi@hemophilia.org
Internet: www.hemophilia.org
*NHF's Information Resource Center

Mission: To find better treatments and cures for bleeding and clotting disorders and to prevent the complications of these disorders through education, advocacy, and research.

Services provided:

Advocacy and public policy
Resources
Treatment center locator

National Organization for Rare Disorders (NORD)

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

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

Services provided:

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

Plasma Protein Therapeutics Association (PPTA)

147 Old Solomons Island Road, Suite 100
Annapolis, MD 21401
Phone: 202-789-3100
Fax: 410-263-2298
Internet: www.pptaglobal.org

Mission: To promote the availability of and access to safe and effective plasma protein therapeutics for patients worldwide.

Services provided:

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

Platelet Disorder Support Association (PDSA)

133 Rollins Avenue, Suite 5
Rockville, MD 20852
Phone: 1-87-PLATELET (1-877-528-3538) or 301-770-6636
Fax: 301-770-6638
Email: pdsa@pdsa.org
Internet: www.pdsa.org

Mission: To enhance the lives of people with immune thrombocytopenia and other platelet disorders through education, advocacy, research, support, and communication.

Services provided:

Advocacy and public policy
Educational programs and meetings for health care providers
Publications for patients
Public service announcements (PSAs)
Support groups

Sickle Cell Disease Association of America, Inc. (SCDAA)

3700 Koppers Street, Suite 570
Baltimore, MD 21227
Phone: 1-800-421-8453 or 410-528-1555
Fax: 410-528-1495
Email: scdaa@sicklecelldisease.org
Internet: www.sicklecelldisease.org

Mission: To advocate for and enhance our membership's ability to improve the quality of health, life, and services for individuals, families, and communities affected by sickle cell disease and related conditions, while promoting the search for a cure for all people in the world with sickle cell disease.

Services provided:

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

Society for Hematology and Stem Cells (ISEH)

330 North Wabash Avenue, Suite 2000
Chicago, IL 60611
Phone: 312-321-5114
Fax: 312-673-6923
Email: info@iseh.org
Internet: www.iseh.org

Mission: To promote the scientific knowledge and clinical application of basic hematology, immunology, stem cell research, cell and gene therapy, and all related aspects through research, publications, discussion, support of young investigators, and organization of scientific meetings.

Services provided:

Educational programs and meetings for health care providers
Publications for health care providers

National Hematologic Diseases Information Service

7 Information Way
Bethesda, MD 20892-3571
Phone: 1-888-828-0877
TTY: 1-866-569-1162
Fax: 703-738-4929
Email: hematologic@info.niddk.nih.gov
Internet: www.hematologic.niddk.nih.gov

The National Hematologic Diseases Information Service is an information dissemination service of the National Institute of Diabetes and Digestive and Kidney Diseases (NIDDK). The NIDDK is part of the National Institutes of Health, which is part of the U.S. Department of Health and Human Services.

The NIDDK conducts and supports biomedical research. As a public service, the NIDDK has established information services to increase knowledge and understanding about health and disease among patients, health professionals, and the public.

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