



## **Directory of Hematologic Diseases Organizations**

This directory lists Government agencies and professional and voluntary associations that provide hematologic 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.

### **AABB**

8101 Glenbrook Road  
Bethesda, MD 20814–2749  
Phone: 301–907–6977  
Fax: 301–907–6895  
Email: [aabb@aabb.org](mailto:aabb@aabb.org)  
Internet: [www.aabb.org](http://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)**

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](mailto:mail@americanhs.org)  
Internet: [www.americanhs.org](http://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

**The 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
- 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)**

375 West 5th Avenue, Suite 201  
Vancouver, BC, Canada V5Y 1J6  
Phone: 604-484-2851  
Fax: 604-874-4378  
Email: [asfa@apheresis.org](mailto:asfa@apheresis.org)  
Internet: [www.apheresis.org](http://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: 1-888-282-2552 or 571-483-1300  
Email: [membermail@asco.org](mailto:membermail@asco.org)  
Internet: [www.asco.org](http://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](mailto:info@asgct.org)  
Internet: [www.asgct.org](http://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: 1-866-828-1231 or 202-776-0544  
Fax: 202-776-0545  
Email: [ash@hematology.org](mailto:ash@hematology.org)  
Internet: [www.hematology.org](http://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)**

4700 West Lake Avenue  
Glenview, IL 60025  
Phone: 847-375-4716

Email: [info@aspho.org](mailto:info@aspho.org)  
Internet: [www.aspho.org](http://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  
Email: [abc@americasblood.org](mailto:abc@americasblood.org)  
Internet: [www.americasblood.org](http://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, Inc. (AA&MDSIF)**

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](mailto:help@aamds.org)  
Internet: [www.aamds.org](http://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

### **Children's Cancer and 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](mailto:info@childrenscbf.org)  
 Internet: [www.childrenscbf.org](http://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, #200  
 New York, NY 10001  
 Phone: 1-800-522-7222  
 Fax: 212-279-5999  
 Email: [info@cooleysanemia.org](mailto:info@cooleysanemia.org)  
 Internet: [www.thalassemia.org](http://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](mailto:dbafoundation@juno.com)  
 Internet: [www.dbafoundation.org](http://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](mailto:info@fanconi.org)  
Internet: [www.fanconi.org](http://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

**The Hemochromatosis Information Center**

P.O. Box 675  
Taylors, SC 29687  
Phone: 1-888-565-4766 or 864-292-1175  
Fax: 864-292-1878  
Email: [info@irondisorders.org](mailto:info@irondisorders.org)  
Internet: [www.hemochromatosis.org](http://www.hemochromatosis.org) or [www.irondisorders.org](http://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)**

210 7th Street SE, Suite 200B  
Washington D.C. 20003  
Phone: 1-800-230-9797 or 202-675-6984  
Fax: 202-675-6983  
Email: [info@hemophiliafed.org](mailto:info@hemophiliafed.org)  
Internet: [www.hemophiliafed.org](http://www.hemophiliafed.org)

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

### **Services provided:**

- Advocacy and public policy
- Support groups

## **Hereditary Hemorrhagic Telangiectasia (HHT) Foundation International, Inc.**

P.O. Box 329  
Monkton, MD 21111  
Phone: 1-800-448-6389 or 410-357-9932 (for calls outside the U.S. only)  
Fax: 410-357-0655  
Email: [hhtinfo@hht.org](mailto:hhtinfo@hht.org)  
Internet: [www.hht.org](http://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 (HAA)*)

332 North Broadway  
Pitman, NJ 08071  
Phone: 1-800-548-2758 or 856-589-6606  
Fax: 856-589-6614  
Email: [info@histio.org](mailto:info@histio.org)  
Internet: [www.histio.org](http://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  
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  
Email: headquarters@isth.org  
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  
Fax: 864-292-1878

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

Internet: [www.irondisorders.org](http://www.irondisorders.org) or [www.hemochromatosis.org](http://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

**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 result from neglect of iron overload.

**Services provided:**

- 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](mailto:infocenter@lls.org)

Internet: [www.lls.org](http://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)
- Education programs for patients
- Publications for patients
- Support groups

## **Lymphoma Research Foundation (LRF)**

115 Broadway, Suite 1301  
New York, NY 10006  
Phone: 212-349-2910  
Helpline: 1-800-500-9976  
Fax: 212-349-2886  
Email: [lrf@lymphoma.org](mailto:lrf@lymphoma.org) or [helpline@lymphoma.org](mailto:helpline@lymphoma.org)  
Internet: [www.lymphoma.org](http://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  
Internet: [www.marchofdimes.com](http://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 medical education (CME)
- 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](mailto:handi@hemophilia.org)

Internet: [www.hemophilia.org](http://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 Marrow Donor Program (NMDP)**

3001 Broadway Street NE, Suite 100  
Minneapolis, MN 55413-1753  
Phone: 1-800-MARROW2 (1-800-627-7692) or 612-627-5800  
Internet: [www.marrow.org](http://www.marrow.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

**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](mailto:orphan@rarediseases.org)  
Internet: [www.rarediseases.org](http://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](http://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, #5  
Rockville, MD 20852  
Phone: 1-87-PLATELET (1-877-528-3538) or 301-770-6636  
Fax: 301-770-6638  
Email: [pdsa@pdsa.org](mailto:pdsa@pdsa.org)  
Internet: [www.pdsa.org](http://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)**

231 East Baltimore Street, Suite 800  
Baltimore, MD 21202  
Phone: 1-800-421-8453 or 410-528-1555  
Fax: 410-528-1495

Email: [scdaa@sicklecelldisease.org](mailto:scdaa@sicklecelldisease.org)  
Internet: [www.sicklecelldisease.org](http://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)**

401 North Michigan Avenue, Suite 2200  
Chicago, IL 60611  
Phone: 312-321-5114  
Fax: 312-673-6923  
Email: [info@iseh.org](mailto:info@iseh.org)  
Internet: [www.iseh.org](http://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

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**National Hematologic Diseases Information Service**

7 Information Way  
Bethesda, MD 20892-3571  
Phone: 1-888-828-0877  
TTY: 1-866-569-1162  
Fax: 1-703-738-4929  
Email: [hematologic@info.niddk.nih.gov](mailto:hematologic@info.niddk.nih.gov)  
Internet: [www.hematologic.niddk.nih.gov](http://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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October 2012