



## **Directory of Endocrine and Metabolic Diseases Organizations**

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

### **American Academy of Otolaryngology—Head and Neck Surgery (AAO–HNS)**

1650 Diagonal Road  
Alexandria, VA 22314–2857  
Phone: 703–836–4444  
Internet: [www.entnet.org](http://www.entnet.org)

**Mission:** To advance the art, science, and ethical practice of otolaryngology—head and neck surgery through education, research, and lifelong learning.

#### ***Services provided:***

Advocacy and public policy  
Certification activities  
Continuing medical education (CME)  
Clinical guidelines, policy statements, standards of care, and clinical indicators  
Educational programs, meetings, and events for health care providers  
Publications for health care providers and patients  
Specialist locator  
Resources

### **American Association of Clinical Endocrinologists (AACE)**

245 Riverside Avenue, Suite 200  
Jacksonville, FL 32202  
Phone: 904–353–7878  
Fax: 904–353–8185  
Internet: [www.aace.com](http://www.aace.com)

**Mission:** To enhance the ability of a professional community of physicians specializing in endocrinology, diabetes, and metabolism to provide the highest-quality patient care.

***Services provided:***

Advocacy and public policy  
Chapter locator  
Clinical practice guidelines and position statements  
Continuing medical education (CME)  
Educational programs, meetings, and events for health care providers  
Endocrinologist locator  
Information for the media  
Publications for health care providers and patients  
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](http://www.porphyrifoundation.com)

***Mission:*** To improve the health and well-being of individuals and families affected by porphyria, enhance public awareness, develop educational programs and distribute educational materials, and support research to improve treatment and ultimately lead to a cure.

***Services provided:***

Continuing medical education (CME)  
Information for the media  
National Porphyria Registry  
Publications for health care providers and patients  
Research  
Resources

**The American Society for Bone and Mineral Research (ASBMR)**

2025 M Street NW, Suite 800  
Washington, D.C. 20036-3309  
Phone: 202-367-1161  
Fax: 202-367-2161  
Email: [asbmr@asbmr.org](mailto:asbmr@asbmr.org)  
Internet: [www.asbmr.org](http://www.asbmr.org)

***Mission:*** To promote excellence in bone and mineral research, foster integration of clinical and basic science, and facilitate the translation of that science to health care and clinical practice.

**Services provided:**

Advocacy and public policy  
Educational programs, meetings, and events for health care providers  
Publications for health care providers

**The American Society of Human Genetics (ASHG)**

9650 Rockville Pike  
Bethesda, MD 20814–3998  
Phone: 1–866–HUM–GENE (1–866–486–4363) or 301–634–7300  
Fax: 301–634–7079  
Email: [society@ashg.org](mailto:society@ashg.org)  
Internet: [www.ashg.org](http://www.ashg.org)

**Mission:** To serve research scientists, health professionals, and the public by providing forums to share research results at annual meetings and in *The American Journal of Human Genetics*; to advance genetic research by advocating for research support; to enhance genetics education by preparing future professionals and informing the public; and to promote genetic services and support responsible social and scientific policies.

**Services provided:**

Advocacy and public policy  
Educational programs, meetings, and events for health care providers and patients  
Resources

**American Thyroid Association (ATA)**

6066 Leesburg Pike, Suite 550  
Falls Church, VA 22041  
Phone: 703–998–8890  
Fax: 703–998–8893  
Email: [thyroid@thyroid.org](mailto:thyroid@thyroid.org)  
Internet: [www.thyroid.org](http://www.thyroid.org)

**Mission:** To promote thyroid health and understanding in thyroid biology and to focus on prevention and treatment through excellence and innovation in research, clinical care, education, and public health.

**Services provided:**

Clinical guidelines  
Educational programs, meetings, and events for health care providers  
Publications for health care providers and patients  
Thyroid specialist locator

## **Association for Glycogen Storage Disease (AGSD)**

P.O. Box 896  
Durant, IA 52747  
Phone: 563-514-4022  
Email: [info@agsdus.org](mailto:info@agsdus.org)  
Internet: [www.agsdus.org](http://www.agsdus.org)

**Mission:** To serve as a parent- and patient-oriented support group, increase public awareness of glycogen storage disease (GSD), stimulate research in the various forms of GSD, and disseminate results to parents, patients, and the public.

### ***Services provided:***

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

## **Congenital Adrenal Hyperplasia Research Education & Support (CARES) Foundation**

2414 Morris Avenue, Suite 110  
Union, NJ 07083  
Phone: 1-866-227-3737 or 908-364-0272  
Fax: 908-686-2019  
Email: [contact@caresfoundation.org](mailto:contact@caresfoundation.org)  
Internet: [www.caresfoundation.org](http://www.caresfoundation.org)

**Mission:** To improve the lives of the congenital adrenal hyperplasia community and seek to advance quality health care through support, advocacy, education, and research.

### ***Services provided:***

Information for the media  
Resources  
Support groups

## **Cushing's Support & Research Foundation (CSRF)**

60 Robbins Road, #12  
Plymouth, MA 02360  
Phone: 617-723-3674  
Internet: [www.csrf.net](http://www.csrf.net)

**Mission:** To provide information and support for patients and their families, increase awareness and educate the public about Cushing's disease and Cushing's syndrome, be a resource for information and support to health care professionals, and raise and distribute funds for Cushing's disease and Cushing's syndrome research.

**Services provided:**

Resources  
Support groups

**Cystic Fibrosis Foundation**

6931 Arlington Road, 2nd Floor  
Bethesda, MD 20814  
Phone: 1-800-FIGHT-CF (1-800-344-4823) or 301-951-4422  
Fax: 301-951-6378  
Email: [info@cff.org](mailto:info@cff.org)  
Internet: [www.cff.org](http://www.cff.org)

**Mission:** 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.

**Services provided:**

Advocacy and public policy  
Cystic fibrosis care center locator  
Cystic fibrosis chapter locator  
Educational programs, meetings, and events for health care providers  
Resources

**Endocrine Society**

2055 L Street NW, Suite 600  
Washington, D.C. 20036  
Phone: 1-888-363-6274 or 202-971-3636  
Fax: 202-736-9705  
Email: [societyservices@endocrine.org](mailto:societyservices@endocrine.org)  
Internet: [www.endo-society.org](http://www.endo-society.org)

**Mission:** To advance excellence in endocrinology and promote its essential role as an integrative force in scientific research and medical practice.

***Services provided:***

Advocacy and public policy  
Clinical practice guidelines  
Continuing medical education (CME)  
Educational programs and meetings for health care providers  
Information for the media  
Maintenance of certification (MOC) programs  
Publications for health care providers and patients

**Fatty Oxidation Disorders (FOD) Family Support Group**

Deb Lee Gould, M.Ed., Director  
P.O. Box 54  
Okemos, MI 48805-0054  
Phone: 517-381-1940 (8 a.m. to 8 p.m. EST every day)  
Fax: 1-866-290-5206  
Email: deb@fodsupport.org  
Internet: www.fodsupport.org

***Mission:*** To connect and network with fatty oxidation disorders families and professionals around the world and to provide emotional and grief support, family stories, practical information about living with these disorders, and medical updates to inform families of new developments in screening, diagnosis, research, and treatment.

***Services provided:***

Resources

**Genetic Alliance**

4301 Connecticut Avenue NW, Suite 404  
Washington, D.C. 20008-2369  
Phone: 202-966-5557  
Fax: 202-966-8553  
Email: info@geneticalliance.org  
Internet: www.geneticalliance.org

***Mission:*** To transform health through genetics and promote an environment of openness centered on the health of individuals, families, and communities.

***Services provided:***

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

## **Graves' Disease and Thyroid Foundation**

P.O. Box 2793  
Rancho Santa Fe, CA 92067  
Phone: 1-877-643-3123  
Fax: 1-877-643-3123  
Email: info@gdatf.org  
Internet: www.gdatf.org

**Mission:** To provide patient services, public education, and professional education, and to fund research.

### ***Services provided:***

Meetings for health care providers  
Resources  
Support groups

## **Hormone Health Network** (*Formerly The Hormone Foundation*)

Phone: 1-800-HORMONE (1-800-467-6663)  
Email: hormone@ endocrine.org  
Internet: www.hormone.org

**Mission:** To serve as a resource for the public by promoting the prevention, treatment, and cure of hormone-related conditions through outreach and education. The Hormone Health Network is the public education affiliate of the Endocrine Society.

### ***Services provided:***

Endocrinologist locator  
Information for the media  
Publications for health care providers and patients  
Resources

## **Human Growth Foundation (HGF)**

997 Glen Cove Avenue, Suite 5  
Glen Head, NY 11545  
Phone: 1-800-451-6434  
Fax: 516-671-4055  
Email: hgf1@hgfound.org  
Internet: www.hgfound.org

**Mission:** To help children and adults with disorders of growth and growth hormone through research, education, support, and advocacy.

***Services provided:***

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

**The Hypoglycemia Support Foundation, Inc. (HSF)**

P.O. Box 451778  
Sunrise, FL 33345  
Email: [rruggiero@hypoglycemia.org](mailto:rruggiero@hypoglycemia.org)  
Internet: [www.hypoglycemia.org](http://www.hypoglycemia.org)

***Mission:*** To inform, direct, support, and encourage people with hypoglycemia.

***Services provided:***

Publications for health care providers  
Resources  
Support groups

**The MAGIC Foundation**

6645 West North Avenue  
Oak Park, IL 60302  
Phone: 1-800-3MAGIC3 (1-800-362-4423) or 708-383-0808  
Email: [ContactUs@magicfoundation.org](mailto:ContactUs@magicfoundation.org)  
Internet: [www.magicfoundation.org](http://www.magicfoundation.org)

***Mission:*** To provide support services for the families of children afflicted with a wide variety of chronic and/or critical disorders, syndromes, and diseases that affect a child's growth.

***Services provided:***

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

**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](mailto:askus@marchofdimes.com)  
Internet: [www.marchofdimes.com](http://www.marchofdimes.com)



**Mission:** To improve the health of babies by preventing birth defects, premature birth, and infant mortality through research, community services, education, and advocacy.

**Services provided:**

Advocacy and public policy  
Chapter locator  
Continuing nursing education (CNE)  
Publications for patients  
Resources  
Support groups

**National Adrenal Diseases Foundation (NADF)**

505 Northern Boulevard  
Great Neck, NY 11021  
Phone: 516-487-4992  
Email: [nadfsupport@nadf.us](mailto:nadfsupport@nadf.us)  
Internet: [www.nadf.us](http://www.nadf.us)

**Mission:** To provide support, information, and education to individuals who have Addison's disease or other diseases of the adrenal glands.

**Services provided:**

Meetings and events for patients  
Publications for patients  
Support groups

**National Diabetes Information Clearinghouse (NDIC)**

1 Information Way  
Bethesda, MD 20892-3560  
Phone: 1-800-860-8747  
TTY: 1-866-569-1162  
Fax: 703-738-4929  
Email: [ndic@info.niddk.nih.gov](mailto:ndic@info.niddk.nih.gov)  
Internet: [www.diabetes.niddk.nih.gov](http://www.diabetes.niddk.nih.gov)

**Mission:** To increase knowledge and understanding about diabetes among patients, health care professionals, and the general public. To carry out this mission, the NDIC works closely with the NIDDK's Diabetes Research Centers; the National Diabetes Education Program; professional, patient, and voluntary associations; Government agencies; and state health departments to identify and respond to informational needs about diabetes and its management.

**Services provided:**

Publications for health care providers and patients

## Resources

### **National MPS Society**

P.O. Box 14686  
Durham, NC 27709-4686  
Phone: 1-877-MPS-1001 (1-877-677-1001) or 919-806-0101  
Email: [info@mpssociety.org](mailto:info@mpssociety.org)  
Internet: [www.mpssociety.org](http://www.mpssociety.org)

**Mission:** To find a cure for mucopolysaccharidoses and related diseases; provide hope and support for affected individuals and their families through research, advocacy, and awareness of these devastating diseases; and increase public and professional awareness.

#### ***Services provided:***

Continuing medical education (CME)  
Publications for patients  
Resources  
Support groups

### **National Organization for Rare Disorders (NORD)**

55 Kenosia Avenue  
Danbury, CT 06810  
Phone: 203-744-0100  
Fax: 203-798-2291  
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 programs of education, advocacy, research, and service.

#### ***Services provided:***

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

### **National Osteoporosis Foundation (NOF)**

1150 17th Street NW, Suite 850  
Washington, D.C. 20036  
Phone: 1-800-231-4222 or 202-223-2226  
Fax: 202-223-2237  
Email: [info@nof.org](mailto:info@nof.org)  
Internet: [www.nof.org](http://www.nof.org)

**Mission:** To prevent osteoporosis and broken bones, promote strong bones for life, and reduce human suffering through programs of public and clinician awareness, education, advocacy, and research.

**Services provided:**

Advocacy and public policy  
Continuing medical education (CME)  
Educational programs for health care providers and patients  
Information for the media  
Meetings and events for health care providers  
Physician locator  
Publications for patients  
Resources  
Support groups

**The National Urea Cycle Disorders Foundation (NUCDF)**

75 South Grand Avenue  
Pasadena, CA 91105  
Phone: 1-800-38-NUCDF (1-800-386-8233) or 626-578-0833  
Fax: 626-578-0823  
Email: info@nucdf.org or cindy@nucdf.org  
Internet: www.nucdf.org

**Mission:** To save and improve the lives of all those affected by urea cycle disorders.

**Services provided:**

Meetings and events for patients  
Patient registry  
Resources  
Support groups

**Organic Acidemia Association, Inc. (OAA)**

Kathy Stagni, Executive Director  
13210 35th Avenue North  
Plymouth, MA 55441  
Phone: 763-559-1797  
Fax: 1-866-539-4060  
Email: kstagni@oanews.org  
Internet: www.oanews.org

**Mission:** To empower families and health care professionals with knowledge in organic acidemia metabolic disorders.

***Services provided:***

Events for health care providers, patients, and families  
Resources

**The Oxalosis and Hyperoxaluria Foundation (OHF)**

201 East 19th Street, Suite 12E  
New York, NY 10003  
Phone: 1-800-OHF-8699 (1-800-643-8699) or 212-777-0470  
Fax: 212-777-0471  
Internet: [www.ohf.org](http://www.ohf.org)

***Mission:*** To promote research to find a cure for oxalosis, primary hyperoxaluria, and related stone diseases and improve the care and treatment of those they affect.

***Services provided:***

Events for patients and families  
Patient registry  
Resources

**The Paget Foundation**

P.O. Box 24432  
Brooklyn, NY 11202  
Phone: 1-800-23-PAGET (1-800-237-2438)  
Email: [PagetFdn@aol.com](mailto:PagetFdn@aol.com)  
Internet: [www.paget.org](http://www.paget.org)

***Mission:*** To serve patients with Paget's disease of bone, primary hyperparathyroidism, fibrous dysplasia, and the rare disease osteopetrosis and to assist the medical community that treats patients.

***Services provided:***

Publications for health care providers and patients  
Resources

**Pediatric Endocrine Society**

6728 Old McLean Village Drive  
McLean, VA 22101  
Phone: 703-556-9222  
Fax: 703-556-8729  
Email: [info@pedsendo.org](mailto:info@pedsendo.org)  
Internet: [www.pedsendo.org](http://www.pedsendo.org)

***Mission:*** To advance the care of children and adolescents with endocrine disorders.

***Services provided:***

Resources and materials  
Physician locator  
Events and training for health care providers

**Pituitary Network Association (PNA)**

P.O. Box 1958  
Thousand Oaks, CA 91358  
Phone: 805-499-9973  
Fax: 805-480-0633  
Email: [info@pituitary.org](mailto:info@pituitary.org)  
Internet: [www.pituitary.org](http://www.pituitary.org)

***Mission:*** To support, pursue, encourage, promote, and where possible, fund research on pituitary disorders in a sustained and full-time effort to find a cure for these illnesses. The PNA disseminates information helpful to the medical community, the public, and pituitary patients and their families on matters regarding early detection, symptoms, treatments, and resources available to patients with pituitary disease.

***Services provided:***

Information for the media  
Publications for patients  
Resources

**The Pituitary Society**

VA Medical Center  
423 East 23rd Street, Room 16048aW  
New York, NY 10010  
Phone: 212-263-6772  
Fax: 212-447-6219  
Email: [pituitary.society@med.nyu.edu](mailto:pituitary.society@med.nyu.edu)  
Internet: [www.pituitarysociety.org](http://www.pituitarysociety.org)

***Mission:*** To provide scientists, clinicians, and trainees with the most up-to-date, reliable research and education on the biology of the pituitary and the causes, diagnosis, and treatment of pituitary disease, in order to improve patient care, and to provide a uniquely international forum for professional growth and scientific exchange.

***Services provided:***

Meetings and events for health care providers  
Physician locator  
Publications for health care providers  
Resources

## **Society for Inherited Metabolic Disorders (SIMD)**

Leslie Lublink, SIMD Administrator  
18265 Lower Midhill Drive  
West Linn, OR 97068  
Phone: 503-636-9228  
Fax: 503-210-1511  
Email: [lublinkl@ohsu.edu](mailto:lublinkl@ohsu.edu)  
Internet: [www.simd.org](http://www.simd.org)

**Mission:** To promote the worldwide advancement of research and medical treatment of inherited disorders of metabolism.

### ***Services provided:***

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

## **United Leukodystrophy Foundation (ULF)**

224 North Second Street, Suite 2  
DeKalb, IL 60115  
Phone: 1-800-728-5483 or 815-748-3211  
Fax: 815-748-0844  
Email: [office@ulf.org](mailto:office@ulf.org)  
Internet: [www.ulf.org](http://www.ulf.org)

**Mission:** To help children and adults who have leukodystrophy and assist the family members, professionals, and support services that serve them. The ULF is committed to the identification, treatment, and cure of all leukodystrophies through programs of education, advocacy, research, and service.

### ***Services provided:***

Educational programs, meetings, and events for health care providers, patients, and families  
Resources

## **Wilson Disease Association (WDA)**

5572 North Diversey Boulevard  
Milwaukee, WI 53217  
Phone: 1-888-961-0533 or 414-961-0533  
Email: [info@wilsonsdisease.org](mailto:info@wilsonsdisease.org)  
Internet: [www.wilsonsdisease.org](http://www.wilsonsdisease.org)

**Mission:** To fund research and facilitate and promote the identification, education, treatment, and support of patients and other individuals affected by Wilson disease.

***Services provided:***

Advocacy and public policy

Physician locator

Publications for health care providers and patients

Resources

Support group locator

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## **National Endocrine and Metabolic Diseases Information Service**

6 Information Way  
Bethesda, MD 20892-3569  
Phone: 1-888-828-0904  
TTY: 1-866-569-1162  
Fax: 703-738-4929  
Email: [endoandmeta@info.niddk.nih.gov](mailto:endoandmeta@info.niddk.nih.gov)  
Internet: [www.endocrine.niddk.nih.gov](http://www.endocrine.niddk.nih.gov)

The National Endocrine and Metabolic 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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