



Directory of Endocrine and Metabolic Diseases Organizations

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

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

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

Mission: To provide professional community of physicians specializing in endocrinology, diabetes, and metabolism committed to enhancing the ability of its members to provide the highest quality of 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

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, enhance public awareness, develop educational programs and distribute educational materials, and support research to improve treatment and ultimately lead to cure.

Services provided:

- Continuing medical education (CME)
- National Porphyria Registry
- Publications for health care providers and patients
- Resources

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
Internet: 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

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
Internet: 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: 1-800-THYROID (1-800-849-7643) or 703-998-8890
Fax: 703-998-8893
Email: thyroid@thyroid.org
Internet: 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: maryc@agsdus.org
Internet: 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 and 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@carefoundation.org
Internet: 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 and Research Foundation (CSRF)

65 East India Row, 22B
Boston, MA 02110
Phone: 617-723-3674
Fax: 617-723-3674
Email: cushinfo@csrf.net
Internet: 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
Internet: 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

8401 Connecticut Avenue, Suite 900
Chevy Chase, MD 20815
Phone: 1-888-363-6274 or 301-941-0200
Fax: 301-941-0259
Email: societyservices@endo-society.org
Internet: 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.
PO Box 54
Okemos, MI 48805-0054
Phone: 517-381-1940
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

The 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@ngdf.org
Internet: www.gdatf.org

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

Services provided:

- Meetings for health care providers
- Resources
- Support groups

Hormone Health Network (*Formerly The Hormone Foundation*)

8401 Connecticut Avenue, Suite 900
Chevy Chase, MD 20815-5817
Phone: 1-800-HORMONE (1-800-467-6663)
Fax: 301-941-0259
Email: hormone@endo-society.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

Hypoglycemia Support Foundation, Inc. (HSF)

2638 NW 104 Avenue, #203
Sunrise, FL 33322
Phone: 954-701-3125
Email: rruggiero@hypoglycemia.org
Internet: www.hypoglycemia.org

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

Services provided:

- Publications for health care providers
- Resources
- Support groups

Iron Overload Diseases Association (IOD)

525 Mayflower Road
West Palm Beach, FL 33405
Phone: 561-586-8246
E-mail: iod@irondisorders.org
Internet: www.ironoverload.org

Mission: To lead the search for the millions of Americans and other nationals who have undiagnosed iron overload, promote adequate treatment, and prevent the severe health problems and avoidable deaths that results from neglect of iron overload.

Services provided:

- Resources

The Magic Foundation

6645 West North Avenue
Oak Park, IL 60302
Phone: 1-800-3MAGIC3 (1-800-362-4423) or 708-383-0808
Fax: 708-383-0899
Internet: 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: skus@marchofdimes.com
Internet: 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
Internet: www.nadf.us

Mission: To provide support, information, and education to individuals having Addison's disease as well as 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
Internet: 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, NDIC works closely with NIDDK's Diabetes Research and Training Centers; the National Diabetes Education Program (NDEP); 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
Internet: 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
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
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 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
Internet: 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

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
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

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
Email: kimh@ohf.org
Internet: 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) or 212-509-5335
Fax: 212-509-8492
Email: PagetFdn@aol.com
Internet: 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

The Pituitary Network Association (PNA)

P.O. Box 1958
Thousand Oaks, CA 91358
Phone: 805-499-9973
Fax: 805-480-0633
Email: info@pituitary.org
Internet: 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 to 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
Internet: 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
Internet: 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
Fax: 815-748-0844
Email: office@ulf.org
Internet: 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
Internet: 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:

- Publications for health care providers and patients
- Resources
- Support groups

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
Internet: www.endocrine.niddk.nih.gov

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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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