

Resources for learning more

It can be helpful to learn more about Pompe disease and Myozyme treatment. You can contact these organizations and Web sites for further information and support.

International Pompe Association (IPA)

- Find a patient group contact for your country. If your country does not have a group contact, you can receive information about becoming one
- Read updates on clinical trials, treatment studies, and standards of care
- Access links to research articles, IPA conference summaries, and accounts from patients and parents of young children who have taken part in clinical trials
- Read more about Pompe disease and the management of the disease in the original *'Pompe Connections'* available in several languages.
- Obtain a list of worldwide sources of financial support for children in need
- Hear from individual patients about their experiences with treatment by reading Patient Testimonials

www.worldpompe.org

Other worldwide organizations

European Alliance of Neuromuscular Disorders Associations (EAMDA)

- Learn more about Pompe disease and other neuromuscular conditions by obtaining fact sheets
- Find an EAMDA member association in your country
- Attend conferences and seminars in Europe

MDG Malta 4, Gzira Road
Gzira GZR 04
Malta

Phone: 356 21 346688

www.eamda.net

World Alliance Neuromuscular Disorder Associations (WANDA)

- Find contact information for neuromuscular disorder associations in your country
- Learn how to form a neuromuscular disorder association if your country does not have one
- Obtain links for Web sites and other sources of information about neuromuscular disorders

www.worldmuscleforum.org

www.wandaweb.org

Other names for Pompe disease

Acid alpha-glucosidase deficiency, acid maltase deficiency (AMD), glycogen storage disorder (GSD) type II, glycogenosis II, and lysosomal alpha-glucosidase deficiency. In different parts of the world, Pompe may be pronounced "*pom-PAY*," "*POM-puh*," or "*pom-PEE*."

Language-specific Web sites

Pompe disease information is available in languages other than English on the following Web sites:

Danish: www.muskelsvindfonden.dk

Dutch: www.vsn.nl

French: www.glycogenoses.org

German: www.glykogenose.de

Italian: www.aig-aig.it

Japanese: www.5b.biglobe.ne.jp/~pompe

Polish: www.idn.org.pl/tzchm

Spanish: www.glycogenesis.org

Turkish: www.kashastalıkları.org.tr

Other organizations you may want to contact

Acid Maltase Deficiency Association (AMDA)

- Learn more about Pompe disease through teleconferences at www.amda-pompe.org/communication.htm and through newsletters
- Read personal accounts written by patients and families
- Obtain referrals and phone support
- Find or become a mentor for families affected by Pompe disease

PO Box 700248
San Antonio, TX 78270-0248
USA
Phone: 1-210-494-6144 (USA)

www.amda-pompe.org

Association for Glycogen Storage Disease (USA) [AGSD(USA)]

- Share your experiences with patients and parents and find a Pompe role model through an electronic mailing list called **GSDnet**

- The mailing list can be accessed through the AGSD in the United States at www.agsdus.org or through the AGSD UK Pompe disease page at www.pompe.org.uk/agsdnet.html

- Receive newsletters and updates about Pompe disease

PO Box 896
Durant, IA 52747
USA
Phone: 1-563-785-6038 (USA)

www.agsdus.org

Association for Glycogen Storage Disease (UK) [AGSD(UK)]

- Receive newsletters and updates about glycogen storage disease
- Attend conferences and workshops and gain support from other families

www.agsd.org.uk

Web site for the AGSD(UK) Pompe group:
www.pompe.org.uk

Resources for learning more (continued)

Muscular Dystrophy Campaign (MDC)

- Find a range of useful fact sheets and other printed information on neuromuscular diseases
- Obtain reading materials for children with neuromuscular diseases

Head Office
7-11 Prescott Place
London SW4 6BS
England
Phone: 44-20-7720-8055 (UK)

www.muscular-dystrophy.org

Muscular Dystrophy Association (USA)

- Learn about neuromuscular diseases
- Find an MDA chapter near you

3300 East Sunrise Drive
Tucson, AZ 85718
USA
Phone: 1-800-344-4863 (USA)

www.mdaua.org

Pompe Community

- View current information related to Myozyme at www.Myozyme.com
- Sponsored by Genzyme Corporation
- Obtain lists of patient support groups, medical specialists, medical facilities, and organizations for people with Pompe disease
- Enroll in clinical trials for enzyme replacement therapy
- Contact groups specializing in insurance issues and providing support for unmet medical needs
- Participate in the **Pompe Disease Registry** (www.pomperegistry.com) that collects information about the disease's course to improve the quality of care

- Access a glossary of terms related to Pompe disease

Genzyme Therapeutics
500 Kendall Street
Cambridge, MA 02142
USA
Phone: 1-617-768-9000 (USA)
Toll-free phone: 1-800-745-4447

Genzyme Europe BV
Gooimeer 10
1411 DD Naarden
The Netherlands
Phone: 31-35-699-1200 (Netherlands)

www.pompe.com

www.genzyme.com

www.myozyme.com

Children Living with Inherited Metabolic Diseases (CLIMB)

- For families outside of the United Kingdom: Receive information by mail about Pompe disease
- For families in the United Kingdom: Access support groups, telephone counseling, a pen pal service that matches children with similar interests, a national conference, and other services

Climb Building
176 Nantwich Road
Crewe CW2 6BG
England
Phone: 44-800-652-3181 (UK)

www.climb.org.uk

(The CLIMB Web site refers to Pompe disease as Glycogen Storage Disease Type II.)

Resources for learning more (continued)

United Pompe Foundation (UPF)

- Obtain financial support for medical and other expenses
- Read articles about the disease
- Attend UPF conferences in the United States

David W. Hamlin
5100 N. Sixth Street #149
Fresno, CA 93710
USA
Phone: 1-559-227-1898 (USA)

www.unitedpompe.com

National Organization for Rare Disorders (NORD)

- Search the database of rare diseases
- Access the index of organizations
- Obtain the *NORD Resource Guide* that describes more than 1300 patient organizations, foundations, and registries for people affected by rare diseases

- Receive a free booklet, *The Physician's Guide to Pompe Disease*

55 Kenosia Avenue
PO Box 1968
Danbury, CT 06813-1968
USA
Phone: 1-203-744-0100 (USA)

www.rarediseases.org

Family Caregiver Alliance

- Obtain information and support for caregivers
- Find resources and local groups in the United States

180 Montgomery Street, Suite 11001
San Francisco, CA 94104
USA

Phone: 1-415-434-3388 (USA)
Toll-free phone: 1-800-445-8108

www.caregiver.org

Other Resources

- For information on clinical trials, visit www.clinicaltrials.gov
- **Understanding Pompe Disease** is a free booklet that gives a good introduction to Pompe disease. It is available on the Pompe Community Web site at www.pompe.com
- **Abledata** (www.abledata.com) is an excellent source of information about adaptive equipment and devices from around the world
- To view the official label for Myozyme, please visit www.fda.gov if you live in the United States or outside of Europe, or www.emea.eu.int if you live in Europe

This publication is designed to provide general information in regard to the subject matter covered. It is distributed as a public service by the International Pompe Association, with the understanding that the International Pompe Association is not engaged in rendering medical or other professional services. Medicine is a constantly changing science. Human error and changes in practice make it impossible to certify the precise accuracy of such complex materials. Confirmation of this information from other sources, especially one's physician, is required. Please keep in mind that the effectiveness of Myozyme varies from person to person.