



## Resources for learning more

It can be helpful to learn more about Pompe disease. You can contact these organizations and Web sites for 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
- Obtain a list of worldwide sources of financial support for children in need

[www.worldpompe.org](http://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: 00356 21 346688

[www.eamda.net](http://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](http://www.worldmuscleforum.org)

[www.wandaweb.org](http://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](http://www.muskelsvindfonden.dk)

Dutch: [www.vsn.nl](http://www.vsn.nl)

French: [www.glycogenoses.org](http://www.glycogenoses.org)

German: [www.glykogenose.de](http://www.glykogenose.de)

Italian: [www.aig-aig.it](http://www.aig-aig.it)

Japanese: [www5b.biglobe.ne.jp/~pompe](http://www5b.biglobe.ne.jp/~pompe)

Polish: [www.idn.org.pl/tzchm](http://www.idn.org.pl/tzchm)

Spanish: [www.ucip.net/aeeg/default.htm](http://www.ucip.net/aeeg/default.htm)

Turkish: [www.kashastaliklari.org.tr](http://www.kashastaliklari.org.tr)

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### 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](http://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: 210-494-6144 (USA)

[www.amda-pompe.org](http://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](http://www.agsdus.org) or through the AGSD UK Pompe disease page at [www.pompe.org.uk/agsdnet.html](http://www.pompe.org.uk/agsdnet.html)
- Receive newsletters and updates about Pompe disease

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

[www.agsdus.org](http://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](http://www.agsd.org.uk)

**Web site for the AGSD(UK) Pompe group:**  
[www.pompe.org.uk](http://www.pompe.org.uk)

## Resources for learning more (continued)

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### 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: 020-7720-8055 (UK)

[www.muscular-dystrophy.org](http://www.muscular-dystrophy.org)

### Pompe Community

- 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: 617-768-9000 (USA)  
Toll-free phone: 800-745-4447

### Pompe Community (continued)

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

[www.pompe.com](http://www.pompe.com)  
[www.genzyme.com](http://www.genzyme.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: 0800-652-3181 (UK)

[www.climb.org.uk](http://www.climb.org.uk)

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

### 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: 559-227-1898 (USA)

[www.unitedpompe.com](http://www.unitedpompe.com)

## Resources for learning more (continued)

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### 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: 203-744-0100 (USA)

[www.rarediseases.org](http://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: 415-434-3388 (USA)  
Toll-free phone: 800-445-8108

[www.caregiver.org](http://www.caregiver.org)

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## Other Resources

- For information on clinical trials, visit [www.clinicaltrials.gov](http://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](http://www.pompe.com)
- **Abledata ([www.abledata.com](http://www.abledata.com))** is an excellent source of information about adaptive equipment and devices from around the world

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