

# The Genetic and Rare Diseases Information Center (GARD)



A rare disease typically affects a patient population estimated at fewer than 200,000 in the U.S. There are more than 6,800 rare diseases known today and they affect an estimated 25 million persons in the U.S.

## Yesterday

- In 1989, the National Commission on Orphan (Rare) Diseases found that patients and families as well as physicians had great difficulties obtaining needed information about rare diseases.
- The Commission recommended a central source of information on rare diseases to facilitate access to information for patients and their families and to draw from existing information systems in the public and private sectors.
- In 1999, the Special Emphasis Panel of the National Institutes of Health (NIH) on the Coordination of Rare Diseases Research reinforced the findings of the Commission.
- Though great strides had been made through the Internet and various databases, more needed to be done to provide information to patients and their families through multiple channels.
- The Rare Diseases Act of 2002 included directions for the Office of Rare Diseases Research (ORDR) to support a centralized clearinghouse for rare diseases information.
- The ORDR partnered with the National Human Genome Research Institute (NHGRI) (<http://www.genome.gov/>) and established the Genetic and Rare Diseases Information Center (GARD) in 2002.

## Today

- By late 2010, GARD had provided close to 29,000 direct responses on more than 7,000 rare and/or genetic diseases. GARD receives approximately 400 direct requests for information per month and approximately 62,000 Website visits per month. Each visit to the Web pages lasts approximately 25

minutes. Requests come not only from patients and their families, but also from researchers, physicians, nurses, and other health care professionals.

Responses draw primarily from existing information sources in the public and private sectors. To learn more about GARD and find up-to-date statistics, visit the *About GARD* page at

<http://rarediseases.info.nih.gov/GARD/AboutGARD.aspx>.

- The Information Center provides comprehensive responses Monday through Friday, noon to 6 pm EST by telephone, e-mail, letter, or fax in English or in Spanish. Generalized responses are regularly posted on the ORDR Web site as part of Rare Diseases and Related Terms at <http://rarediseases.info.nih.gov/RareDiseaseList.aspx?PageID=1>. You can also search for disease-specific information and find general information on the GARD home page at <http://rarediseases.info.nih.gov/GARD/>.

The responses contain up-to-date, reliable, and useful summaries of information and contact information for the information sources.

## Tomorrow

- To ensure easier access to even more comprehensive information on rare diseases, GARD will continue to change in order to meet the future information needs of the public. GARD will continue to expand open and instantaneous access to information on rare diseases for patients, families, health professionals, and researchers.

**Contact Information:**

**(888) 205-2311 (Telephone)**

**(301) 251-4911 (Fax)**

**(888) 205-3223 (TTY)**

**(301) 251-4925 (International Telephone Access Number)**

**By E-mail:**

**[GARDinfo@nih.gov](mailto:GARDinfo@nih.gov)**

**By U.S. Mail:**

**The Genetic and Rare Diseases Information Center**

**P.O. Box 8126 Gaithersburg, MD 20898-8126**

**To submit a question on the Web site, go to**

**<http://rarediseases.info.nih.gov/GARD/EmailForm.aspx>**