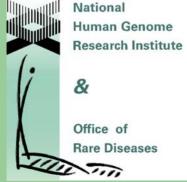
The Genetic and Rare Diseases Information Center (GARD)





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National Institutes of Health (NIH)

GARD Information Center

Created by the

National Institutes of Health's (NIH's)

Office of Rare Diseases (ORD)

and

National Human Genome Research Institute (NHGRI)

Services

- Provides free access to accurate, reliable information about genetic and rare diseases.
- Provides both individualized assistance in finding information to patients and families, health professionals, and other interested parties and generalized information on the Web that is based on public inquiries.
- Provides current, accurate information about specific conditions and illnesses from high-quality resources from Web sites, organizations, and institutions.

Services (cont.)

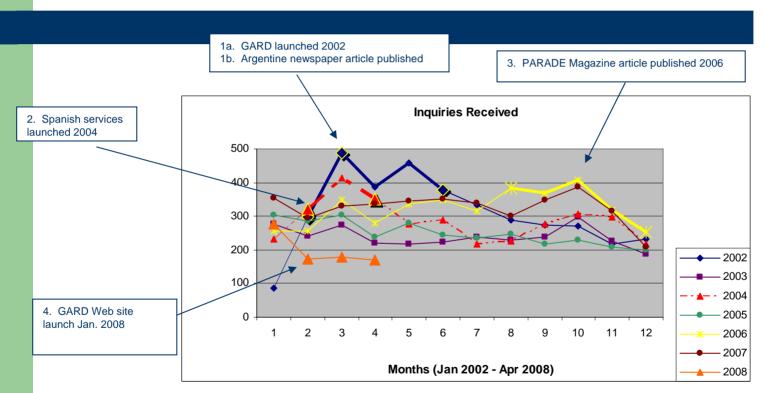
- Telephone and TTY calls are answered Monday through Friday from noon to 6 p.m. Eastern Time.
- Written responses are sent via e-mail, individualized Web page, fax, or letter. Responses—without identifying information—are also posted on recently launched GARD Web pages on the ORD Web site for general use.

^{**}GARD staff do not provide genetic counseling or offer advice about diagnostic testing, referrals, or medical treatment.**

Statistics Overview

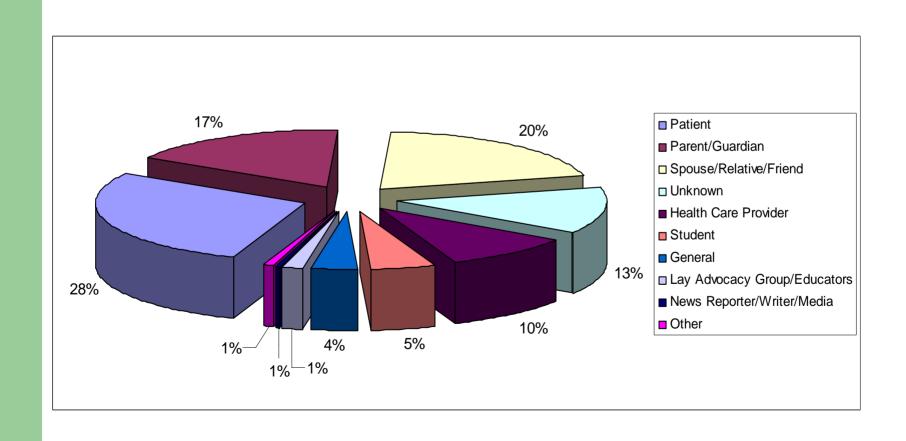
- More than 21,000 inquiries received in 6 years.
- Inquiries concern 5,876 separate diseases.
- Spanish inquiries represent 5% of total received since February 2004.
- Inquiry responses sent in 2 to 6 business days (unless request is urgent).

Inquiries by Month (Yearly Comparison)

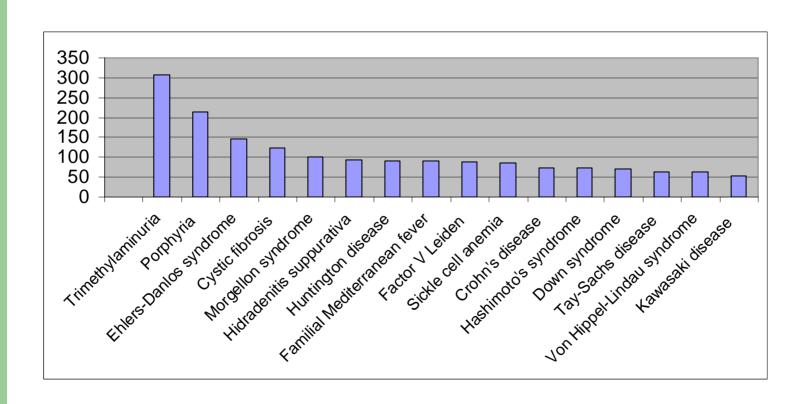


- (1a) Feb. 2002 NIH News Release: The National Human Genome Research Institute (NHGRI) and the National Institutes of Health's Office of Rare Diseases (ORD) Launch Information Center.
- (1b) March 2002 Argentine newspaper article entitled "Lanzan un centro de información gratuita sobre enfermedades genéticas y raras" published in Jan. 2002 in Clarín.com.
- (2) Feb. 2004 NIH News Release: Genetic and Rare Diseases Information Center Now Offers Assistance in Spanish.
- (3) July 2006 Newspaper article in Parade entitled "Could You Have A Rare Disease?"
- (4) Jan. 2008 GARD Web pages launched on Office of Rare Diseases (ORD) Web site.

Who Uses GARD? (2002-2007)



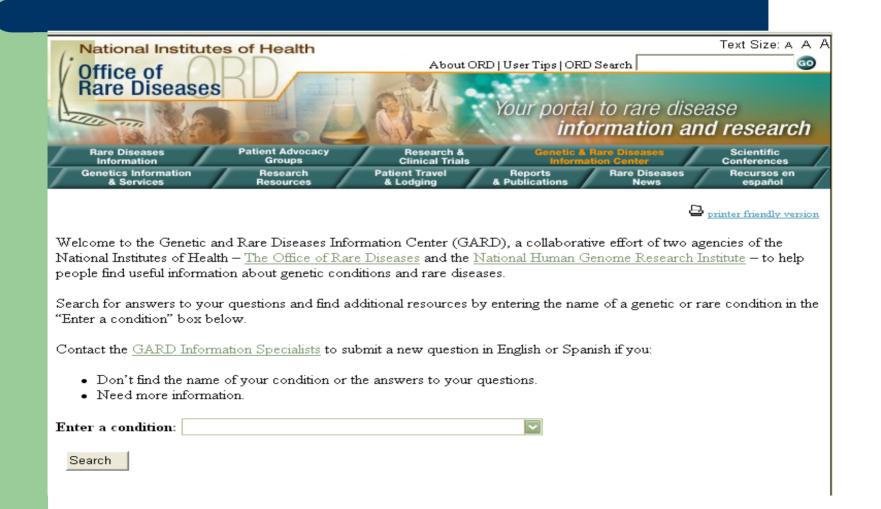
Inquiries by Condition (Top 15)



GARD Web Pages

- GARD Web pages were developed to move the Information Center to a Web-based self service model supported by Information Specialists staff.
- The extensive information collected as a result of preparing customized responses to inquiries is now posted to the Internet assisting both the original inquirer and the general public.
- In March and April, the GARD Web pages had more than 45,000 visitors per month.
- Ongoing efforts to increase the Web pages' ranking in major search engines.

GARD Web Pages on ORD Web Site



Future Directions of GARD

Web pages for Spanish Q&As.

A "select-a-question" box.

Customizable fact sheets.

Integration of CDC's <u>GeT-EQuIP</u> database.

Contact Information

Genetic and Rare Diseases Information Center

Toll-free: 888-205-2311

International: 301-519-3194

TTY: 888-205-3223

Fax: 240-632-9164

E-mail: <u>GARDinfo@nih.gov</u>

Web site: http://rarediseases.info.nih.gov/GARD/Default.aspx?PageID=4

Mail: P.O. Box 8126

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