

# The Genetic and Rare Diseases Information Center (GARD)



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May 21, 2008

# GARD Information Center

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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.)

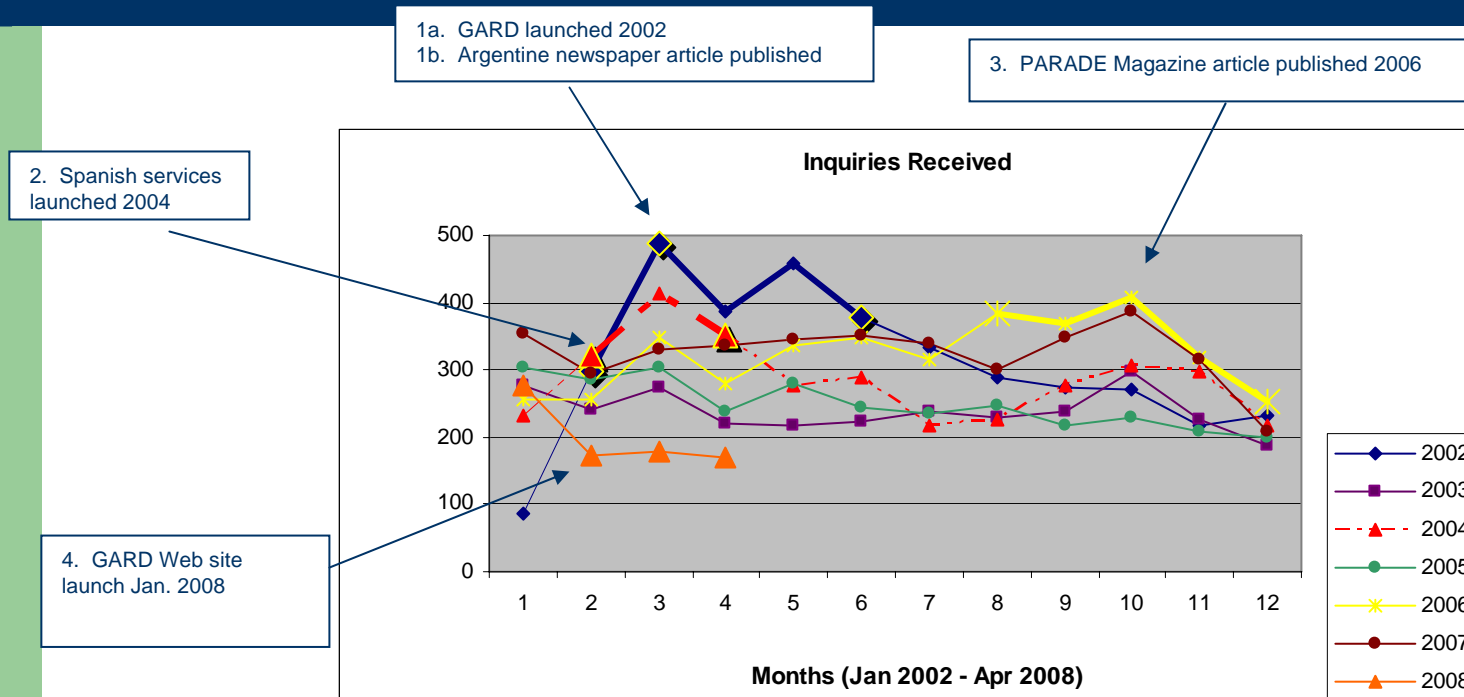
- Telephone and TTY calls are answered Monday through Friday from noon to 6 p.m. Eastern Time.
- Written responses are sent via e-mail, individualized Web page, fax, or letter. **Responses—without identifying information—are also posted on recently launched GARD Web pages on the ORD Web site for general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

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

# Statistics Overview

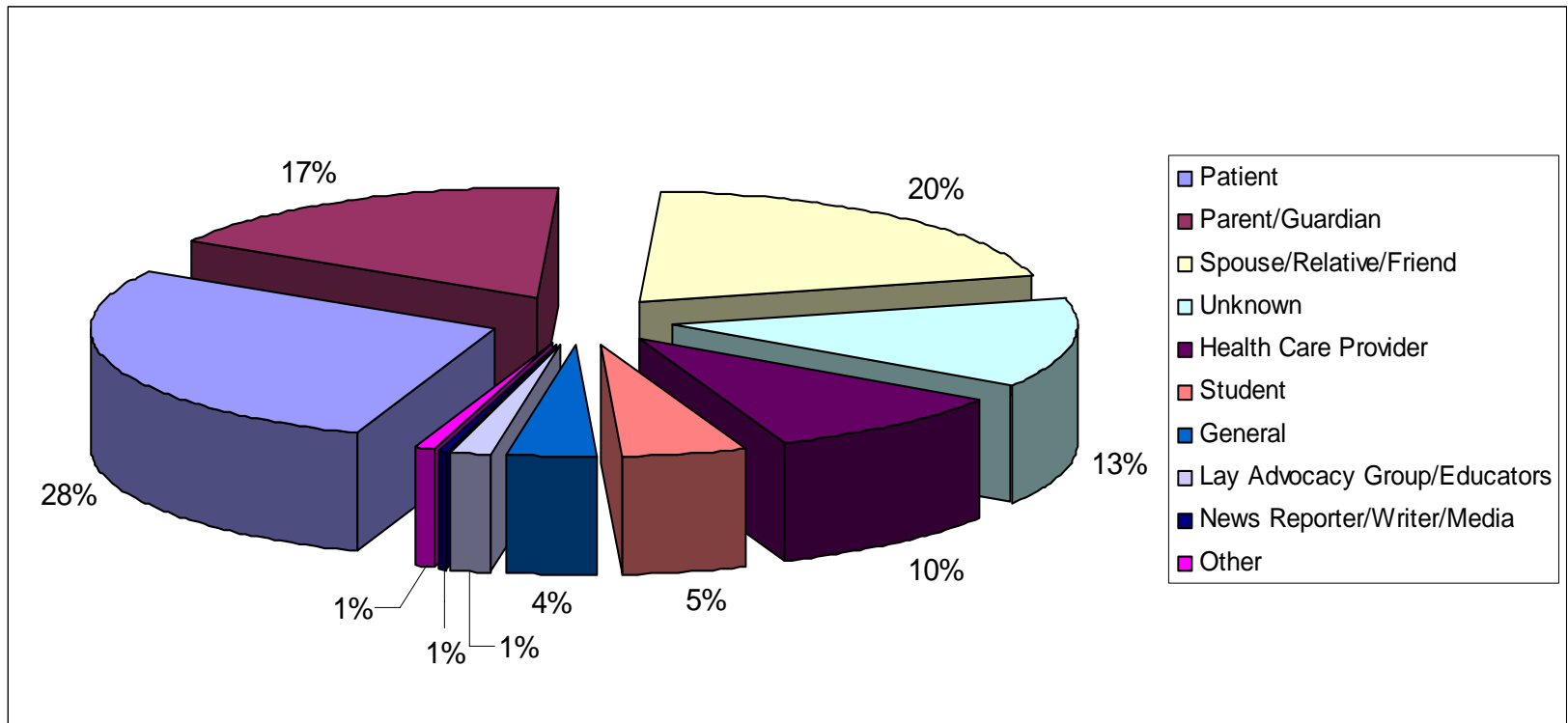
- More than 21,000 inquiries received in 6 years.
- Inquiries concern 5,876 separate diseases.
- Spanish inquiries represent 5% of total received since February 2004.
- Inquiry responses sent in 2 to 6 business days (unless request is urgent).

# Inquiries by Month (Yearly Comparison)

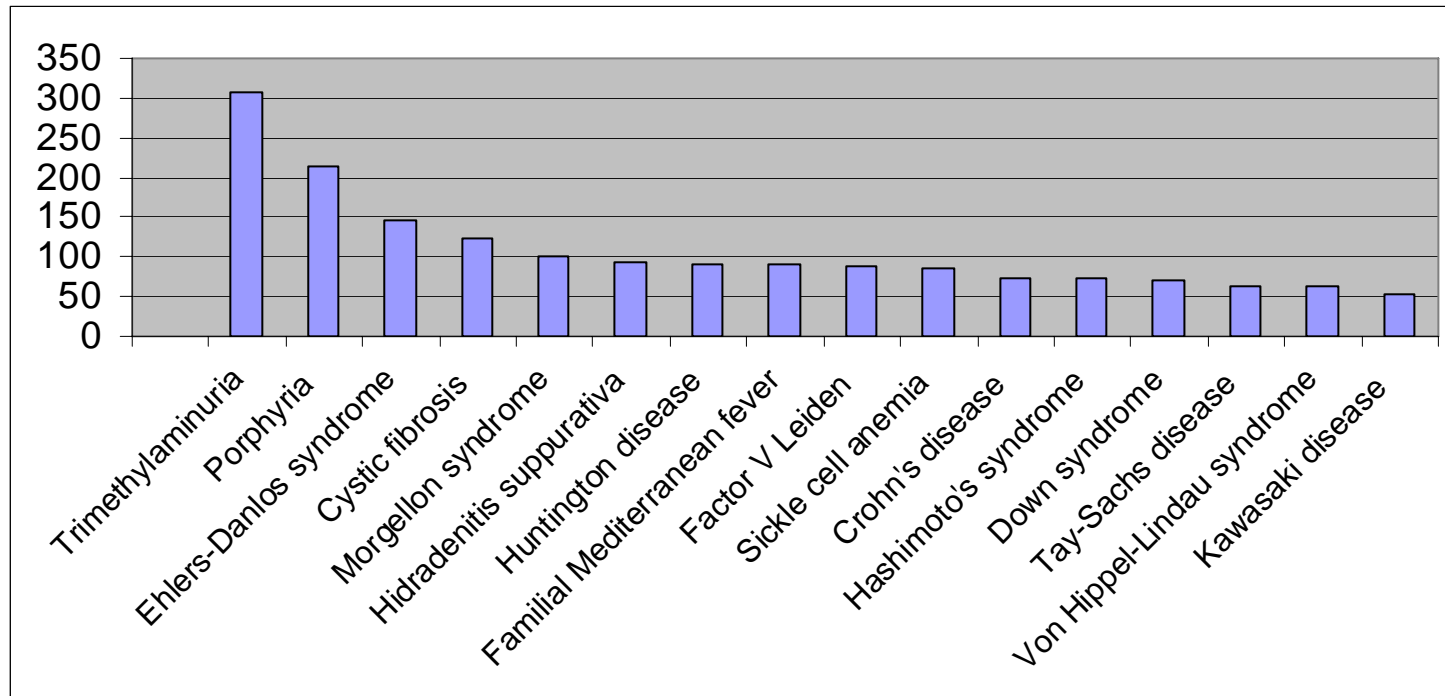


- (1a) Feb. 2002 - NIH News Release: The National Human Genome Research Institute (NHGRI) and the National Institutes of Health's Office of Rare Diseases (ORD) Launch Information Center.
- (1b) March 2002 - Argentine newspaper article entitled "Lanzan un centro de información gratuita sobre enfermedades 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

National Institutes of Health  
Office of Rare Diseases  
ORD  
About ORD | User Tips | ORD Search  GO  
Text Size: A A A  
*Your portal to rare disease information and research*

Rare Diseases Information	Patient Advocacy Groups	Research & Clinical Trials	Genetic & Rare Diseases Information Center	Scientific Conferences
Genetics Information & Services	Research Resources	Patient Travel & Lodging	Reports & Publications	Recursos en español

[printer friendly version](#)

Welcome to the Genetic and Rare Diseases Information Center (GARD), a collaborative effort of two agencies of the National Institutes of Health – [The Office of Rare Diseases](#) and the [National Human Genome Research Institute](#) – to help people find useful information about genetic conditions and rare diseases.

Search for answers to your questions and find additional resources by entering the name of a genetic or rare condition in the “Enter a condition” box below.

Contact the [GARD Information Specialists](#) to submit a new question in English or Spanish if you:

- Don't find the name of your condition or the answers to your questions.
- Need more information.

Enter a condition:

# Future Directions of GARD

- Web pages for Spanish Q&As.
- A “select-a-question” box.
- Customizable fact sheets.
- Integration of CDC’s GeT-EQuIP 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: [GARDinfo@nih.gov](mailto:GARDinfo@nih.gov)**

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

**Mail: P.O. Box 8126**

**Gaithersburg, MD 20898-8126**