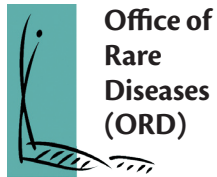




**NATIONAL
HUMAN GENOME
RESEARCH INSTITUTE
(NHGRI)**

NHGRI led the NIH's participation in the International Human Genome Project. The main goal of that project was sequencing of the human genome. When the full genome sequence, and thus the Human Genome Project, was completed in April 2003, NHGRI's mission expanded to include studies that investigate structure and function of the human genome and its role in health and disease. NHGRI helps with the development of resources and technology that will speed up genome research and its application to human health. NHGRI also helps train investigators and distribute genome information to the public and health professionals. For more information, visit the NHGRI Web site at <http://www.genome.gov>.



**Office of
Rare
Diseases
(ORD)**

ORD, a part of the Office of the Director of the National Institutes of Health, works with and brings together rare diseases researchers from the NIH and from around the world. ORD funds rare diseases research programs at the NIH and across the USA that include the Rare Diseases Clinical Research Network with ten research centers (each of which has many sites) that study rare disorders that are not well understood; training of rare diseases researchers; support for about 100 scientific conferences per year; and development of information about rare diseases. For more information, visit the ORD Web site at <http://rarediseases.info.nih.gov>.



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**GENETIC
AND
RARE
DISEASES
INFORMATION CENTER**


**NATIONAL
HUMAN GENOME
RESEARCH INSTITUTE**

AND

OFFICE OF RARE DISEASES

OF THE

NATIONAL INSTITUTES OF HEALTH



DEPARTMENT OF HEALTH AND HUMAN SERVICES

What is The Genetic and Rare Diseases Information Center (GARD)?

Two agencies at the National Institutes of Health (NIH), the National Human Genome Research Institute (NHGRI) and the Office of Rare Diseases (ORD), created GARD to help people find useful information, in English or Spanish, about genetic and rare diseases.

What are genetic and rare diseases?

There are more than 7,000 rare diseases. A disease is rare if fewer than 200,000 people in the United States have it. About 25 million Americans have a rare disease. Many rare diseases are caused by changes in genes and are called “genetic diseases.”

Why contact GARD?

Information is often hard to find for many genetic and rare diseases. Even if you can find information, it is often hard to know if it is correct. GARD can help you if you want to know more about a genetic or rare disease for yourself, a family member, a friend, or someone you take care of. GARD can provide you with timely and correct information.

Who should contact GARD?

- ❖ People who have a genetic or rare disease.
- ❖ Parents, family members, and friends of people with a genetic or rare disease.

- ❖ Doctors, nurses, genetic counselors, occupational and physical therapists, other health care providers, social workers, and teachers who work with people with a genetic or rare disease.
- ❖ Scientists who are studying a genetic or rare disease and who need information for their research or for people taking part in a study.
- ❖ Community leaders who are helping people find resources for those with genetic or rare diseases.
- ❖ Advocacy groups who want up-to-date disease information for their members.
- ❖ Members of the media who are writing stories about genetic or rare diseases.
- ❖ People in the general public who want to learn more about a genetic or rare disease.

What can GARD do for you?

Information Specialists will search for answers to your questions and help you understand:

- ❖ What is known about the disease.
- ❖ What research studies are going on.
- ❖ What genetic testing and genetic services are available.
- ❖ Which advocacy groups you can contact.
- ❖ What has been written recently about the disease in medical journals.

Where does GARD get information?

Information Specialists search:

- ❖ NIH resources.
- ❖ Medical textbooks.
- ❖ Journal articles.
- ❖ Web sites.
- ❖ Advocacy groups’ literature and services.
- ❖ Medical databases.

How do I contact GARD?

You can talk to an Information Specialist from noon to 6 p.m. Eastern time by:

- ❖ Telephone: 1-888-205-2311
- ❖ TTY: 1-888-205-3223
- ❖ International number: 1-301-519-3194

You can write to GARD anytime by:

- ❖ E-mail: GARDinfo@nih.gov
- ❖ Letter:
Genetic and Rare Diseases
Information Center
P.O. Box 8126
Gaithersburg, MD 20898-8126
- ❖ Fax: 1-240-632-9164