



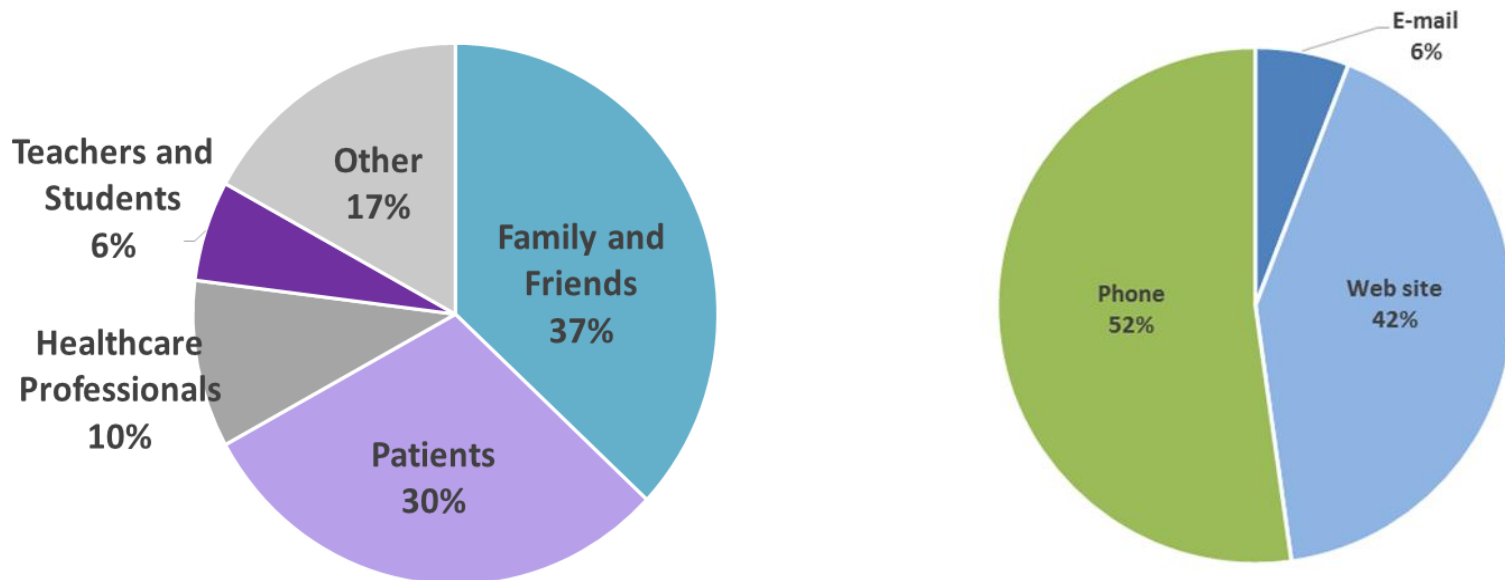
- Funded by the National Institutes of Health: National Center for Advancing Translational Sciences and National Human Genome Research Institute
- Established in 2002 (Rare Diseases Act of 2002)

GARD Services

- GARD answers questions about rare or genetic diseases in English or Spanish
 - GARD website provides plain language disease information and resources
 - GARD staff provide individualized support and custom responses
- Staff have advanced degrees in genetics and experience working with people who have rare conditions
 - Medical consultants, as needed.

- Answered more than 58,000 questions since 2002 about more than 4000 diseases.
 - 75% from the United States; 13% international
- Most questions come from patients or their family members.

GARD Users





National Center
for Advancing
Translational Sciences

GARD

Genetic and Rare Diseases
Information Center

- Commonly asked questions in order of frequency:
 - Where can I find information on treatment?
 - How can I find an expert?
 - Are there research or clinical trials available?
 - Who can help make a diagnosis?
 - 1 in 15 (6%) have an undiagnosed condition
 - How do I get/understand genetic testing?
 - I've seen a doctor, but need more about symptoms/cause/inheritance/outlook.
 - How can I get financial assistance?
 - Is there a support group?

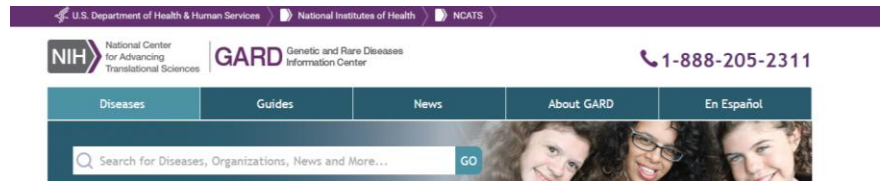
People need help and express frustration with understanding medical language and outcomes, and finding information in plain language 4



<https://rarediseases.info.nih.gov/>

- GARD Website receives more than 350,000 visits per month
 - 50% of traffic from mobile devices
- Diseases section covers more than 6,600 rare diseases
 - Content driven by questions from the public
- Guides section includes pages on frequently asked questions depending on user roles:
 - How to Find a Disease Specialist
 - Tips for the Undiagnosed
 - How to Get Involved in Research
 - Caring for Patients with Rare Diseases
 - Tools for Diagnosis
 - Many more...
- Spanish content available for more than 200 diseases

- Left navigation for frequently asked questions
- Condition searchable synonym
- GARD Information Navigator
- Your Questions Answered section
- Crowdsourcing disease information, organizations, review articles and more via the “Suggest an Update” form



Do you have updated information on this condition? Let us know.

Do you know of an organization? Send us your suggestions.

Have a question? Contact a GARD Information Specialist.

Do you know of a review article? Send us your suggestions.

more severe just before and during menstruation in women. Factors that promote sweating, such as exercise, stress, and emotional upsets, may also worsen the odor.^{[1][2]}

Affected people typically do not have any additional signs and symptoms and appear healthy. However, the odor can interfere with many aspects of daily life, leading to social and psychological problems.^{[1][2]}

Last updated: 3/25/2015

The Human Phenotype Ontology (HPO) provides the following list of features that have been reported in people with this condition. Much of the information in the HPO comes from Orphanet, a European rare disease database. If available, the list includes a rough estimate of how common a feature is (its frequency). Frequencies are based on a specific study and may not be representative of all studies. You can use the MedlinePlus Medical Dictionary for definitions of the terms below.

Signs and Symptoms	Approximate number of patients (when available)
Anemia	-
Autosomal recessive inheritance	-
Depression	-

Contact GARD



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