

GARD Article for Health-Care Professionals' Newsletters

The following article is designed for use in newsletters aimed at health-care professionals. It describes the free services offered by the NIH's Genetic and Rare Diseases Information Center. Newsletter editors are free to edit the article to meet their publication's particular needs.

NIH's Genetic and Rare Diseases Information Center Offers New, Web-based Search Feature

To help health-care professionals meet the challenge of providing patients and their families with timely and reliable information, the National Institutes of Health (NIH) recently launched a searchable, updated Web site for its Genetic and Rare Diseases (GARD) Information Center. The free site is located at:

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

Accessible 24 hours a day, seven days a week, the centerpiece of the updated GARD Web site is a search feature that enables users to quickly locate disease-specific information and resources. New features include a pull-down menu of disorders and links to GARD specialists' answers to previous questions about the disorder.

Funded by the NIH's Office of Rare Diseases and the National Human Genome Research Institute (NHGRI), GARD has responded to more than **22,000** inquiries on **6,000** rare and genetic diseases since it was established in February 2002. The requests include many inquiries from physicians, nurses and other health-care professionals, as well as from patients and patients' families who were directed to the site by health-care professionals.

If users cannot find what they need using the GARD Web search feature, they can contact GARD's information specialists by e-mail at GARDinfo@nih.gov. They can also call GARD's toll-free telephone: (888) 205-2311 or the international access number: (301) 519-3104. The phone lines are answered from noon to 6 p.m. Eastern, Monday through Friday. Requests can also be sent to GARD by fax, (240) 632-9164; TTY, (888) 205-3223; or mail, P.O. Box 8126, Gaithersburg, MD 20898-8126.

On average, people requesting information by e-mail or phone receive a response from GARD within four to seven business days. However, depending on the nature of the inquiry, the turnaround time for inquiries from health-care professionals often is much faster. For example, an urgent request may receive a response within 24 hours or even immediately.

Statistics are far from the only measure of GARD's success. Health-care professionals who have taken advantage of the services offered by the center have responded enthusiastically. In the words of one physician: "This is stunningly helpful. Really a superb service."

In fact, feedback from health-care professionals plays a critical role in GARD's ongoing effort to fine tune the services that it provides. For example, based on

comments from some of its initial users, GARD now offers responses that go into greater detail on how to find and use information resources than when the center first opened. "I am very impressed with the services provided by this organization," one health-care professional comments, "The information that was sent was very helpful and allows me to thoroughly research this topic."

Information specialists provide people who contact GARD with current, accurate and authoritative information drawn from public domain sources, such as reliable Web sites, brochures, medical literature, lay articles and support organizations. While patients and their families often contact GARD seeking direct referrals to health-care professionals or asking for treatment or medical management suggestions, it is important to emphasize that GARD does not directly provide this type of information. Instead, GARD information specialists point patients to resources that might offer treatment information, e.g. journal articles or clinical trial information sites. GARD also does not provide genetic counseling or offer diagnostic testing. The center, however, will steer the inquirer to appropriate sources of information about such services.

GARD views itself as working in partnership with the health-care community, always strongly recommending that patients seek the advice of their own health-care providers about any questions regarding their medical care. That collaborative approach has drawn praise from one nurse who turned to GARD for answers: "What I like best is how generous you are in your links to other organizations, which I think communicates concern for the person. As a nurse, I also like the advice encouraging people to consult a professional."

The center also strives to connect individuals with a support system whenever possible, as evidenced by the remarks of a physician who recently sought information from GARD: "The information you have provided not only would benefit me and my colleagues, but also would benefit the child and the parents and would help the parents to register with the [disease registry]."

In addition to furnishing health-care professionals with accurate, up-to-date information on genetic and rare diseases, GARD can serve as a timesaving tool to help them reinforce or expand upon genetic and rare disease information that they may have already provided to patients.

Consider the experience of just one of the many parents who have taken advantage of GARD's round-the-clock resources. "This is an awesome site. I really enjoyed reading the articles. Being informed more about my daughter's condition may help us to understand what has happened to her at such a young age," the parent says. "I am surely going to let my family know everything I have learned here."