New Resource For Information On Genetic Or Rare Diseases

(NAPSA)—An unexpected diagnosis of a serious illness often comes as a shock to people receiving the news, as well as their families and friends. When the disease is rare or genetic, information is hard to find and even harder to understand. Patients and their loved ones may waste hours sorting through outdated, unreliable information before finding anything useful.

To help in these situations, the National Institutes of Health has established the Genetic and Rare Diseases Information Center (GARD). Funded by the NIH's National Human Genome Research Institute and the Office of Rare Diseases, the Center is staffed by information specialists, many of whom have experience in genetic counseling. They've provided up-to-date and accurate, personalized information about almost 4,000 genetic and rare diseases.

Since February 2002, GARD staff members have responded to more than 12,000 inquiries on rare and genetic diseases. These inquiries come from patients, their families and friends, health care professionals, teachers, researchers and others in either English or Spanish.

GARD's impact can be measured by more than statistics. Many of those who have taken advantage of this free service have responded enthusiastically. For example, "...thank you very much for the time, energy and expertise that went into gathering these resources for me...," a middle school counselor recently commented. "I have read through the material and have found it to be very helpful."

The federal government has created an office to answer questions about genetic or rare diseases.

Patients and their families often contact GARD seeking referrals to health care professionals or asking for recommendations for treatment or medical management. GARD, as an arm of the federal government, cannot provide this type of information. Instead, GARD information specialists direct inquirers to resources that give treatment information; e.g., journal articles or clinical trials. GARD also does not provide genetic counseling or diagnostic testing, but will point inquirers to information about such services.

People seeking information on rare or genetic diseases can call 888-205-2311 or e-mail GARDinfo@nih.gov for information in English or Spanish or write to P.O. Box 8126, Gaithersburg, MD 20898-8126.

For more information about GARD, visit the National Human Genome Research Institute at http://www.genome.gov/Health/GARD/ or the Office of Rare Diseases at http://rarediseases.info.nih.gov/html/resources/info_cntr.html.