



spotlight on health

Help And Support For People With Rare Diseases

(NAPSA)—What is a rare disorder? A rare or “orphan” disease affects fewer than 200,000 people in the U.S. There are more than 6,000 rare disorders that together affect approximately 25 million Americans.

Fortunately, the people with these conditions—who, with such small numbers, might slip through the cracks of standard research and funding—have someone on their side: the National Organization for Rare Disorders (NORD). This organization:

- Provides understandable information about rare diseases;
- Helps connect patients and their families with support groups;
- Offers grants and fellowships to encourage research on rare diseases; and
- Helps low-income patients get the medication they need to survive.

In 2005, NORD administered the distribution of approximately \$130 million worth of medications and \$9.8 million worth of co-pay assistance for needy patients through various patient assistance programs. The organization also awarded 14 grants and one fellowship in 2005 with a total value of \$486,380 to further advance knowledge and treatment of rare diseases and how to fight them.

NORD's Rare Disease Database (RDB) contains understandable reports written for patients and families on approximately 1,170 rare diseases, with referrals to support groups and other resources. Some of the better known rare diseases the organization helps to fight are Lou Gehrig's disease (ALS) and severe combined immune deficiency (also known as the “Bubble Boy” disease).



Help and support are available for people with rare or “orphan” diseases.

“Everyone at least knows someone with a rare disease,” says Abbey Meyers, president of NORD. “People think rare diseases aren’t important, but they don’t realize how many Americans are affected.”

Since its founding in 1983, NORD has been a source of information on rare diseases and has helped patients and their families find support groups. Today, NORD distributes grants and fellowships to encourage lifesaving research on rare diseases and helps ensure that patients get the medication they need.

“It’s pretty scary to be told you have something you’ve never heard of,” Meyers says. “The first thing people want to do after they get a rare diagnosis is connect with others affected by the same disease. NORD runs a networking program to help people do this. We also refer people to organizations for their diseases.”

To learn more, visit the Web site at www.rarediseases.org.