

RARE DISEASE DAY:

To the Editor:

I am writing to alert your readers to a special day that's coming up soon. On the last day of February, millions of people around the world will be observing the second annual Rare Disease Day. There will be activities across the U.S., throughout Europe, in Canada, in Australia, in China and elsewhere to focus attention on rare diseases as a public health issue.

In the U.S., a disease is considered rare if it affects fewer than 200,000 people. Some rare diseases, such as Lou Gehrig's disease (ALS), are well known to the public. However, many others are not, and you can imagine the loneliness of having a disease that most people have never heard of, that has no treatment, and that is not even being studied by any medical researchers.

Many rare diseases are serious and/or chronic. Many are life-threatening. Even so, people with rare diseases often have trouble accessing the medical or other services they need because those making the decisions are not familiar with their diseases.

Nearly 30 million Americans (about 1 in 10) have rare diseases. All of us know someone with a rare disease. I encourage your readers to visit the website of the National Organization for Rare Disorders (NORD) on or before February 28, 2009, to read about Rare Disease Day activities in the U.S. and the global Rare Disease Day website (www.rarediseaseday.org) to learn what's being done around the world.

Sincerely,

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Speech-Language Pathologist

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