

PATIENT ADVOCATES FORM A COALITION TO UNIFY THE NEEDS OF THE RARE DISEASE COMMUNITY

By: Thuy Nguyen

Do you or a family member live with a rare disease? Is there a disease you can't find information on? Or how can you connect with other patients with your same disease?



Well, The National Organization for Rare Diseases is here to help. NORAD has supported and helped improve the lives of individuals and families affected by rare diseases, as well as provide services to rare patient organizations, medical professionals, and industries. In the United States, there are nearly 7,000 diseases that are considered rare and about 30 million Americans living with these diseases. The NORAD database has more than 1,200 reports on rare diseases, so if there is one you cannot find, they have provided a link to the Genetic and Rare Diseases Information Center (GARD).

There are great resources and links that are available for Patients & Families, Patient organizations, Industry as well as Clinicians & Researchers such as:

- Genetics Counseling and information for patients
- Health Insurance information
- Legal Resources
- Mobility Assistance
- How to grow your organization
- Patient support opportunities for industry
- Resources and research opportunities for Clinicians and Researchers.

<http://rarediseases.org/>

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