

FINDING & CONNECTING WITH OTHERS IN THE RARE COMMUNITY

Produced by the National Organization for Rare Disorders (NORD®)

When you or a loved one receives a diagnosis of a rare disease, you may find yourself using the internet to learn more, find support and connect with others living with the condition. This process may prove difficult, since there is often little or no current information readily available about a rare disease; there are fewer people living with the condition, and there is likely no nonprofit organization to serve as a centralized location to gather the community and offer support.

Included in this document are strategies for finding and connecting with people living with rare diseases to start growing your community. Although it may be challenging, you are not alone on your rare journey. NORD is home to all in the rare community, and we are here to support you!

SEARCH STRATEGIES

Find Patient Organizations:

- NORD's Organizational Database includes over 1,000 supportive patient organizations with self-reported information, including their website, contact email, telephone number and a brief description of their work: bit.ly/nord-find-patient-org.
- The National Institutes of Health (NIH) Genetic and Rare Diseases Information Center (GARD) provides the public with access to information in English and Spanish about rare or genetic diseases – including nonprofit organizations. Learn more about NIH GARD's resources for patients and families: bit.ly/nih-patient-family-support.
- Search online for national and international patient organizations that support your rare disease. An established nonprofit should have a robust network that you can join. You can search for: [your disease name] AND "nonprofit organization" OR "foundation."

When You Can't Find a Nonprofit:

There are 7,000 rare diseases in the United States and the majority do not have a nonprofit organizational "home" for these disease communities¹.

1. Research Related Diseases:

If your rare disease is related or similar to another rare disease, you can consider looking into the supporting organization and support groups for the related disease to find patient connections. A related disease may share a similar cause or origin to your disease or exhibit the same signs and symptoms. NORD's Rare Disease Database includes a section on related disorders for each rare disease report: bit.ly/nord-rd-database. If your disease does not have a NORD rare disease report, visit NIH's Genetic and Rare Diseases Information Center, which categorizes rare diseases; you can review the disease states within your disease category to find any that may be related or similar: bit.ly/nih-disease-category. A rare disease may be similar to another disease due to comorbidities.

What is a comorbidity?

Comorbidity describes 'the existence of more than one disease or condition within your body at the same time.'
Go to Link: wb.md/36Dqlej

2. Search Social Media:

If you cannot locate a nonprofit patient organization, there may be informal support groups on social media platforms or otherwise on the internet. You can search for public and private Facebook groups, personal blogs, or through hashtags to locate posts or groups raising awareness for your rare disease. If you cannot locate anything, you could start a blog or a Facebook group of your own to help others locate you and start building a community.

How to search Hashtags? Learn more at: bit.ly/hashtag-linking

3. Share Your Story:

If you're comfortable with sharing your story, promote it far and wide because you don't know who might read it. Begin by writing your story and sharing it with trusted friends and family members.

Check out NORD's Share Your Story page for more tips: rarediseases.org/shareyourstory

Once you've considered their feedback and refined your story, consider sharing it with a wider audience, including your friends, on social media, and with local news channels. By being vulnerable and honest in your story, you will allow people into your world who can more easily connect with your experience.

4. Medical Outreach:

If there are reports or scholarly papers written on your rare disease, note the authors so that you can connect with them. Scientists and researchers may have a network of patients that could form your community. In addition to academic journals, search for top medical centers or for a center of excellence for your rare disease. An example of your search could look like: [your disease name] AND "medical center" OR "center of excellence." If one exists, you will likely locate interested medical professionals and researchers as well as fellow patients searching for medical care and support.

Some well-known journals to explore: pubmed.ncbi.nlm.nih.gov and ojrd.biomedcentral.com

5. NORD:

NORD is a convener of patients and families in the rare community. If you are struggling to find other people living with your rare disease, you are always welcome to join our patient and family community by attending in-person and virtual events to connect with others. Learn more about our patient and family resources:

bit.ly/nord-resource-center.

Connect with us and learn about opportunities to connect with others in the rare community!



REFERENCES:

1. Based upon NORD's Organizational Database, there is a general estimate of 1,000 to 1,200 nonprofit organizations focused on rare diseases. With 7,000 rare diseases identified in the United States, this suggests there is an estimated 6,000 rare diseases for which patients have no nonprofit "homes" for professionals support and organized patient connections.

2. "Rare Can Be Everywhere" NORD RareLaunch Workshop (<https://rarelaunch.org/video/rare-can-be-everywhere-finding-community-when-your-population-is-small/>)