

[Home](#) > [Coping With Cancer](#) > [Finding Support and Information](#) > Finding Information and Support Resources for Rare Cancers

PDF generated on July 19, 2016 from

<http://www.cancer.net/coping-with-cancer/finding-support-and-information/finding-information-and-support-resource-s-rare-cancers>

[Finding Information and Support Resources for Rare Cancers](#) [1]

This section has been reviewed and approved by the [Cancer.Net Editorial Board](#) [2], 12/2015

After a cancer diagnosis, it's important to find credible information and support. With rare types of cancer, sometimes finding resources can be difficult. Cancer.Net provides comprehensive information about several types of rare cancers, in addition to more common types.

On Cancer.Net, you can find the following resources for rare cancers:

- Disease-specific information for many [rare adult and childhood cancers](#) [3], including sections on diagnosis, treatment, clinical trials, areas of the latest research, what to expect after treatment, and questions to ask the doctor
- [Listings of cancer-specific national organizations](#) [4] that offer support to people with cancer and their families
- Information about [support groups](#) [5] and how to find one that is the right fit for you
- National Cancer Institute-designated [comprehensive cancer centers and cooperative groups](#) [6] that specialize in the treatment of rare cancer types

- How to [find an oncologist](#) [7] who specializes in the treatment of a rare cancer
- A section on [clinical trials](#) [8]

Additional educational and support resources are listed below. These links will take you outside of Cancer.Net.

National Organization for Rare Disorders (NORD)

www.rarediseases.org [9]

Phone: 203-744-0100

Social media: NORD on Facebook (www.facebook.com/NationalOrganizationforRareDisorders [10]) and Twitter (twitter.com/rarediseases [11])

NORD is a nonprofit organization that provides information about rare diseases, patient resource organizations, and educational research programs. NORD databases give you access to patient organizations and other support services. Online support is also available for people with a rare disease, their families and friends, and their caregivers.

Rare Cancer Alliance

www.rare-cancer.org [12]

Social media: Rare Cancer Alliance on Facebook (www.facebook.com/groups/rarecancer [13]) and Twitter (twitter.com/rare_cancer [14])

The Rare Cancer Alliance provides information and support to children and adults with cancer. Its website includes patient forums, where you can communicate with others who may have the same type of cancer. In addition, it offers links to other websites with disease-specific information and educational resources about specific cancers.

CureSearch for Children's Cancer

www.curesearch.org [15]

Toll-free: 800-458-6223

Social media: CureSearch on Facebook (www.facebook.com/curesearch [16]) and Twitter (twitter.com/curesearch [17])

CureSearch for Children's Cancer provides information on childhood cancers, treatment strategies, and wellness programs. A listing of [Community Help](#) [18] options offers resources for families and those with cancer. Discussion forums give patients and families a way to communicate with others who may share a similar experience.

National Cancer Institute (NCI)

www.cancer.gov [19]

Toll-free: 1-800-4 CANCEr (1-800-422-6237)

Social media: NCI on Facebook (www.facebook.com/cancer.gov [20]) and Twitter (twitter.com/thenci [21])

The NCI website, a service of the National Institutes of Health, provides up-to-date information on rare adult and childhood cancers. An important part of the website is the NCI [clinical trials section](#) [22], which provides a database of research studies that are open to patients, clinical trial results, and more. In addition, the NCI's [Cancer Information Service](#) [23] (CIS) provides online support and you can speak directly with a specialist about your questions or concerns.

Association of Cancer Online Resources (ACOR)

www.acor.org [24]

ACOR is a collection of online communities for patients, families and friends of those diagnosed with cancer. You can access information about many cancers, find support groups, learn about research findings, and find clinical trials. These online discussion groups provide a forum where patients and caregivers can share experiences.

National Library of Medicine (NLM)

www.nlm.nih.gov [25]

Phone: 888-346-3656

Social media: NLM on Facebook (www.facebook.com/nationallibraryofmedicine [26]) and Twitter (twitter.com/nlm_news [27])

The National Library of Medicine offers information on all areas of health care. Through its website, you can search medical research using a service called [PubMed](#) [28].

More Information

[Evaluating Cancer Information on the Internet](#) [29]

Cancer.Net Blog: [Living With a Rare Cancer - My Dr. Seuss World](#) [30]

Links

- [1] <http://www.cancer.net/coping-with-cancer/finding-support-and-information/finding-information-and-support-resource-s-rare-cancers>
- [2] <http://www.cancer.net/about-us>
- [3] <http://www.cancer.net/cancer-types>
- [4] <http://www.cancer.net/coping-with-cancer/finding-support-and-information/cancer-specific-resources>
- [5] <http://www.cancer.net/node/25383>
- [6] <http://www.cancer.net/navigating-cancer-care/cancer-basics/cancer-care-team/find-nci-designated-cancer-center>
- [7] <http://www.cancer.net/find-cancer-doctor>
- [8] <http://www.cancer.net/node/24863>
- [9] <http://www.rarediseases.org/>
- [10] <http://www.facebook.com/NationalOrganizationforRareDisorders>

- [11] <https://twitter.com/rarediseases>
- [12] <http://www.rare-cancer.org/>
- [13] <http://www.facebook.com/groups/rarecancer>
- [14] https://twitter.com/rare_cancer
- [15] <http://www.curesearch.org/>
- [16] <http://www.facebook.com/curesearch>
- [17] <https://twitter.com/curesearch>
- [18] <http://curesearch.org/Community-Help>
- [19] <http://www.cancer.gov/>
- [20] <http://www.facebook.com/cancer.gov>
- [21] <http://twitter.com/thenci>
- [22] <http://www.cancer.gov/clinicaltrials>
- [23] <http://www.cancer.gov/aboutnci/cis>
- [24] <http://www.acor.org/>
- [25] <http://www.nlm.nih.gov/>
- [26] <http://www.facebook.com/nationallibraryofmedicine>
- [27] https://twitter.com/nlm_news
- [28] <http://www.ncbi.nlm.nih.gov/pubmed/>
- [29] <http://www.cancer.net/node/24514>
- [30] <http://www.cancer.net/node/33596>