

Non-Hodgkin's Lymphomas Resources

This list includes resources you're likely to use most often, those that are the richest sources of NHL-specific information. All entries in each category are listed in alphabetical order, not by importance.

■ NHL Organizations

Cure for Lymphoma

215 Lexington Avenue
New York, NY 10016
(212) 213-9595

Offers support and information and funds research to fight lymphoma.

Leukemia and Lymphoma Society

600 3rd Avenue
4th Floor
New York, NY 10016
(800) 955-4572

Offers assistance to lymphoma and leukemia survivors.

Lymphoma Research Foundation of America

8800 Venice Blvd., Suite 207
Los Angeles, CA 90034
(310) 204-7040

Offers support and information and funds research to fight lymphoma.

National Lymphedema Network, Inc.

Latham Square
1611 Telegraph Avenue, Suite 1111
Oakland, CA 94612-213178
(800) 541-3259

Provides information on swollen limbs, which may occur soon or many years after treatment.

■ NHL Internet support groups

A list of NHL-related Internet support groups follows. Because the Internet is a dynamic resource, this list may not be comprehensive. The number of subscribers given was approximate at the time of writing and will vary over time. The Association of Cancer Online Resources (ACOR) has pointers to all of the hematologic cancer email discussion groups. ACOR offers a handy automatic subscription feature for these and other discussion mailing lists, at <http://www.acor.org>.

NHL. Run by Robert Scott Pallack, offering medical discussion and emotional support for all non-Hodgkin's lymphoma survivors. NHL has about three hundred subscribers.

NHL-LOW. Discussion of medical treatment for those with low-grade NHL. About one hundred seventy subscribers. On the Web at <http://www.egroups.com/group/nbllow/>.

HEM-ONC. Run by GrannyBarb Lackritz, offering medical discussion and emotional support for the hematologic malignancies, including NHL. Several oncologists are subscribed to this list. About eight hundred subscribers.

BMT-TALK. Medical discussion and emotional support for those who will be having or who have had bone marrow transplantation for any cancer. Several oncologists are subscribed to this list. About five hundred subscribers.

PED-ALL. Medical discussion for pediatric acute lymphocytic leukemia, which resembles some NHLs. This list was formed in early 1998.

CLL. Medical discussion and emotional support for chronic lymphocytic leukemia, which can convert into one form of NHL, called small-cell lymphocytic leukemia (SLL). About three hundred subscribers.

SICKKIDS. A discussion group just for children but supervised by adults. On the Web at www.isoft.com/scripts/wl.exe?SL1=sickkids&H=MAELSTROM.STJOHNS.EDU.

YAP. A discussion group for young adults age 18-25 dealing with their own illness or that of a loved one. This list was formed in late 1998.

■ NHL reading and reference material

Non-Hodgkin's Lymphomas: Making Sense of Diagnosis, Treatment & Options by Lorraine Johnston. Sebastopol, California: O'Reilly & Associates, Inc., 1999. Straightforward information for the non-Hodgkin's lymphoma survivor, caregivers, and loved ones; includes personal stories. The source of this list.

The Cancer Dictionary by Robert Altman and Michael Sarg, is a good medical dictionary specifically for cancer survivors.

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The Non-Hodgkin's Lymphomas, 2nd Edition, edited by Ian Magrath. New York: Arnold and Oxford University Press, 1997. As of this writing, this is the most current and comprehensive textbook available that is specifically devoted to NHL. You might be able to find a copy in your doctor's office, a hospital library, or a university library. It can be purchased through any bookstore, including Web-based bookstores, by ordering it from the publisher.

■ Companies that will do medical information searches for a fee:

The Health Resource, Inc.
(501) 329-5272

Can Help

(360) 437-2291

Schine On-Line Services

(800) FIND-CURE

■ Major organizations providing cancer information

American Cancer Society (ACS) National Office

1599 Clifton Road NE
Atlanta, GA 30329-4251
(800) ACS-2345
<http://www.cancer.org>

The American Cancer Society has many national and local programs to help cancer survivors with problems such as travel, lodging, and emotional support. ACS publishes an excellent book, *Informed Decisions: The Complete Book of Cancer Diagnosis, Treatment and Recovery*, a comprehensive guide to care and treatment for all aspects of all cancers. They also offer a 24-hour support line for both English- and Spanish-speaking cancer survivors. Check your local phone directory for the office nearest you.

National Cancer Institute (NCI)

Bethesda, MD 20892
(800) 4-CANCER
<http://cancernet.nci.nih.gov>

A division of the US National Institutes of Health, the

NCI has a hotline to help cancer survivors with a variety of issues such as physician referrals, an enormous web site, and numerous statements, booklets, and books about cancer treatment and care. Many of the statements about cancer come in two versions, patient's and physician's. You might prefer to start with the patient's version, but it's likely that, as you learn more, the physician's statements will provide better, more detailed answers to your questions. The physicians' information is often part of PDQ, Physicians' Data Query.

National Library of Medicine

MEDLINE database
<http://www4.ncbi.nlm.nih.gov/PubMed/>

The best place to find the published results of studies on cancer treatment and care. If you need help with searching, you can call the National Library of Medicine at (800) 272-4787 or (301) 496-6308. Document retrieval services can fax or mail you the full text of any published research paper. On the Internet, the Medline service providers HealthGate, Medscape, Helix, PhyNet, PDRnet.Com, SilverPlatter, Ovid On Call, Infotrieve, PaperChase, and others offer full-text services for a fee.

■ General cancer reading

Dunn, Steve. *CancerGuide*. Read this online at <http://www.cancerguide.org>.

Harpham, Wendy Schlessel. *Diagnosis: Cancer*. New York: W.W. Norton, 1998.

Harpham, Wendy Schlessel. *When a Parent Has Cancer: A Guide to Caring for Your Children*. New York: HarperCollins, 1997.

Keene, Nancy. *Childhood Leukemia: A Guide for Family, Friends, and Caregivers*, 2nd Edition. Sebastopol, California: O'Reilly & Associates, Inc., 1999. A good reference for the parents of a child with NHL, some forms of which can resemble one form of childhood leukemia.

Lerner, Michael. *Choices in Healing: Integrating the Best of Conventional and Complementary Approaches to Cancer*. Cambridge: The MIT Press, 1996.

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McKay, J., N. Hirano, and M. Lampenfeld. *The Chemotherapy and Radiation Therapy Survival Guide*. Oakland, California: New Harbinger Publications, 1998.

The Merck Manual, available in either the paper version or at their web site (<http://www.merck.com>), is a vast resource. Many public libraries have a copy of *The Merck Manual* in their non-circulating reference section. The new 17th edition was published in 1999.

Radiation Therapy and You, a fifty-page booklet, is available from the U.S. National Cancer Institute by calling (800) 4-CANCER.

Schover, L. *Sexuality and Fertility After Cancer*. New York: John Wiley & Sons, 1997.

■ Bone marrow transplantation reading material and web sites

HLA Gene and Haplotype Frequencies in the North American Population: The National Marrow Donor Program Donor Registry: http://www.swmed.edu/home_pages/ASHI/prepr/Motomi.htm.

Martin, Paul, M.D. (Member, Fred Hutchinson Cancer Research Center, Professor of Medicine, University of Washington.) *A Short Primer on HLA and Bone Marrow Transplantation*. On the Web at: <http://www.giftoflife.com/primer.htm>.

Stewart, Susan. *Autologous Stem Cell Transplants: A Handbook for Patients*. Blood & Marrow Transplant Information Network, 1999. (888) 597-7674

Stewart, Susan. *Bone Marrow Transplants: A Book of Basics for Patients*. Blood & Marrow Transplant Information Network, 1992. (888) 597-7674

Tissue Typing for Beginners. On the Web at: <http://www.umds.ac.uk/tissue/what1.html>.

Transplant Center Access Directory. National Marrow Donor Program. Call (800) 526-7809; or on the Web at: <http://www.bmtinfo.org>.

■ Transplant advocacy and support groups

Blood & Marrow Transplant Information Network (formerly BMT Newsletter)

2900 Skokie Valley Road, Suite B
Highland Park, IL 60035
(847) 433-3313 or toll-free (888) 597-7674
Fax: (847) 433-4599

Email: help@bmtnews.org
<http://www.bmtnews.org>

Publishes *Blood & Marrow Transplant Newsletter*, for bone marrow, peripheral stem cell, and cord blood transplant patients, and books on bone marrow and stem cell transplantation. Also available are the Transplant Center Database of more than 250 transplant programs in the US and Canada, a resource directory, an attorney referral service for those having difficulty persuading their insurer to pay for treatment, the Patient-to-Survivor Link Service, and a comprehensive web site.

Bone Marrow Transplant Family Support Network

P.O. Box 845
Avon, CT 06001
(800) 826-9376

Offers counseling and support for those going through a transplant.

National Marrow Donor Program

3433 Broadway Street, NE, Suite 500
Minneapolis, MN 55413
(800) MARROW-2

Coordinates national and international testing and matching of marrow donors and recipients.

National Foundation for Transplants

1102 Brookfield, Suite 200
Memphis, TN 38119
(800) 489-3863

Provides a variety of services, including financial services, to those receiving transplants.

This fact sheet was adapted from *Non-Hodgkin's Lymphomas: Making Sense of Diagnosis, Treatment, & Options*, by Lorraine Johnston, copyright 1999 by Patient-Centered Guides. For more information, call (800) 998-9938 or see www.patientcenters.com.