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.


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.


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


The Cancer Dictionary by Robert Altman and Michael Sarg, is a good medical dictionary specifically for cancer survivors.
Non-Hodgkin’s Lymphomas Resources

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
  - 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

      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) 496-6508.

      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
Non-Hodgkin’s Lymphomas Resources


*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.


### Bone marrow transplantation reading material and web sites


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](http://www.giftoflife.com/primer.htm).


*Tissue Typing for Beginners*. On the Web at: [http://www.umds.ac.uk/tissue/webat1.html](http://www.umds.ac.uk/tissue/webat1.html).


### 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: belp@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](http://www.patientcenters.com).