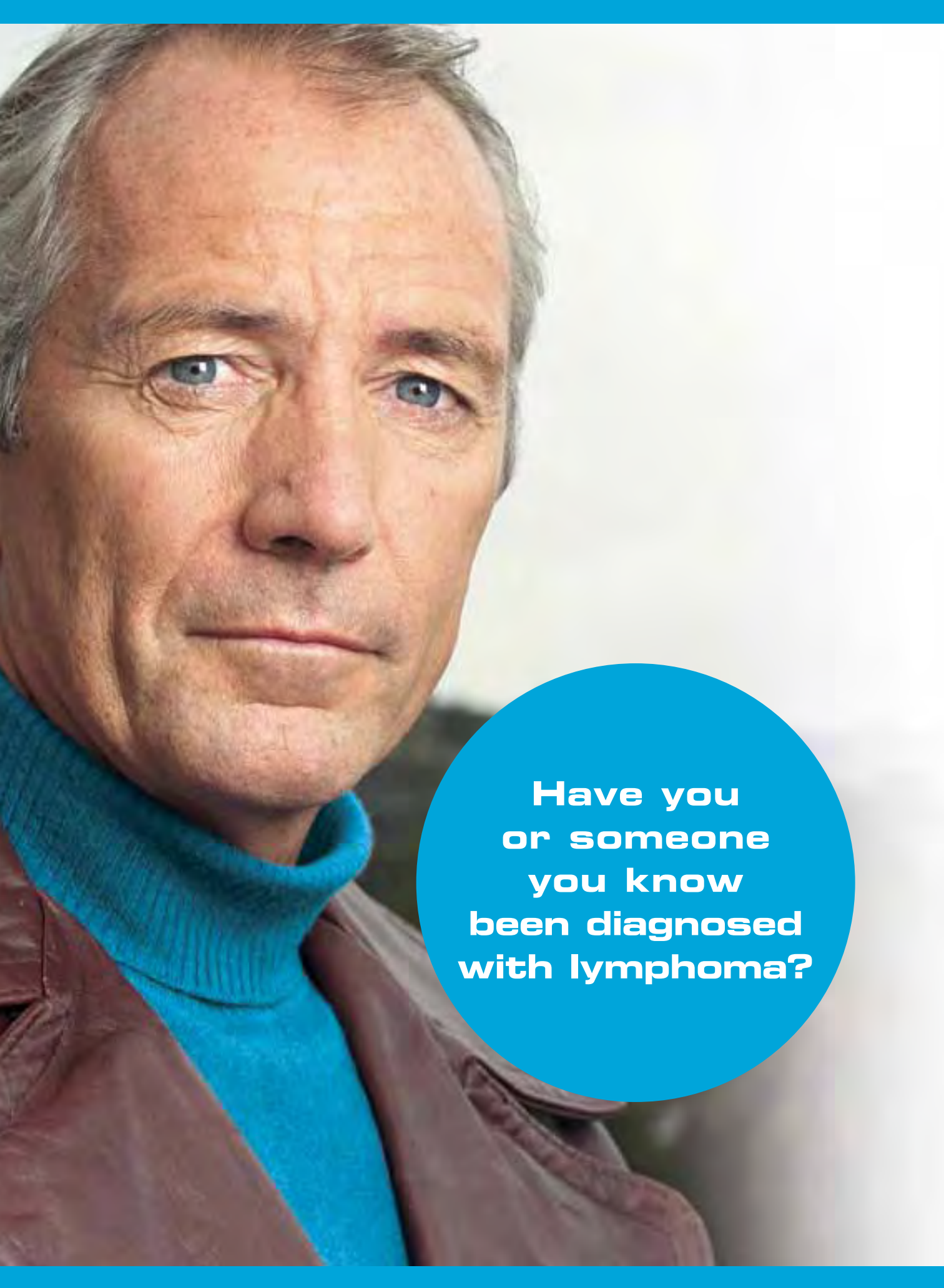


Lymphoma

Resource Guide

A collection of Websites that inform and support patients with lymphoma and the oncology professionals who treat them.





**Have you
or someone
you know
been diagnosed
with lymphoma?**

If so, you may want to learn more about the PILLAR clinical trials.

The PILLAR clinical trials involve patients with mantle cell lymphoma (MCL) or diffuse large B-cell lymphoma (DLBCL).

These trials are evaluating the efficacy and safety of an investigational drug for the treatment of MCL and DLBCL.

Eligible patients for PILLAR-1*

- Have confirmed diagnosis of **MCL**
- Are 18 years of age or older
- Have disease that did not respond to previous treatment

Eligible patients for PILLAR-2*

- Have confirmed diagnosis of **DLBCL**
- Are 18 years of age or older
- Have disease that responded to treatment with R-CHOP†

For more information about the PILLAR-1 or PILLAR-2 clinical trials, ask your health care professional or visit www.novartisclinicaltrials.com.

*Additional eligibility criteria apply.

†Rituximab in combination with cyclophosphamide, doxorubicin, vincristine, and prednisone.

These are investigational trials; efficacy and safety for the treatment of lymphoma has not been established and there is no guarantee that this investigational drug will become commercially available for these indications.

PILLAR





Novartis Oncology Reimbursement & Patient Assistance Program (PAP) Hotline 1-800-282-7630

Services provided:

- Insurance verification
- Denials/appeals
- Coding/billing questions
- Alternative funding searches
- Referrals to copay cards
- Referrals to patient assistance for low income uninsured patients

Novartis is committed to providing access to our medications for those most in need. Through a variety of resources, including the Novartis Oncology Patient Assistance Program, the Novartis Oncology Reimbursement Hotline, and our support of independent charitable copay foundations, we have made a firm commitment to enable patients in need to access medicines.

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From the Publisher

A Broad Network of Support

There are several types of lymphoma. Some forms respond readily to treatment, and others are more difficult to treat. Learning that you or a loved one has lymphoma might leave you with many questions and concerns. The advocacy groups featured in this Lymphoma Patient Resource Guide can help you find the answers and support you on your journey to wellness. Many of the organizations offer toll-free hotlines staffed by trained representatives; some will connect you with a peer who has shared a similar experience. Several of the Websites included in the Guide are specifically for people affected by lymphoma, and others are designed for anyone concerned with any cancer type.

We describe the history of each organization and some of its programs and achievements, and help you navigate the various Websites to find the information you need. You will learn which sites offer clinical trial matching services, Podcasts, financial assistance, and downloadable brochures. We also help you identify where to go for explanations of diagnostic tests and treatments or to chat with others online who also face a cancer diagnosis.

In addition to supporting patients, these organizations raise funds to sponsor important research and have contributed to many of the advances in lymphoma care. Many of the people involved with the advocacy groups in this Guide work tirelessly to petition for legislation that will improve the quality of life for patients with lymphoma and other malignancies and hopefully bring us closer to finding a cure for all types of cancer.

Whether you are a patient with lymphoma, a caregiver or friend of someone with lymphoma, or just a person who wants to help in the worthwhile cause of improving life for people with lymphoma, we hope you find this Guide useful.



Cutaneous Lymphoma Foundation

www.clfoundation.org



HISTORY & MISSION

The Cutaneous Lymphoma Foundation (CLF) was created by Judy Jones, Judith Shea, and Dr. Stuart Lessin. Judy received a cutaneous T-cell lymphoma (CTCL) diagnosis in 1990, but could find little information about her disease or other patients with CTCL to connect with. Frustrated by this lack of support, Judy created a CTCL information and support listserv in 1996, which grew rapidly as the Internet gained popularity. In 1994, Judith Shea's husband was found to have Sézary syndrome—an advanced form of mycosis fungoides, which is a common form of CTCL. He passed away 2 years later. Judith created the Lee Allen Cohen Fund in his memory, with the goal of making it easier for people with CTCL diseases to find information and support. Dr. Lessin, the dermatologist who treated Judith's husband and other patients with CTCL, felt a patient advocacy group would help call attention to the need for CTCL research and patient support. In 1999, after learning of Judy's CTCL listserv, Dr. Lessin contacted both

ADDRESS:
PO Box 374
Birmingham, MI 48012-0374

CONTACT INFO:
Phone: (248) 644-9014
E-mail: via Website

Judy and Judith to discuss starting a foundation for patients with mycosis fungoides. Using the Lee Allen Cohen Fund, the three began the Mycosis Fungoides Foundation, which became CLF in 2005 to include all forms of cutaneous lymphoma. The goal of CLF is to offer all patients with CTCL support and information to help them deal with their disease and to fund research in the hopes of one day finding a cure.

PROGRAMS & ACHIEVEMENTS

CLF collaborates with other lymphoma advocacy groups to host educational workshops across the country throughout the year and helps individuals organize and publicize meetings that enable patients and caregivers to meet face-to-face to socialize and share their stories. The organization also provides several services to patients with CTCL and their families, including two free CLF e-mail listservs, one of which serves as a support group to parents with children who have CTCL.

Visitors to the site can access numerous free publications and fact sheets that cover a range of CTCL topics, including the different forms of CTCL and quality of life issues. Visitors can also sign up for CLF's quarterly newsletter, *Cutaneous Lymphoma Foundation Forum*, which includes information on CTCL treatments, clinical trials, new research, events, and more. Patients who need assistance finding a clinical trial can use the clinical trial locator. The tool searches for clinical trials based on the region of the country where the treatment center is located.

NAVIGATION & USEFUL LINKS

CLF's mission, "Making sure each person with cutaneous lymphoma gets the best care possible," appears at the top of the home page next to its circular brush-stroke logo. Two columns of links beneath the mission connect patients to CLF resources, helpful Web links, or lymphoma news updates. **Newly diagnosed?** takes visitors to the same page as **About cutaneous lymphoma**, which appears in the left navigation pane, and includes numerous fact sheets and a glossary of medical terms.

Clicking **Educational opportunities**, which appears under the main menu bar that runs along the left-hand side of the home page, lists information about the various upcoming lymphoma workshops being cosponsored by CLF. Links to podcasts, slides, and fact sheets of past educational events are also accessible by clicking the hyperlinked **Here** at the top of the page.



Support allows visitors to join CLF's e-mail listservs, organize face-to-face meetings, or view a compilation of other organizations that offer financial or travel assistance to patients. The **CTCL-MF Online Support Group** listserv is a general cutaneous lymphoma support group, while **CTCL-MF Parent Online Support Group** applies to parents of children with CTCL.

Publications brings up a list of the various articles, guides, and fact sheets written by CLF experts. These publications can be read online or downloaded as PDF files. Notable downloads include "Your CTCL Treatment Guide" and "Living with CTCL." The **Publications** section also enables visitors to sign up for CLF's newsletter and access back issues.

On the **Treatment** page, visitors can read descriptions of common CTCL treatments and access a listing of CTCL diagnosis and treatment centers by region. Under **Clinical Trials**, patients can read clinical trial myths and frequently asked questions; link to National Cancer Institute and National Institute of Arthritis and Musculoskeletal and Skin Diseases information about clinical trials; or search for current clinical trials by region in the United States, as well as access European and Australian clinical trials.

Resource Checklist

- ✓ Podcasts
- ✓ E-mail listservs
- ✓ Quarterly newsletter
- ✓ Free publications
- ✓ Patient meeting organization assistance
- ✓ Clinical trials search tool

The Leukemia & Lymphoma Society

www.lls.org

The screenshot shows the homepage of the Leukemia & Lymphoma Society (LLS). At the top left is the LLS logo with the tagline "Fighting Blood Cancers". To the right is a search bar with options for "SEARCH THIS SITE", "SEARCH GLOSSARY", and "CHAPTER FINDER". A "LIVE PATIENT HELP 10-5 ET" button is also visible. The main content area is divided into several sections: "HOME" with a date "3.31.10", "PATIENT SERVICES" (including Call Center, Spanish info, support programs), "DISEASE INFORMATION" (listing various cancer types), "TOP STORIES" (featuring articles like "All Now! Urge Your Representatives to Retain Funding for Blood Cancer Education Program" and "Enter the Ready, Set Give and Get Contest on Facebook"), "INSIDE STORY" (with "Co-Pay Assistance" for patients), "DONATE NOW" (encouraging donations to help living with blood cancers), "LIFE MOSAIC" (stories of hope and courage), and "VISIT OUR EVENT SITES" (including "Team in Training").

HISTORY & MISSION

The Leukemia & Lymphoma Society (LLS) was founded in 1949 by Rudolph and Antoinette de Villiers as the Robert Roesler de Villiers Foundation, following the loss of their son Robert to leukemia. Beginning as a small office on Wall Street with limited funding and few volunteers, the organization expanded, opening chapters around the country. In the 1960s, the name was changed to the Leukemia Society of America to reflect its nationwide reach. In 2000, the name LLS was adopted to match its goal of curing all forms of blood cancer. LLS funds research in pursuit of this goal and commits additional resources to supporting and educating patients with blood cancers and their caregivers. In addition, LLS's Office of Public Policy advocates at the state and federal levels for legislation that will improve the lives of patients with hematologic malignancies.

ADDRESS:
1311 Mamaroneck Ave.
Suite 310
White Plains, NY 10605

CONTACT INFO:
Phone: (800) 955-4572
E-mail: Online

PROGRAMS & ACHIEVEMENTS

LLS has raised more than \$600 million for research. Several researchers LLS has supported have revolutionized cancer research and treatment, and three are Nobel Prize winners. LLS has supported the work of Nobel recipient E. Donnall Thomas, MD, the first scientist to successfully perform a human-to-human bone marrow transplant, and Joseph Burchenal, MD, who established the chemotherapy program at New York's Memorial Sloan-Kettering Cancer Center, which became the model used worldwide.

LLS provides financial assistance to patients in serious need through the Patient Financial Aid Program. All patients residing in the United States with a blood cancer diagnosis are eligible for assistance. US residents with a disease-specific blood cancer diagnosis who meet eligibility criteria may also qualify for the Co-Pay Assistance Program, which helps patients with their health insurance premiums or treatment copayment expenses. For information on the programs, LLS has set up an Information Resource Center, available at (800) 955-4572. Information Specialists help patients, families, and caregivers to communicate with their healthcare teams and connect them with one of the 64 LLS chapters or other sources of assistance.

In 2008, LLS launched the Therapy Acceleration Program as part of its research grant program. The Therapy Acceleration Program works to identify promising projects advancing toward patient use, helps fund submissions to the Food and Drug Administration prior to clinical trial initiation and coordinates with clinical trial centers to increase patient enrollment.

NAVIGATION & USEFUL LINKS

While LLS's Website contains a vast amount of information for patients in English and Spanish, it is surprisingly well organized and easy to navigate. Front and center on the home page are headlines for top stories relating to blood cancer and press releases on LLS's latest efforts. In the top right corner of the Website, visitors can use the [Live Patient Help](#) button to chat online with an LLS Information Specialist. There is also a [Chapter Finder](#) tool on the top of the home page that can help you locate a nearby LLS chapter.

The right column includes several sections, such as Life Mosaic, where patients post stories and pictures of their struggle with blood cancer, and How to Help. Clicking [more](#) in these sections takes you to

a new page detailing available opportunities. Under Free Newsletters, you can sign up for up to five different newsletters.

The left-hand side features a list of topics organized into six sections: [Patient Services](#), [Disease Information](#), [How to Help](#), [Advocacy](#), [Science/Professionals](#), and [LLS](#). At [Patient Services](#), you can access LLS's [Call Center](#) or you can also register for the [First Connection Request](#) support program that matches patients, loved ones, and caregivers with a trained peer who has been through treatment. You can also sign up for free [Chapter Education Programs](#) in your area. Selecting [Free eNews](#) under [Stay Informed](#) allows patients to sign up for LLS's RSS news feeds, podcasts, or newsletters. It also includes a list of [National Education Programs](#) and a [Blood Cancer Resource Directory](#) with links to additional Websites and organizations. [Discussion Boards](#) offers a forum for patients and caregivers to discuss all things related to blood cancer. Patients can apply for financial assistance and advance on the [Financial Support](#) page. [Cancer Centers](#) contains a state-by-state list of cancer treatment centers supported by the National Cancer Institute. [Questions & Answers](#) lists commonly asked questions about treatment and LLS.

[Disease Information](#) gives specifics on all types of blood cancers. Visitors can view [Facts & Statistics](#) on topics ranging from stem cell transplantation to quality of life. [Treatment & Clinical Trials](#) contains articles explaining common treatments such as radiation therapy and chemotherapy and describes [New Approaches](#) to care. This section also has a [Clinical Trial Service](#) to help patients find a trial; descriptions of [Lab and Imaging Tests](#); and subjects related to quality-of-life concerns, including [Pain Management](#), [Food and Nutrition](#), [Cancer-Related Fatigue](#), and [Blood Cell Counts](#). At [Free Materials](#), visitors can access LLS's publication library. Most are available in English, Spanish, and French.

Resource Checklist

- ✓ Information call center
- ✓ Financial aid
- ✓ Free downloadable booklets
- ✓ Live chat with a specialist
- ✓ Monthly e-Newsletters
- ✓ Online community

Lymphoma Information Network

www.lymphomainfo.net



HISTORY & MISSION

The Lymphoma Information Network (www.LymphomaInfo.net) is part of the Deep Health Network's interconnected group of health-related sites that provide patient access to healthcare information and a multitude of interactive resources. LymphomaInfo.net compiles accurate and up-to-date information relating to lymphoma for the benefit and education of patients with lymphoma and their caregivers. The Website is organized, searchable, and written for maximum patient comprehension. LymphomaInfo.net also facilitates communication between people affected by lymphoma who are seeking information or emotional support.

ADDRESS:
Unlisted

CONTACT INFO:
Phone: (310) 476-4924
E-mail: ajay@deepdivemedia.net

PROGRAMS & ACHIEVEMENTS

In addition to a plethora of educational pages, LymphomaInfo.net offers programs to help connect members of the lymphoma community. One section of the Website, “Have a Question? Know an Answer?” lets visitors who have registered with the site post questions or answer questions posted by others. The extensive archive of previously answered questions serves as a useful educational tool and helpful checklist of the major issues confronting patients with lymphoma. The site also connects to Deep Health Network’s SupportGroups.com, which offers several online lymphoma support groups. Additionally, the site’s state-by-state listings help patients find treatment facilities.

NAVIGATION & USEFUL LINKS

Three words in the top-right corner of LymphomaInfo.net’s home page summarize the organization’s purpose: Facts, Resources, and Community. Menu bars appear at the top and along the left-hand side of the page. The central column displays introductions and quick links to the site’s primary resources with a blog entry format. In the right-hand column, visitors can log in or register for membership, vote in the site’s poll, or read the “Did You Know” fact.

The top navigation bar repeats several of the central column’s links. **Ask** connects to the “Have a Question? Known an Answer?” section where patients may ask or answer questions. All of the posts are archived and a list of topics enables a quick search of the major categories. The **News** area features links to the latest articles relating to lymphoma. **Blogs** displays excerpts from various cancer-related blogs, and **Support Groups** links to www.SupportGroups.com, a Website with online support groups for patients with lymphoma. **Hodgkin’s Disease** and **Non-Hodgkin’s Lymphoma** contain information on the various aspects of the respective diseases, covering topics such as risk factors, common symptoms, characteristics, and statistics. Most of the articles are accompanied by charts and diagrams to help illustrate the content. Links at the bottom of these pages connect to related articles with more detailed information on subjects such as diagnosis, treatment, incidence, and chemotherapy. **Surviving Lymphoma** features articles covering various issues relating to surviving the disease and how to deal with them. Issues addressed include **Recurrence Fear**,



Stress/PTSD, Checkup Anxiety, Sex & Sterility, Post Cancer Fatigue, Late Effects, Secondary Cancers, Hair Loss, After Cancer, and Lymphedema.

The vertical navigation bar on the left-hand side also duplicates links, but here they are subdivided into categories for quicker information access. There are also a few links not featured on the primary navigation bar: **Understand** and **Treatment**. **Understand** links to articles targeted at newly diagnosed patients or visitors with a limited understanding of lymphoma. Articles include **Where to Start**, which advises the newly diagnosed on what to do first; **What is Lymphoma?**, a general summary and description of the disease; **The Lymphatic System**, an explanation of the areas of the body affected by Lymphoma; and **Lymphoma Symptoms, Lymphoma Causes, and Lymphoma Prognosis**, which offer details on these specific topics. **Treatment** contains **Hodgkin’s Treatment**—summaries of treatments used for Hodgkin’s Disease—and **NHL Treatment**, which describes the treatments for Non-Hodgkin’s Lymphoma. **Treatment** also has an article on **Clinical Trials** that includes descriptions of the clinical trial process, the pros and cons of participation, and the important factors to consider when selecting a trial. Finally, the **Treatment Centers** page allows patients to search by state for suitable treatment centers.

Resource Checklist

- ✓ Community Question & Answer Exchange
- ✓ Online Support Groups
- ✓ News Articles
- ✓ Blogs
- ✓ Treatment Center Listings

Lymphoma Research Foundation

www.lymphoma.org



East Coast

ADDRESS:
115 Broadway, 13th Floor
New York, NY 10006

CONTACT INFO:
Phone: (212) 349-2910 or
(800) 235-6848
E-mail: lrf@lymphoma.org

West Coast

ADDRESS:
8800 Venice Blvd., Suite 207
Los Angeles, CA 90034

CONTACT INFO:
Phone: (310) 204-7040 or
(800) 500-9976
E-mail: helpline@lymphoma.org

HISTORY & MISSION

In 2001, the Cure for Lymphoma Foundation (CFL) and the Lymphoma Research Foundation of America (LRFA) merged to become the Lymphoma Research Foundation (LRF). LRF describes itself as the “nation’s largest lymphoma-focused voluntary health organization devoted exclusively to funding lymphoma research and providing patients and healthcare professionals with critical information on the disease.” LRF helps people affected by lymphoma by providing support and educational materials. The mission of LRF is to fund quality research in an effort to improve the lives of patients and eliminate lymphoma.

PROGRAMS & ACHIEVEMENTS

To date, LRF has funded more than \$37 million in lymphoma research and launched specific research initiatives, such as a major study of mantle cell lymphoma (MCL), a hard-to-treat variant of non-Hodgkin Lymphoma. The MCL Initiative was established in 2003, followed by the MCL Consortium in 2005. The Consortium includes 24 research teams in the United States, Canada, and Europe. Following the success of this effort, LRF is raising funds to create similar programs for follicular lymphoma and chronic lymphocytic leukemia/small lymphocytic lymphoma.

LRF arranges Lymphomathons, which are 5K walks, throughout the country to raise money for its research and advocacy efforts. Since 2003, the Lymphomathon has raised more than \$7.5 million.

LRF offers a number of programs and services for patients, such as the national Lymphoma Support Network, which provides one-on-one peer support to patients and their caregivers. LRF's Healthcare Provider Grant Program helps uninsured or underinsured patients with unpaid medical expenses, excluding copayments and general living expenses. The Lymphoma Helpline and Clinical Trials Information Service provides information on all aspects of lymphoma, referrals to financial assistance programs, and help with clinical trial matching.

Each year, LRF sponsors the North American Educational Forum on Lymphoma, a two-and-a-half day meeting designed to educate patients with lymphoma on what they need to know from diagnosis to long-term survival. Another educational conference, "Lymphoma Workshop: Understanding Lymphoma Basics and Current Treatment Options," provides patients and their families with the latest information concerning lymphoma treatment and patient support and is held monthly at various U.S. locations.

NAVIGATION & USEFUL LINKS

The LRF home page features a navigation bar on the left side with links to different areas, each with its own submenu of options. [For Patients](#) includes [About Lymphoma](#), a section that provides an overview of lymphoma and lists lymphoma subtypes on the right. Selecting a specific type of lymphoma will take you to a page with information on the subtype and links to other resources. At [Booklets/Fact Sheets](#), visitors can submit mailing information to request free educational materials or read them online.

LRF recognizes that young people make up a fair percentage of individuals who develop lymphoma. They have included a section for [Children and Adolescents with Lymphoma](#) and one for [Young Adults with Lymphoma](#). These pages include a statistical overview of the rates of lymphoma in young people and offer several links to other organizations that help younger patients and their families. [Young Adults with Lymphoma](#) contains several Webcasts and Podcasts geared toward issues younger people face, such as "Relationships," and "I'm in My 20s and 30s and I Have Indolent Lymphoma- Now What?"

[Support Programs](#) discusses the [Lymphoma Support Network](#). A form is available at [Join Now](#) that will get you started on connecting with a lymphoma survivor who can offer advice and support. You will find information under [Support Programs](#) on contacting the toll-free Lymphoma Helpline and Clinical Trials Information Service or applying for financial assistance from the Healthcare Provider Grant Program. This section also includes Stories of Hope. [Read](#) stories from others or [Submit your story of hope](#).

[Webcasts And Podcasts](#) features several audio and video recordings from medical experts to help patients and families understand lymphoma. [Clinical Trials](#) explains the clinical trials process and offers to help patients locate a trial. The [Lymphoma News & Features](#) section offers LRF press releases, recent headlines on lymphoma, and an opportunity to sign up for LRF's quarterly newsletter, *Lymphoma Today*.

LRF has several local affiliates throughout the United States, and you can search for one by ZIP code under [Local Chapters](#). At [Programs & Events](#), you can learn more about upcoming [Educational Programs](#) and [Fundraising Events](#), including [Lymphomathons](#). [Advocacy](#) is a major part of LRF's efforts to improve life for people with lymphoma, and this section details how to become an advocate for patients. You can also take advantage of the [Advocacy Tool Kit](#) to learn more.

Resource Checklist

- ✓ Clinical trial matching service
- ✓ Financial aid
- ✓ Free booklets and fact sheets
- ✓ Toll-free helpline
- ✓ Webcasts and podcasts

CancerCare

www.cancercare.org

EN ESPAÑOL TELL A FRIEND CANCERCare E-NEWS DONATE

About Us | Get Help | Reading Room | Support Us Find Services by Cancer Type

CANCERCare

CancerCare is a national nonprofit organization that provides free, professional support services for anyone affected by cancer.

Call 1-800-813-HOPE or email info@cancercare.org

Online Support Groups
Log In

what's new
at CancerCare

March is...
both Colorectal and Kidney Cancer Awareness Month. Learn more about the services we offer for those affected by [colorectal](#) and [kidney cancer](#).

Co-Pay Help Available
The CancerCare Co-Payment Assistance Foundation provides financial help to patients in treatment for breast cancer, colorectal cancer, head and neck cancer, glioblastoma, non-small cell lung cancer, pancreatic cancer, and renal cell cancer.

calendar
at a glance

Calendar of Events

Ask CancerCare - Colorectal Cancer

Connect® Education Workshops

March 10
[Medical Update on Ovarian Cancer](#)

March 23
[Caring for Your Bones When You Have Prostate Cancer](#)

March 24
[Caring for Your Bones When You Have Breast Cancer](#)

April 13
[Travel Planning \(Step, Benac, no Fee\)](#)

Need help paying for your cancer medications?

e-shop
SUPPORT US

HISTORY & MISSION

CancerCare was founded in New York City in 1944 to help patients with advanced cancer. It is a national nonprofit organization that provides free professional support services to anyone affected by cancer, including patients, caregivers, children, loved ones, and the bereaved. The organization chose a lamp as its symbol because light represents warmth, comfort, and hope. From its inception, CancerCare has provided financial assistance for home care and emotional and practical counseling by professional oncology social workers. By 1980, CancerCare was helping more than 25,000 people each year through its free counseling service, which is still the heart of the organization's work.

ADDRESS:
275 Seventh Ave.
Floor 22
New York, NY 10001

CONTACT INFO:
Phone: (212) 712-8400
(800) 813-HOPE
Fax: (212) 712-8495
E-mail: info@cancercare.org

Now, with more than 100 staff members, CancerCare helps more than 100,000 people annually face the crisis of cancer, and the Website has become a leading online resource for cancer information, with more than 1 million unique visitors last year. While the size and focus of the organization have grown tremendously since 1944, the essential work remains the same: caring for the individual, supporting loved ones, and providing help and hope to anyone affected by cancer.

PROGRAMS & ACHIEVEMENTS

CancerCare programs include a toll-free counseling line, support groups, education, financial assistance, and practical help provided by professional oncology social workers free of charge.

The organization also offers **Telephone Education Workshops** that are interactive and made available by telephone replay or Podcast. The programs feature oncology experts helping patients and families understand and cope with a cancer diagnosis.

In 2007, CancerCare established the CancerCare Co-Payment Assistance Foundation to help patients with cancer afford their insurance and drug copayments. The need-based program provides partial or full coverage of essential services and treatments.

NAVIGATION & USEFUL LINKS

The three main sections of the CancerCare Website are tailored for persons with cancer, loved ones and friends, and healthcare professionals. In the first two sections, visitors can review frequently asked questions about the organization; access free educational programs and publications about the disease; sign up for free counseling online, by phone, or in person from professional oncology social workers; and apply for financial assistance. In the healthcare



professionals section, visitors can download educational materials, participate in distance-learning programs, and consult with any of CancerCare's staff of professional oncology social workers.

In addition to the **Connect Education Workshops**, the Website offers online learning programs, Podcasts, booklets on research, and fact sheets with quick tips and easy reference material on a range of cancer topics. The **Get Help** section is a quick way for visitors to peruse categories on counseling, support groups, publications, and financial assistance. A detailed calendar of events provides a thorough list of upcoming programs, workshops, and meetings.

CancerCare's online **Reading Room** is intended for those dealing with cancer whose world has become flooded with new information, vocabulary, challenges, and worries. This section is the place to go for all cancer questions—whether they are medical, practical, or emotional. Visitors can order publications through an online order form or download files in PDF format. You can share your story, or read about others' experiences with cancer at **Stories of Help and Hope** accessible from the home page and in the **Reading Room** subsection. Those who sign up to receive free **E-News** will be notified whenever new content becomes available.



Resource Checklist

- ✓ Telephone education workshops: *Better Bone Health*
- ✓ Toll-free helpline
- ✓ Financial assistance
- ✓ Online support groups
- ✓ Downloadable fact sheets and booklets

Cancer Support Community

(formerly The Wellness Community and Gilda's Club Worldwide)

www.cancersupportcommunity.org



ADDRESS:
919 18th St. NW
LL 54
Washington, DC 20006

CONTACT INFO:
Phone: (888) 793-9355
Fax: (202) 659-9703
E-mail: help@cancersupportcommunity.org

HISTORY & MISSION

In July 2009, The Wellness Community (TWC) and Gilda's Club Worldwide merged to become the Cancer Support Community, "A Global Network of Education and Hope." The Washington, D.C.-based Cancer Support Community encompasses approximately 50 Wellness Community centers and Gilda's Clubs, as well as more than 100 satellite offices worldwide. TWC was founded by Dr. Harold Benjamin in 1982 to provide free support, education, and hope to people with cancer and their loved ones internationally. Gilda's Club was founded in 1995 in honor of late comedian Gilda Radner and had a similar mission. The Website describes the merger as "a new beginning of the highest quality cancer support for the millions of people facing this disease."

PROGRAMS & ACHIEVEMENTS

The merger of The Wellness Community and Gilda's Club means that the Cancer Support Community now has more than 50 local affiliates and more than 100 satellite locations in the United States. It also has four international affiliates. Another 12 affiliates are in development.

Open to Options, a new project being piloted in Philadelphia, Cincinnati, and San Francisco's East Bay, seeks to help blood cancer patients with one-on-one decision making and to help care providers discuss clinical trials as a treatment option with patients who have a hematologic cancer. Cancer Support Community offers the program in collaboration with the Education Network to Advance Cancer Clinical Trials.

Cancer Support Community is also continuing to develop the Cancer Survivorship Research & Training Institute, an initiative of The Wellness Community. The institute conducts peer-reviewed research, sponsors forums and retreats for patients and caregivers, and coordinates training programs for healthcare professionals.

NAVIGATION & USEFUL LINKS

The Cancer Support Community Website, available in English and Spanish, is so rich in content that visitors can find information on nearly every aspect of dealing with cancer. The home page welcomes visitors with a quote from a cancer survivor on the comfort afforded by belonging to a support group. Below is a photomontage of people from all walks of life, titled "We are the face of cancer." A **Search** button in the upper right allows users to search instantly for affiliates and programs by zip code to find one in their area. The red navigation bar across the top includes the following clickable categories: **Newly Diagnosed**, **Learn About Your Cancer**, **Cancer Survivorship**, **Caring for Your Loved One**, and **Get Support Online 24 x 7**. Selecting one of these opens up a new page, with a gray box on the right containing expandable links for each section.

Learn About Your Cancer takes you to a page where you can find information by tumor type. You can also find information about **Cancer Treatment Options**, **Managing Side Effects of Cancer Treatment**, **Managing Emotional Health**, and even what to expect when treatment is finished.

Going to **Get Support Online 24 x 7** opens up a portal to the Online Social Network, where registered members share their experiences with one another,



blog, or use instant messaging; registration is free. You can also sign up for a scheduled online support group, based on your situation or diagnosis. From the home page of the Website, under **Our Communities**, you can also select a community specific to **Patients**, **Teens**, **Caregivers**, or **Healthcare Professionals**. Teens are redirected automatically to Group Loop (www.grouploop.org), a site specifically for young people.

Cancer Support Community offers several multimedia options, with links to **Podcasts** providing in-depth answers to questions about cancers; **Videos**, including excerpts from the book *Seven Levels of Healing*; the **Internet Radio** show "Frankly Speaking About Cancer," hosted by Kim Thiboldeaux, president and chief executive officer of the Cancer Support Community; and the organization's official **Blog**, which keeps visitors up-to-date on important cancer news.

In the dropdown menu for the **Learn About Your Cancer** section, you will find a link to the **Frankly Speaking About Cancer** educational series. On the right of this page are links to **Frankly Speaking About Cancer - Books**, a page listing available books and booklets on different cancer types or treatment-related issues that can be ordered for home delivery or viewed online as a PDF. The other link, to **Frankly Speaking About Cancer - Workshops**, discusses benefits of the series' educational workshops. Beneath these options, you can select **Search** to locate a Cancer Support Community affiliate or program in your area.

Resource Checklist

- ✓ Online community
- ✓ Clinical trials matching service
- ✓ Internet radio show
- ✓ Podcasts/Webcasts
- ✓ Book excerpts

Lance Armstrong Foundation

www.livestrong.org

The screenshot shows the homepage of the Lance Armstrong Foundation website. At the top, a navigation bar includes the LAF logo, a search bar, and menu items: HOME, CANCER SUPPORT, GET INVOLVED, GRANTS & PROGRAMS, ABOUT US, DONATE, and SHOP. The main content area features a large banner for 'Cancer Support' with the text 'We can help you face the challenges and changes that come with cancer.' To the right of the banner is a sidebar with a video thumbnail and a list of links: 'Get Over Your Fear', 'Clinical Trials', 'Cancer Treatment Decisions', 'Living Beyond Cancer', and 'Pay the Doctor'. Below the banner are several smaller promotional tiles: 'Thank You Austin Marathoners', 'LIVESTRONG Quarterly' magazine, 'Fundraising Tips' with a video player, 'From the Blog' featuring a recent article, and a 'Get Help Dealing with Cancer' contact box with the phone number 866.673.7205. A 'Headlines' section is visible at the bottom left of the page.

ADDRESS:
2201 E. Sixth St.
Austin, TX 78702

CONTACT INFO:
Phone: (877) 236-8820
(866) 673-7205
E-mail: Online

HISTORY & MISSION

The Lance Armstrong Foundation (LAF), also known as LIVESTRONG, was created in 1997 by famed bicyclist and Tour de France winner Lance Armstrong while he was undergoing treatment for testicular cancer, which had spread to his lungs and brain. LAF is not dedicated to fighting any one form of cancer, but to all cancers. LAF has posted its mission on the Website as a “manifesto” that outlines its many goals; although too lengthy to include here, it is definitely worth a read. In essence, LAF’s objectives include helping anyone with any type of cancer fight it from the time of diagnosis to the end, whenever that may be. LAF supports patients with cancer in multiple ways, advocating for patients’ rights and funding research into better treatments and possible cures.

PROGRAMS & ACHIEVEMENTS

By now, everyone recognizes the yellow LIVESTRONG wristbands, which LAF introduced in 2003; LAF sold more than 47 million in the first year alone, raising more than \$6 million for cancer research. Since LAF's inception, the organization has raised more than \$250 million to sponsor research and education. It has contributed to more than 550 cancer research institutes and awarded numerous grants.

LAF wants patients to slow down, breathe, and regain control over their lives. LAF believes cancer care does not end when treatment ends, and it has established a network of LIVESTRONG Survivorship Centers to coordinate services for survivors.

The Foundation also provides a one-on-one support program, which patients or their clinicians can request. The program pairs a patient with an advisor, who offers counseling, aids in locating nearby resources, and addresses concerns patients may have with finances, employment, or insurance. The advisor can also help connect the patient with suitable clinical trials. Services are available in English and Spanish.

Last year, LAF announced plans to go global. To launch this initiative, LAF held a global summit in August 2009, inviting leaders, organizations, and advocates from across the globe to discuss the urgent need to decrease cancer deaths.

NAVIGATION & USEFUL LINKS

The motto at the top of the colorful site reads, "At the Lance Armstrong Foundation, we unite people to fight cancer believing that unity is strength, knowledge is power and attitude is everything." Like Lance Armstrong, the LAF Website is energetic and dynamic. It actually consists of a network of LIVESTRONG sites addressing various aspects of the organization. At [About Us](#), you can read [Lance's Story](#), which encourages other young people with cancer to "live strong" and follow their dreams.

Visitors to the home page are greeted with a rotation of information and images at the center of the screen. Other items on the home page include regularly updated headlines related to cancer and summaries of LAF blog posts. Despite the tremendous amount of resources at the site, visitors will find it easy to find the information they seek. The top has a short navigation bar, and pointing to any link unrolls a list of subsections. Scrolling over [Cancer Support](#) displays a menu of resources for cancer



survivors, such as the [Get One-On-One Support](#) section and the [Get Organized](#) section, which includes the worksheets and guidebook. This page also has an area to help patients locate [Clinical Trials](#), using the LIVESTRONG Cancer Clinical Trial Matching Service. [Cancer Treatment Decisions](#) provides patients with access to cancer Profiler Tools. After registering, patients can summon up information on the latest treatment options based on their particular cancer type. This area of the site also includes a subsection [For Professionals](#) and stories from survivors to provide encouragement.

Selecting [LIVESTRONG Quarterly](#) on the Website's entry page takes you to [www.livestrongmagazine.com](#), where you can register to view free issues of the online publication. [LIVESTRONG Quarterly](#) includes articles on fitness, health, and various cancer concerns. You can also provide your address to receive a keepsake print copy. LIVESTRONG also provides resources specifically for adolescents and young adults with cancer, which is accessible from the site's home page.

LAF challenges everyone to [Get Involved](#). This might be through [Advocacy](#), participating on the [LIVESTRONG blog](#), [Grassroots Fundraising](#), or taking up a [LIVESTRONG Challenge](#).

Resource Checklist

- ✓ Online community
- ✓ Clinical trials matching service
- ✓ Toll-free helpline
- ✓ One-on-One Support
- ✓ Videos
- ✓ Free guidebook and worksheets

National Cancer Institute

www.cancer.gov



HISTORY & MISSION

The National Cancer Institute (NCI) was authorized under the National Cancer Act of 1937 and is part of the National Institutes of Health (NIH). It was formed with the purpose of conducting and supporting cancer research, reviewing and approving grants for promising research projects, gathering and analyzing cancer research from across the globe, and training healthcare professionals in the proper diagnosis and treatment of cancer. The creation of the National Cancer Program by the National Cancer Act of 1971 expanded NCI's focus to support other programs and research projects involving cancer prevention, rehabilitation, and continued care for patients with cancer and their families. Today, NCI is the world's leading funder of cancer research.

ADDRESS:
6116 Executive Blvd.
Room 3036A
Bethesda, MD 20892-8322

CONTACT INFO:
Phone: (800) 422-6237
E-mail: Online

PROGRAMS & ACHIEVEMENTS

Since its establishment, NCI has allocated billions of dollars to cancer research and awarded tens of thousands of research grants. NCI has funded the research of at least 20 Nobel Prize winners. One of its most important projects to date is the launching of The Cancer Genome Atlas in 2005 with the National Human Genome Research Institute, also part of NIH. The Cancer Genome Atlas plans to map genetic changes for at least 20 cancers in the next two years.

Although NCI is not a patient advocacy organization, it offers a range of useful services and tools for patients and their loved ones. Specialists at NCI's Cancer Information Service helpline at (800) 4-CANCER answer questions on a range of cancer topics, including the latest treatments and clinical trials. NCI's biweekly e-Newsletter, *The NCI Cancer Bulletin*, provides the latest cancer research news, including findings from major research journals, detailed articles and reports, information on new clinical trials, and legislative updates related to cancer and healthcare. NCI also has its own YouTube channel, which patients can follow to view various cancer-related videos.

Another valuable resource offered by NCI is its massive publications library. These publications can be ordered through the mail, downloaded and printed, or viewed online at no cost. They come in a variety of forms, including CDs/DVDs, pamphlets, fact sheets, and more. The hundreds of publications listed on NCI's Website can be searched by cancer type, subject, and target audience. Over 100 of these are also available in Spanish.

NAVIGATION & USEFUL LINKS

NCI's busy home page is compartmentalized to facilitate visitor navigation. A Quick Links box in the upper left-hand corner of the Website provides access to a [Dictionary of Cancer Terms](#), the [NCI Drug Dictionary](#), and the volumes of cancer information found in [NCI Publications](#). On the primary navigation bar at the top of the home page, patients can connect to the [Cancer Topics](#) section. Under [Common Cancer Types](#), you can select [Leukemia](#) or [Non-Hodgkin Lymphoma](#) to go directly to those sections. Or, you can select [All Cancer Types](#) for an [A to Z List of Cancers](#).

Whatever cancer type you select, the menu bar at the top stays the same. It includes a tab for [Clinical Trials](#), a section with several clinical trial-related tools and articles. [Find a Clinical Trial](#) lets patients search the more than 8,000 NCI-sponsored clinical trials that are

accepting new patients. [Educational Materials About Clinical Trials](#) contains a number of articles explaining the purpose and process of clinical trials. Links to clinical trial information are also available on the bottom of the page, some specific to the type of cancer.

In the right column of each cancer's page, the Related Pages and General Cancer Resources sections include links to similar disease states or articles that address a range of subjects applicable to patients with all cancer types, such as [How to Find Treatment, Complementary and Alternative Medicine](#), and [Screening and Testing](#). There is also a [Coping with Cancer](#) section, with guides on [Managing Physical Effects](#), [Managing Emotional Effects](#), and [Finding Healthcare Services](#). A box on the right contains Quick Links, providing rapid access to such useful features as a [Dictionary of Terms](#) and the [NCI Drug Directory](#).

The small *NCI Cancer Bulletin* box in the home page's right-hand column allows visitors to subscribe to NCI's biweekly newsletter. A small row of links appearing at the bottom of every page includes [Contact Us](#). Here, visitors can access NCI's Cancer Information Service helpline or use the [LiveHelp Online Chat](#) service, which allows visitors to have a confidential online chat with an NCI cancer information specialist.

NCI's Hodgkin and non-Hodgkin lymphoma pages share an identical layout and can be accessed through [Cancer Topics, Types of Cancer](#). Each page begins with a brief definition of the disease and current-year estimates of new diagnoses and fatalities. Directly below this information is a link to NCI's booklet on the disease, [What You Need To Know About™ Hodgkin/non-Hodgkin Lymphoma](#). The remainder of the two pages consists of various links sorted by category that connect to articles on treatments, prevention and risk factors, clinical trials, related literature, research, and statistics. Several of these sections include pages with information pertaining to Hodgkin and non-Hodgkin Lymphoma in children.

Resource Checklist

- ✓ Clinical trial matching
- ✓ Free downloadable booklets
- ✓ Live online chat with a specialist
- ✓ Toll-free helpline
- ✓ Biweekly e-Newsletter

Patient Advocate Foundation

www.patientadvocate.org

PAF Patient Advocate Foundation
Solving Insurance and Healthcare Access Problems | 501(c)(3)

1.800.532.5274

HOME PERSONAL HELP RESOURCES PROGRAMS NEWS GET INVOLVED DONATE ABOUT US EN ESPAÑOL

The PAF Mission:
to provide effective mediation and arbitration services to patients to remove obstacles to healthcare including medical debt crisis, insurance access issues and employment issues for patients with chronic, debilitating and life-threatening illnesses.

We assist patients with:
 • Medical Debt Crisis
 • Insurance Access Issues
 • Job Retention Issues

• Request Help from a PAF Case Manager
 • View Videos About PAF

Have a Question?
Talk with a Professional Case Manager
[CLICK TO EMAIL NOW](#)
Privacy Policy / FAQs

Call Us: 1-800-532-5274
 Email Us
 PAF Webinars

Resources at PAF
 African American Outreach
 Blood Cancer Resources
 Chronic-Related Avascular Disease
 Clinical Trials
 Corporate Case Law
 Co-Pay Relief
 Disease-Specific Info
 Employment-Related Issue
 Insurance/Litigation Outreach
 Insurance Information
 Money Matters
 National Financial Guide
 PAF Publications
 Pediatric Resource Center
 Senior Services
 Shelia G. Crain Memorial
 Fund for Multiple Myeloma
 VA Cards Unreused Program

Get the NBC Features PAF

 Visit the NBC website to view video of the Dateline NBC interview with Ben Darius, President of Mission Delivery. Interviews filmed at the office of PAF.
 View copy of the Dateline NBC segment featuring PAF and Robert Chubb, a PAF patient that aired on Sunday, January 26, 2010. This segment featured three patients and discussed Mr. Chubb's challenges in accessing potentially life-saving medical care and PAF's role in a compassionate appeal on his behalf.

Mid-Winter Beach Party
 A Promise of Hope Affair
 Let's Get It On! (Weekend) - Norfolk, VA
 (Weekend) - Chesapeake, VA

PAF Search

03-22-2010 - 014 and a 014 Patient was featured on Dateline NBC
 03-20-2010 - Patient Advocate Foundation receives former National Team Executive as New Executive Vice-President of National Partnership
 03-22-2010 -

Become an Advocate
 Donate directly to PAF
 Join the Advocates Network

Other Programs at PAF
 A Promise of Hope Affair
 Scholarship for Current National Local Symposium

YouTube
 View PAF Videos on YouTube

HISTORY & MISSION

The Patient Advocate Foundation (PAF) is a national nonprofit organization that seeks to safeguard patients' rights. PAF facilitates mediation to negotiate assured access to care, job retention, and financial stability for those who receive a diagnosis of a life-threatening or debilitating disease. PAF has been "solving insurance and healthcare access problems since 1996," and comprises a network of research and community oncologists, attorneys, legislators, healthcare industry representatives, and case managers. Through the support of myriad donors and grants, PAF provided education and information to more than 6.5 million Americans in fiscal year 2006/2007.

ADDRESS:

421 Butler Farm Road
Hampton, VA 23669

CONTACT INFO:

Phone: (800) 532-5274
 Fax: (757) 873-8999
 E-mail: help@patientadvocate.org

PROGRAMS & ACHIEVEMENTS

The Co-Pay Relief Program provides direct financial support to insured patients, including Medicare Part D beneficiaries. To receive assistance in making copayments for drugs, patients must qualify financially and medically. The program offers one-on-one service, providing call counselors who guide patients through the enrollment process. The program assists insured patients being treated for breast, lung, lymphoma, prostate, kidney, colon, pancreatic, head/neck cancers, malignant brain tumors, sarcoma, diabetes, multiple myeloma, myelodysplastic syndrome, osteoporosis, chronic pain, hepatitis C, rheumatoid arthritis, and certain autoimmune disorders.

PAF also offers the National African American Outreach Program (NAAOP), designed to reduce racial disparities in healthcare. NAAOP works to help patients in disenfranchised communities with high-risk health concerns obtain a better quality of life by disseminating information to those who typically lack reliable healthcare.

PAF also hosts an annual fundraising gala and holds a yearly Patient Congress (www.pc.patientadvocate.org). The latter features speeches and presentations on public policy concerns for people with serious diseases and sends advocates to Congress to discuss their challenges. In 2009, 173 individuals from 46 states and the District of Columbia attended the Patient Congress, which featured Elizabeth Edwards as a keynote speaker.



NAVIGATION & USEFUL LINKS

On the front page, visitors can find a link to chat live online with a Professional Case Manager about their concerns. In addition, the **Personal Help** drop-down list presents several patient/provider hotlines designed to provide assistance to patients and providers seeking education, access to care, or assistance navigating the reimbursement system. You can also select **Success Stories**, to read about patients whom PAF has helped in overcoming some of their challenges.

The **Resources** area has several helpful subsections, including **Disease Specific Information & Support**, **Insurance Information**, **Clinical Trials** (a list of links to Websites that list clinical trials), **Senior Services**, **Employment Related Information**, **African American Outreach**, and **Money Matters**.

Visitors can select **Get Involved** or **Donate** to discover how they can help further PAF's efforts. Giving time can be hard work, but it can be rewarding and fun. Volunteers will learn about current state and federal initiatives that affect the healthcare of all Americans.

Resource Checklist

- ✓ Financial resources guidebook
- ✓ Toll-free helpline
- ✓ Co-pay assistance
- ✓ Colorectal care hotline
- ✓ Downloadable publications
- ✓ Survivor scholarships

Additional Lymphoma Resources

The Lymphoma Coalition

www.lymphomacoalition.org

The Lymphoma Coalition worldwide network was created in 2002 to raise lymphoma awareness, ensure patients with lymphoma get proper care, and create lymphoma patient groups. To date, the Lymphoma Coalition consists of 42 organizations in 33 countries. An interactive global map connects patients to the individual member groups. The Website's primary resource consists of information on lymphoma topics such as symptoms, causes, and treatment. Information can be viewed in English, Spanish, Dutch, French, or Italian. The **Know Your Nodes** program (www.knowyournodes.org), accessible from the **World Lymphoma** page, includes a quiz and fact sheets that educate individuals on the lymphatic system and lymphoma.

- ✓ Multilingual Website
- ✓ Quiz and fact sheets
- ✓ Links to worldwide member organizations

Lymphoma Foundation of America

www.lymphomahelp.org

The Lymphoma Foundation of America (LFA) is a national nonprofit organization that supports patients with lymphoma and their families. LFA runs a toll-free, counseling helpline that assists patients with the emotional burden of cancer. Callers can get advice on finding lymphoma specialists, treatment centers, information, and support networks. Patients seeking a second opinion on diagnosis or treatment can view LFA's contact list of lymphoma specialists across the country. LFA also hosts various educational events each year and gives research grants and awards to lymphoma scientists and researchers at university-based medical centers.

- ✓ Counseling and resource helpline
- ✓ Contact list of lymphoma specialists
- ✓ Educational events

Non-Hodgkin's Lymphoma Cyberfamily

www.nhlcyberfamily.org

The Non-Hodgkin's Lymphoma (NHL) Cyberfamily is an online group of patients and caregivers that is open to anyone affected by NHL. The group is e-mail based, with over 2100 members sharing support, information, and advice. A link on the home page connects visitors to a signup page for the support group on Yahoo! The NHL Cyberfamily Website contains information about NHL and its various types and treatments and an FAQ. Visitors can read about new NHL studies at the research library and download guides on NHL.

- ✓ Online support group
- ✓ Free downloadable booklets
- ✓ FAQs

Patients Against Lymphoma (PAL)

www.lymphomation.org

Patients Against Lymphoma (PAL) was founded in 2002 to provide evidence-based lymphoma information and a patient perspective on research and clinical trials. The Website's content is driven by questions from patients and caregivers. The questions provide the impetus for site topics, with compiled information, commentary, and links from the Web's best cancer resources. Visitors can review existing information or submit a question. For patients seeking support, the **Support and Survivorship** page's assistance categories include **Alerts and Keeping Safe; Psychosocial and Physical Effects; Doctors; Drug resources; Financial, Insurance & Legal support; Immunization Support; Treatment Support; and Patient-to-Patient Support**. PAL also includes free downloadable guides and Webcasts featuring lymphoma experts.

- ✓ Q&As
- ✓ Free downloadable booklets
- ✓ Educational Webcasts

Bone Marrow–Specific Resources

Blood & Marrow Transplant Information Network

www.bmtinfonet.org

The Blood & Marrow Transplant Information Network (BMT InfoNet) is a nonprofit organization dedicated to informing and supporting patients who need blood or marrow transplants. On BMT InfoNet, visitors can search a database of medications administered to transplant patients during treatment, access a news bulletin, browse a resource directory of more than 100 organizations, watch webcasts about post-transplant survivorship issues, or find details on more than 200 transplant centers in the United States and Canada. A free quarterly newsletter is also available. A member of BMT InfoNet's team of transplant survivors will offer emotional support to a patient who is about to undergo or has already undergone a transplant. Signup for this service is available online. For patients having issues with their insurance company regarding transplant coverage, BMT InfoNet has a referral service for nonprofit organizations and attorneys.

- ✓ Transplant center search engine
- ✓ Survivor contact support service
- ✓ Quarterly newsletter

National Bone Marrow Transplant Link

www.nbmtlink.org

The National Bone Marrow Transplant Link (nbmtLINK) helps individuals cope with the various challenges bone marrow/stem cell transplants present from diagnosis through survivorship. nbmtLINK's **Peer Support on Call** service sets up one-on-one conversations with trained volunteers who have experienced similar circumstances. The volunteers also answer questions and offer support via nbmtLINK's toll-free helpline. FAQs are compiled in the **Common Questions** section of nbmtLINK's Website. Additional resources and support available through the Website include a telephone education and support group; webcasts on bone marrow transplant–related topics; an online library with hundreds of articles and a

wealth of resource links; free, downloadable versions of nbmtLINK original publications, including transplant resource guides; an Emmy Award–winning video on post-transplant survivorship (\$10); and the **Celebrating Second Birthdays** program, which recognizes patients' continuing need for support on the anniversary of their transplant. nbmtLINK also sponsors an in-person support group for patients in the Detroit metro area only.

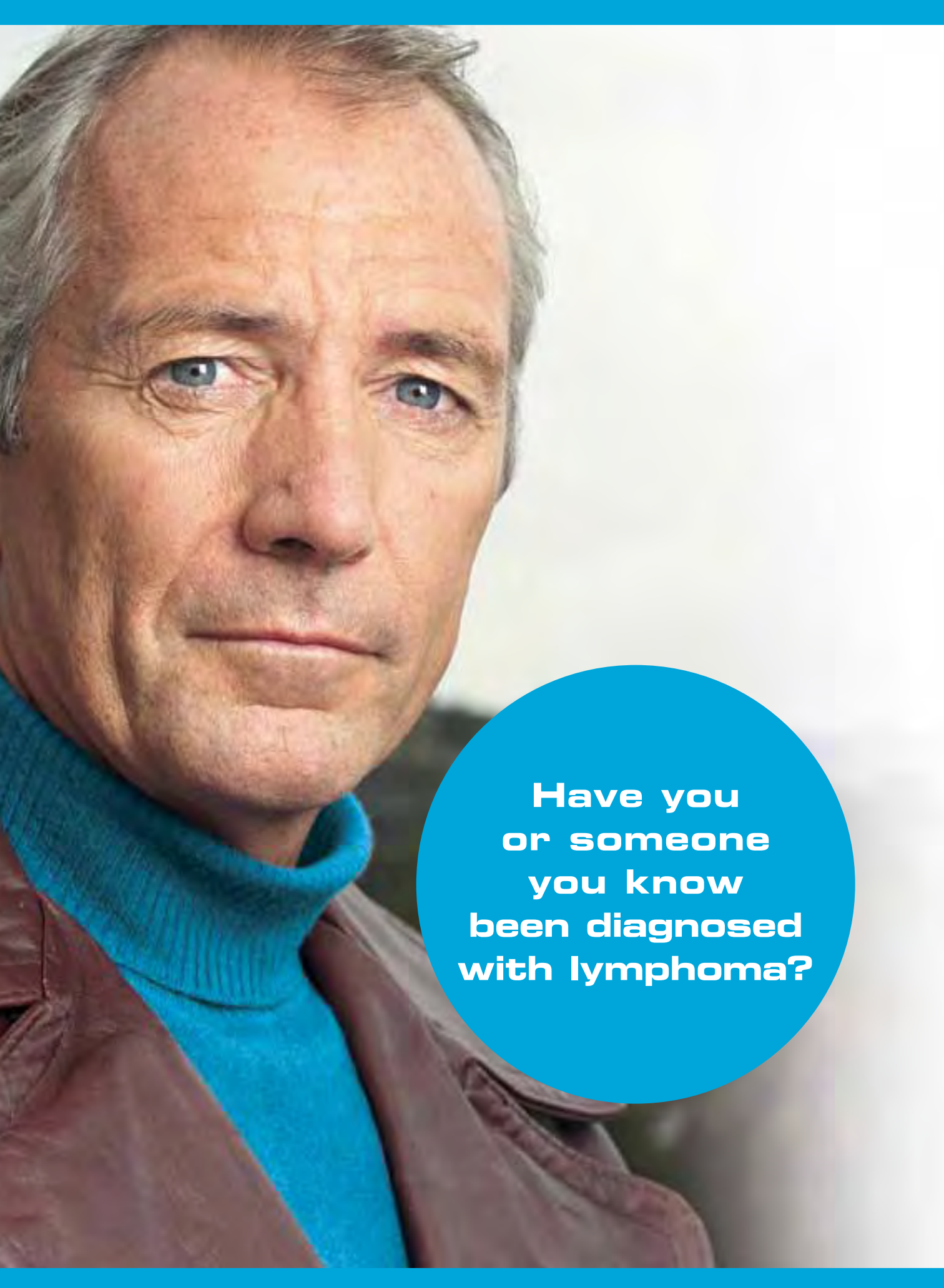
- ✓ Toll-free helpline
- ✓ Peer matching for support
- ✓ Webcasts and downloadable booklets

National Marrow Donor Program

www.marrows.org

National Marrow Donor Program (NMDP) has been helping patients receive bone marrow transplants for more than 20 years, finding donor matches and providing informational and supportive resources. In 2009, more than 12,000 searches were conducted through the Be The Match Registry®, operated by NMDP. Through these searches, patients have access to more than 8 million potential donors and 160,000 cord blood units, as well as those listed on international registries. Case managers are also available for direct support through the NMDP Office of Patient Advocacy helpline (interpreters are available for non-English speakers). In addition to assisting with donor matching and background information on the transplant process, NMDP's Website features resources on discussing transplants with a doctor, choosing a transplant center, managing financial and insurance matters, and preparing for life as a transplant survivor. Free educational materials offered through the Website include teleconferences, webcasts, DVDs, and downloadable booklets. The site also has a searchable directory of additional organizations and sections with patient stories, FAQs, and information for parents of children who need transplants.

- ✓ Marrow donor registry
- ✓ Toll-free expert helpline
- ✓ Webcasts and teleconferences



**Have you
or someone
you know
been diagnosed
with lymphoma?**

If so, you may want to learn more about the PILLAR clinical trials.

The PILLAR clinical trials involve patients with mantle cell lymphoma (MCL) or diffuse large B-cell lymphoma (DLBCL).

These trials are evaluating the efficacy and safety of an investigational drug for the treatment of MCL and DLBCL.

Eligible patients for PILLAR-1*

- Have confirmed diagnosis of **MCL**
- Are 18 years of age or older
- Have disease that did not respond to previous treatment

Eligible patients for PILLAR-2*

- Have confirmed diagnosis of **DLBCL**
- Are 18 years of age or older
- Have disease that responded to treatment with R-CHOP[†]

For more information about the PILLAR-1 or PILLAR-2 clinical trials, ask your health care professional or visit www.novartisclinicaltrials.com.

*Additional eligibility criteria apply.

[†]Rituximab in combination with cyclophosphamide, doxorubicin, vincristine, and prednisone.

These are investigational trials; efficacy and safety for the treatment of lymphoma has not been established and there is no guarantee that this investigational drug will become commercially available for these indications.

PILLAR



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Value-Based
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Cardiology