

# LUNG CANCER

## Resource Guide

*A collection of Websites that provide information and support for patients with lung cancer and the oncology professionals who treat them.*





Intellisphere

Oncology Specialty



This **Lung Cancer Resource Guide** has been developed to help inform and support patients with lung cancer and the oncology professionals who treat them. If you would like additional copies of this resource guide, please fill out the form below and drop this postage-paid postcard in the mail.

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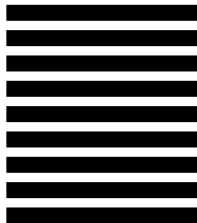
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## Foreword

# A Resource for Patients with Lung Cancer

My name is Deb Violette, and if you are reading this resource guide, either you or someone you love has been diagnosed with lung cancer. I know firsthand what a devastating diagnosis this can be. Many thoughts cloud your mind when your doctor tells you, “You have lung cancer,” and almost immediately, you find yourself crippled with questions - What treatment should I take? How will treatment affect my overall health and well being? How do I navigate insurance, support, and work issues? How do I talk to my family, friends, and coworkers about my diagnosis? I know this because I was diagnosed with stage III-A non-small-cell lung cancer in 1998. I was 44.



In 1998, there was little information about lung cancer and the few resources that existed offered little hope. With the lack of information and survivorship, I struggled through the process alone. However, I was determined to beat the statistics. I searched the Internet to find as much information on lung cancer as I could. This helped me take an active role in my care when I met with my team of doctors. It is so important to educate yourself about the disease so that you can interact with your healthcare team.

I went through many diagnostic tests before I began my treatment, which included three rounds of chemotherapy spaced 21 days apart, surgery to remove my right lower lobe, and 25 rounds of radiation. By the time I had completed treatment, I was exhausted but inspired to give back. That is why I became an advocate and spokesperson for the lung cancer community.

Many things have changed since my diagnosis in 1998. Treatment options now include more direct and targeted therapies, and many lung cancer advocacy groups have been developed to provide patients with support and guidance through their lung cancer diagnosis.

This Resource Guide highlights some of those organizations in the United States whose mission is to increase research funding; provide emotional and financial support for patients, their families, and caregivers; and promote public awareness and acceptance of patients with lung cancer. Information is provided that describes the organizations and their efforts, and explains how to navigate the Websites to find the information you need to help guide you through your journey. You are not alone; many of these organizations are staffed with supportive personal to help you or offer programs to connect you with other survivors for support. Several other organizations are designed to help patients with work and insurance issues, and provide advice on talking to your family, friends, and coworkers about your diagnosis.

I hope you find this Lung Cancer Resource Guide useful, and I wish you the best in your journey to wellness.

### **Deb Violette**

Lung cancer survivor/advocate

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*We would like to acknowledge Deb Violette of Augusta, Maine, who supported our efforts by sharing her expertise.*

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# EmergingMed.com Trial Matching Service

[www.emergingmed.com/networks/CancerCare](http://www.emergingmed.com/networks/CancerCare)

## CONTACT INFO:

Phone: (800) 698-0931

Many leading lung cancer advocacy organizations have teamed up for the Lung Cancer Clinical Trial Call to Action campaign, which helps match patients with lung cancer to an appropriate clinical trial. Clinical trials are an essential step in improving lung cancer care and offer treatment options that are often as good as or better than standard care. Despite this fact, less than 5% of adults participate, often finding it difficult to identify a clinical trial to discuss with their physician.

Visitors to any of the partner Websites—Lung Cancer Alliance, lungCANCER.org, Uniting Against Lung Cancer, National Lung Cancer Partnership, LUNGevity, and Respiratory Health Association of Metropolitan Chicago—can access the clinical trials matching service via a link in the Clinical Trials section of the Website or the home page. This takes you to the EmergingMed welcome screen for the Lung Cancer Clinical Trial Matching Service, describing the free, confidential program and the benefits of taking part. Click on [read more](#) under “How does the service work?” for an outline of the steps involved.

Selecting [Find a Match](#) invites you to create an anonymous, password-protected account to store your patient profile. You can also sign up to receive e-mail alerts whenever new clinical trials are added to the database. After you create your account, log in to complete a questionnaire on your diagnosis, condition, and treatment history. This is your patient profile, which you can update or delete at any time. Next, click the [Match to Clinical Trials](#) button, which compares your answers against enrollment criteria for each trial and location. You will receive a list of trials that might be matches, and your profile and search results will be stored automatically under [Saved Patient Profiles](#). EmergingMed encourages you to review results with your physician or speak with



other patients or a representative from a patient advocacy organization. If you do not want to create a profile but would still like to learn about trials, select [View All Trials](#).

Registered users of the Website must submit an application to EmergingMed to inquire about specific trials. With your permission, someone from EmergingMed will contact you to verify the application, provide more information about the trial, and tell you how to reach the trial coordinator. The trial coordinator will verify your eligibility, answer your questions, and arrange an appointment. For questions, you can call a Clinical Trial Specialist at the toll free number or click the [Live Chat](#) link to the left of the Website.

# Lung Cancer Alliance

www.lungcanceralliance.org

ADDRESS:  
888 16th St NW  
Suite 150  
Washington, DC 20006

CONTACT INFO:  
Phone: (202) 463-2080  
(800) 298-2436  
E-mail: info@lungcanceralliance.org

## HISTORY & MISSION

*No more excuses. No more lung cancer.* Eradicating lung cancer is what the Lung Cancer Alliance (LCA) is all about. Describing itself as the only national, nonprofit organization dedicated solely to providing patient support and advocacy for people living with or at risk for the disease, LCA says it has a clear mission: to reverse decades of stigma and neglect by empowering patients, elevating awareness, changing health policy, and making lung cancer a national public health priority.

Headquartered in Washington, D.C., LCA is led by an international board of directors that includes top lung cancer physicians, nurses, survivors, and advocates. The medical and scientific advisory board includes specialists from a broad spectrum of disciplines related to lung cancer, who focus on research, diagnosis, early detection, treatment, and care.

### PROGRAMS & PATIENT ADVOCACY

LCA provides a multitude of patient empowerment, national awareness, and health policy programs. The Phone Buddy Program, a free peer-to-peer mentoring support system, matches survivors or caregivers with others who have had similar experiences and provides long-distance calling cards for all participants. Each volunteer undergoes training sessions and has access to LCA resources and manuals.

The Lung Cancer Information Line (800-298-2436) is a toll free information and referral service that gives callers current and reliable information on lung cancer, including symptoms, screening, recent diagnoses, treatments, clinical trials, and second opinions. The service also offers advice on smoking cessation, psychosocial and financial concerns, and transportation issues. The information line operates weekdays from 9 AM to 5 PM.

A third program, the Lung Cancer Clinical Trials Matching Service (800-698-0931), is a toll free connection to a prescreening and referral service that quickly identifies clinical trial options based on an individual's specific diagnosis, stage, and treatment history. LCA also publishes and widely distributes an annual *New Directions* newsletter.

### ACHIEVEMENTS & INITIATIVES

LCA sponsors a national public awareness campaign, working with a celebrity spokesperson to raise lung cancer awareness through public outreach using a variety of media sources. LCA also organizes the *No One Deserves Lung Cancer* national bus tour, which transports the “Faces of Lung Cancer” collage to various cities throughout the United States. The collage is also hosted on the Website and includes pictures and stories from survivors and those who have died from lung cancer. Every year, LCA issues the Annual State of Lung Cancer Report Card, assessing progress made on the federal and state level against lung cancer.



### NAVIGATION & USEFUL LINKS

At the Website, [Facing Lung Cancer](#) provides detailed information about the disease. It explains the two most common types of lung cancer, non-small cell (80% of cases) and small cell (20% of cases). The [Support](#) subsection provides links to the [Phone Buddy Program](#), [Stories of Hope](#), and the toll-free [Information Line](#) for patients with questions about screening, diagnosis, symptoms, and treatment options. The *New Directions* newsletter can be found under [Publications](#) in the [News/Events](#) subsection.

Under [Take Action](#), you can learn about LCA's legislative initiatives, access a calendar of [Upcoming Events](#), and find out about [Volunteering](#). You can also review the Report Card on Lung Cancer through the [Advocacy](#) link.

Lower down on the page, you will find [Helpful Shortcuts](#), offering links to several LCA endeavors, such as the [Survivors' Support Community](#). This will take you to [www.inspire.com/groups/lung-cancer-alliance-survivors](http://www.inspire.com/groups/lung-cancer-alliance-survivors), a free interactive site that connects patients, their families, friends, and caregivers. [Lung Cancer in the News](#) connects to a current list of lung cancer articles in major newspapers, radio programs, and medical journals.

# Lung Cancer Foundation of America

www.lcfamerica.org

The screenshot shows the homepage of the Lung Cancer Foundation of America (LCFA). At the top, there are social media links for Twitter and Facebook, and a sign-up link for LCFA updates. The navigation menu includes Home, Lung Cancer, Media, Blogs & News, Donate, Get Involved, About LCFA, and Contact Us. The main banner features the LCFA logo and a woman with her arms outstretched in a field, with the text: "Lung cancer is the leading cause of cancer deaths for both men and women, causing 30% of all cancer deaths; more deadly than breast, prostate, colon, liver, melanoma and kidney cancers combined. Now, let's cure it." Below the banner, there is a "Welcome to LCFA, the LUNG CANCER FOUNDATION OF AMERICA" section with a mission statement. To the right, there are buttons for "DONATE and give Hope" and "WATCH and be Inspired". Below these are sections for "PERSONAL BLOGS" with three entries, "LUNG CANCER NEWS" with two entries, and "EVENTS" with one entry. At the bottom left, there is a promotional banner for "LCFA 'Day at the Races'" on 8.8.2010 at Del Mar Race Track.

## HISTORY & MISSION

The Lung Cancer Foundation of America (LCFA) was established by two lung cancer survivors and a widow whose husband died of the disease. The group believes the poor survival rate is a direct result of inadequate funding for research. The LCFA mission is to increase the five-year survival rates for all stages and types of lung cancer significantly, ultimately saving patients' lives. In an effort to meet this goal, LCFA provides crucial funding for creative and cutting-edge research programs in lung cancer.

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CONTACT INFO:  
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E-mail: info@LCFAmerica.org

## PROGRAMS & PATIENT ADVOCACY

Programs focus on efforts to develop effective predictive protocols, foster early detection, and establish prognostic and treatment protocols that recognize, support, and encourage researchers. LCFA also supports established lung cancer research programs. Through career development awards, LCFA works to encourage new lung cancer research. LCFA says it strives to uncover opportunities for action and identify ways people can get involved.

## ACHIEVEMENTS & INITIATIVES

LCFA works to spur the private sector to donate money to support research that predicts, detects, and treats lung cancer. They have partnered with OPI Products, which makes nail polish, to develop the BREATHELIFE campaign. OPI developed a special “BREATHELIFE” nail lacquer and promotes lung cancer awareness through displays at nail salons nationwide. The program solicits donations from salon patrons and owners. LCFA also works to increase awareness of the need for increased funding through media outreach and charity events.

## NAVIGATION & USEFUL LINKS

The opening page of the LCFA Website features rotating phrases, one of which reads “Every 2½ minutes someone in the United States is diagnosed with lung cancer, and every three minutes someone will die from lung cancer. Now, let’s cure it.”



Under the **Lung Cancer** section, **The Facts** links to a list of particulars about lung cancer, ranging from statistics on how many men and women have the disease to the survival rates and how much money is budgeted annually for research. Noting the disease will kill more than 160,000 Americans this year, **The Need** subsection stresses the lack of support and funding for lung cancer research compared with other cancers.

The LCFA site has a section titled **Media, Blogs & News**, which includes stories and anecdotes from people with lung cancer about their daily challenges. It also highlights important developments in lung cancer care. The **Get Involved** section features **Scheduled Events**, a list of upcoming events held by organizations that work to raise funds to combat lung cancer. **How You Can Help** outlines ways to join in the fight. **Lung Cancer Advocacy** explains the active involvement of LCFA founders in the nationwide lung cancer advocacy community. LCFA works with organizations to form a strong coalition that leverages its combined influence to increase research funding.



# LUNgevity Foundation

www.lungevity.org

**LUNGEVITY**  
Find it. Treat it. Live.

YouTube f t

ABOUT US | ABOUT LUNG CANCER | RESEARCH | EVENTS | NEWSROOM | LUNG CANCER SUPPORT COMMUNITY | BLOG | DONATE NOW

## YOUR GENES NEVER FIT YOU SO WELL.

Targeted therapies work. Use your own unique genetic chemistry to design lung cancer treatments especially for you.

You Can Help.  
Fund research for the development of targeted therapeutic treatments. **TAKE ACTION**

### Our Vision

Our vision is a world where no one dies from lung cancer. A world that LUNgevity helped to create by bringing together world-class scientific minds, passionate advocates, and an efficient and effective organization. Our vision is to unite the country in one movement to end lung cancer now.

### Our Mission

The mission of LUNgevity Foundation is to have a meaningful and immediate impact on improving lung cancer survival rates, ensure a higher quality of life for lung cancer patients, and provide a community for those impacted by lung cancer.

In order to accomplish our mission, LUNgevity funds the most promising research into the early detection and successful treatment of lung cancer as identified by our board of leading scientists. LUNgevity also supports the largest national grassroots lung cancer network.

We hope to inspire the nation to commit to ending lung cancer.

### About Us

LUNgevity moves forward firmly resolved to provide the energy, inspiration, and resources that are critical to making lung cancer a national priority. Our goal is to Stop Lung Cancer Now.

#### FEATURED RESEARCHER

**Dr. Margaret Spitz**  
Dr. Spitz is wielding her exceptional mastery of lung cancer epidemiology to develop ways to identify risk factors so that earlier diagnosis is possible.

#### FEATURED EVENT

**LUNgevity Foundation's 10th Anniversary Fall Benefit**  
Please join us for this very special evening celebrating ten years of hope and courage!

#### FEATURED NEWS

**Lynda Carter Speaks Out**  
Actress and singer Lynda Carter speaks frankly about lung cancer.

#### FEATURED BLOG ENTRY

**The Compassionate Cycle**  
"My entry into the world of cancer began when my own father was diagnosed with lung cancer in 2002. I became a caregiver and later a patient advocate."

Please Login | Upcoming Events | Latest News | Latest Blog Entries

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Fax: (312) 464-0737  
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## HISTORY & MISSION

In November 2000, seven lung cancer survivors from the Chicago area established the LUNgevity Foundation in an effort to raise money for research into lung cancer diagnosis, treatment, and cures. Resources are directed toward those studies that seem the most promising. LUNgevity has partnered with a variety of organizations to sponsor research grants. It also provides support to those affected by lung cancer through establishing a support community.

The organization says its mission is to "save lives and to ease the burden of lung cancer on patients and their loved ones."

## PROGRAMS & PATIENT ADVOCACY

LUNGeVity now serves as the umbrella for the Lung Cancer Support Community (LCSC), an online network for anyone affected by lung cancer. This includes patients, their families, and friends. Free registration includes access to 24-hour online support, a telephone buddy program, a card circle program, and a personal Webpage to “blog your cancer journey.” LCSC has more than 4,000 members and sponsors online chats with specific themes throughout the month, including “Ask the Experts” question and answer sessions.

LUNGeVity also recruits volunteers for Team LUNGeVity. Members organize and/or participate in marathons across the United States. Those who join Team LUNGeVity have access to a special message board to communicate with other participants and receive coaching from national running experts.

## ACHIEVEMENTS & INITIATIVES

In its efforts to promote research, LUNGeVity partners with leading cancer research advocacy groups, such as the American Cancer Society Illinois Chapter, American Lung Association, American Thoracic Society, Goldman Philanthropic Partnerships, and The CHEST Foundation, to provide grants to clinicians and institutions. To date, more than \$5 million has been awarded, funding more than 50 medical projects. LUNGeVity was named the fastest growing charity in the United States in 2009 by Charity Navigator and received a four-star rating for “sound fiscal management” in 2008.

## NAVIGATION & USEFUL LINKS

At the top of the LUNGeVity homepage is a navigation bar connecting to the primary sections of the Website, which include [About Lung Cancer](#), [Research](#), [Events](#), [Newsroom](#), [Lung Cancer Support Community](#), and [Blog](#). At the bottom of the page is a list of upcoming events that visitors can take part in to raise money for lung cancer research. Encouraging people to volunteer in the effort to raise funds for this important work is a key initiative of the LUNGeVity Website. Links to the LUNGeVity social sites on YouTube, Facebook, and Twitter are found on the upper right corner.

The [About Lung Cancer](#) includes subsections like “The Statistics” and “Lung Cancer FAQs” that provide statistics on survival rates, how many men and women have the disease, and answers to common questions. On the left navigation bar are links to [LUNGeVity’s Lung Cancer](#)

[Clinical Trials Matching Service](#), a free, confidential service that matches patients to clinical trials for which they are eligible, and a list of [Patient Advocacy and Support Groups](#) to contact for more information.

Under the [Research](#) tab at the top of the site are links to pages that discuss the goals of the research LUNGeVity has funded and award recipients. At [Events](#), visitors can select their state to find events in their area to participate in, or click on [Calendar](#) to view the full list of events by month. [Team LUNGeVity](#) offers an additional opportunity to raise money for cancer research.

The [Newsroom](#) features links to the latest articles relating to lung cancer and the LUNGeVity Foundation, as well as lung cancer reports published by other organizations. From this page, visitors can also [Sign Up to Receive the Foundation Newsletter](#).

[Lung Cancer Support Community](#) connects visitors to the [Message Board](#), a [Glossary](#) of common medical terms, and the [Light a Candle](#) page to light a virtual candle in memory or in honor of a loved one with lung cancer. The online, live chat, in which patients can communicate with other survivors, can be accessed via the [Enter the Chatroom](#) link. The voices of lung cancer patients and their loved ones are also expressed on the organization’s [Blog](#).

By clicking the [Donate Now](#) button on the homepage, followed by [In Honor/In Memory](#), you can search for specific lung cancer research efforts and make a contribution in honor of your loved one. You can also make general donations or select [Alternative Giving](#) to learn about other creative ways to fundraise for LUNGeVity.



# National Lung Cancer Partnership

www.nationallungcancerpartnership.org

The screenshot shows the homepage of the National Lung Cancer Partnership website. At the top, there is a navigation bar with links for HOME, MARKETPLACE, MEDIA CENTER, NEWSLETTER, and CONTACT US. Below this is a search bar and a secondary navigation menu with links for Who We Are, What We Do, You Can Help, Lung Cancer Info, Events, Chapters, and Donate. The main content area features a large banner for 'Explore Early Stage Treatment Options' jointly presented by the National Lung Cancer Partnership and Research To Practice. To the right of the banner is a paragraph describing the organization's mission. Below the banner are several content boxes: 'Living With Lung Cancer' (with links to educational materials, expert advice, and clinical trials), 'Free Resources' (with links to newly diagnosed information, clinical trials, newsletters, and facts), 'Health Professionals' (with links to grants, events, and resources), and 'Join Us' (with links to become a member, chapters, funding petitions, donations, PSA distribution, and Facebook). On the right side, there is a 'We Are...' section with three sub-sections: 'Funding Research', 'Helping Patients', and 'Raising Awareness', each with a small image and a 'more info >>>' link.

#### ADDRESS:

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Madison, WI 53705

#### CONTACT INFO:

Phone: (608) 233-7905  
Fax: (608) 233-7893  
E-mail: [info@NationalLungCancerPartnership.org](mailto:info@NationalLungCancerPartnership.org)

#### HISTORY & MISSION

Founded in 2001 as Women Against Lung Cancer, this organization became the National Lung Cancer Partnership (NLCP) in 2006 to better reflect the relationship it has forged with physicians, researchers, lung cancer survivors and their families, advocacy organizations, and the media. Lung cancer statistics are dramatic, the odds are overwhelming, and the need to change the status of lung cancer in the United States grows more urgent each day. To that end, NLCP is a nonprofit organization dedicated to decreasing lung cancer deaths and helping patients live longer and better through

research, awareness, and advocacy. NLCP seeks to raise awareness of the deadly effects of lung cancer on both sexes and works to increase funding for lung cancer research, including studies on sex differences in lung cancer. NLCP encourages professionals to participate in lung cancer research, treatment, and care; and, through education, NLCP encourages patients to participate in their treatment.

## PROGRAMS & PATIENT ADVOCACY

NLCP funds research to increase understanding of how lung cancer starts and progresses and to improve detection and treatment for the disease. NLCP provides grants for survivors, patient advocates, and trainees to travel to major scientific and medical conventions, in an effort to extend the lung cancer knowledge base and to network with other advocates and professionals. The organization hosts lung cancer awareness events and performs educational outreach to physicians, allied health professionals, and patients and their families.

NLCP offers telephone workshops featuring leading oncology experts, who provide current information on lung cancer issues for people living with cancer, their families and friends, and healthcare professionals. It also supplies a toll free teleconference series for members of cancer advocacy organizations, survivors, family members, and friends that discusses the National Cancer Institute's important cancer programs and outlines how advocates can get involved.

## ACHIEVEMENTS & INITIATIVES

NLCP collaborates with the Lance Armstrong Foundation, the Oncology Nursing Society Foundation, and the International Association for the Study of Lung Cancer to fund cancer research. In 2008, NLCP announced its first state chapter and is actively working to establish chapters in other states. NLCP supports the Young Investigator Research Grant for junior researchers involved in clinical and basic lung cancer studies.

## NAVIGATION & USEFUL LINKS

The [Lung Cancer Info](#) section includes subsections like [Books](#), which provides overviews on books about lung cancer; [Web Resources](#), with links to major Internet resources; and [FAQs](#) on lung cancer advocacy. It also includes helpful maps, graphs, factsheets, and articles about who is at risk for lung cancer and provides a detailed list of lung cancer symptoms.

In the [You Can Help](#) section, NLCP outlines various ways to raise lung cancer awareness in the community. It asks that people learn the symptoms of the disease and talk to their doctors, help distribute NLCP brochures and educational materials, or organize a community event (luncheon, bake sale, bike ride, run/walk, golf outing) to raise lung cancer awareness. Under [Free to Breathe](#)<sup>®</sup>, you will find a list of runs/walks that NLCP sponsors all across the country to raise money for lung cancer research. The association also asks people to advocate for increased research funding by signing its online petition to Congress or writing a letter to Congressional, state, and regional representatives asking for help. You can further support NLCP by becoming a member, donating a portion of business sales, or purchasing items through the [Marketplace](#) link, found at the top of the Web page.

The [Events](#) subsection provides information about upcoming lung cancer educational and fundraising events. This includes walks, golf tournaments, and marathons sponsored by various organizations. On the right side of every page, visitors will find a link to an inspiring story from a lung cancer survivor or a friend or family member of someone who died from the disease.



# Uniting Against Lung Cancer (formerly Joan's Legacy)

www.unitingagainstlungcancer.org

The screenshot shows the homepage of the Uniting Against Lung Cancer website. At the top, there is a navigation bar with the organization's name, a search bar, and a "Donate now" button. Below the navigation bar, the main content area features a large banner with the text "Funding Lung Cancer Research", "Raising Awareness", and "Finding a Cure". To the right of the banner is a dandelion seed head. Below the banner is a horizontal menu with links for HOME, ABOUT UNITING, RESEARCH, LUNG CANCER RESOURCES, AWARENESS, PARTNERS, GET INVOLVED, EVENTS, and CONTACT US. The main content area is divided into several sections: "Uniting Against Lung Cancer" with a sub-section "Funding Lung Cancer Research" (close to \$10 million in grants), "Raising Awareness" (sharing facts about lung cancer), "Finding a Cure" (research is the key to finding a cure), and "Getting Involved" (the need for research funding is greater than ever). On the right side, there are two promotional boxes: one for a "2010 Strolling Supper with Blues and News" event on Wednesday, November 11, 2010, and another for an NBC News segment where Brian Williams anchors a short film about the organization.

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Suite 304  
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E-mail: Online

## HISTORY & MISSION

Joan's Legacy was named for Joan Scarangelo McNeive, a gifted writer and lifelong New Yorker. McNeive was a nonsmoker who died at age 47 in 2001 after a 9-month fight with lung cancer. The organization recently announced its new name, Uniting Against Lung Cancer (UALC), selected to illustrate how committed the organization is to fighting lung cancer. The group's mission is to fund innovative research and increase awareness of the world's leading cancer killer, with an emphasis on non-smoking-related lung cancer.

## PROGRAMS & PATIENT ADVOCACY

To achieve its vision and mission, UALC affirms six core values: compassion, innovation, collaboration, openness, commitment, and focus. The organization promotes the concept that all patients with lung cancer deserve compassion and support regardless of smoking status.

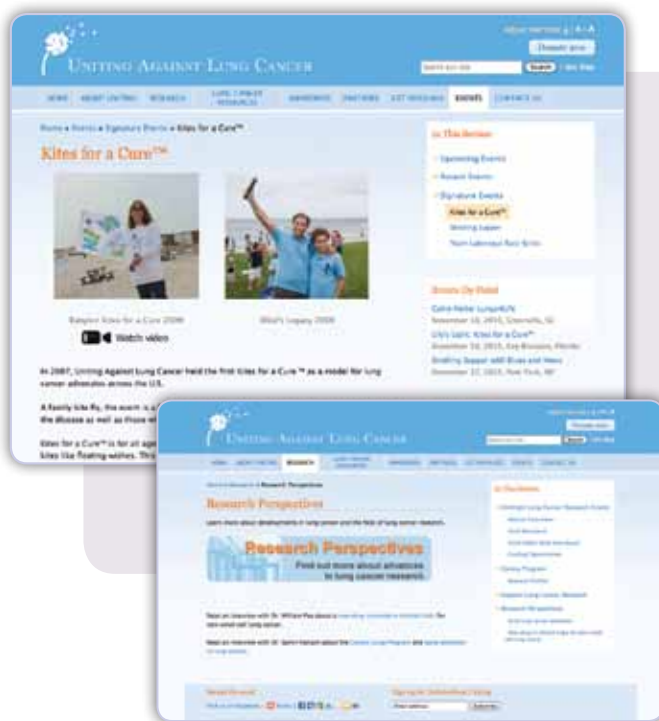
Kites for a Cure is a special way that UALC works to lift people's spirits. This family kite flying event is held at two beachside locales and seeks to fund lung cancer awareness and research efforts. For those interested but unable to participate, UALC accepts donations to sponsor a kite, personalized with your message, that will be flown on your behalf on the day of the event. Even better, UALC provides the donor with a digital photo of the kite in flight that day and offers to ship the kite anywhere in the United States.

## ACHIEVEMENTS & INITIATIVES

Over six years of funding, the organization and its partners have awarded more than \$6 million in direct research grants to individual researchers at top cancer centers. Dedicated to increasing awareness of lung cancer, UALC awards excellence in journalism about lung cancer with its annual Joanie Award. Every November, a journalist whose work "speaks to the issues, dangers, and medical developments about lung cancer," receives a beautiful bronze statue and a \$5,000 financial award. UALC also awards a leading researcher in the fight against lung cancer with the Caine Halter Hope Now Award for Lung Cancer Research. The recipient is awarded \$25,000 to apply toward lung cancer research.

## NAVIGATION & USEFUL LINKS

Categories in the toolbar across the top of the homepage include [Research](#), [Lung Cancer Resources](#), and [Get Involved](#). Selecting a category takes you to a new page that includes a menu of options on the right side of the page. For example, under [Research](#), visitors can select [Medical Committee](#) and [News](#) for a list of upcoming UALC news and events. The page also provides a link to subscribe to the [Breathing Room Newsletter](#). UALC also provides the unique opportunity to read interviews with researchers or Medical Committee members through the [Research Perspectives](#) link.



[Lung Cancer Resources](#) is a valuable section, providing a large list of links to Websites and interactive tools with brief descriptions of the kind of information each site offers. Links to [Lung Cancer Facts](#) and [Patient Resources](#) are also provided, which offers a list of organizations to contact for information and support. Like many patient support groups in the lung cancer community, UALC is working with EmergingMed in support of their efforts to increase patient participation in clinical trials. You will find information and a link to this program at the [Clinical Trials](#) page.

[Get Involved](#) outlines ways that people with lung cancer can work to increase awareness of lung cancer and help further understanding of the needs of people with the disease. Visitors can [Volunteer](#) to help raise funds, [Join Our Mailing List](#), or [Host an Event](#) to start their own fundraiser. Under [Events](#) in the navigation bar on the front page of the Website, you will find [Upcoming Events](#) and [Signature Events](#), such as Kites for a Cure™, a family kite fly event to honor survivors and remember loved ones.

At the bottom of the homepage, UALC provides a link to its Facebook and Twitter communities.

# Lung Cancer Circle of Hope

www.lungcancercircleofhope.org

ADDRESS:  
7 Carnation Drive  
Suite A  
Lakewood, NJ 08701

CONTACT INFO:  
Phone: (732) 363-4426  
Fax: (732) 370-9180  
E-mail: info@lungcancercircleofhope.org

## HISTORY & MISSION

Susan Levin founded the Lung Cancer Circle of Hope (LCCH) in 2006 after her mother Chasia, a nonsmoker, contracted lung cancer and died from the disease. The organization believes those affected by lung cancer, especially patients and survivors, deserve compassion and understanding, regardless of smoking history. Levin says “No one deserves lung cancer, smoker or not.”

LCCH is committed to educating the public and members of the medical community about lung cancer. The organization advocates on behalf of patients, families, and others at risk. It also seeks to influence public policy decisions related to lung cancer and increase funding for lung cancer research. The LCCH sums up its short-term and long-term visions, respectively, as follows: to reduce incidence and mortality rates of lung cancer and to find the cure.

The LCCH has adopted four principles that constitute the framework for all its endeavors: commitment, compassion, collaboration, and focus. LCCH is willing to collaborate with all groups that share its vision.

### PROGRAMS & PATIENT ADVOCACY

Previous programs include Women and Lung Cancer, an educational series that focused on differences in risk factors and treatment for women; sponsorship of local health fairs; and, in partnership with Gilda's Club of North New Jersey, designating January as National Radon Action Month. The Website describes radon as a "leading cause of lung cancer," and its advocacy efforts have included encouraging legislative efforts to regulate radon detection and mitigation in schools, nurseries, and residential buildings.

### ACHIEVEMENTS & INITIATIVES

LCCH works with NJ state, county, and local governments to promote better understanding of lung cancer. An educational symposium entitled *Lung Cancer: Dispelling the Myths, Dispensing the Facts* has been presented in various venues throughout the state and across the nation. LCCH recently announced creation of the Chasia Fund, which will raise money for lung cancer research and awareness.

### NAVIGATION & USEFUL LINKS

Visitors to the Website are met with the declaration "It's not just about smoking! No one is immune." Underneath, the sentence "Every 2 minutes someone is diagnosed with lung cancer" is punctuated with a ticking clock with lungs in the center. The front page also includes links to personal stories and current lung cancer-related news.

The **Lung Cancer Facts** section provides a detailed, biological explanation of the lungs and their operation. It offers statistics on the incidence and mortality rates for various types of cancer, pointing out that although lung cancer is the most common and deadly malignancy, there is less research funding for lung

cancer than for many other types of cancer. This section also provides visitors to the site with a helpful summary of the various histological types of lung cancer.

A subsection called **Risk Factors** details the leading causes of lung cancer, including age, genetics, nicotine use, radon, and exposure to certain chemicals. LCCH explains that although stopping smoking decreases the risk of lung cancer, more than 50% of all lung cancer occurs in former smokers who stopped as many as three decades prior to their diagnosis and the smoking-related risk never disappears completely.

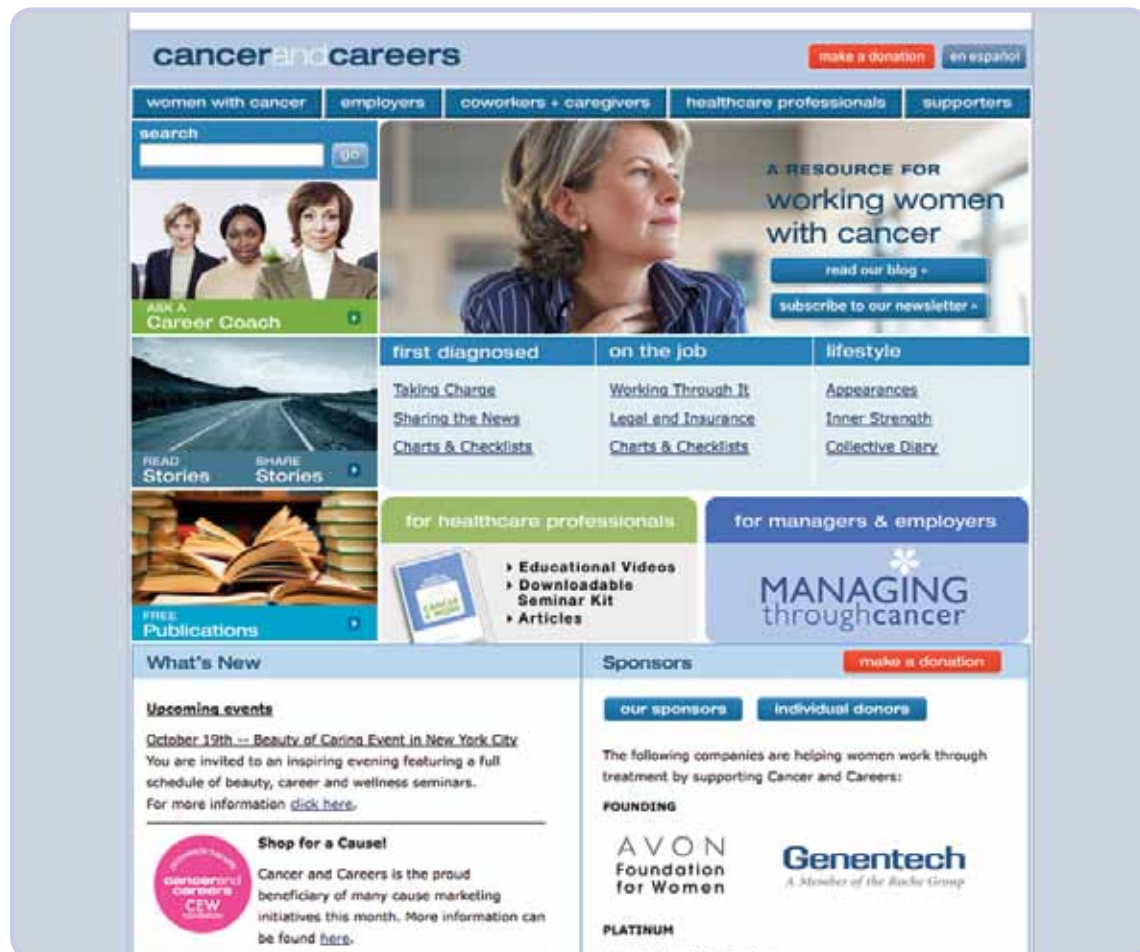
Other subsections include **Symptoms, Diagnosis, Treatment,** and **Clinical Trials.** The **Diagnosis** section offers a detailed explanation of lung cancer testing. The **Treatment** section calls surgery "the gold standard" for potential cure and describes various surgical procedures used to treat lung disease, as well as follow-up treatments, such as chemotherapy and radiation.



On the home page, **Resources** takes visitors to a list of lung cancer-related Websites, with direct links to each one. In addition to sites geared specifically toward lung cancer information, the page includes links to major cancer organizations. The **Donations** section outlines the organization's needs for assistance in its mission of educating the public about lung cancer and supporting efforts to increase research funding. It encourages visitors to help by contributing time, skills, and funds.

# Cancer and Careers

www.cancerandcareers.org



## HISTORY & MISSION

According to the Cosmetic Executive Women (CEW) Foundation, “Work doesn’t stop once you’ve been diagnosed with cancer.” More than 80% of cancer survivors return to work after treatment, and employment becomes even more important. CEW, the charitable arm of Cosmetic Executive Women, Inc, created www.cancerandcareers.org, with a mission to change the face of cancer in the workplace. The free Website is available in English or Spanish and has more than 120,000 visitors annually. Its primary goal is to provide essential tools and information to employees with cancer, but its reach extends to employers, coworkers, and caregivers.

ADDRESS:  
Cosmetic Executive Women  
286 Madison Avenue  
19th Floor  
New York, NY 10017

CONTACT INFO:  
Phone: (212) 685-5955  
Fax: (212) 685-3334  
E-mail: cancerandcareers@cew.org

## PROGRAMS & PATIENT ADVOCACY

This Web-based organization highlights employer programs, including sections covering relevant laws, best practices information for chief executives, and details for human resources departments. Free publications and an educational seminar kit are also available. One of the Website's main components includes advice on how coworkers can help their colleagues with cancer and offers legal and financial planning for caregivers.

## ACHIEVEMENTS & INITIATIVES

A new program was launched in 2009, with the aid of the Avon Foundation, to educate oncology nurses, social workers, and other healthcare providers on how to help patients combine work with cancer treatment. The program was captured on video, and the four-part seminar is housed on the Website for long-term access.

## NAVIGATION & USEFUL LINKS

The site's home page is titled "A Resource for Working Women With Cancer." Main sections include [Women With Cancer](#), [Employers](#), [Coworkers + Caregivers](#), [Healthcare Professionals](#), and [Supporters](#). An online newsletter and the [Ask a Career Coach](#) subsection supply advice on managing your career during and after cancer treatment. Planning tips, communication strategies, and other resources for career development are available, and the site hosts a blog that contributors can use to share career information and recommendations.



[First Diagnosed](#), [On the Job](#), and [Lifestyle](#) sections offer quick connections to information on understanding the cancer diagnosis, creating an action plan, conducting online research, or reading a pathology report. Other useful content areas provide advice on how to handle discrimination at work, taking time off, and reentering the workforce. Important topics include dressing while undergoing cancer treatment, staying physically fit, and selecting skin care products, cosmetics, and wigs.

Visitors to the site can access a virtual toolkit of charts, checklists, questions, and forms to map personal disease progress and navigate employment and hospital systems. Available charts include logs for doctor's office visits, appointments, and prescriptions. Helpful checklists and question sheets, such as [Five Key Questions to Ask Your Doctor](#), and forms for medical and cancer treatment history are also available.



# Cancer Support Community

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

www.cancersupportcommunity.org

The screenshot shows the Cancer Support Community website. At the top, there is a navigation bar with links for 'Expand', 'Orders', 'Events', 'About CSC', 'Site Map', 'Contact Us', and 'For the Media'. Below this is a search bar and a navigation menu with categories: 'Newly Diagnosed', 'Learn About Your Cancer', 'Cancer Survivorship', 'Caring For Your Loved One', 'Get Support Online - Login Now', and 'Donate Today'. The main content area features a 'FRANKLY SPEAKING ABOUT CANCER' section for Lung Cancer. The text reads: 'Learning that you have lung cancer or that someone you love has been diagnosed with lung cancer is very frightening. You may ask yourself, "Now What?" We hope that the information on our website will help you understand as much as you can about your specific case of lung cancer. We also hope that you will feel more confident about what you do if you choose to become an active partner with your health care team, ensure that you have a network of support and learn how to reduce stress and regain hope. Experiencing a renewed sense of hope, no matter what stage of cancer you have, is invaluable.' Below this, it lists common questions for newly diagnosed patients, such as 'How serious is my cancer?' and 'How do I find the best medical team?'. A sidebar on the right offers 'Connect with us' via social media, a 'Lung Cancer' resource menu, and a search for local community affiliates.

## 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."

### ADDRESS:

1050 17th St. NW  
Suite 500  
Washington, DC 20036

### CONTACT INFO:

**Phone:** (202) 659-9709  
**Fax:** (202) 659-9301  
**E-mail:** help@cancersupportcommunity.org

## PROGRAMS & ACHIEVEMENTS

Having cancer can be isolating, but it does not have to be. The focus of the Cancer Support Community is to provide no-cost access to support groups, ensuring that no one faces cancer alone. The organization welcomes all cancer survivors and caregivers, regardless of disease type or stage and regardless of whether they received a diagnosis a few hours ago or a few decades ago. The Cancer Support Community support groups, educational workshops, nutrition and exercise programs, and stress reduction classes are led by professionals trained in working with people with cancer. Patients and families learn vital skills that enable them to regain a sense of control, rediscover hope, and feel more secure.

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. 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 – Login Now**. Selecting one of these opens up a new page, with a gray box on the right containing expandable links for each section.

The **Learn About Your Cancer** dropdown menu provides several links, including **Type of Cancer**, which takes you to a page where you can find information on lung cancer. From there, you can find information on **Understanding Lung Cancer**, **Managing Side Effects**, **Social and Emotional Concerns**, and even what to expect when treatment is finished.



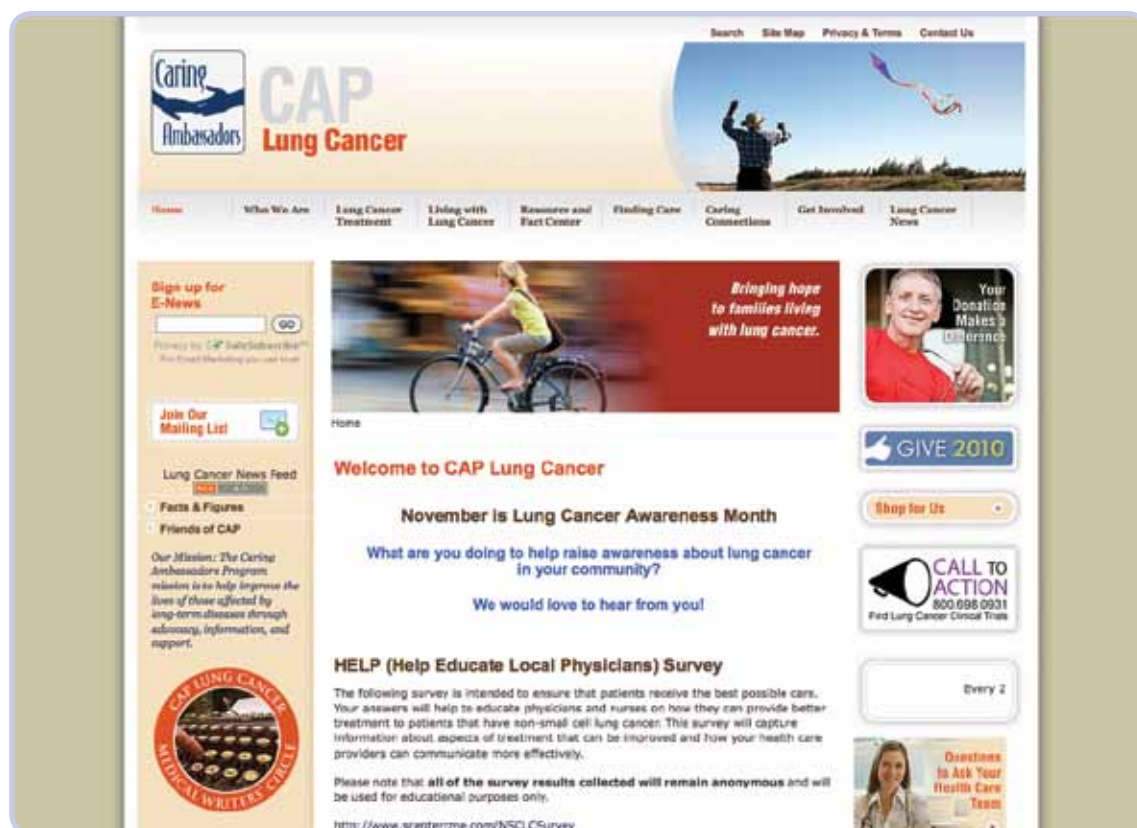
Going to **Get Support Online – Login Now** opens up a portal to the Online Social Network, where registered members share their experiences with one another, blog, or use instant messaging; registration is free. You can also sign up for a scheduled online support group, based on your situation or diagnosis. From the home page of the Website, under **Our Communities**, you can also select a community specific to **Patients**, **Caregivers**, or **Teens**. Teens are redirected automatically to Group Loop ([www.grouploop.org](http://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 CEO of the Cancer Support Community; and the organization’s official **CSC Blog**, which keeps visitors up-to-date on important cancer news.

The **Frankly Speaking About Cancer: Lung Cancer** page provides a plethora of informational resources specifically for patients with lung cancer. To access this section, scroll over **Learn About Your Cancer** on the homepage’s main menu bar and click **Type of Cancer**. When the next page comes up, click **Lung Cancer** in the gray sidebar on the right-hand side of the page.

# Caring Ambassadors Lung Cancer Program

[www.lungcancer.org](http://www.lungcancer.org)



ADDRESS:  
P.O. Box 1748  
Oregon City, OR 97045

CONTACT INFO:  
Phone: (503) 632-9032  
E-mail: [cindy.langhorne@lungcancer.org](mailto:cindy.langhorne@lungcancer.org)

## HISTORY & MISSION

The Caring Ambassadors Program's (CAP) focus on disease-specific challenges began in 1997 with its first initiative, the Caring Ambassadors Lung Cancer Program (CAP Lung Cancer). The stated goals of CAP Lung Cancer are to address the informational needs of people living with lung cancer and their loved ones; provide compassion and support to those facing the many challenges of lung cancer; increase lung cancer awareness to augment the priority of lung cancer on local, state, and national health agendas (both public and private); and bring hope to families living with lung cancer. CAP strives to uphold the positive, proactive approach of founder Ken Giddes, who survived with stage IV lung cancer for over four years.

## PROGRAMS & PATIENT ADVOCACY

Beyond its wealth of informational resources and plethora of additional support links, CAP Lung Cancer offers its own programs and advocacy efforts. The organization encourages people to become Caring Ambassadors, whereby individuals coordinate a fundraising or advocacy project with CAP Lung Cancer. The Constellation of Love Quilt—sewn by a 5th grade class and donated to CAP Lung Cancer in 2005—is lent out to inspire hope at lung cancer events and projects throughout the country. CAP Lung Cancer also started a letter-writing campaign that facilitates correspondence with public officials aimed at directing public health and media discourse to lung cancer.

## ACHIEVEMENTS & INITIATIVES

*Faces of Lung Cancer* is a compilation of photographs and stories from patients, caregivers, and healthcare providers discussing lung cancer diagnoses and clinical trial participation. The Thoracic Oncology Program at the Moffitt Cancer Center in Tampa, Florida, and photo-documentarian Beth Reynolds collaborate on the book. A portion of its proceeds benefits CAP Lung Cancer.

## NAVIGATION & USEFUL LINKS

The center of CAP Lung Cancer's busy home page welcomes visitors with a bulleted list of the organization's goals and a hyperlinked aggregation of the week's lung cancer news stories. Two sidebars bookend this information with quick links to some of the site's features, including an E-News signup, lung cancer facts and figures, and a guide to getting the most from your treatment team. The site's main menu bar rests atop the home page beneath the CAP Lung Cancer logo and an inspirational image.

The menu bar displays the site's eight sections: **Who We Are**, **Lung Cancer Treatment**, **Living with Lung Cancer**, **Resource and Fact Center**, **Finding Care**, **Caring Conditions**, **Get Involved**, and **Lung Cancer News**. These sections offer educational information, links to additional support, and descriptions of CAP Lung Cancer programs.

**Living with Lung Cancer** details both conventional and alternative treatment and supportive care options. Its **Kids' Corner** subsection offers advice on discussing cancer with children.

In addition to background information and links, **Resource and Fact Center** contains **CAP Publications**. CAP literature includes the *Choices & Hope* CAP Lung Cancer newsletter and the **Medical Writers' Circle**. The latter consists of a monthly article dedicated to giving patients hope and helping them make informed treatment decisions.

**Caring Connections** offers a variety of ways to honor patients with lung cancer. **Kids Coloring Pages** provides nine downloadable pictures to help children express their concern for a loved one. The **E-cards** section allows users to send inspirational electronic messages. Other sections post reflections, tributes, and stories of hope.

**Get Involved** rallies the public to CAP Lung Cancer's cause with information on **Becoming a Caring Ambassador**. The section's other primary call to action is a **Lung Cancer Letters** campaign.



# GRACE: Global Resource for Advancing Cancer Education

www.cancergrace.org

The screenshot shows the GRACE website homepage. At the top, there is a navigation bar with links for 'About Us', 'Support GRACE', 'Find Info About', 'FAQ', 'Events & Publications', 'Contact Us', 'Store/Cart', and 'Text Size'. The main content area features a video player for a Discovery Channel CME program titled 'Discovery Channel Lung Cancer Program: Catch It Online'. Below the video, there is a section for 'Newest Content' with three columns: 'Latest Grace Posts', 'Latest Comments', and 'Latest Forum Posts'. The right sidebar contains a search bar, a 'FORUMS' section, a 'STAY CONNECTED' section with social media icons, and a 'OUR SUPPORTERS' section with a 'Thank You to Our Supporters' message. At the bottom of the sidebar, there is a 'SYNDICATION' section with a 'Subscribe' button and a 'Signup for the GRACE newsletter' button.

## History & Mission

The nonprofit Global Resource for Advancing Cancer Education (GRACE) is primarily an online community dedicated to providing expert-mediated information on cancer care to patients and health professionals. GRACE seeks to empower patients to become informed, active participants in their medical care. To facilitate GRACE's mission, its medical faculty works to disseminate information on the latest research as timely as possible. Seattle-based oncologist Dr. Howard West founded GRACE in 2007, to ensure that patients and their families had access to a high-quality, credible resource for cancer information.

ADDRESS:  
501 N 34th Street  
Suite 201  
Seattle, WA 98103

CONTACT INFO:  
Phone: (888) 501-1025  
E-mail: info@cancergrace.org

## Programs & Patient Advocacy

The GRACE forums boast nearly 6,000 registered members and thousands of messages. As a complement to its vibrant online community and wealth of resources, GRACE recently introduced a community outreach program, with the goal of promoting face-to-face interaction between patients, caregivers, and oncology experts. Although most scheduled events take place in the Seattle area, others are interactive online events, available to everyone.

GRACE is supported by individual donors and also raises funds through the Create a Tribute program. In exchange for a donation, GRACE provides space on the Website for individuals to write a dedication to a loved one who succumbed to cancer or express appreciation for a valued caregiver or healthcare provider. The names of supporters scroll continuously in the navigation bar featured on the right side of every page.

## Achievements & Initiatives

Since GRACE's formation in 2007, it has grown from a staff of one oncologist (Dr. West) to nearly 20 healthcare professionals and one rotating guest expert. The recognition of GRACE as a trustworthy provider of quality information has contributed to a steady increase in visitors; GRACE receives more than 15,000 unique visitors per month who come from at least 100 different countries. The Lance Armstrong Foundation (LAF) recently commended GRACE in a letter of support, with its vice president of Programs and Policy for the Foundation describing GRACE as a "valuable resource to cancer survivors and healthcare professionals."

## Navigation & Useful Links

The GRACE Website is easy to navigate, but those who need a little help finding their way around will find the [GRACE Website Tutorial](#) a useful resource. It provides a comprehensive, illustrated overview of how to navigate the heart of the GRACE community: its forums. To reach the forums, patients can submit a question to the GRACE faculty by navigating to [Ask a question about](#) and selecting their topic from the drop-down menu on the right of the home page. This takes you to a registration/login screen before redirecting you to the appropriate forum. If you would prefer to browse the forums without registering, select [Forums](#) from the home page. Once there, you can read patients' experiences at [Share Your Success Story](#) or learn all the basics about cancer, including [Survivorship and Follow-up](#) issues, [Clinical Trials and Drug Development](#), and [Oncology Economics/Industry](#)



[Health Care Policy](#). Other forums offer opportunities to share [Patient Experiences](#), discuss [Treatment-Related Side Effects](#), and learn about existing and emerging cancer therapies. One section focuses exclusively on lung cancer, with sub-forums for the various types of lung cancer, [Screening/Prevention](#), [Lung Cancer Complications](#), and even [Smoking Cessation](#). You will also find multiple forums on different aspects of radiation therapy, managing the psychological aspects of cancer, and complementary and alternative therapies. Dr. West and other medical faculty at GRACE are active participants in the forums, jumping in to answer patients' questions or to provide their perspective on a particular issue. On the home page of the GRACE Website, you will find titles with links to the most recent forum posts, GRACE posts, and the latest comments, providing quick access to whatever piques your interest.

Under [Find Info About](#) in the navigation bar at the top, visitors can access some of the faculty's recent forum posts, presented in blog form and sorted by topic. The [Glossary of Terms/Abbreviations](#) found in the [FAQ](#) menu is an invaluable read before joining in at the forums. To get a sense of how much GRACE's many visitors value the community, read the testimonials in the [Guestbook](#), located under the [Contact Us](#) tab. Here, you can also leave comments or suggestions for the site administrators. Under [Contact Us](#), you can also [Suggest a Topic](#) that you would like to see discussed at GRACE.

Don't forget to [Signup for the GRACE newsletter](#), which you can do from the navigation bar on the right of the Website. You can also follow GRACE on Twitter, Facebook, and YouTube by clicking on the appropriate icon in the "Stay Connected" section.

# Lance Armstrong Foundation

www.livestrong.org

**LIVESTRONG** GET HELP TAKE ACTION WHAT WE DO WHO WE ARE DONATE SHOP BLOG LOG IN

We fight to improve the lives of people affected by cancer.

Search

## MAKE YOUR VOICE COUNT

WE'RE BRINGING THREE GREAT PROGRAMS TO COMMUNITIES ACROSS THE COUNTRY AND YOU GET TO DECIDE WHERE THEY GO

VOTE NOW

### GET HELP

Need support for yourself or a loved one? We can help you handle the challenges and changes of cancer survivorship, head-on.

- GET ONE-ON-ONE SUPPORT
- LEARN ABOUT CANCER
- FIND MORE RESOURCES
- EN ESPAÑOL
- SEE ALL >

### TAKE ACTION

Find out how you can get involved in the fight against cancer with LIVESTRONG — online or on the streets.

- VISIT LIVESTRONG ACTION
- FIND TEAM LIVESTRONG EVENTS
- LEARN ABOUT LIVESTRONG LEADERS
- SEE ALL >

WHAT WE DO FROM THE BLOG HEADLINES

ADDRESS:  
2201 E. Sixth Street  
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.

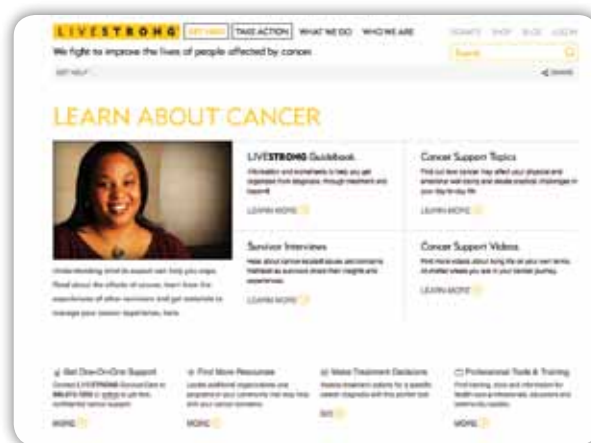
## PROGRAMS & ACHIEVEMENTS

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, “We fight to improve the lives of people affected by cancer.” 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 [Who We Are](#), 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 [Get Help](#) displays a menu of resources for cancer survivors, such as the [Get One-On-One Support](#) section and the [Learn About Cancer](#) section, which includes the worksheets and guidebook. The [Find Clinical Trials](#) link in the [Get One-on-One Support](#) section helps patients locate clinical trials, using the LIVESTRONG Cancer Clinical Trial Matching Service. [Make 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.

LAF challenges everyone to [Take Action](#). This might be through [Grassroots Fundraising Event](#), posting on the [LIVESTRONG blog](#), or participating in the [LIVESTRONG Challenge Series](#).



# lungcancer.org

(a program of CancerCare)

www.lungcancer.org

INFORMACION EN ESPAÑOL TELL A FRIEND CANCERCare E-NEWS

lungCANCER.org  
a program of CANCERCARE®

FOR HELP, CALL 1-800-813-HOPE (4673) OR EMAIL INFO@CANCERCARE.ORG

About Us Get Help Lung Cancer 101 In The News Support Us

I am a person with lung cancer.

I am a loved one or a friend.

I am a healthcare professional.

**what's new** at lungcancer.org

**New E-Booklet**  
Our Connect® booklet *Communicating with Your Health Care Team* is now available.

**Clinical Trial for NSCLC Currently Recruiting**  
Over 400 medical centers in more than 33 countries are participating in the largest Phase III trial ever conducted in non-small cell lung cancer. The goal of the clinical trial is to prevent recurrence in previously treated patients.  
[Learn more...](#)

**Virtual Wall of Hope**  
Celebrate survivors and honor loved ones who have faced lung cancer at CancerCare's [Virtual Wall of Hope](#).

**calendar** at a glance

**Calendar of Events**

From the Ask CancerCare archive:  
[Lung Cancer](#)

Upcoming Connect Education Workshops:

- [For Caregivers: Coping with a Loved One's Cancer During the Holidays](#) (Dec. 12)
- [Understanding and Managing Chemotherapy Side Effects](#) (Jan. 21)

Connect Education Workshop Podcasts:

ADDRESS:  
275 Seventh Avenue  
Floor 22  
New York, NY 10001

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

## HISTORY & MISSION

Lungcancer.org was created in 1998 by CancerCare to help patients with lung cancer and their families. CancerCare is a national nonprofit organization and a leading online resource for cancer information. Initiatives such as lungcancer.org help CancerCare address the specific needs of individual patients. Lungcancer.org establishes a central hub for CancerCare's lung cancer assistance programs while simultaneously extending access to all of CancerCare's valuable resources.

## PROGRAMS & PATIENT ADVOCACY

Lungcancer.org partnered with five patient advocacy organizations to implement the Lung Cancer Clinical Trial Call to Action. The initiative provides educational resources to engender and facilitate patient-doctor discussions on clinical trials. The program's Lung Cancer Clinical Trial Matching Service identifies optimum clinical trial options based on a patient's diagnosis, stage, and treatment history.

The Virtual Wall of Hope compiles and displays posts celebrating lung cancer survivors and remembering individuals who battled lung cancer. A scroll bar beneath the Wall enables individuals to navigate through the messages of inspiration and remembrance. All visitors are welcome to create their own post.

## ACHIEVEMENTS & INITIATIVES

Lung cancer patients struggling with medical bills are directed by lungcancer.org to the CancerCare Co-Payment Assistance Foundation. The need-based program helps patients with cancer afford their insurance and drug copayments. Patients receive partial or full coverage of essential services and treatments.

The CancerCare 7th Annual Lung Cancer Walk in November 2009 raised more than \$200,000 for CancerCare's National Lung Cancer Program. Close to 1000 individuals participated in the event.

## NAVIGATION & USEFUL LINKS

The top of lungcancer.org's home page features its lamp logo, which represents warmth, comfort, and hope. A helpline number, email address, and E-News signup appear to the right of the logo. The main menu bar appears directly below this information. Clicking on [Get Help](#) allows visitors to peruse categories on [Counseling](#), [Support Groups](#), [Publications](#), and [Financial Help](#). [In the News](#) provides links to the latest cancer headlines.

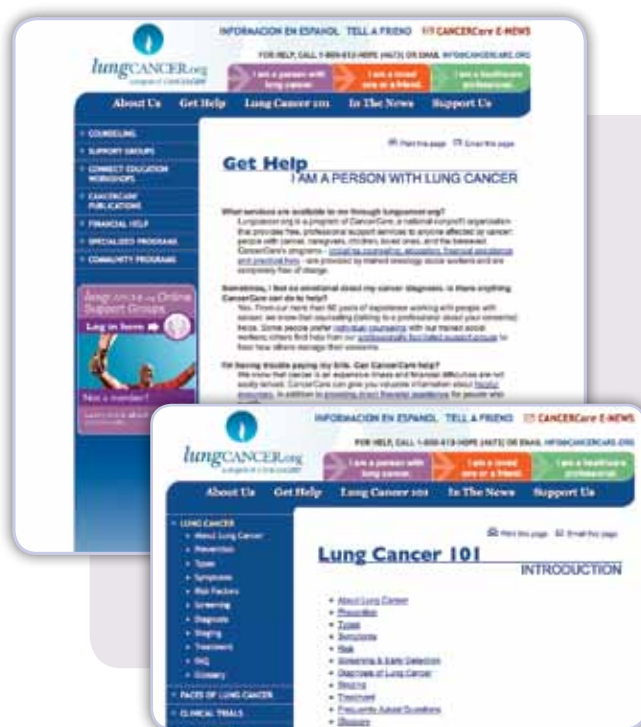
[Lung Cancer 101](#) is the site's primary resource page. The link appears in the center of the menu bar. This section provides a lung cancer glossary, answers to frequently asked questions, and educational resources. Informational subsections include [Prevention](#), [Types](#), [Symptoms](#), [Risk](#), [Screening & Early Detection](#), [Diagnosis of Lung Cancer](#), [Staging](#), and [Treatment](#). [The Faces of Lung Cancer](#) page allows individuals to share coping mechanisms and stories of hope. [Clinical Trials](#) includes

[Pros & Cons](#), [Questions to Ask](#), and [Find Trials](#) pages. At [Lung Cancer 101](#), visitors can also access publications and resources in Spanish and online support groups.

Images below the home page menu bar link users to three sections filled primarily with CancerCare resources: [I am a person with lung cancer](#), [I am a loved one or a friend](#), and [I am a healthcare professional](#). In the first two sections, visitors can review frequently asked questions about the organization; access free educational programs and publications about cancer; 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.

Two additional sections fill out the home page.

[What's New at lungcancer.org](#) provides links to major initiatives, including the e-booklet, *Communicating with Your Health Care Team*, and the Virtual Wall of Hope. [Calendar at a Glance](#) details upcoming events and provides links to CancerCare's Connect Education Workshop Podcasts.



# Patient Advocate Foundation

www.patientadvocate.org

The screenshot shows the Patient Advocate Foundation website. At the top, the logo 'PAF Patient Advocate Foundation' is displayed in blue and orange, with the tagline 'Solving Insurance and Healthcare Access Problems | since 1996'. A navigation menu includes links for Home, Get Help, Patient Services, Resources, Press Room, Events, Meet PAF, Get Involved, Careers, and Donate. A search bar and contact information (1-800-532-5274) are also visible. The main content area features a large banner with the text 'UNDERinsured? FIND THE MISSING PIECES' and 'National UNDERinsured Resource Directory'. To the right, 'Our Mission' is stated: '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.' Below this, it lists assistance for 'Medical Debt Crisis', 'Insurance Access Issue', and 'Job Retention Issues'. Three circular icons represent communication, email, and a person. The lower section is divided into three columns: 'ACCESS' with a form for 'Access to Medical Devices', 'EDUCATE' with a 'PAF Publications' dropdown and a 'Submit' button, and 'PROGRESS' with a list of recent news items and social media links for Facebook and YouTube.

ADDRESS:  
421 Butler Farm Road  
Hampton, VA 23666

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

## 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 like prostate cancer. 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.

## PROGRAMS & ACHIEVEMENTS

The Co-Pay Relief Program ([www.copays.org](http://www.copays.org)) 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. In addition to patients with prostate cancer, the program assists insured patients being treated for breast, lung, lymphoma, 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 the yearly Patient Congress ([www.pc.patientadvocate.org](http://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 features 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 **Get 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 Related Resources**, **The National Underinsured Resource Directory** (for patients who have health insurance but still struggle to meet their out-of-pocket costs), **Employment-Related Information**, and the **National Financial Resources Guide** (a state-by-state directory of information for patients seeking financial relief for housing, utilities, food, transportation to medical treatment, etc.).

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, including those with lung cancer.



# Additional Resources



## Addi's Cure

[www.addiscure.org](http://www.addiscure.org)

Bo and Christi Johnson started Addi's Cure in 2006 following Bo's stage IV lung cancer diagnosis. Addi's Cure, named after the couple's daughter, holds events and fundraisers for lung cancer research. The Website provides background information on lung cancer and links to additional resources. Christi maintains the patient's journey blog Bo began immediately following his diagnosis.



## American Association for Cancer Research

[www.aacr.org](http://www.aacr.org)

The American Association for Cancer Research's (AACR) Survivor and Patient Advocacy Program strengthens communication and supports collaboration among cancer survivors, patient advocates, and scientists. AACR launched a clinical trial awareness campaign in 2008. AACR's Website provides stories and interviews with patients regarding their clinical trial experiences. Site visitors will find cancer fact sheets and information on obtaining financial aid and advice. The site also includes a science and advocacy education series and AACR webcasts and podcasts.



## American Cancer Society

[www.cancer.org](http://www.cancer.org)

The American Cancer Society (ACS) is a nonprofit, national organization devoted to eliminating all types of cancers. The Choose a Cancer Topic drop-down menu allows visitors to find information on specific lung cancer diagnoses, including non-small cell lung cancer, small cell lung cancer, and lung carcinoid tumor. Articles cover a range of issues, from key statistics about lung cancer to treatments to postoperative plans. ACS has more than 3400 affiliates nationwide.



## American Lung Association

[www.lungusa.org](http://www.lungusa.org)

The American Lung Association's (ALA) comprehensive Website allows registered users to customize their view of site content through My LungUSA. The site's Lung Cancer page includes sections entitled Making Treatment Decisions, Social Support, and Management Tools. The latter offers a program that allows users to enter data and receive a personalized treatment-options report tailored to their diagnosis. The report outlines the pros and cons of various treatments, suggests questions to ask physicians, and provides summaries of relevant clinical studies. Other useful ALA features include a Lung HelpLine and E-Newsletter.



## The Beverly Fund

[www.beverlyfund.org](http://www.beverlyfund.org)

This national nonprofit organization works to increase awareness of lung cancer, educate and support patients, and fund research. The Website provides Facts & Statistics about the diagnosis, staging, and treatment of lung cancer (in English and Spanish); a description of Clinical Trials; and patient stories under Discover the Truth. Under Get Involved, you will find links to pending legislation concerning cancer and information on contacting your legislative representatives. The Beverly Fund maintains a Facebook community and a Twitter account.



## Brittany's Battle

[www.brittanybattle.org](http://www.brittanybattle.org)

Brittany's Battle honors Brittany Coppedge's battle with lung cancer. The Website provides both an online and downloadable application for patient assistance, including financial support. Site visitors will find educational information, support links, and updates on Brittany's Battle's unique advocacy and fundraising events. The organization's 2009 efforts produced several donations supporting families at the University of North Carolina Lineberger Comprehensive Cancer Center.



## International Association for the Study of Lung Cancer

[www.iaslc.org](http://www.iaslc.org)

The International Association for the Study of Lung Cancer (IASLC) is an organization of physicians and healthcare professionals dedicated to promoting the study of lung cancer and disseminating lung cancer information. In this endeavor, the IASLC awards fellowships, supports workshops, and holds biennial world conferences. Visitors to the Website will find podcasts and videos from leading experts discussing the latest lung cancer research.



## Kate MacIntyre Foundation

[www.katemacintyrefoundation.com](http://www.katemacintyrefoundation.com)

The Kate MacIntyre Foundation's advocacy efforts emphasize the significant number of nonsmokers diagnosed with lung cancer. Kate, a nonsmoker, recognized the need to raise funds and awareness supporting early detection tests and effective clinical trials. The organization supports programs at the University of North Carolina Lineberger Comprehensive Cancer Center that promote patient advocacy, encourage clinical trial participation, and educate young women interested in the healthcare profession. The Website tells Kate's story, details advocacy efforts, and lists additional resources.



## Linda's Legacy Foundation

[www.lindaslegacyfoundation.org](http://www.lindaslegacyfoundation.org)

Linda's Legacy Foundation, a Florida regional nonprofit, primarily raises funds through a women's doubles tennis tournament. All tournament proceeds directly benefit northeast Floridians affected by lung cancer. The Foundation prioritizes women's lung cancer in memory of Linda Paul-Skeeles. It hopes the tournament's publicity continues to raise awareness and generate funds for lung cancer research.



## Lung Cancer Online Foundation

[www.lungcanceronline.org](http://www.lungcanceronline.org)

Karen Parles created The Lung Cancer Online Foundation (LCOF) shortly after receiving a lung cancer diagnosis and became a passionate advocate for patients with lung cancer. Inspired by Karen's passion and dedication, LCOF operates a research grant program and maintains a supportive Web presence. Its comprehensive site has been described as offering "one-stop shopping directories" with links categorized according to every practical and emotional concern of people affected by lung cancer. LCOF also provides its own educational material for patients and survivors of lung cancer.



## Mesothelioma.org

[www.mesothelioma.org](http://www.mesothelioma.org)

Patients with a diagnosis of mesothelioma, an asbestos-related lung cancer, have unique concerns. While Mesothelioma.org is not a nonprofit organization, the Website provides comprehensive information on treatment options, a list of mesothelioma specialists and cancer centers, advice on managing your care, and links to mesothelioma research news. Mesothelioma.org offers a free packet of information via mail.



## Respiratory Health Association of Metropolitan Chicago

[www.lungchicago.org/lung-cancer](http://www.lungchicago.org/lung-cancer)

The Respiratory Health Association of Metropolitan Chicago launched its Lung Cancer Initiative in 2005 in response to the disease's major impact on the Chicago community. The Website offers an Understanding Lung Cancer informational page, support links, and a clinical trials section with a phone contact. The Lung Cancer Library section's downloadable fact sheets cover a range of topics in English and Spanish, including Mesothelioma. Contact information is provided for local support groups and cancer resource community centers.



## Rexanna's Foundation for Fighting Lung Cancer

[www.rexannasfoundation.org](http://www.rexannasfoundation.org)

Rexanna's Foundation for Fighting Lung Cancer serves as a testament to Rexanna Hawkins's courageous lung cancer battle. The Website outlines the Foundation's advocacy efforts and highlights ways to get involved. The Foundation also awards college scholarships to students affected by cancer. Other notable efforts include providing grants for lung cancer research at the University of Texas M. D. Anderson Cancer Center; sponsoring a partial fellowship in thoracic oncology; supporting publication of a cancer booklet for new patients and creation of a comprehensive database of patients with thoracic cancer; and providing lap prayer blankets to individuals with lung cancer.



## *With Every Breath: A Lung Cancer Guidebook*

[www.lungcancerguidebook.org](http://www.lungcancerguidebook.org)

The main purpose of this site is to allow visitors to download or view chapters of *With Every Breath: A Lung Cancer Guidebook*, written for individuals with a recent lung cancer diagnosis and their loved ones. The book is provided at no cost by author Tina M. St. John, MD, whose husband died of non-small cell lung cancer in 1998. The book is for informational purposes and is not a substitute for medical advice.







## Helping to make access to the therapies you need easier

Novartis Oncology is committed to helping patients living with cancer receive the medicines they need. **Patient Assistance NOW Oncology** offers quick and easy access to information about the many reimbursement and support programs available.

You can get information about our **Patient Assistance NOW Oncology** support programs in two ways:

- Call **1-800-282-7630** to speak to one of our knowledgeable staff dedicated to making access to our programs as simple and convenient as possible; or
- Visit our web site at: **[www.PatientAssistanceNow.com/oncology](http://www.PatientAssistanceNow.com/oncology)**

### Support for Patients Includes:

- Insurance verification
- Medicare education
- Assistance with denials/appeals
- Therapy-specific support programs for out-of-pocket costs
- Assistance searching for other sources of coverage/funding that could alleviate or reduce costs for patients.
- Referrals to Independent Charitable Foundations for assistance with co-pay costs
- Patient assistance for low-income and uninsured patients
- Patients pre-qualified via phone screening for the Patient Assistance Program (PAP) will be sent a 30-day supply of their needed medication while completing the application



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ONC-1006918

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