

# Voice

## Improving Access to Treatment for Lung Cancer Patients



What happens when a person receives a diagnosis of lung cancer? In the best of cases, the individual is counseled on all their treatment options – including treatment appropriate for their stage of disease, palliative care, clinical trial availability, resources for financial or emotional support, and anything else pertinent to their new way of life. Too often, however, we hear of people who are given their diagnosis and never referred for treatment. Rather, they are told, “Get your affairs in order,” or, “There’s nothing I can do for you.” Research has shown that only 30-40% of stage IV lung cancer patients receive chemotherapy—a treatment that is likely to improve their survival and quality of life. While some stage IV patients may not be able to receive chemotherapy (for example, if they have

significant other lung or heart disease), it is likely many patients simply aren’t given the opportunity to receive chemotherapy. We want to verify and better understand what the delays to treatment are so we can create effective programs for health care providers to improve patient care. We firmly believe with the treatment options we have available today, appropriate and timely referral to the right care should improve survival statistics.

The National Lung Cancer Partnership has initiated a unique collaboration with the University of Wisconsin-Madison, the University of North Carolina, our North Carolina Chapter, and Healthcare Performance Consulting to address these issues head-on. This project, dubbed Improving Access to Treatment for Lung Cancer Patients (AccessTLC), will measure the time it takes for lung cancer patients to receive appropriate care in Wisconsin and North Carolina, states representing the low and the high ends of lung cancer incidence, respectively. We will also uncover reasons behind treatment delays, such as patients not calling a specialist vs. patients never being referred to a specialist. Then, we will use this information to launch comprehensive educational outreach activities to improve the care patients receive throughout the country. We are grateful for

an educational grant from Pfizer, which is making the first part of this project possible.

The driving force behind everything we do at the Partnership is hope: hope for an improved outlook for the person facing lung cancer, hope for a longer, better life after diagnosis and hope for the families who have lost loved ones who wish for others not to be so tragically affected. It is with this hope that we embark on this ambitious project to help fulfill our mission of decreasing deaths due to lung cancer and helping patients live longer and better lives.



### Announcing the Louisiana Lung Cancer Partnership!

We are extremely pleased to welcome the Louisiana Lung Cancer Partnership as our third State Chapter! To read more about the Louisiana Lung Cancer Partnership, please turn to page 6.

## November is Lung Cancer Awareness Month Stopping Lung Cancer Starts with You: Research is Key

We continue to be inspired by people who have faced lung cancer and continue to live their lives, like Stephanie, profiled on page 4. Stephanie’s survival - and thriving - has been made possible by research advances leading to new therapies and ways to improve cancer survivors’ quality of life.

You can play an important role in improving the lives of people like Stephanie. Your donations are used to fund the early-stage research leading to clinical trials—and survival. Research funded by the Partnership will provide the basis for new treatments,

diagnostic tests and screening methods that will touch families around the world.

This November, please help us fund research that saves lives. Each life saved begins with a single donation, made by someone like you.

**Please donate today** – visit [www.NationalLungCancerPartnership.org](http://www.NationalLungCancerPartnership.org), or mail your tax-deductible donation in the pre-addressed envelope enclosed.

**Our work can’t continue without you!**

### Inside:

Letter from our President:  
Joan H. Schiller, MD

Advancing Lung Cancer Research:  
National Lung Cancer Partnership’s  
2010 Annual Meeting

Stories of Strength:  
Survivor, Stephanie Dunn Haney  
Physician, Suresh Ramalingam, MD

Patient Point of Interest:  
Recent Updates in Lung Cancer  
Research: What They Mean for You

Partnership Events and Updates:  
**Free to Breathe**®, Advocates in Action,  
Welcome to our Louisiana Chapter

Research, Awareness and **Change**  
Clear Future Society Planned  
Giving Program, Memorial Gifts

# Letter from the President



Joan H. Schiller, MD

As we look towards the end of 2010 and complete our next three-year planning phase, we wanted to share with you how we are meeting our goals of raising awareness of lung cancer, increasing

funding for lung cancer research, and improving patient care through patient and provider education and empowerment.

## Raising Awareness

The Susan G. Komen Foundation's Race for the Cure events are a household name, with over 100 events bringing in \$120 million annually for breast cancer research. We have a lot to learn from their success as we enter the 6th season of our **Free to Breathe**® event series. In 2011, the Partnership will hold about 40 walks, runs, yogathons and golf outings across the nation. In comparison, Race for the Cure took 12 years to get to 57 events. We will reach that point with **Free to Breathe**® by 2013 in only an eight-year time span. Through increasing event participation and the incredible media attention the events garner, we are achieving our goal of raising awareness of lung cancer among the public.

The opportunity for grassroots awareness-building is tremendous. We are so grateful to the groups of individuals who have spearheaded events and programs within their communities to form our North Carolina, Pennsylvania, and now Louisiana Chapters of the National Lung Cancer Partnership (see page 6 for more information). The purpose of the Chapter program is to provide a framework for grassroots advocates to come together and truly make a difference in lung cancer awareness, research funding and education in their communities. If there's not yet a Partnership Chapter near you, please contact our national office to be connected with other advocates in your area. Or better yet, meet them in person at our annual Lung Cancer Advocacy Summit, scheduled for April 28-May 1, 2011, in Denver, CO.

## Increasing Research Funding

It's a cycle – we need to make money to fund research; the more money we bring in, the more research we can fund. This year, we will surpass \$2 million in total research supported since 2005. Researchers we've supported have gone on to receive additional research funds from the Department of Defense, the National Cancer Institute, the

American Cancer Society and other funders, showing the investments we've made have been strategic in achieving progress in lung cancer research. We want to be able to fund many more researchers – and we will – with the support of everyone who wants to see progress in lung cancer screening, diagnosis, treatment and care.

## Improving Patient Care

On the front page, you've learned about our newest program, AccessTLC, which is designed to improve patient care by reducing the time it takes for patients to get from diagnosis to treatment. This large undertaking promises to create the beginning of change we need to see in lung cancer care to ensure all patients are provided the comprehensive treatment they deserve.

We've also been pleased to revise our *Living with a Diagnosis of Lung Cancer* patient booklet, and to translate it into Spanish, with the support of corporate partners Abbott, Novartis, Genentech & Lilly. These resources are completely free to anyone, and available to order, view or download at [www.NationalLungCancerPartnership.org](http://www.NationalLungCancerPartnership.org). A simple way for you to get involved with the fight against lung cancer is to distribute these materials to your local cancer clinics. Patients' lives depend on their ability to advocate for their quality care, and these materials are one resource to help them do that.

Our mission is vast, and we have much work to do. But we are proud of what we've achieved in the last nine years, and we look forward to celebrating our 10th anniversary in 2011 with continued successes and progress. We hope you will join us!

Joan Schiller  
Chief, Division of Hematology and Oncology  
Deputy Director, Simmons Comprehensive  
Cancer Center  
Andrea L. Simmons Distinguished Chair in  
Cancer Research

## New Board Members

The National Lung Cancer Partnership would like to welcome Jean Kamla, RN, and Charles Florsheim, JD, to the Board of Directors! We look forward to working with them to achieve our mission of decreasing deaths due to lung cancer and helping patients live longer and better lives.

## Board of Directors:

### President

Joan H. Schiller, MD  
University of Texas-Southwestern  
Medical Center

### Vice President

Kathy S. Albain, MD  
Cardinal Bernardin Cancer Center  
Loyola University Chicago

### Secretary/Treasurer

Antoinette J. Wozniak, MD  
Karmanos Cancer Institute  
Wayne State University

Amy Cipau, MBA  
North Carolina Lung Cancer Partnership  
Key Healthcare Partners

Lawrence Einhorn, MD  
Indiana University School of Medicine

Deborah A. Fuderer

Jennifer Garst, MD  
Duke University Medical Center

Nancy Gatschet  
Pennsylvania Lung Cancer Partnership

Charles Florsheim, JD  
Cantey Hanger LLP

Pasi Jänne, MD, PhD  
Dana-Farber Cancer Institute,  
Harvard Medical School

Jean Kamla, BSN, RN  
Christus St. Patrick's Hospital

Lorraine C. Pastore, MBA  
Reagent USA

## Staff:

Regina Vidaver, PhD  
Executive Director

David LeDuc, CFRE  
Development Director

Jackie Ford  
Development Director, National Events

Alice Yuroff, PhD  
Senior Programs Manager

Julie Chrisler  
Office Manager

Susan Smedley Gerber  
Development Manager, National Events

Tracy Fischer, MSc  
Communications Manager

Bridget Purchatzke  
Development Coordinator, National Events

Elizabeth Goers, MS  
Communications Coordinator

Kim Bautz  
Development Assistant

Michelle Bissen  
Administrative Assistant

# Advancing Lung Cancer Research

## National Lung Cancer Partnership 2010 Annual Meeting



Session moderator Dr. Fred Hirsch asks a question to panelists, while Dr. Denise Aberle looks on.

The Partnership's 8th Annual Meeting, **Lung Cancer 2010: Barriers & Roads to Advancement**, was held on June 4, 2010, in Chicago, IL. This half-day conference brought together researchers, health care professionals and patient advocates to learn about the latest ground breaking lung cancer treatment and screening research.

The presentations highlighted the hope and progress for improving screening, treatment, and ultimately, survival for lung cancer patients now and in the future. As one of the session panelists, **Dr. Pasi Jänne** (Dana-Farber Cancer Institute, Harvard Medical School), remarked, "The last five years have really seen an explosion in our biologic understanding of lung cancer, and I think it's fair to say that in no other cancer has this information been more rapidly translated into new therapies as in lung cancer. Lung cancer has become the model for personalized medicine for all cancers."

### New Avenues for Lung Cancer Screening

The first panel discussion of the conference delved into issues surrounding lung cancer screening. As the panel moderator, **Dr. James Jett** (Mayo Clinic), reminded the audience, currently, there is no generally recommended screening method for lung cancer. However, there is great hope that research will soon show which screening method(s) save lives from the disease.

Several panelists discussed research into new ways to screen for lung cancer and identify who is at risk for developing the disease. One promising topic was biomarkers – molecular patterns in DNA, proteins and chemicals in airway cells, sputum and breath. These biomarkers may be able to one day identify people at risk for developing lung cancer or people with

early-stage disease before it presents other symptoms.

There was also a discussion of the ongoing National Lung Screening Trial (NLST), which compares two lung imaging techniques, x-rays and computed tomography (CT scans), for detecting lung cancer in individuals at high risk for developing the disease. The highly anticipated results of this study, expected in 2011, may determine whether CT screening or x-rays are effective in reducing lung cancer deaths. **Dr. Denise Aberle** (UCLA) explained that this study also presents a unique and valuable opportunity for researchers to access patient samples, such as blood, sputum and tissue, collected during this study. Future research using these samples might help identify people at risk for developing lung cancer, find biomarkers to detect cancer earlier and promote individualized treatment for patients.

### New Targets for Lung Cancer Treatment

Dr. Pasi Jänne described a very exciting advance in the development of a targeted treatment for lung cancer patients whose tumors have a specific genetic alteration called an ALK translocation. Early studies show some lung cancer patients with the ALK translocation have a remarkable response to a drug called crizotinib. ALK and crizotinib were a hot topic discussed throughout the American Society of Clinical Oncology (ASCO) Annual Meeting, which immediately followed the Partnership's meeting (see page 5 for more details).

**"Lung cancer has become the model for personalized medicine for all cancers."**

**-Dr. Pasi Jänne**

Dr. Jänne shared that the most remarkable aspect of the ALK story is how quickly it moved from the initial discovery to a targeted therapy for patients. The ALK translocation was discovered in 2007, the first patient entered clinical therapy in 2008, and a large phase III clinical trial was started this year. Dr. Jänne said, "We hope that this is one example of many to come, which will speed the development of active therapies for more patients with lung cancer."

We were also pleased to welcome two researchers whose work was funded by donations made to the National Lung Cancer Partnership's research grant program.

**Dr. Adam Marcus'** (Emory University, 2008 National Lung Cancer Partnership Career Development Award recipient) research focuses on understanding the mechanisms that control how cancer cells move, spread and cause metastasis. By dissecting the complex interactions between the proteins that control and cause cells to move, Dr. Marcus hopes to expose new molecular targets and drugs to prevent metastases.

Over the two years of his Partnership Career Development Award, Dr. Marcus focused on studying a few key proteins that appear to play a significant role in the biology of non-small cell lung cancer (NSCLC) and in the movement of lung cancer cells. He also worked to identify a drug that stops movement of lung cancer cells in culture by interfering with these proteins. Dr. Marcus is continuing his research to characterize how these proteins promote the spread of cancer. He is also investigating whether the identified drugs can be used as treatments for patients to slow or stop this spread.

**Dr. Hildegard Schuller** (University of Tennessee, 2008 National Lung Cancer Partnership / LUNGeity Research Grant recipient) studies how a carcinogen found in tobacco, nitroso-nicotine ketone (NNK), promotes growth of adenocarcinoma lung cancer cells. At the meeting, Dr. Schuller described her work to understand the complex interactions between NNK, estrogen, and several cell signaling pathways that lead to uncontrolled growth of lung tumor cells. She found long-term exposure to both estrogen and NNK act to stimulate certain growth factors and, at the same time, cause a decrease in other factors that could stop cell growth. Dr. Schuller likened this to "an out of control car where the accelerator is stuck and the brakes don't work." Given the role of estrogen in this process, her work might help explain why women have a higher risk of developing lung adenocarcinoma than men, and may lead to new ways to prevent or treat the disease.

For a more detailed summary of the meeting presentations, please visit [www.NationalLungCancerPartnership.org](http://www.NationalLungCancerPartnership.org).

### Save the Date!

The Partnership's next Annual Meeting will be held June 3, 2011, in Chicago, IL.

# Stories of Strength

## A Survivor's Story



Stephanie  
Dunn Haney

devastation of lung cancer and its dismal research funding.

### Q: When were you diagnosed with lung cancer? How are you doing now?

A: In the Fall of 2005, I went to seek an x-ray for right side pain from what I thought was a broken rib. For the next two years, I endured MRIs, EMGs, physical therapy, chiropractic services, and high-dose anti-inflammatories, to no avail. Finally, in the Spring of 2007, a CAT scan showed something. A biopsy confirmed lung cancer on October 3. Every doctor felt the need to repeat the entire mouthful to me like it was my new name—"terminal, stage IV, metastatic lung cancer." I did the Carboplatin/Paclitaxil/Avastin combo for six cycles, which were completed in the Spring of 2008, interspersed with a collapsed lung and a blood clot in the collarbone. I was put on Tarceva/Avastin in June, 2008, and have been on it ever since (incidentally, my lung cancer doesn't have an EGFR mutation!). I have learned that I am ALK positive, and once Tarceva has run its course, I'll be entering the phase III trial

for crizotinib. Thankfully, three years after diagnosis, I am still running at full speed. When this thing started I truly believed that I would be gone before my baby began kindergarten and here I am to see it, none the worse for the wear! I am living with cancer in the truest sense—tumors in two separate lobes of my right lung and in the lymph nodes in my chest. I've had some decrease and some increase, but we have been able to keep things relatively controlled along the way.

### Q: What is the reaction you get when you talk about having lung cancer?

A: I have faced looks of confusion as others tried to quietly ascertain if I had been a smoker. Like so many, I have endured outright inquisitions about my habits and insensitive questions to family, friends, and even my hospital nurses! Some even declared to me, as if it is a fair or relevant assumption, "Gee, I didn't realize you smoked!" People always feel the need to define the source for me, so they run down the list of popular risk factors to assign blame for contracting this disease.

### Q: How has living with lung cancer changed your life?

A: Everything in the world looks different to me. I pray so much more and have a stronger faith and relationship with my God. I watch every move my daughters make and deliberately soak them in. I've found my voice. I have freed up inner restraints that I had imposed upon myself for years and enjoy

my life. I jump in and follow my heart. I try my hardest to not waste time getting upset about the silly stuff.

### Q: What advice would you give to others diagnosed with lung cancer?

A: Let someone else do internet research for you until you've regained your footing after your diagnosis. It's devastating and says nothing about YOUR case. Those statistics don't apply to YOU—every person in those stats was an individual with an individual case, lumped into an aggregate to make oversimplified points.

### Q: What is the most important thing you believe the general public needs to know about lung cancer?

A: No one should be blamed for a lung cancer diagnosis; why is that blame reserved so strongly for this disease, when a variety of behavioral factors influence many health issues that are not questioned? Finally, I want people to understand the inequities we have suffered as lung cancer patients...how much other cancers are seeing of federal and private dollars, while lung cancer, even as the greatest cancer killer in multiples sees only a fraction of that.

**Want to know more about Stephanie's experience with lung cancer? Visit our blogs at [www.NationalLungCancerPartnership.org](http://www.NationalLungCancerPartnership.org) to follow Stephanie and her fellow survivor blogger, Tom Cappiello, who was diagnosed with stage IIIA lung cancer in 2007 and is now free of disease.**

## A Physician's Perspective



Suresh  
Ramalingam, MD

Suresh Ramalingam, MD, is chief of Thoracic Oncology at the Winship Cancer Institute of Emory University and a valued member of the National Lung Cancer Partnership's Scientific Executive Committee.

### Q: What inspired you to enter lung cancer research and treatment?

A: During residency training, I was fortunate to work on both a laboratory-based and a clinical research project on lung cancer under the mentorship of Dr. Greg Kalemkerian (currently at University of Michigan). Those experiences gave me a better appreciation of the challenges and opportunities in lung cancer research. I also cared for a number of patients with advanced lung cancer; one case of a young man was especially heart-breaking. Watching him slip away was perhaps the decisive factor in my decision to pursue lung cancer research as a career.

### Q: What would you like young professionals entering into lung cancer research/treatment to know about this field?

A: More than a million people die from lung cancer each year. It will require our collective efforts, teamwork and commitment to alleviate the burden of lung cancer. It is also important to know that every patient with lung cancer is unique and holds the key to improving our understanding of this disease.

### Q: What would you like patients to know about lung cancer treatment - now and for the future?

I am constantly inspired by the courage and optimism of my patients. Their enthusiasm to participate in research studies and to serve as advocates for lung cancer research has already made an impact. I truly believe that the goal of changing lung cancer from a killer disease to a chronic condition, and in some instances to a cure, is well within our reach.

### Q: What is the most important thing you have learned from your patients?

A: I have learnt from my patients that no

setback is final and that no success is trivial.

### Q: Why should people looking to get involved in the fight against lung cancer work with the Partnership?

I believe that the Partnership will play a robust role in stimulating exciting research, supporting careers of aspiring researchers and serving as a strong voice for increasing the resources for lung cancer research. I see the Partnership as a tool to coordinate the fight against lung cancer. No one person has a lock on good ideas. We learn from each other. It is easier to make a difference cooperating with other like-minded individuals rather than working by oneself. I also have personally observed the zeal and commitment of its leadership to the cause. It is an honor to work with this group.



**National Lung  
Cancer Partnership**  
RESEARCH. AWARENESS. CHANGE.

# Partnership Events and Updates

## Become a part of the **Free to Breathe®** Movement!



Jakob Reens and his father, Jeff Reens, participate in **Free to Breathe® Milwaukee** in memory of Jeff's father, Steven Reens.

### Now Announcing 2011 Events

We're already starting to post 2011 event dates and locations on [www.FreetoBreathe.org](http://www.FreetoBreathe.org). Watch for an event near you!

### Advocates in Action

The **Every Breath Festival** in Bethlehem, PA on July 24, organized by Tina Edwards in memory of her father, raised over \$1,500 for the Pennsylvania Lung Cancer Partnership.

Erin Fenske and a team of volunteers are organizing the **Look Deeper Concert** in Dallas, TX on November 13.

Gretchen Wieland is running in four different **5K events** in 2010 in memory of her uncle, Gary Wieland. She has raised \$550 so far.

Joe Hamilton hosted a **Young Brokers and Agents of San Diego networking bowling event** in San Diego, CA on October 6 with a portion of the proceeds benefiting the Partnership.

The following advocates staffed exhibits or organized marches at **Independence Day community events**:

- Terri Law - Plymouth, MN
- Susan Bradie - Franklin, MA
- Suzanne Dahlberg - Chelmsford, MA

Suzanne Dahlberg and Pat Dunn exhibited at two **health fairs** in Massachusetts to raise awareness of the disease. Brian Brubaker attended a health fair in Lewes, DE to spread the word about the Partnership's mission and the **Free to Breathe®** 5K in Lewes.

Wendy Larimore, Raphael Pereira, Brad Levinson and Anna Briones all set up personal **fundraising webpages** on [www.FirstGiving.com](http://www.FirstGiving.com).

Montessa Lee ran a **booth at a local cancer event** in Silver Spring, MD on June 11.

One of the National Lung Cancer Partnership's goals is to build awareness of lung cancer. The **Free to Breathe®** program is fulfilling this goal while simultaneously raising funds for lung cancer research, awareness and education programs to improve the lives of everyone affected by lung cancer.

Together, survivors, friends, neighbors and family members are forming a nationwide movement to defeat lung cancer. Tens of thousands of participants, fundraisers, donors, sponsors and volunteers have come together at more than 30 **Free to Breathe®** events across the country this year.

You too can join the movement! Registration is still open for many November events, and 2011 event dates and locations are already being announced. For more information about **Free to Breathe®**, to view photos from past events, or to register, donate, volunteer or sponsor, visit [www.FreetoBreathe.org](http://www.FreetoBreathe.org)!

Jennifer Melton helped organize a **Lung Cancer Awareness Night at a Flying Squirrels baseball game** in Richmond, VA on July 29.

Stephanie Haney and her **Free to Breathe®** National Walk Team, Team Haney, raffled off a custom-built playhouse at the Danville Arts and Craft Fair on September 11. They also hosted a **Basket and Doll Bingo** in Bloomsburg, PA on October 10.

Students at the **Ronald C. Wornick Jewish Day School** in Foster City, CA raised over \$1,000 and voted to donate it to the Partnership! Dr. Millie Das accepted the check on the Partnership's behalf.

Kari Newport organized the 2nd annual **Breathe OK Walk** on in Yukon, OK on September 11.

Nick Tees hosted the 2nd Annual **Lanes for Lungs** Bowling Beef-n-Bier in Philadelphia, PA on August 28 and raised \$4,954.

Deb Violette hosted a **pancake breakfast** at Applebees in Augusta, ME on September 18.

Ron Youngs organized the **3rd annual Denise Youngs Memorial Poker Run** in Bradner, OH on June 19. The event raised more than \$5,000 for the Partnership!

These are just a few of the creative ways advocates have supported the Partnership and the fight to defeat lung cancer! For more event details, or for ideas on how you can get involved, please visit [www.NationalLungCancerPartnership.org](http://www.NationalLungCancerPartnership.org).

## Announcing the Louisiana Lung Cancer Partnership

The National Lung Cancer Partnership would like to welcome our third State Chapter: The Louisiana Lung Cancer Partnership!

The goal of the Partnership's Chapter Program is to provide a framework for advocates around the country to help fight the disease by raising awareness, increasing research funding and reducing the stigma surrounding the disease. Just like the North Carolina Chapter and the Pennsylvania Chapter, the Louisiana Chapter will host lung cancer awareness, fundraising and education events to spread the messages of the Partnership across the state.

Since 2008, Jean Kamla and a team of committed advocates have been working with the National Lung Cancer Partnership to raise awareness and increase funding for lung cancer research. In 2010, the Lake Charles **Free to Breathe®** 5K Run/Walk raised over \$100,000 for lung cancer research.

For more information about the Louisiana Lung Cancer Partnership and ways for you to get involved, please visit [www.NationalLungCancerPartnership.org/LA](http://www.NationalLungCancerPartnership.org/LA).

If you have a group of individuals interested in setting up a Chapter in your state, please contact David LeDuc, Development Director, at 608-233-7905 or [David@NationalLungCancerPartnership.org](mailto:David@NationalLungCancerPartnership.org).

### THANK YOU!

We'd like to say a very special thank you to each and every one of our event organizers for enthusiastically giving your personal time and energy to make sure every event is successful. You are the spirit behind the movement! None of this would be possible without your hard work and amazing dedication!

We'd also like to thank all the volunteers, donors, fundraisers, participants and sponsors who make our events possible, and all of the advocates who give their time to educate the people in their communities about lung cancer and spread the word about the Partnership's mission. Each and every one of you is integral to our goal of building awareness and raising vital research funds!



**National Lung Cancer Partnership**

RESEARCH. AWARENESS. CHANGE.

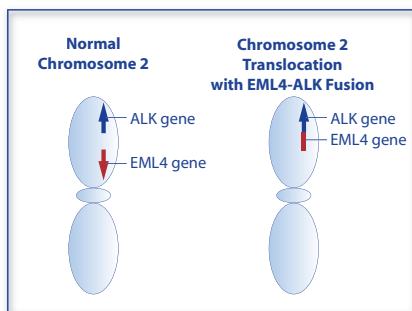
# Patient Point of Interest

## Recent Updates in Lung Cancer Research: What They Mean for You

Each year, some of the most important cancer research updates are presented at the Annual Meeting of the American Society of Clinical Oncology (ASCO). These updates often wind up changing how cancer care is delivered, from new screening and treatment options to new guidelines for nutrition and follow-up care. Here are some of the most ground breaking updates from ASCO and what they might mean for you!

### Treatment: New Agents

ASCO was abuzz with excitement over a new targeted therapy: crizotinib. This drug showed remarkable promise in an early clinical trial that treated a select group of non-small cell lung cancer (NSCLC) patients, in whose tumors the ALK gene had fused with another gene. This ALK translocation is relatively rare, occurring in about 3-5% of people with NSCLC, but is more common in those who have never smoked and have adenocarcinoma. Because of the remarkable response in the first phase of testing, the drug has rapidly moved into the final phase of testing and is widely available to patients with the ALK gene fusion as part of a global clinical trial. All patients with the ALK fusion gene are encouraged to join this trial. If you don't know if your tumor has the ALK translocation, ask your doctor about whether further tumor testing is right for you.



The EML4-ALK gene fusion occurs on Chromosome 2 when a portion of the EML4 gene is reversed and fused with the ALK gene. This gene fusion fuels cancer growth.

Results of a worldwide study testing a novel agent, ARQ 197 were also presented. ARQ 197 is designed to interfere with the c-Met protein, which often kicks into high gear to lead to resistance to other cancer therapies, including erlotinib (Tarceva). ARQ 197 was found to significantly improve progression-free survival for patients with locally advanced or metastatic NSCLC when added to erlotinib after chemotherapy. While promising, the drug will need to go through further testing. ARQ 197 and several other inhibitors of the c-Met protein are currently available to patients as part of clinical trials.

### Clinical Trials Matching Service

Interested in learning about whether you qualify for any of the clinical trials described here? Call 1-800-698-0931 or visit [www.emergingmed.com/networks/NationalLungCancerPartnership](http://www.emergingmed.com/networks/NationalLungCancerPartnership) to find the right trial for you.

### Treatment: Applying What We Know to Older Patients

A few years ago, we learned that giving a combination of two chemotherapy drugs to advanced lung cancer patients led to better survival than one drug alone. However, whether the combination strategy would be effective for patients over 70 years old has been questioned. A study presented at ASCO conclusively showed that this standard chemotherapy treatment (a combination of paclitaxel [Taxol] and carboplatin [Paraplatin]) is superior to treatment with a single chemotherapy drug in patients 70 or older. Patients who received the combination therapy lived about four months longer than patients who received the standard single drug treatment for patients in this age group. People receiving the combination therapy were more likely to develop side effects, however. No matter what your age, you should be offered combination chemotherapy if you have advanced lung cancer unless other health matters get in the way.



### Treatment: Palliative Care Effective, Too

A significant finding on the merits of palliative care (care focused on reducing or preventing pain, symptoms and stress caused by a disease) was presented at ASCO and published this August in the New England Journal of Medicine. This study showed advanced lung cancer patients who received palliative care at the point of diagnosis in addition to standard chemotherapy lived two and a half months longer than those without palliative care. There is a general misconception that providing palliative care is limited to the final stages of life. However, this study documented that early

referral to palliative care was associated with improvements in symptoms and more importantly, survival. If your doctor or clinic doesn't offer palliative care options, talk with your nurse or social worker for resources available to you.

### Palliative Care Resources

The National Lung Cancer Partnership is a proud member of a variety of coalitions, including the Alliance for Quality Psychosocial Cancer Care ([www.cfah.org/activities/alliance.cfm](http://www.cfah.org/activities/alliance.cfm)), which advocates for a comprehensive approach to cancer care, including depression screening, palliative care and family care.

### Cancer Survivorship: Dealing with Continued Risk

Early-stage lung cancer can often be cured with surgery, chemotherapy and/or radiation therapy. However, up to 10% of patients cured of their original tumor will experience another lung tumor later in life. At ASCO, we learned selenium supplements did not prevent the formation of a second tumor in people who had previously been cured of stage I NSCLC. In fact, the study was stopped early because patients receiving selenium had a slightly higher risk of developing a second tumor than patients who did not receive selenium. For lung cancer survivors, this result reinforces the importance of talking with your doctors about anything you are taking, including supplements.

The field of lung cancer research is rapidly changing, with more hope for prevention, screening, diagnosis and treatment being offered every day. Your support helps us fund such important research, which is critical to making progress for the over 1 million people worldwide who are diagnosed with lung cancer each year.

### Ahora Está Disponible en Español

The National Lung Cancer Partnership's updated patient information booklet, *Living with a Diagnosis of Lung Cancer*, is now also available in Spanish (*Vivir con Diagnóstico de Cáncer de Pulmón*.)

All our FREE patient information materials can be ordered at [www.NationalLungCancerPartnership.org](http://www.NationalLungCancerPartnership.org).

# Research, Awareness and Change

## Partnership Announces Planned Giving Program: the Clear Future Society



**"The true meaning of life is to plant trees, under whose shade you do not expect to sit." -Nelson Henderson**

On April 19, the National Lung Cancer Partnership was blessed to receive an unexpected and generous gift from the Estate of Elizabeth Katz. Ms. Katz was a longtime librarian in Woodinville, WA who unfortunately battled cancer several times in her life, eventually succumbing to the disease. She spent her life helping the people and the community of Woodinville, paying particular attention to the less fortunate who often do not have a voice in our society. Deciding she wanted to continue to make a difference even after she passed away, Ms Katz took time to meet with her attorney and draft a plan that would carry out her philanthropic wishes.

Ms. Katz made the decision to include the Partnership in her will based on the power of our mission, the programs we offer and a timely word of recommendation from her oncologist. We are eternally grateful for that support.

### Anyone can participate in planned giving.

For many individuals, the idea of making an estate gift, like Ms. Katz did, seems

farfetched. In fact, some individuals exclude themselves from this process because they believe planned giving is only for the extremely wealthy, or that charitable choices are to be made at an advanced age. Actually, almost anyone can participate; individually-tailored plans that meet one's personal and financial goals are at the heart of planned giving. And because most planned gifts are made from assets rather than current income, people can sometimes make much larger gifts than they ever thought possible.

### Why is planned giving so important to the Partnership's future?

Dr. Pasi Jänne, Chair of the Partnership's Scientific Executive Committee and member of the Board of Directors, recently shared with us why he chose to get involved with the Partnership and why continued support is so important. Dr. Jänne said he went into the lung cancer field because, at the time, he saw no hope for lung cancer patients. He felt if he dedicated the proper time, energy and resources to the cause, he could help change that perspective.

Today, with the effort of individuals like Dr. Jänne, things have changed for the better and the lung cancer community sees great hope in the form of new drugs, new opportunities for screening and diagnosis, and new treatment options. While Dr. Jänne is excited to see the progress, he finished his thought by saying that now is not the time to become complacent and that only a sustained, dedicated and long term effort will bring true hope of survival for all lung cancer patients.

In memory of Ms. Katz, and to ensure that our programs will receive the sustained, dedicated support that patients and their families need, the National Lung Cancer Partnership is pleased to announce the creation of our new planned giving program: the Clear Future Society.

### The Clear Future Society

The Clear Future Society enables donors to play a role in the Partnership's future by remembering us in their estate plans. Individuals can join the Society through:

- Bequests in wills or living trusts assigned to the Partnership
- Charitable trusts and annuities
- Gifts through life insurance and retirement plans

The benefits of planned giving include:

- The ability to make a significant gift without affecting current income or cash flow
- The qualification to receive a charitable estate tax deduction
- The knowledge that the Partnership will benefit from your generosity for years to come

A planned gift is the best way to guarantee the things you care about today will be provided for in the future. For more information or to become a member of the Clear Future Society, please contact David LeDuc, Development Director, at 608-316-3774 or [David@NationalLungCancerPartnership.org](mailto:David@NationalLungCancerPartnership.org)

## Memorial Giving

Donations have been made to the National Lung Cancer Partnership in memory of the following people (April 27, 2010, through September 27, 2010):

Joann Alligier  
Aleksandr Arefyev  
Mimi Arfin  
Rosalie Babineaux  
Martin Benjamin  
Sheila Bernstein  
Sharon Brockunier  
Cherry Brown  
Florence Brown  
Pearl Buchalter  
Nick Bunce  
Charlene Burns  
Sandi Callaway  
Guy Cassara  
Kent Cattlett  
Linda Champion  
William Clarvit  
Gary Coker  
Regina Cola  
Jill Costello  
Jill Cotoia  
Harold Cotton

Roger Craig  
Patricia (Trish) Creegan  
Mary Pat Darling  
Larry Davies  
Anne DeLuca  
Nirmala Desai  
Joseph Dowd  
Angela Dzorney  
Robert (Bob) Eastman  
Warren Stanely Eldredge  
Joanne Fanelli-Panus  
Joan Ferris  
Jeanie Fischer  
Mary Foster  
Ruth Frerichs  
Coach Fuller's mother  
Julia Gattone  
Coleman Goldberg  
Donna Greene  
Erik Hansen  
Jeffrey Hayes  
Leia Marie Heller

Don Hill  
Ava Schaffer Howard  
Louis Iocca Jr.  
David Jefferson  
Karen Johnson  
Susan Johnson  
Sharyn Kay  
Wilburn Doyle King  
A.J. Knowles  
Helen Kochuk  
Jim Lafargue  
Susan Lane  
Betsie Leach  
Mendige Lederman  
Paul LeRoy  
Jean Lister  
Delio Londono  
Douglas Madison  
Joli Mallick  
Peter Mareneck  
Jack Marino  
James & Brigitta McKenna

Thomas Michael McLaughlin  
Anita Tatom Miller  
Emma Napier  
Louis Lou Nocito  
Kay Strickland Nunnery  
Faye Osborne  
Judy Osler  
Sarah Pace  
Gerald Paprocki  
Melissa Peterson  
Raymond Porth  
Neva Powell  
Barbara Raynor  
Patrick Redmond  
Dawn Rivard  
Michaelene Robida  
Glenn Roiz  
Dolores Ross  
Robert Rothlein  
Bill Rounds  
Fred Rush  
Ingrid Saporito

Judy Scherer  
June Hanusa Schubert  
Marianne Schumacher  
Thomas Setnikar  
Angie Shoborg  
Charlotte Simpson  
Krista Smith  
Willem Spiegel  
Sandra Gillen Staudt  
Kathy Williams Stemm  
Alice Tallamy  
Brigadier General  
(Retired) Robin Tornow  
Thorn Walker  
Jodi Watts  
Eileen Weidner  
Rita Wells  
William R. Williamson Jr.  
I.F. (Bud) Winterberg  
Bobbie Wonder  
Lisa Woody  
Anne Woolner

# The Latest Lung Cancer Research Developments - How They Affect YOU!

See inside for more information about what recent developments in lung cancer research could mean for you, a new Partnership program to help all lung cancer patients get the treatment they need, news about the *Free to Breathe*® event series and more new ways you can help defeat lung cancer!

The National Lung Cancer Partnership is dedicated to decreasing deaths due to lung cancer and helping patients live longer and better through research, awareness and advocacy.



Thanks to Genentech BioOncology, Novartis Pharmaceuticals, Abraxis BioScience and Boehringer Ingelheim Pharmaceuticals, Inc., for unrestricted educational grants that made this issue of the *Lung Cancer Voice* possible.

PRSRKT STD  
U.S. POSTAGE  
**PAID**  
BEDFORD PARK IL  
PERMIT No 601

222 N. Midvale Blvd, Suite 6 Madison, WI 53705  
National Lung  
Cancer Partnership

