

# fresh air

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## IN THIS ISSUE

LUNGevity Support Leads to Clinical Trials to Study T-cell Immunotherapy [page 1](#)

Making Medical Research Advances Accessible to Patients [page 1](#)

May is Lung Cancer Hope Month [page 2](#)

LUNGevity Partners with Patient Power [page 3](#)

LUNGevity Receives Innovation Impact Award from Celgene [page 4](#)

Collaboration Creates Lung Cancer Experience Registry [page 4](#)

LUNGevity's Fall 2014 Premier Events [page 5](#)

Clinical Trial App Puts Information at Patients' Fingertips [page 6](#)

WHY LUNGevity? [page 6](#)

Meet Two of LUNGevity's Passionate Volunteers [page 7](#)

Spring/Summer 2015 Events Listing [back cover](#)

## LUNGevity's MISSION

**LUNGevity Foundation is firmly committed to making an immediate impact on increasing quality of life and survivorship of people with lung cancer by accelerating research into early detection and more effective treatments, as well as by providing community, support, and education for all those affected by the disease.**

## LUNGevity Support Leads to Clinical Trials to Study T-cell Immunotherapy

Dr. Prasad Adusumilli, a chest surgeon at Memorial Sloan Kettering Cancer Center, is particularly focused on translating novel immunotherapies to treat patients with aggressive, therapy-resistant lung cancer. T-cell therapies have shown dramatic results in lymphoma and leukemia patients. With LUNGevity funding,

Dr. Adusumilli conducted a pioneering study to determine whether a patient's own immune cells can be genetically engineered and delivered to the lung cancer patients to target and kill cancer cells. The immune cells were engineered to recognize a protein on the tumor cells called mesothelin. [continued on page 7](#)

## Making Medical Research Advances Accessible to Patients

*Resources on cutting-edge immunotherapy and much more*

LUNGevity is excited to release its new education materials on immunotherapy, supported by an unrestricted education grant from Bristol-Myers Squibb. Immunotherapy is a promising new area of investigation, with the first immunotherapy drug, nivolumab, approved for use in squamous cell lung cancer just this past March. Many more immunotherapy drugs are currently in clinical trials for all other types and stages of lung cancer.

"By providing resources on this and many other medical areas relevant to someone with a lung cancer diagnosis, LUNGevity is focused on empowering patients and caregivers to make the most informed decisions about their health care," said Susan C. Mantel, LUNGevity's Senior Vice President of Research and Education.



LUNGevity is committed to making the latest advances in research readily available to people living with a lung cancer diagnosis. Comprehensive, up-to-date patient education materials are available on the Lung Cancer 101 section of LUNGevity's website: [www.LUNGevity.org/about-lung-cancer/lung-cancer-101](http://www.LUNGevity.org/about-lung-cancer/lung-cancer-101)



*At LUNgevity, we are driven every day to improve outcomes for people living with lung cancer through research, education, and support. But we can't go it alone. To have the greatest impact, we actively develop strategic partnerships to bring added value to our programs and, ultimately, to people affected by lung cancer.*

*We're proud to be the go-to organization for individuals, companies, and organizations working within the lung cancer field. We've partnered with Patient Power to create HOPE Summit Live: Living Well with Lung Cancer Today. The first of these patient education forums was held this past March in Tampa, Florida.*

*We are also working with TrialReach to develop a mobile app that enables patients to more easily learn about and join clinical trials, and we are expanding the reach of the patient-focused experience registry in partnership with Cancer Support Community.*

*This May, recording artist and actress Hayley Orrantia is joining with LUNgevity during Lung Cancer Hope Month to bring a message of hope to everyone affected by lung cancer. We hope you'll join us in raising awareness about the incredible advances coming to fruition for people diagnosed with the disease. Help us spread the word!*

*Thank you for your support, and for giving hope to so many.*

Andrea Ferris

# May is Lung Cancer Hope Month

LUNgevity celebrates May, Lung Cancer Hope Month, with activities focused on raising awareness and highlighting the advances being made for people living with the disease.

LUNgevity will kick off lung cancer Hope Month 2015 with the fifth annual national HOPE Summit, a two-day conference in Arlington, Virginia, that brings together survivors and caregivers from across the nation to celebrate, learn, and unite with others connected to the disease. LUNgevity Foundation's lung cancer community continues to grow, with a record-breaking number of lung cancer survivors expected to attend the National HOPE Summit.

LUNgevity will also raise awareness during Lung Cancer Hope Month by launching a new social media campaign: The Hope Challenge! Hayley Orrantia, recording artist and actress on ABC's "The Goldbergs," will launch a video campaign. Anyone can make a video revealing the things in their lives that make them happy and/or they are passionate about. Fill in the blank with whatever takes your breath away. Hayley says, "Music takes my breath away. So don't let lung cancer take yours." Join in by sharing a video of what takes

*continued on page 3*

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Recording artist and actress Hayley Orrantia is kicking off the Hope Challenge this May.

## Hope Month

continued from page 2

your breath away with the hashtag #ChangeLC to make a difference in the fight against lung cancer. Add Hayley's hashtag #HayleyOrrantia and the star may even repost your video if it takes her breath away!

## GET INVOLVED!

There are many ways to join LUNGevity for Lung Cancer Hope Month:

**ADVOCATE** for people affected by lung cancer. Visit the LUNGevity website to download the Advocacy Toolkit to help you get started!

**ATTEND** or **VOLUNTEER** at an event near you! For an up-to-date listing of spring and summer events, please see the back cover of this newsletter.

**SHARE** news stories and press releases about LUNGevity and the lung cancer community via social media!

**SUPPORT** LUNGevity's mission to change outcomes for people living with lung cancer. By donating today, you can help create a world where people live longer and live better with lung cancer. You may make a one-time donation, a recurring monthly donation, or a gift in honor or in memory of someone.

# LUNGevity Partners with Patient Power

Free patient education forums at Moffitt Cancer Center in Tampa, Florida



**1)** Dr. David Carbone, Director of the Thoracic Oncology Center, The Ohio State University, shared why his bout with cancer has fashioned him into an even better physician. **2)** Dr. Scott Antonia, Chair of the Department of Thoracic Oncology at Moffitt Cancer Center, encouraged all patients to investigate and participate in clinical trials in order to take advantage of the latest medical advancements. **3)** Host Andrew Schorr (left) is a medical journalist, patient advocate, and two-time cancer survivor. **4)** Over 200 patients/survivors attended the town hall event to learn about emerging topics in lung cancer research and treatment. **5)** Expert panelists included health care professionals and patient advocates.

In March 2015, LUNGevity teamed up with Patient Power and Patient Empowerment Network (PEN), a nonprofit focused on delivering education to people living with cancer. These programs feature top medical experts from some of the world's leading medical institutions, dedicated advocates, and inspiring, knowledgeable patients. Together we produced the first LUNGevity live lung cancer patient education forum in Tampa, Florida. This free event for lung cancer survivors was broadcast online so that people affected by lung cancer could attend virtually.

During this interactive forum broadcast from Moffitt Cancer Center, patients, survivors, and caregivers heard from leading lung cancer experts about emerging therapies, current treatment options, and support resources. Close to 200 people joined the meeting live and via internet.

Keynote speakers included internationally-renowned lung cancer oncologists Scott J. Antonia, MD, PhD, and LUNGevity Scientific Advisory Board Member David Carbone, MD, PhD, who spoke about the latest breakthroughs in lung cancer research and treatment options. The expert panels and survivor panels spoke about the importance of participating in clinical trials and how to live well with lung cancer. LUNGevity's next educational forum with Patient Power will take place in Chicago in June 2015.

# LUNGeivity Receives Innovation Impact Award from Celgene

LUNGeivity is the proud recipient of one of Celgene Corporation's three 2014 Innovation Impact Awards given to organizations that show excellence in crafting novel solutions that



creatively meet patient, caregiver, and/or healthcare providers' needs in hematology, oncology, and immune-inflammatory conditions. In conjunction with researchers at Johns Hopkins, LUNGeivity is developing an initiative to engage patients and other stake-

holders. Known as "Project Transform," this initiative aims to integrate the patient's experience into lung cancer policy, treatment, and research. LUNGeivity is committed to giving patients a voice in the process.

As a first step in this initiative, LUNGeivity and researchers at Johns Hopkins will collaborate on a pilot study to measure the stated preferences of people diagnosed with lung cancer. This pilot study will lay the groundwork for the larger benefit/risk tradeoff analysis surrounding patient decision-making.

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*"We're honored to receive this award and are grateful to Celgene for helping give patients a stronger voice in their own care and future treatment options."*

**Andrea Ferris**, *President and Chairman, LUNGeivity Foundation*

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## Ask the Experts

Have a question about a specific lung cancer medical term or process?



Want to understand the latest advances associated with lung cancer research, explained in clear terms a person without medical training can understand?

Submit your question to the medical experts at GRACE through Ask the Experts at: [www.LUNGeivity.org/AskTheExperts](http://www.LUNGeivity.org/AskTheExperts)

# Collaboration Creates Lung Cancer Experience Registry

LUNGeivity Foundation has joined with Cancer Support Community (CSC) and other prominent lung cancer organizations on a new registry for people affected by lung cancer. CSC launched this first-of-its-kind resource in February 2015 as an extension of its Cancer Experience Registry.

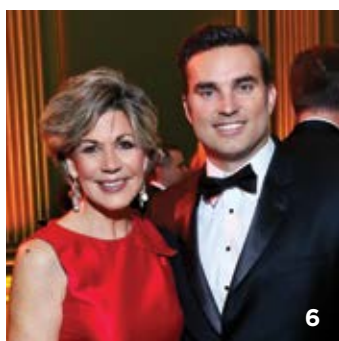
The overarching goal of the "Cancer Experience Registry: Lung Cancer" is to measure the social, emotional, and financial impact on people living with lung cancer, so we can improve care and support together.

In order to join, users will answer a series of questions about their experiences. Topics include the psychological impact of lung cancer and its stigma and a patient's understanding of available treatment options, among others. Upon completion of registration, users will be able to compare their responses with others in the community and access invaluable support and resources.

"LUNGeivity is honored to join CSC in this important effort," said Andrea Ferris, President and Chairman of LUNGeivity. "Our hope is that this new patient-focused registry will help shine a light on the unique challenges and unmet needs of lung cancer patients."

# LUNGEVITY'S FALL 2014 PREMIER EVENTS

Business leaders, philanthropists, survivors, and researchers came together to celebrate the progress in research and in changing outcomes for people living with lung cancer.



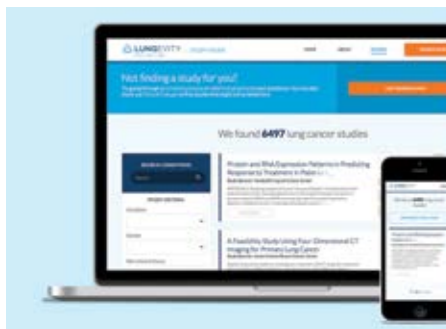
**LUNgevity's CELEBRATION OF HOPE Gala, NYC** 1) Event attendees included survivor David Gobin (center), his wife Stephanie Gobin (left), and world-class lung cancer researcher Dr. Julie Brahmer (right). 2) Gala chairs Ashley and Jason Bernhard celebrated achievements in lung cancer research and the people who are making this tremendous progress possible. 3) The iconic Pierre Hotel provided an elegant setting for a memorable evening. 4) Fashion designer and philanthropist Donna Karan was presented with the Face of Hope Award in recognition of her commitment to improving the lives of people with cancer through Urban Zen Foundation. 5) Teresa Bitetti, Senior Vice President, US Oncology, Bristol-Myers Squibb, accepted LUNgevity's Hope Award for Corporate Leadership in NY. **LUNgevity's MUSICAL CELEBRATION OF HOPE Gala, Washington, DC** 6) Doug Kammerer, News4's Chief Meteorologist and gala emcee, together with lung cancer survivor and former

ABC7 journalist Greta Kreuz. 7) Christopher J. Jowett, Global Commercial Head, Companion Diagnostics, Abbott Molecular, accepted the Hope Award for Corporate Leadership in DC. 8) LUNgevity President and Chairman Andrea Ferris (left) with gala chairs Bob Norton (center) and Suzy Pence (right). 9) Tony Award Winner John Lloyd Young performed classic Broadway favorites, including songs from the Grammy-winning, Certified-Platinum Jersey Boys Original Broadway cast album. 10) Guests partake in a night of dinner, dancing, and musical performances. **LUNgevity's FALL BENEFIT, Chicago, IL** 11) Fall Benefit Chairs, Cathie Levitt (left), longtime LUNgevity volunteer and lung cancer survivor, Jill Feldman (center), and board member Sue Bersh (right). 12) Fall Benefit guests played casino games and listened to live music in support of changing outcomes for people living with lung cancer.

# Clinical Trial App Puts Information at Patients' Fingertips

LUNGevity is using mobile technology to put easy-to-understand information about clinical trials where it is needed most—in the hands of lung cancer patients. LUNGevity is working with TrialReach and Composite Apps to develop a mobile application that enables patients to easily find clinical trials that may benefit them.

LUNGevity's Clinical Trials Finder App uses filters set by the patient to display potentially relevant clinical trials from clinicaltrials.gov that fit the criteria. The information is rendered in patient-friendly language and icons, displaying the most pertinent data first, such as the goals of the clinical trial and the exclusion



criteria. This patient-centric app is part of LUNGevity's comprehensive approach to breaking down barriers to participation in clinical trials for lung cancer patients.

Clinical trials are critical to the discovery of new prevention, diagnostic, and treatment methods for cancer, yet many people are unaware of them or the potential benefits of

participating. In lung cancer, clinical trials often offer the most cutting-edge treatment that a patient can receive, yet the misperceptions and lack of information about clinical trials may prevent people from enrolling.

According to Susan C. Mantel, LUNGevity's Senior Vice President of Research and Education, "It is important that survivors have easy access to this information so they can take advantage of all available treatment options at each stage of their cancer journey. Our goal is to have clinical trial participation become a standard of care where appropriate."

The app will be launched in early summer 2015.

## WHY LUNGevity?

*In the first of our series, we spoke with Charlotte, North Carolina, volunteer Anne Marie Graves about her experience with LUNGevity.*



### **Q: Why did you first reach out to LUNGevity?**

**Anne Marie:** My older brother was diagnosed with Stage III lung cancer in October of 2012. He had never smoked and was very fit; it was so unexpected. A doctor gave Mike and his wife, Rita, LUNGevity bracelets, and when I saw them, I wanted every family member to wear one. I called LUNGevity and asked for a dozen bracelets, and was treated so kindly. Our family wore the bracelets the whole time my brother was being treated, and still wear them today.

### **Q: How did LUNGevity help you cope with your brother's diagnosis?**

**Anne Marie:** The diagnosis was a real roller coaster for me. I learned a lot from the LUNGevity website—the facts, the prevalence of lung cancer in never-smokers, and about treatment options. Mike was a great guy, very active and well known in his community. When he passed away in May 2014, I knew there would be a large turnout for his funeral. When I called LUNGevity for 250 bracelets to give

to those attending, they sent them out right away. They got it that these friends were a part of our community "family."

### **Q: You've become an active volunteer for the Foundation. What engaged you?**

**Anne Marie:** I participated in the Breathe Deep DC walk on the three-year anniversary of Mike's diagnosis. My sister, Erin, created a team of over 25 people, and we were excited to raise almost \$5,000 our first time out. When LUNGevity staff member Beth Stern contacted me looking for someone to start an event in Charlotte, I knew this was what I would do. My interaction with the staff has been very positive.

I like that LUNGevity has funded research in North Carolina. I also believe in our model of funding science that can make things happen quickly for patients. The new website is wonderful—it's so important for people to have a resource when so much is being thrown at you. We all have a personal reason why we're involved; for me, it helps me to be proactive and make a difference.

### **Q: What can you tell us about your upcoming event?**

**Anne Marie:** We're hosting our first event, a family-friendly "Happy Hour," to raise awareness in the community about the importance of lung cancer research. I was grateful to get a sponsorship from my employer, Wells Fargo. My hope is to connect with enough people to have another Breathe Deep event here in Charlotte in the future.

I can't say enough about my experience with LUNGevity. The staff is so passionate. I'm excited to see the progress being made for people with lung cancer.

# Meet Two of LUNGeivity's Passionate Volunteers

LUNGeivity's Breathe Deep events program is creating and strengthening communities of support across the country, with the help of passionate, dedicated volunteers. These events build unity while raising awareness and funds for vital research and programs. Sue Bersh and Margot Cohen are two of hundreds of volunteers across the country who are contributing their time, resources, energy, and passion to engage their local communities to support better outcomes for people living with lung cancer.

Sue Bersh is a LUNGeivity Board Member and the founder and co-event coordinator of Breathe Deep North Shore in Deerfield, Illinois. Sue founded Breathe Deep North Shore four years ago to honor the memory of her dear friend Elyse Bernstein Keefe and her grandmother Harriet Serck, who both passed away from lung cancer. Sue remains firmly committed to changing the course of the disease.

Margot Cohen, a freshman at University of Pittsburgh, was 15 years old when she lost her mother, Rhonda Cohen, to

lung cancer. Seeking to channel her grief into action, Margot found LUNGeivity through Jerry Sorkin, a lung cancer survivor and LUNGeivity Foundation Board Member. After attending Breathe Deep DC in 2013, Margot founded Breathe Deep Pittsburgh, which took place at Schenley Park on March 22.

Though both Sue and Margot started their events in honor of loved ones lost to lung cancer, they are both determinedly hopeful for a world where no one dies of lung cancer.

"It's passionate, dedicated people like Sue and Margot who are building our national movement for lung cancer awareness and funding," says Beth Stern, LUNGeivity's Vice President of Community Engagement, "They've turned their grief into something so positive by establishing Breathe Deep events in their communities. Grassroots activism can result in people living better with lung cancer."

"Breathe Deep North Shore is so much more than an annual walk and run to raise awareness and funds for lung cancer research. It's an event that unites a compassionate community with lung cancer patients, survivors, and their caregivers."

**SUE BERSH**, (right) pictured with her dear friend Elyse Bernstein Keefe



"It wasn't until I found LUNGeivity and their Breathe Deep events that I was able to turn my grief into something productive. We've seen the impact of medical research on the survivorship of diseases like breast cancer. Now I want to do whatever I can to be part of curing cancer."

**MARGOT COHEN**, pictured with some participants at Breathe Deep Pittsburgh

## Clinical Trials, T-cell Immunotherapy

*continued from page 1*

Dr. Adusumilli and his team have published that mesothelin expression actively promoted cancer cell growth.

With the support of a Department of Defense (DOD) grant, he is now conducting a clinical trial to test whether mesothelin levels can predict which lung cancers in patients would be more likely to be aggressive, resistant to cancer drugs, and prone to recur after surgery. To date, the data point to mesothelin as

a new biomarker of tumor aggressiveness and a potential target for therapy in lung cancer.

Dr. Adusumilli's group has tested T-cells, a type of immune cell, to target mesothelin-expressing cancer cells in unique mouse models that mimic lung cancer characteristics observed in patients. The engineered immune cells were shown to be effective against the tumors when delivered directly to lung tissue in animals. The group's impressive results were published in the presti-

gious *Science Translational Medicine* in November 2014. Based on the findings from this project, Dr. Adusumilli obtained regulatory approvals from the NIH, the FDA, and Memorial Sloan Kettering's Institutional Review Board to initiate a clinical trial in lung cancer patients.

This spring, Dr. Adusumilli is beginning a phase I trial to study the impact of delivering these immune cells directly to the tumors in people. Stay tuned for more updates on this exciting work!



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## JOIN US AT THESE LUNGEVITY SPRING/SUMMER EVENTS

<b>May 1-3</b>	5 <sup>th</sup> Annual LUNGEvity HOPE Summit	Arlington, VA
<b>May 6</b>	Ping-Pong & Pour at SPiN NYC	New York, NY
<b>May 9</b>	Breathe Deep Kankakee 3-Mile Walk & Fun Run	Kankakee, IL
<b>May 9</b>	Breathe Deep Newark 5K Walk & Rally	Newark, OH
<b>June 5</b>	Nashville HOPE Summit	Nashville, TN
<b>June 6</b>	Ante Up for HOPE Casino Night	Bethesda, MD
<b>June 6</b>	Breathe Deep Michigan 5K Walk	Birmingham, MI
<b>June 6</b>	Breathe Deep NEPA 5K Walk & Fun Run	Wilkes-Barre, PA
<b>June 7</b>	Breathe Deep Bay Area 5K Walk & Fun Run	San Jose, CA
<b>June 13</b>	Breathe Deep Columbus 5K Walk	Columbus, OH
<b>June 13</b>	Breathe Deep Fort Collins 5K Walk & Fun Run	Fort Collins, CO
<b>June 13</b>	John Whiteside/Beatrice Green Lung Cancer Walk & Fun Run	Arlington Heights, IL
<b>June 20</b>	Breathe Deep Des Moines 5K Walk & Fun Run	Des Moines, IL
<b>June 27</b>	Breathe Deep Cleveland 5K Walk & Fun Run	Cleveland, OH
<b>July 25</b>	Breathe Deep Springfield 5K Walk & Fun Run	Springfield, IL
<b>August 8</b>	Breathe Deep Seattle 2.4-Mile Walk & Fun Run	Seattle, WA
<b>August 15</b>	Breathe Deep DuPage <sup>3</sup> / <sub>4</sub> -Mile or 1.5-Mile Walk	Naperville, IL
<b>August 15</b>	Breathe Deep Eugene 5K Walk & Fun Run	Eugene, OR
<b>August 22</b>	Breathe Deep Salt Lake City 5K Walk & Fun Run	Salt Lake City, UT