

living well

WITH LUNG CANCER



Participants at HOPE Summit celebrate survivorship, connect with others affected by lung cancer, and learn about ways to live well.

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HOPE Summit Celebrates 5 Years of Making Connections

This May, LUNgevity will reach an important milestone by hosting its 5th Annual National HOPE Summit. This Washington, DC-based event has grown tremendously from only 20 participants in the first year to over 200 in 2015. Last year, at the urging of survivors and medical professionals, LUNgevity brought HOPE Summits into the local community with one-day regional conferences. These “mini-summits” serve as a bridge connecting patients, families, caregivers, and medical professionals in the community to each other and to local resources. In 2014, LUNgevity successfully hosted regional summits in Columbus, Dallas, Houston, and Seattle. This year, LUNgevity has also added regional HOPE Summits in Tampa, Nashville, and Chicago.

Through the HOPE Summit program, LUNgevity is building communities and creating connections for people living with lung cancer across the country.



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.



YOUR QUESTIONS ANSWERED: What Palliative Care Means

The goal of palliative care, or symptom management, is to improve quality of life for both you and your family. It is provided by a specialist who may work with an interdisciplinary team that might include doctors, nurses, social workers, and other specialists. Your palliative care team works closely with you and your loved ones to help provide relief from the symptoms and stress of living with lung cancer.

Palliative care differs from hospice care, as it begins at diagnosis, can be helpful at any stage, and can be employed along with curative treatment.

Here are several reasons to consider palliative care if you're living with lung cancer:

Palliative care teams can help relieve your symptoms. Palliative care teams understand that lung cancer—and the treatments for it—can cause suffering. Lung cancer and treatment for it may cause pain, nausea, vomiting, fatigue, constipation, diarrhea, confusion, or shortness of breath. Many of these can be relieved using medicines or alternative methods, such as nutrition therapy, physical therapy, or deep breathing techniques.

Palliative care teams can provide emotional support. Palliative care specialists can help address the difficult emotions arising from a lung cancer diagnosis and treatment, including, but not limited to, depression, anxiety, and fear.

Palliative care teams can provide practical support. Experts can make referrals for counseling or support groups, as well as for resources for help with financial counseling or understanding medical forms or legal advice.

Palliative care teams can provide spiritual support. Palliative care specialists can help patients and families explore their beliefs and values so they can find peace or move toward acceptance.

Talk to your health care provider about finding a palliative care specialist to suit your needs.

Palliative care is comfort care, sometimes also called supportive care, given to a patient who has a serious or life-threatening disease. The goal of palliative care is to prevent or treat the symptoms and side effects of the disease and its treatment.

— www.LUNgevity.org

SURVIVOR AND CAREGIVER PROFILE:

David and Stephanie Gobin

David Gobin is a dedicated husband, loving father, retired Baltimore police officer, and seven-year lung cancer survivor. David's wife, Stephanie, has been his primary caregiver and partner throughout his journey to living well with lung cancer.

David's treatment has included surgeries, radiation, and chemotherapy, but after participating in a two-year clinical trial for an immunotherapy drug, David has been off treatment for more than two years and is symptom-free.

Reflecting on when David was first diagnosed, what was your initial reaction?

David: My initial reaction was "I'm going to die"—pure and simple. Day 2, I woke up and thought, "I'm not dead yet, so let's find out what can be done." I take things one day at a time, one fight at a time.

Stephanie: I didn't know anybody who had survived lung cancer. That was the greatest thing about LUNgevity—they showed us that lung cancer does not have to be a death sentence.

How did you become involved with LUNgevity?

David: We met representatives from LUNgevity in September 2012 at the after-party of the Stand Up to Cancer telethon in California. We learned



Stephanie and David Gobin at the 2014 LUNgevity Musical Celebration of Hope Gala in Washington, DC.

that there was going to be an event taking place right in our hometown: the Breathe Deep Baltimore walk.

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Empower Yourself: Live Well, Survive Well

By Katie Brown, *patient navigator and Vice President of Support and Survivorship for LUNgevity Foundation*

As a patient navigator, young adult cancer survivor, and former caregiver, I know what the term “empowered patient” means.

It's a concept meaning that knowledge about your disease is powerful, and advocating for your own quality healthcare aids in your survivorship. There is a checklist of questions I can arm you with along with disease-related information and education—all of the things that make you a more informed patient. And while all of those things are relevant and even critical, the fact of the matter is that all the tools in the workshed won't ensure that you can build a house or build it well.

My best advice to new patients is to get informed about your disease and treatment options, connect with other patients who have been through what you have been through, and never stop fighting for yourself until you are heard and receive quality care.

At LUNgevity, we know that when someone is diagnosed with lung cancer, there are often more questions than answers. How do you get the information you need to make the best decisions about your care? When exactly does survivorship begin?

To learn the answers to these questions and empower yourself to be a more proactive patient, visit the Support & Survivorship section of LUNgevity's website to find information on many aspects of living with lung cancer, resources in your area, and specific kinds of assistance.

5 Simple Dietary Strategies to Help Improve Your Mood

Improve your mood and enhance your overall well-being by following these five guidelines from Jessica Iannotta, MS, RD, CSO, CDN, and Chief Operating Officer at Meals to Heal:

1. Consume well-balanced meals and snacks

Most importantly, do not skip meals. Aim to have regularly spaced meals and snacks throughout the day, being sure to start off with a healthy breakfast that contains lean protein, whole grains, and fruit. This provides the proper energy to fuel optimal brain function throughout the day.



2. Focus on whole grains

Whole grains provide a slower release of glucose into your system, avoiding spikes in insulin and hunger which can affect mood. Choose whole wheat or multi-grain breads, rice, cereals, and pastas along with beans, nuts, and seeds rather than their refined counterparts.

3. Choose more healthy fat, especially omega-3 fats

Omega-3 fatty acids have been studied in relation to depression and are healthy for the brain and central nervous system. Although dietary supplementation has yielded inconsistent results, research has found fish eaters to have lower risk of depression and suicidal thoughts. Good sources of omega-3 fatty acids include fatty fish like salmon, tuna, and mackerel, and plant sources from flax, walnuts, canola oil, and omega-fortified eggs.



4. Consume the right nutrients

Although supplementation with micronutrients such as folate, vitamin B12, selenium, and vitamin D have been studied with mixed results, adequate food sources remain important for a well-balanced diet that maintains a healthy nervous system. Folate is found in legumes, nuts, and dark green vegetables. B-12 can be found in all animal products, preferably lean meats and low-fat dairy products. Selenium can be found in seafood, nuts (Brazil nuts are a particularly good source), beans, and meats. Vitamin D can be obtained through adequate sun exposure, along with smaller amounts from dietary sources such as fish and fortified dairy and foods.



5. Limit Caffeine

Too much caffeine can cause large swings in energy level and increases in anxiety and nervousness. If you consume more than 2 cups per day, it would be helpful to reduce intake slowly and try to use alternative decaffeinated, lower-calorie beverages like water, tea, and diluted juices. Avoid sugary drinks, which can only make the problem worse.



Stephanie: It was awesome to see all of the survivors at Breathe Deep Baltimore. I was amazed by all of the people affected by lung cancer who came out to support the survivors.

David Gobin: Every year, we see a lot more green survivor shirts at the Breathe Deep walks. Things are changing for lung cancer. And LUNGeivity is a big part of it.

Which LUNGeivity programs/events have you participated in and attended?

David: We've attended the 2013 and 2014 HOPE Summits, Breathe Deep Baltimore walks, and the DC and New York galas. The galas have been some of the most fun we've ever had. And HOPE Summit is wonderful. It's not sad. We're celebrating life, not death.

What has living with cancer/being a caregiver taught you about yourselves and each other?

Stephanie: We're more of a team. When we go to the doctor, if he doesn't hear it, I hear it. Sometimes you miss things, but together, we get it. And we have to lean on each other sometimes. If I can't be strong one day, then he has to be strong.

What does it mean to both of you to "live well" with lung cancer?

Stephanie: We try to live normal lives. We have family get-togethers and game nights, and we take short trips.

David: At the beginning, I kept hearing that my chances of survival were slim, and I was hesitant to make plans. But you know what, now we make plans, we make reservations—because we're going to go! That's the change in our attitudes. We're just not going to let it hold us back. You've got to live well, and you've got to love well. And we're doing both of those things. I'm just grateful for the here and now.

Changing the Lung Cancer Conversation

By Jill Feldman, *lung cancer survivor and mother of four*

When I got involved with LUNGeivity 13 years ago, lung cancer was thought of as "one disease" and treatment was the same for everyone. Today there are several advocacy organizations, and because of more funding for research there has been a tremendous increase in the understanding of lung cancer biology and significant advances in all treatment modalities. But the media still isn't talking about lung cancer. What is it going to take for lung cancer to become a national priority?

[There is] a barrier that is holding the lung cancer community back—the perpetuated stigma within the community itself. The stigma in the general public is so strong that survivors who have never smoked feel the need to immediately, and constantly, declare three words "I never smoked" to avoid the three words "Did you smoke?" that imply self-infliction. Those three words have a detrimental effect by dividing a community that desperately needs to unite.

The only person who should ask those three words is the doctor and only for files, research purposes, or treatment decisions. As someone who was diagnosed with lung cancer almost 6 years ago, after already losing many loved ones to this disease, I know that facing a lung cancer diagnosis is already an uphill battle—no one should have to defend themselves or their loved one for getting this insidious disease. Cancer is complicated—there's no simple cause and effect.

Anyone can get lung cancer and regardless of what caused it, no one deserves to die of lung cancer! Let's focus on patients and their families and the devastation we go through watching lung cancer physically and emotionally destroy the people we love, because that does matter. Now is the time to change the conversa-

tion. Let's show our faces, share our stories, and humanize the disease. Let's stop talking about smoking and start talking about the realities of lung cancer.

If you would like to join the conversation regarding issues facing lung cancer survivors, please share your story with the Support and Advocacy team via LUNGeivity's website. Whether you are a person living with lung cancer, a family member, a caregiver, a medical professional, a scientist, or just someone who supports LUNGeivity's mission, you have a story to tell.



**Become a LUNGeivity
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Ambassador
and help us spread
the word to change
lung cancer!**

**For more information,
visit [www.LUNGeivity.org/
about-us/get-involved](http://www.LUNGeivity.org/about-us/get-involved)**

