

LVNG

WITH
LUNG
CANCER

Be inspired by a community of people like you

How Having a Cancer Entourage Can Keep You on Track

Bruce: A Survivor's Story

Molecular Testing

What It Is and Why It's Important

Advocacy Spotlight

Events and Opportunities

LVNG With Events

Loved One's Perspective

ISSUE TWO

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A Note from the LVNG With Lung Cancer Team

WELCOME TO LVNG WITH LUNG CANCER, ISSUE #2.
As 2016 gets underway, we're excited to present this second edition of the LVNG With Lung Cancer newspaper. In this issue, you'll meet some very special people. Our cover story features Bruce, who was diagnosed with lung cancer and found the strength he needed in his family. Similarly, Genevieve has dealt with lung cancer in her life, but in this case, she's the one offering support. You'll read about how she's been helping her husband, Dann, truly live despite his lung cancer diagnosis nine years ago.

Also in this issue: a look at molecular testing, a recap of last year's very popular live events, as well as an Advocacy Spotlight highlighting some of the great resources being offered by our friends and partners at lung cancer organizations.

Whether you need support, information, or encouragement, our wish is that this issue helps you live a little easier with lung cancer. So please find us on Facebook and Instagram. Go to our website. Call a friend. Whatever you do, reach out. People want to share.

With much love and warmth,

The LVNG With Lung Cancer Team

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3221009 Last Updated 3/16

We're Better Together

How LVNG With Events helped people make life-affirming connections.

THERE'S SOMETHING THAT HAPPENS when you put a bunch of people in a room. The muffled, overlapping voices. The shifting in seats. The quiet that falls as the first speaker walks onto the stage.

The LVNG With Lung Cancer Events were created to activate and connect the lung cancer community. The mission is simple — empower people living with lung cancer and their loved ones by connecting them to the right information and resources as well as connecting them to each other.

Everyone has a story to tell. But at the LVNG With Events in San Diego, Dallas, and Philadelphia, many found that they had the same one. The stories weren't exactly the same, but a lot of details were reassuringly similar. A symptom. A diagnosis. A lot of tears. Then hope. They were honest, inspiring, and even funny — and they were all about living with lung cancer.

Laughter Is an Instant Vacation

The LVNG With Events included survivor stories followed by panels composed of people living with lung cancer, their loved ones, healthcare professionals, and representatives from advocacy groups. Everything from medical questions to emotional guidance was discussed. Many attendees walked away with a sense of relief and a new understanding of their disease. One attendee said, "For a recently diagnosed patient, the volume of information we received was very, very helpful."

Many people shared more than the day together; they shared their phone numbers and their commitments to ongoing support. As one attendee put it, "It was wonderful to hear how others were coping and how they were living their lives day to day."

Whether diagnosed 10 days or 10 years ago, and whether in remission or undergoing weekly chemo treatment, many found they shared a lot of the same questions, same dark days and same triumphant moments.

You saw it in the nods and the smiles. You heard it in the laughter and sighs of relief. For a group that understood



LVNG With Lung Cancer Event attendees Deena, April and Lysa.

what it's like to live with a cancer still stigmatized as a smoker's disease, talking about it helped. Among the one hundred attendees, there was common ground. "I love that I've been able to connect with others like me," said one attendee.

"I love that I've been able to connect with others like me."

— LVNG With Lung Cancer Event Attendee

Hugging Counts as Exercise

The LVNG With Events left an impression and helped fill a gap for many. Those on the panels felt empowered and many attendees walked away feeling less isolated and more hopeful for the future. "I believe people want to be with others to learn and share — this is that golden opportunity," said one attendee. Another summed it up this way: "I know now that I could be one of the survivors."

Our schedule of events is over for now. But the LVNG With Lung Cancer program is just getting started. A big thank-you to everyone who joined us at this year's events for your valuable feedback to inform future planning. For more lung cancer events, check out what our incredible partners have planned (p. 11). Visit us at www.lvngnews.com, or call 800-236-9933 to register for updates. ◆

So Many Options, Even More Hope

New treatment approaches may offer more options to people living with lung cancer.

EACH YEAR, MORE THAN 200,000 Americans are diagnosed with lung cancer, but in the past few years, there have been breakthroughs in genetic testing, which have led to exciting new approaches.

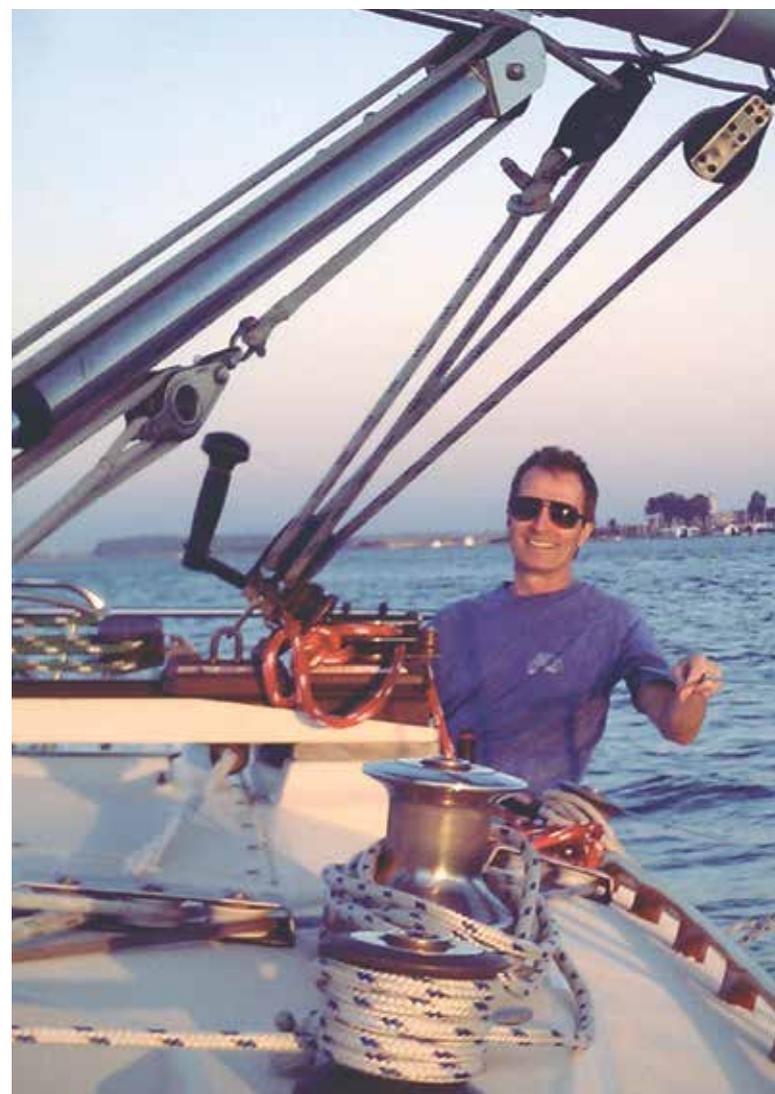
**“Get molecular testing.
If your oncologist doesn’t
think you need it, get a
second opinion.”**

— Dann, living with Stage IV EGFR,
T790M mutated NSCLC since 2006

Sweat the Molecularly Small Stuff

Targeted drug therapy is one of these promising new approaches. Doctors are treating tumors based on the type of cancer it is, rather than location in the body. Although all lung cancer tumors are on the lungs, they may not be made up of the same cancer cells. This is the thinking behind targeted therapy. It focuses on the specific mutation of the tumor in order to stop the tumor from growing and spreading.

Mutation testing (aka molecular biomarker testing or molecular profiling) is done by biopsy of the cancer cells to identify and tailor treatments to the genetic mutation of the tumor – whether that be a change in DNA sequence, a structural rearrangement of a chromosome or repeated copying of a piece of DNA. Some of the most common mutations include: EGFR, ALK and KRAS. All people diagnosed with lung cancer should be tested. These biopsy results inform treatment decisions.



Dann setting sail in 2013, seven years after his diagnosis.

Help Turn Up the T-Cells

Getting right down to the molecule is one way to go. But for other lung cancers, harnessing specific properties of the immune system may work too.

Immunotherapy works by using your own immune system to help your body defend itself. Your immune system is what protects your body against infections. When a new substance such as a virus or bacteria is in your body when it shouldn't be, your immune system goes on the attack. T-cells are one part of the natural immune system involved in immunotherapy. A T-cell is a type of white blood cell that circulates around the body scanning for cellular abnormalities and infections. Among other properties these multi-functional cells have is the ability to destroy cancer cells and help other immune cells create antibodies. However, the immune system doesn't always recognize the cancer cells as being harmful. Immunotherapy helps the body to identify and

unveil these hidden threats and cues the immune system to fight the cancer cells.

There are several different kinds of treatments that fight the cancer cells. Once thought of as a type of cancer that was poorly recognized by the immune system, lung cancer has recently emerged as a new target of immune-based therapies.

Chemo Is Not a Dirty Word

Whether you have been touched by cancer or not, chemotherapy is probably a word we're all familiar with. For many, it's the other "Big C" word you hope you never have to hear. But it's often the treatment that many living with lung cancer are eventually prescribed. This is partly because chemotherapy is one of the oldest, most common treatments for lung cancer. But just because it's one of the oldest therapies does not mean it hasn't evolved. It has.

Chemotherapy depends on a few pieces of information. Is the cancer advanced? Where is the tumor? How big is it? How is the person's health? Healthcare teams need this information because there are different chemotherapy treatments available, and they're often used in combination with one another to help shrink tumors or, when possible, kill them. For later-stage cancers, Stages III and IV, chemo is often given repeatedly. Talk to your doctor for the best treatment plan for you.

You'd Be Surprised Who Has a Tattoo

Radiation is another well-known word in the cancer treatment world. Without getting too "you have to take a physics class to really understand this stuff," radiation therapy uses extremely fast-moving, high-energy waves or particles to basically break up the cancer cell. Pretty advanced, right? Well, while you may have known about radiation, you may not have known about the tattoos. To precisely target the area to be treated, some forms of

radiation require a tiny, tattooed dot to mark the spot, as they say. And, yes — it is permanent.

Radiation therapy is one of the most common treatments for cancer. It can be used before surgery to help shrink tumors, after surgery to help kill any remaining cancer cells, or to help reduce symptoms such as pain, trouble swallowing, or a cough. There are two basic types of radiation used.

External beam radiation therapy (EBRT) uses painless energy beams from outside the body to target the cancer inside the body. There are several types of EBRT. Some use computers to pinpoint exactly where and what size the tumors are. The strength and dose can also be adjusted for greater precision.

Brachytherapy is a type of radiation that may also help to shrink tumors from inside the body. Small pellets are placed directly into the tumors or very close to them. A surgical procedure is sometimes used to place the pellets, but brachytherapy radiation can also be introduced to the body with a catheter or a needle.

"Have hope. Cancer treatment is exploding right now."

— Dann

Given the vast number and complexity of available treatments, more and more people with lung cancer are exploring their options, discussing them with their healthcare teams, and often seeking a second opinion before deciding on which treatment is right for them and their cancer. For more news from Dann, visit his blog, www.dannwonsen.com. For more information and inspiring stories, visit us at www.lvngnews.com or call 800-236-9933 and register for updates. Like and follow us at facebook.com/lvngwith and instagram.com/lvngwith to learn more. ◆

Getting Cancer and Getting On with Life

One man's story
of how a cancer
diagnosis gave
him a new
outlook on life.

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WHEN A SIMPLE BRUISED LEG led to an unexpected stage IV lung cancer diagnosis, Bruce did what many people do – he stopped living his life. The days of traveling the world, volunteering, and actively checking off his bucket list with his wife, Sharon, came to an abrupt end. Bruce resigned himself to the fact that he was dying. His longtime philosophy of living life to the fullest and “skidding into the finish line sideways, screaming, “Whoo-hoo, what a ride!” came to a halt.

The Upside to Being a Hypochondriac

When it comes to your health, Bruce jokingly recommends embracing your inner hypochondriac. “Macho males’ don’t think they need to see a doctor. But that was not me. I vowed to myself that I would rather be a living hypochondriac than a dead procrastinator.” While not many people rush to the doctor over a bruise, fortunately, Bruce did. That visit led to an ultrasound, a referral to a hematologist, a CT scan, and the new knowledge that one of the things that can cause a person’s blood to clot is cancer. Another CT scan later confirmed a diagnosis of Stage IV Non-Small Cell Lung cancer. Bruce recalls, “Being diagnosed with terminal cancer was scary, sad and final.”

“I call them my cancer entourage.”

When You Can’t Hold It Together, Hug Someone Who Can

Bruce’s family wasn’t about to let it go at that. Bruce explains, “My wife and my son and my two stepdaughters rallied the wagons and wrapped their arms around me. We’re all in it together, as they say.”

This support was especially meaningful coming from his son, whom Bruce was estranged from prior to his diagnosis. “But all that changed when I broke the news,” Bruce says. “We hugged and we cried and I think we both realized how much we mean to each other.”

Even his 98-year-old mother helped lighten the load when Bruce told her the news. “She said, ‘Well, you can’t die before I do!’” “Despite her tears, she still managed to make me laugh,” Bruce recalls with a smile.

The family banded together and joined Bruce at every oncologist visit, where they made sure to ask questions. They learned that Bruce’s tumors have the EGFR mutation and that there is real progress being made to deal with this kind of cancer. “They have done all the heavy lifting in finding out as much as possible about my cancer. I call them my cancer entourage. I couldn’t even fathom doing this without them.”

Fit Happens

With his family’s support, Bruce has gone to a nutritionist to learn how to eat healthy and has begun energy work with a massage therapist. “My family is my support team, and they encouraged me to explore strategies, increase strength, and reduce stress.”

Meet Bruce

- From: Eugene, OR
- Age: 70
- Occupation: Fundraising, retired
- Family: Married with 2 children, 2 stepchildren, 2 grandchildren, 2 stepgrandchildren
- Loves: Traveling and volunteering
- Diagnosed: Stage IV lung cancer in October 2014
- Tumor Biomarker: Stage IV EGFR mutated NSCLC
- Status: Stable

It's not a happy thing to be told you will die of cancer. But Bruce has learned that a stark reminder of your finality can also be an opportunity to take inventory of what matters to you and how you want to spend those final years, months, and hours.

"I am lucky to have my support team on my side. My journey has brought us all together — it rekindled my relationship with my son and I now spend a lot of time with my daughter, granddaughters, stepdaughters, and others who have become important in my life."

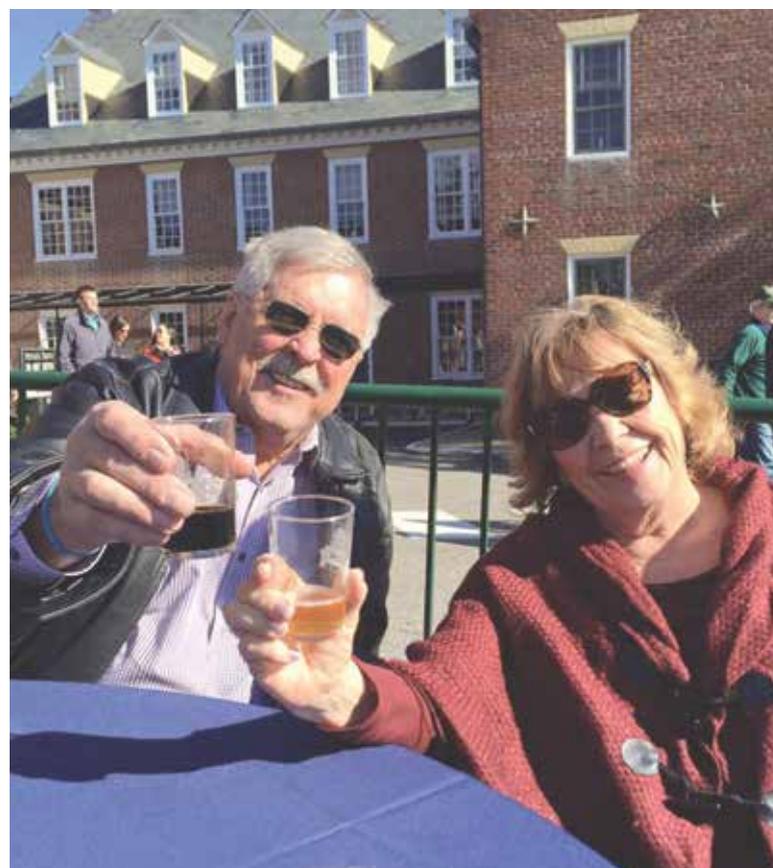
In Life's Darkest Moments, There Are Still Light Bulbs

After attending the LVNG With Lung Cancer Events, Bruce had what he calls "one of those light bulb moments." He shares that "the more my team did for me, the more I realized that I hadn't been taking ownership of my disease, so I had some work to do."

Now, rather than slowing down, he's actually doing more than he did before. He credits his newfound positive attitude to his family and the LVNG With community. "The strength I've gotten from meeting people with lung cancer is comparable to what the support of my family has given me. It has shown me how much I have to learn and how I need to get on with my life."

"I am filled with excitement to get on with my life."

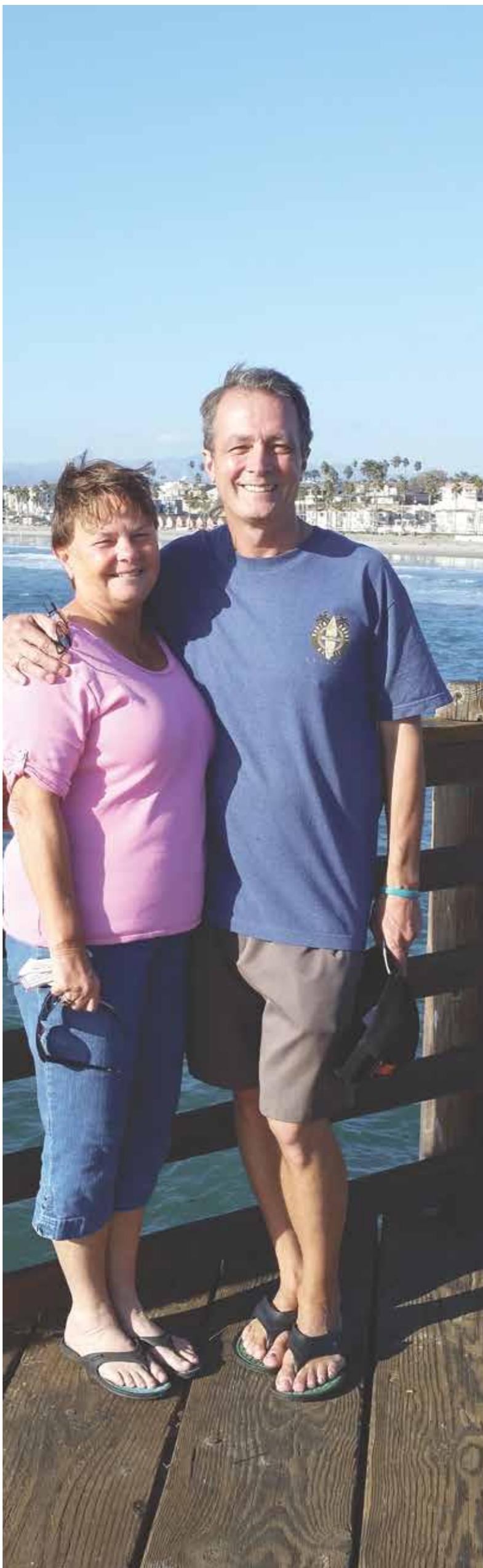
With excitement, he shares his plans. "I coerced the leadership of my Rotary Club to let me be Club President for a second time, and my term will start on July 1, 2016. I have also decided to get involved with the Lung Association in Oregon and with the LVNG With community." Bruce sums it all up this way: "You have to find your own support team, the ones that will be honest with you, help bring you back to being yourself, and remind you that you can still keep on living your life." And as for Bruce, he is "filled with excitement to get on with my life. I'm back on the rails screaming, 'Whoo-hoo, what a ride!'" ◆



Bruce celebrating life with his wife, Sharon.



Bruce socializing at a LVNG With Event.



The Role of a Loved One

Relax. If you feel lost, you're in the right place.

SUPPORTING SOMEONE WITH LUNG CANCER can be overwhelming. In this role, loving spouses, children and friends are asked to provide emotional support, help with medical care, deal with complex financial and insurance issues, as well as become their loved one's advocate and communicator to their healthcare team. Sometimes all in one day. After her husband was diagnosed with lung cancer, Genevieve found herself in this very situation.

Genevieve and Dann were married for 10 years when he was diagnosed with Stage III lung cancer. They had just moved to Portland to be closer to their jobs when Dann began experiencing back pain. Long after the moving boxes were put away, the pain continued, ultimately revealing a malignant tumor.

Her husband is a healthy vegetarian who never smoked. So a lung cancer diagnosis was the last thing Genevieve expected.

Losing control of your life can be just as disorienting for the person giving the care as the one receiving it. Genevieve found her whole world changed along with Dann's. Now everything revolved around Dann's care and needs. Genevieve remembers, "I felt like my life was on hold and I didn't have any control. I felt helpless. Like I didn't have a voice."



Dann started treatment with surgery and chemotherapy. Even while undergoing chemo, Dann would get up and go to the gym, go to work, come home, and proceed with daily activities. And while he was losing his hair, Genevieve realized she was losing herself. “Dann emerged a different person. He started writing and sharing his experiences with others. I, however, was frozen in the fear that I would lose Dann and be alone.”

As Genevieve wrestled with her fears, she decided she had to tap into her inner strength. “Dann was the one with the physical cancer, but I was the one with the emotional cancer. I realized I needed to do an overhaul or I would be the only one at the pity party.”

“Dann was the one with the physical cancer, but I was the one with the emotional cancer.”

Who Hid the How-To Manual?

Genevieve’s struggle is common to many who find themselves in the role of the supporter. While there are plenty of resources for people living with lung cancer,

many find themselves wondering where the how-to manuals are for caregivers. Genevieve has asked the same question. “We need a map to navigate the landscape. But where is it? Yes, of course, the person diagnosed needs to have a focused plan of treatment and care. But their loved ones are so often left to wing it at a time when we’re just barely staying aloft.” So what’s the answer? Genevieve smiles and says with a voice of one who knows, “You have entered unknown territory. You have to make your own map as you go along.”

Like so many others, Genevieve has had to come up with the answers for herself. Her “map” is one of balance. It’s being supportive but not smothering. Nurturing but not enabling. Vulnerable but not needy. She reminds us that it’s also about remembering to give yourself space, take care of your own health (“massages are great”) and ask for help when you need it. “Many times you just feel lost. But you don’t have to lose yourself. I couldn’t be there for Dann if I wasn’t there for myself.”

One of the biggest ways LVNG With Lung Cancer has helped Genevieve is by providing resources for support, and she encourages others in her situation to reach out to the many lung cancer organizations and advocacy groups. Other advice she would give to loved ones includes having a neutral person check in with you, being flexible as appointments change, and being open to new ideas and treatments. She also stresses knowing your resources, asking questions and widening your network.



Meet Genevieve

- From: Portland, OR
- Education: USC
- Age: 66
- Profession: Retired occupational therapist
- Spouse: Dann, diagnosed with Stage IV EGFR, T790M mutated NSCLC 9 years ago, married 19 years
- Family: 1 son, 2 stepsons, 6 grandchildren
- Loves: Art, meditation, massage, astrology

Even Chihuahuas Can Be Pit Bulls When They Have to Be

Dann's initial cancer treatments were successful. But after five years of remission, Dann's cancer returned. Fortunately, new treatment options and genetic trials gave the couple renewed hope. Today, Dann is in his ninth year living with lung cancer. Genevieve says that, this time around, she has learned that you don't have to lose yourself and that she does have a voice that makes a difference — especially when it comes to advocating for Dann's best interests.

“You have entered unknown territory. You have to make your own map as you go along.”

“Dann said that he was surprised that his little Chihuahua — me — could turn into a pit bull just when he needed me to,” she laughs. “But more than anything else, I've learned that one of the most important aspects of support is sharing the intimacy of everyday living. The greatest gift I can give Dann is loving him each minute he is with me.” ◆

Advocacy Spotlight



LUNG CANCER ALLIANCE

Lung Cancer? There's an App for That.

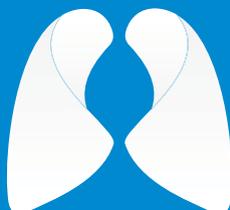
Founded in 1995, Lung Cancer Alliance is the oldest and leading nonprofit lung cancer organization. With the new LCA Unite App, you can connect with lung cancer survivors, track side effects of your treatments, share your calendar of appointments with loved ones, and find support groups, events, and nearby medical centers. For information, visit www.lungcanceralliance.org.



free to breathe
a partnership for lung cancer survival

Bend to Breathe

The Free to Breathe Team Yoga Challenge is a one-of-a-kind yoga event. Teams of 8 participate in 8 hours of instructor-led yoga. A variety of activities round out a day of yoga, community, and fun! Funds raised go to support Free to Breathe's research and education programs and the goal of doubling lung cancer survival by 2022. For information, visit www.freetobreathe.org.



BONNIE J. ADDARIO
LUNG CANCER
FOUNDATION

Read Up

Pick a question, any question, and there's a good chance the 200+ page handbook *360° of Hope* from the Bonnie J. Addario Foundation has the answer. Or at least understands the question in a way most books couldn't. Bonnie herself is a 12-year lung cancer survivor and her foundation empowers and educates patients, funds research, and raises awareness. For information, visit www.lungcancerfoundation.org.

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