Lessons Learned on a Path to Wellness

By Laura Metzger

My journey began eight years ago. I experienced an acute epigastric episode of diarrhea and vomiting for eight hours. It was a red flag. I had just returned home from New York City where I was taking a dog grooming class via a commuter bus. I made a dinner with bowtie pasta, bacon bits with two glasses of red wine. Soon after eating, my husband and I were invited to visit our neighbors. That was when I got incredibly ill, so much so that I could not go to get my husband for help. By morning, I seemed okay again, and I went about my day. I thought maybe it was simply food poisoning, so I never went to the hospital or even to my doctor.

I had a previous history of acid reflux and Zantac use, but after this acute episode, things changed. I developed more symptoms starting with steady burping when I lay down at night. Things progressed with constipation, high cholesterol, hypothyroidism, bloating, hair loss, wheezing and intermittent symptoms were added to the list of fatigue, excessive thirst, back pain (sometimes crippling), itching, a bulging rectocele, and more abnormal labs, including a high BUN for eight years and other abnormal bloodwork. I had an abnormal EKG, I had four abdominal ultra-sounds where my pancreas was obscured, three by gas and one by an incomplete sonographic window (another red flag). I had one CT without contrast of the abdomen and one MRI in a low resolution, 1.5 Tesla scanner. I had other tests, including a blood test for Rocky Mountain Spotted Fever, a rare disease which was negative. I had four CA-125 tests that came in high. My blood sugar levels were also coming in higher than normal.

My general practitioner in Fairfax, Virginia thought that the CA-125 was caused by possible ovarian cancer. The additional scans of that area did not correlate with that notion, although one gynecologist urged me to have a prophylactic oophorectomy along with a hysterectomy. Another consult with a gastroenterologist at a prestigious university hospital in Baltimore suggested I get another gynecologist to see if they would agree to that surgery. He also told me to keep eating popcorn and continue taking a baby colic ease that allowed me to sleep at night through the burping. He seemed comfortable with the fact that he could not come up with a diagnosis. I had seen one of his understudies, whom he thought highly of, in Fairfax, Virginia.

I visited eight gastroenterologists in total, three general practitioners along with two gynecologists and a few other specialists. At no time did any of these doctors mention the word “pancreas.” During the last several years, I had been traveling out to California to help my son who had some gallbladder issues and some financial difficulties. I even drove a car cross country for him, and then drove cross county with my husband in late 2019 to relocate here. It was not until COVID hit in March of 2020 that I had additional symptoms of itching in my shoulder blade, vague stomach pains, fatigue, and bright yellow urine that I realized it was time to see a doctor again. Honestly, I had given up on ever finding out what was wrong with me as so many doctors failed to identify the root cause of my symptoms.

During my crisis, there were two more missed diagnostic opportunities here in California. The first was while visiting a walk-in minute clinic. I was sent home with Cipro and then I started itching like crazy. The next day, I visited an urgent care where I was told I had “big bilirubin” while they took some blood. The next morning, my husband and I reviewed the bloodwork but in haste I missed the third page, my husband found my liver enzymes were extremely high along with a note from the doctor who said come back in for a scan, nothing serious. We went back to the urgent care, but because of COVID, I was redirected to the front door. There were lots of doors and I turned to my husband and said, “Let’s go to the ER, why are we here?” and so we did. Within 20 minutes at the UCLA emergency room in Santa Monica, I had the ‘Aha’ moment. My mystery illness suddenly had a name – pancreatic adenocarcinoma (PDAC). My official diagnosis was adenocarcinoma in the head of the pancreas with a nearly complete blocked bile duct requiring emergency surgery.

Positioned logistically in a perfect place in LA, my healthcare was about to be addressed by some of the most highly skilled doctors in the world. My blocked bile duct was corrected, while I awaited possible curative surgery. My Whipple was done at HOAG Medical Center in Newport Beach by Dr. Marie Stapfer who has done approximately 1,200 Whipples. I cannot imagine what could have happened had I been on one of my cross-country trips when this occurred.

I have since written a book that is soon to be published with a medical timeline of my abnormalities, failed tests, and abnormal bloodwork. I am currently under the care of a wonderful oncologist, Dr. Sidharth Anand at UCLA. I am on an oral chemotherapy and have had a good response. I hope to learn more about how I can help others who suffer from digestive disorders, others who may have been on Zantac, as well as helping other gastroenterologists and general practitioners who can learn from my years of living with acute and chronic pancreatitis that was accompanied by pancreatic cancer.

Nearly all my symptoms have been alleviated or cured by the

Whipple and the chemotherapy. I look forward to a meaningful and full life, although some doctors believe my prognosis is not hopeful. Some have put a limit on my time here, which I wish they had not done. I will continue to fight with every cell in my body to stay healthy, to be a productive human, publishing my book and spreading the word that pancreatic cancer is not always “The Silent Killer”! It has a bad reputation, but I believe the silence is due to the failure of our medical system. Studying patients like me will shine a light where protocols and biomarkers are recognized and followed so no one else falls through the cracks like I did. And may all the doctors learn from Centers of Excellence like UCLA medical center and Hoag Medical Center where they fix our broken pieces and make us whole again. God made sure that I was in the right place at the right time.

Until pancreatic cancer has a medically generated symptom checker, I invite other patients to use mine. Ask questions, talk to your doctor about your pancreas take advantage of this easy to remember acronym I’ve create for pancreas. This disease is not always the silent killer!

Pancreatitis (chronic or acute)
Abnormal Labs (glucose A1c, BUN, cholesterol, thyroid function, amylase, lipase)
Nerve Pain (in the back or radiating to other parts of the body)
Constipation (or other stool changes)
Reflux (acid) or Recurrent Metabolic Issues
Etiology (undetermined) or Exocrine insufficiency
Added late signs (itching, jaundice, changes to urine color, fatigue, vague stomach pain or back pain)
Stomach and/or digestive difficulties (bloating, acid reflux, burping, digestive trouble, unexplained weight loss)

Living Hope, a 19-year Survivor Story

By Roberta Luna

I am a wife, a mother, a bit of a thrill-seeker, an advocate, a volunteer and as of April 1, 2021, a nineteen-year pancreatic cancer survivor, with an inoperable tumor due to artery & vein involvement.

My journey with pancreatic cancer began in 1964 when I was only 9 years old. I was not yet old enough to know anything about the cancer that stole my grandmother from me that year. I was too young to imagine that the same disease would turn my life upside down again more than 30 years later and would eventually steal my father, my mother, my uncle and in time, my own good health.

In 1998, we were preparing for our oldest son's graduation from UC Berkeley when we were hit with the news that my father had pancreatic cancer. I can't remember my father ever being sick a day in his life. He never complained about not feeling well, he never missed a day of work, never so much as taken an aspirin. To hear the words "I'm sorry…. it's pancreatic cancer… there is nothing we can do…. go home and put your father's house in order," shocked us. Less than 2 weeks later, my father died. At his memorial, I was stunned to learn his mother, my grandmother had also died from pancreatic cancer.

After hearing, what I thought could be a family history of pancreatic cancer, I asked my doctor if I should be concerned, what symptoms should I watch for. His reply was a simple, "Don't worry hon, you’re too young, and it isn’t hereditary.”

Still reeling from the sudden death of my father, we were trying to find a new “normal” and couldn’t imagine another loss, let alone to the same disease. But just a few years later, in January of 2002, I lost my favorite uncle, my father’s baby brother, to pancreatic cancer.

Like my father he never complained about not feeling well. We had noticed he had lost some weight. When we questioned him, his reply was that he needed to lose a few pounds any way and was not worried about it. Finally, after much insisting, he begrudgingly went to the doctor. I remember the day he called me to say, “hi squirt, sorry to tell you but it’s pancreatic cancer and they’re telling me to put my house in order.” He died two weeks after he was diagnosed.

Losing a third family member I was really concerned. Again, I approached my doctor and again was told, “don’t worry, you’re too young and it isn’t hereditary.

I began having vague symptoms in November 2001. I was unable to keep any food or water down, had bouts of diarrhea and weight loss. My symptoms went on for too long to be the flu. My doctor’s next thought was that I was pregnant. I’d been pregnant before and I had never suffered from diarrhea, so I suggested he reconsider. The next guess was, “well, it’s probably your gallbladder.” I laughed and gently reminded him that he had removed it many years earlier.

My doctor seemed genuinely baffled, but his next suggestion was, “let’s just wait and see what happens.” Anyone who knows me knows I’m not the wait-and-see-what-happens type of person. I pulled out my checkbook, signed a blank check, and strongly requested we look at the pancreas. After finally agreeing to investigate further, they ran what seemed like an endless number of tests, blood, urine, stool, ultrasounds, MRI's, EUS, and ending with a needle biopsy.

On April 1, 2002, my doctor called and asked me to come in to go over the results. I think I knew what he was going to say even before he said it. With his eyes looking down at the floor, I knew what was coming next. "I'm sorry, it's pancreatic cancer and, as you have seen within your own family, no one survives this disease. You need to go home and put your house in order. However, let us start treatment as soon as possible to give you some extra months." The rest of the visit is pretty much a blur. I don't remember walking out of the office or how I got to my car.

The next memory I have is Bob Marley singing
"This is my message to you-ou-ou,
Singing don't worry about a thing
'cause every little thing gonna be alright."

I know he wasn't really singing to me but at that moment he was. I decided then and there I wasn't going to die, I was going to fight this with everything I had.

During my third year of treatment, the cruel hands of fate dealt our family another heartbreaking blow with my mother's diagnosis in 2005. My mother also defied the odds, surviving eight years before she died of the same disease that took so many family members. It is never easy to lose a loved one, but to have pancreatic cancer keep coming for our family seemed so unfair.

Pancreatic cancer impacts the entire family. My husband Vic, and I met and fell in love when I was only 15 and we married when I turned 18. When you are young and healthy and you promise to stay by each other "in sickness and in health" I don't think you really give much thought to the meaning – until you're forced to.

I started chemotherapy within the same week that I received the diagnosis. I sought a second opinion to confirm the diagnosis, hoping to hear the first was wrong but of course that was not the case. Radiation was added to the treatment regimen after the second opinion confirmed it was indeed pancreatic cancer. Through the years, I have been on many different chemotherapy regimens, and Vic has been by my side through them all. “In sickness and in health” is a promise that we continue to make to each other every day.

We tend to put off doing things we want to do when we are not facing life-threatening situations because we think there is plenty of time down the road to do these things. I too was guilty of this until I was faced with this deadly illness. Since my diagnosis, I completed my first half marathon, got a tattoo, jumped numerous times from a “not so perfectly good airplane” each time recruiting new people to the mix. Fellow survivors, my husband, son, friends, family, students from a local university, even a PanCAN and Hirshberg staff members. My ultimate goal is to get the founders of the Hirshberg Foundation (Agi Hirshberg) and PanCAN (Pamela Acosta Marquardt) to jump with me!

Mark Twain said, “the two most important days in your life are the day you are born and the day you find out why.” Through my experience with this horrific disease, I believe I am here to help those who have also been affected by pancreatic cancer, to hopefully inspire them and give them much needed hope. I share my story with members of Congress, advocating for the allocation of more funding for pancreatic cancer research, served on a Survivor Council for six years and I currently serve as a Patient Research Advocate.

Vic and I have recently been given a great opportunity to take another leap of faith and embark on a new journey with OC Talk Radio. We have created the podcast and radio show, *Living Hope;*

Your Journey with Pancreatic Cancer. The OC Talk Radio platform gives us the power of podcasting with online live radio and video. We hope this latest endeavor will allow us to share the journey of anyone touched and affected by pancreatic cancer and how they face it daily. We want to educate, bring awareness, give hope and inspiration to our audience.

Hopefully, you find inspiration from my story about how, through the good, the bad and the ugly, we can weather the storm with the support of our loved ones, our family, “our purple family” and the many people we meet along this often-difficult journey.

As I lace up my purple boxing gloves for the 19th time, I challenge pancreatic cancer to put on it’s gloves and prepare for the next round.

We’re on round 19 and while I may be a little wobbly, I am still standing and I’m not giving up!

Celebrating a 13-Year Pancreatic Cancer Survivor for Father’s Day

Steven, a husband, father and medical professor, shares his story as a patient and a long-term pancreatic cancer survivor. At the time of diagnosis, his son and daughter were in their mid- to late 20s and both were deeply affected. As a special Father’s Day tribute they’ve shared their unique perspectives.

By Steven Lewis

I am a 13+ year survivor of pancreatic adenocarcinoma, Whipple surgery and liver surgery for metastasis. I was first diagnosed with pancreatic adenocarcinoma in mid-August 2007 after turning yellow from jaundice. A week later I underwent Whipple surgery at Beth Israel Deaconess Medical Center in Boston, where I had virtually all major treatments. The pathology report revealed that more than 99 percent of the tumor was removed from the head of my pancreas but that a few pancreatic cancer cells remained at the surgical margin.

In early October, I underwent CyberKnife radiation which killed the remaining cells and in early November 2007 I began 6 weeks of conventional abdominal radiation. In January 2008, I began 12 weeks of chemotherapy with gemcitabine. The cancer never returned to my pancreas and there was no evidence of disease until April 2010 when a liver metastasis of the PC was noted on a routine surveillance scan and confirmed by liver biopsy. I was then told to expect only palliative care which was unacceptable to me. I told my doctors I wanted treatment that was bold, aggressive, decisive and rapid.

I proposed a treatment in the form of a PET scan to see if there was pancreatic cancer metastasis beyond my liver and, if not, liver surgery to remove the tumor. My doctors first resisted this proposal but later agreed to bring my case to the hospital tumor board. The board evaluated my case – which included a negative PET scan – and finally agreed to the liver surgery.

There are many additional details but, remarkably, I’ve been cancer free since the liver surgery and have regained excellent robust health. Today, at 72 years old, I enjoy all life has to offer, including no dietary restrictions or regular medications, regular strenuous aerobic and resistance exercise, and a vigorous full-time career as a medical school professor. This year, my wife and I celebrated our 50th wedding anniversary.

Steven’s daughter shares…

After my father became ill, I would call my parents and they both had such strength in their voices as if nothing was wrong. The option of “if he doesn’t make it” did not exist. Rather, “when he beats this cancer” prefaced all of their sentences. “When he beats this cancer, your father is going back to work”. “When he beats this cancer, your father will one day walk you down the aisle at your wedding”. The more I listened to my parents, the more I began believing that there was only one option – he would beat the cancer. Now my father is healthy. I am relieved but in my mind that was the only possible outcome. My father is a survivor. And for that matter, my mother brother and I also are survivors. We are survivors for never once believing that the cancer would beat my father and that the only option was my father would beat the cancer.

Steven’s son shares…

As the initial months passed, I felt vulnerable and scared. Dad always protected me from things I did not fully understand. Now he needed my help. I felt scared because he never needed this kind of love before to face a problem. I would have to be his rock and my mom’s too. My dad’s illness taught me some very important emotional lessons. He helped me learn to never doubt myself in what I can achieve. I think he taught everyone that by surviving with such grace. My dad is a very special person to me and I know he will overcome whatever obstacles are in his path.

Healing Blooms, A New Partnership Grows with Viola Floral

The Hirshberg Foundation is honored to partner with Viola Flora for *Healing Bloom Zooms*, a no-cost flower arranging classes for cancer patients and survivors. The class aims to support patients on their healing journey, while raising awareness for pancreatic cancer.

The *Healing Bloom Zoom* was developed by Jelena Trifunovic, M.A., owner of Viola Floral, to help lower anxiety, reduce stress, improve mood, and enhance overall emotional wellness. Mayesh, the top national flower vendor, will be donating the florals and all classes will take place virtually via Zoom. Classes are taught by Trifunovic, a floral designer and seasoned K-12 science educator. Jelena brings her years of experience as an educator to provide informative classes that teach the fundamentals of floral design while providing a safe space for patients to relax, have fun and connect.

As a child growing up, Jelena was surrounded by the beauty of the natural world. In Serbia, later Southern California, holidays and family gatherings were spent in her family's kitchen arranging flowers with her mom, Luby, sharing stories, and laughing. When Luby was being treated for pancreatic cancer, Jelena remembers taking floral arranging classes and how much joy it brought them both. It is in Luby's memory that Jelena continues to give back and provide healing through floral therapy.

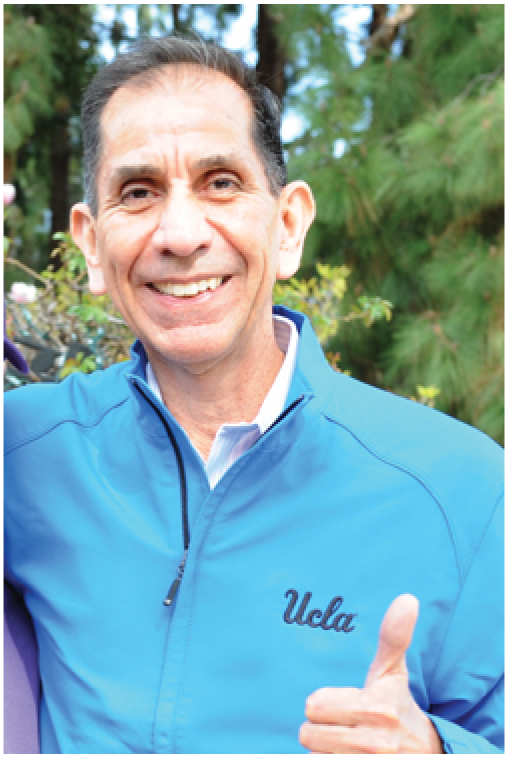
We are excited to partner with Jelena, Viola Flora, and Mayesh to bring our pancreatic cancer community these complimentary flower arranging classes! Our aim is to provide resource and support for all, and we hope the *Healing Bloom Zooms* will help patients on their healing journey and support positive mental health, while we raise awareness of pancreatic cancer.

Learn more and sign up for a *Healing Bloom Zoom* »

Celebrate and Learn from 10, 20 and 30-year Survivors of Pancreatic Cancer

We are honored to present a celebration and conversation with three long-term survivors of pancreatic cancer, Philip, Michelle and Donna. Our guests discuss how they have dealt with the highs and lows of their cancer journey. Moderated by Dr. Elizabeth Cleary of the Simms/Mann-UCLA Center for Integrative Oncology, our panelists share insights into how they weather the bumps in the road as well as how they achieve and appreciate the wins. The panel also addressed audience submitted questions for an informative discussion filled with hope.

Elizabeth Cleary, PhD returns to our Patient and Family Webinar Series to celebrate and speak with three long-term pancreatic cancer survivors. In April 2020, Dr. Cleary presented on *Coping Skills for the Pancreatic Cancer Community: Tools and Tips During Covid-19*. We are happy to welcome her back to moderate our conversation with a 10, 20 and 30-year survivor. In this inspiring discussion they share how they navigate their health challenges to become long-term survivors of pancreatic cancer.



Philip is a 30-year survivor who in 1990 was diagnosed with pancreatic neuroendocrine cancer (NET). There was no internet to research and little information available to him to understand what this diagnosis meant. He was a marathon runner and initially thought his pain was ‘runners stitch’ however, soon after he was told he had pancreatitis. After non-stop pain he entered a hospital in Los Angeles and after 4 weeks without improving he was told by a surgeon, “we need to open you up to see what’s going on.” Philip was in surgery for 19 hours and awoke to a diagnosis of pancreatic cancer. After months in the hospital he was finally released. Eventually he healed and has lived a fairly normal life for the last 30 years. He credits his faith, will to live and the incredible support from his wife and family for his good health.

Michelle is a 20-year survivor of pancreatic adenocarcinoma (PDAC), the most common pancreatic cancer. In 2002 she was diagnosed just one month before her 51st birthday. Other than a cousin who passed from pancreatic cancer in 1994 she had no other family history with this disease. She was tired for years and asked her doctor continually to test her thyroid to see if that was the culprit. Once diagnosed, she went to UCLA and Dr. Howard Reber, a renowned pancreatic cancer surgeon, to see if she was a surgical candidate. She was told she was inoperable and began chemotherapy. Her chemotherapy (5FU/Celebrex/Gemzar) was able to shrink her tumor from the size of an orange to the size of a grape in just six weeks! More chemo and radiation followed a successful surgery with Dr. Reber. Chemo continued for two more years and eventually she felt confident stopping treatment and starting life again. In 2014 she shared during our Annual Symposium that she felt "very healthy and had a good quality of life." It's time to check in with Michelle to see how she is doing six years later as she celebrates 20 years.

Donna is a 10-year survivor of pancreatic cancer (PDAC). Being in the best shape of her life, Donna found herself with a pancreatic cancer diagnosis in 2011. She had the Whipple surgery performed by Dr. Joe Hines with Dr. Zev Wainberg as her oncologist, both of UCLA. The first 5 years post treatment were great! Then she went on a clinical trial which worked well for 2 ½ years. Today she is on a new clinical trial (targeted therapy) and is doing well. Even with the bumpy road Donna appreciates where she is today and has made life changes along the way to live every day to the fullest.

Watch Webinar

A Second Chance at Life after a Whipple

Pancreatic cancer survivor of nearly 4 years, Jennifer Keller, shares her journey of an unimaginable new reality and how she's found happiness and gratitude in living a longer life post-Whipple.