Julie Shares Her Journey and Hopes to Inspire Others

I was diagnosed with pancreatic cancer by chance by my local internist. I had a “tummy ache” which was very unusual for me, so I had to check it out. I minimized it, but my internist said, “I know your body, I’m going to run a few tests.” I was 67 and had just finished my first sprint triathlon only 6 weeks prior. Throughout my life I had been around 10 to 30 pounds overweight but at that time I was in the best shape of my life.

My doctor called me the same day to come to his office and I was given THE News: “You have pancreatic cancer. I’ll try to get you into surgery as soon as I can.” By chance the surgery schedule was filled and I had about a week to worry and call everyone I knew who might be able to help, support and inform me about what to do. The same name came up several times: Dr. Isacoff at UCLA. I made an appointment and trusted him and what at that time was a unique protocol: a low-dose, long-term unique chemo cocktail. Since I lived in Santa Barbara, I had friends drive me to UCLA where I had a chemo infusion for at least an hour, then an appointment with Dr. Isacoff, then met my friend for lunch and was driven back to Santa Barbara. Sometimes I took the train. I had 3 weeks of varied chemo with one week off for 8 months.

People ask, “How bad was it?” It was 18 years ago and life since then has been so good that my memory fades about many of the challenges. The first few days of chemo were insignificant, then it took hold and I felt “yucky” for about two days, came out of it for about a day, then spent two days feeling pretty good, then back for another infusion week. The fourth week without chemo seemed somewhat normal.

During the 8 months of chemo I lost my hair and I lost my appetite —that was a surprise for someone who often over-loved food. I didn’t have a taste for anything raw which surprised my salad loving self. I had a couple of serious dips when I was taken to the hospital oozing from every orifice. There were nights when I was so wired I couldn’t sleep and wrote love letters to family and friends. AND, I also went on ski trips with my family, continued to work from home, drove where I needed to go, went out to dinner, went to church and temple, celebrated holidays and just ***lived life.*** I even had an *actual* witch doctor who was a Harvard & Stanford trained MD. Mostly I did ***everything****.* I desperately wanted to **live** and knew that I ***had to*** *do everything* in **MY** power to support the work the doctors were doing.

My motto was “leave no stone unturned." I thought, if there is a possibility it could help, if it has helped someone else, I’ll do it! There was a monthly support group for pancreatic cancer patients and their families at the **Cancer Support Center in LA**. I didn’t miss a meeting and my family also went to the meetings. There was a **Cancer Support week long** workshop I attended with my family who called it “Cancer Camp.” I worked with a nutritionist who taught me to juice and make smoothies. I bought cancer cookbooks. I hired a weekly cook. I had a friend bring me flowers every week. I had weekly massage and acupuncture. I did daily meditation and listened to meditation and cancer healing tapes. I especially listened to healing tapes while getting chemo. Then, I joined a gym that had a Cancer Program with both information and physical exercise. I was faithful in working out as best I could three times a week. I saw a Chinese doctor and used Chinese herbs daily. I exercised and walked daily and ate healthy as much as I could. I did everything the doctor told me to do, and everything meditative and spiritual my heart and hospice* counselor suggested. Hospice was especially supportive on an emotional level.

After the 8 months of chemo, Dr. Isacoff suggested Dr. Charles Yeo as my surgeon. At that time he was at Johns Hopkins Hospital in Baltimore, Maryland. He is currently at Thomas Jefferson University Hospital in Philadelphia. I had a Whipple surgery in 2005 and no further treatment. As usual with the Whipple surgery there were complications that were handled appropriately by the doctor and hospital. I was there for 4 weeks. I walked the halls every day holding my pole of medicine bottles with tubes and needles going into my body.

In the lobby of the hospital there was a piano. My then-spouse said that the minute he knew I was going to be ok was when he began to play the piano and while he was playing I began to dance with the pole and dangling bottles.

A few years later, there was concern about breast cancer. I had a lumpectomy in 2007 which showed DCIS but no cancer and all subsequent exams show no cancer.

I continue to reach out and tell my story to anyone who is willing to listen. And I can only hope that my story inspires and brings hope to others. It is crucial that we raise awareness, spread information and stories. We need to provide support and more stories about survivors, to give hope to those dealing with this diagnosis. I tell everyone who is interested about my story because there IS hope and there ARE angels. I have lived to see both of my children married, and seen 3 grandchildren born and being raised. I have travelled and lived to enjoy the life and love of my family and many friends. I continue to work out either swimming, walking, or playing Pickleball nearly every day and am engaged in many civic, entertainment, cultural and religious organizations. As of now, 2022, I have been cancer-free for 18 glorious years, I can only thank heaven and all the Angels along the way.

*“Hospice” and “palliative care” have be used interchangeably. Palliative care is now the norm for symptom management when diagnosed with cancer. Learn more about palliative care

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Judith Celebrates her Cancer Recovery at the LA Cancer Challenge

A celebration of my first-place gold medal win at the LA Cancer Challenge on October 23, 2022. For those who have been sharing my 2-year Pancreatic cancer recovery, I wanted to share this exciting news.

I was invited to enter the 5K Run/Walk at UCLA, but my first inclination was to say, "I’m not sure. I’m not much of a large crowd person and I have run/walked alone these last 3 years of COVID and my cancer recovery."

In reality, I was a little afraid of the unknown. I had never entered a 5K in my life.

The next day, *my spirit* nudged me to change my mind. "Why not accept this opportunity for a *new adventure*, a *chance to grow*? And this would give you the opportunity to *honor your own body* – which endured a distal pancreatectomy (removing 40% of your pancreas, all of your spleen, and 8 lymph nodes) at UCLA on October 23, 2020, 2 years to the date of the LA Cancer Challenge.”

So, I entered the race and thoroughly enjoyed mixing with all the other people supporting the pancreatic cancer community – survivors, family members, teams dedicated to someone who died of pancreatic cancer, babies in strollers, young children, teen, adults of every age and ethnicity – donating their time and money to support the Hirshberg Foundation for Pancreatic Cancer Research’s mission to **find a cure for pancreatic cancer**!

The event raised over $520,000!!!! And over $10 million has been raised since the inception of the Annual LA Cancer Challenge 25 years ago by Jon Hirshberg, who lost his father Ron to pancreatic cancer.

One of the highlights of the day was a 5-minute hug with a fellow survivor, 8-years cancer-free, who had bravely undergone multiple surgeries and multiple rounds of chemotherapy. He was trembling at first, but his body was finally able to relax and we both cried and breathed deeply together. It was very moving!

The fact that I won a First-Place Gold Medal for the fastest time in my age category was a total surprise to me and "icing on the cake."

I am grateful that I said "Yes" to the invitation and the challenge. I was blessed beyond measure. I send blessings to cancer patients and their families all over the world and encourage you to ***have faith, fight like a warrior, and know that you are loved and valuable***!

"Your individual spirit is your most powerful weapon in the battle with cancer." ~ Judith Anne

Connect with Judith

Jay Channels His Journey and Luck into Support for Others

My cancer story begins at the end of December 2012 when I was back East at my best friend’s father’s house. Growing up I spent a lot of time in that house. I went to the bathroom and was reminiscing about when the little bathroom was put in, being nostalgic, thinking I was lucky to have such a long history with a friend and a house. I was shocked to look down and see that my urine was very dark. I was concerned, it was so dark I called my primary care doctor in California and left a message to get an appointment.

By the next morning I had an email with an appointment for the following day.

Midway through the exam, the doctor told me I had to see a gastroenterologist immediately and that I needed a CT-scan that was scheduled for the next day. I saw the gastroenterologist the Saturday before Christmas. He confirmed the diagnosis was pancreatic cancer. He recommended surgery and told me there was only one doctor to perform the surgery, Dr. Howard Reber at UCLA. I was so lucky that my tumor was resectable, that the tumor was blocking the bile duct, making a diagnosis easier. I had a Whipple procedure on January 4th 2013. I was lucky.

I started Chemo with Dr. Isacoff about 10 weeks later. I did 6 months of folfirinox and showed no evidence of disease (NED) for 3 or 4 months. Then my CA19-9 went up. Then I got Gem/Abraxane for 4 months and again got to NED. Six months went by and I had the port removed. Then the CA19-9 went up again. Another port was put in, back on chemo again.

Then I heard about a new procedure whereby they isolate circulating cancer cells in your blood and perform genetic testing. The procedure was so new that the doctor didn’t know how or if it would help. We got the test results. I remember the exact words he said, "we can work with this!" He immediately changed my chemo to Gleevec. I was heartened and excited until the pharmacy called and said the cost of the drug was more than $10,000 per month. I was plunged into uncertainty again, I didn’t know what would happen. Then I got a call from the pharmacy. They told me they found a Prescription Assistance Plan to cover my out of pocket costs. I started taking Gleevec and rapidly proceeded to show no evidence of disease (NED) and have been NED for 5 years. I was lucky.

It has taken awhile to get past all the chemo but I’ll cherish every drop, because it got me to the liquid biopsy and then to where I am now. For the last couple of years I have been lucky to be on the Patient Council of the Canopy Cancer Collective. The Canopy is a group of 14 hospitals that have a Multi-Discipline Center for Pancreatic Cancer. UCLA is a member as well as Johns Hopkins, Stanford, Mass General, UCSD, UCSF & UC Davis to name a few. With the other patients and caregivers in the Canopy Patient Council we have started a peer-to-peer support group that meets monthly to create a community for people fighting this disease. Our group, AnCan (Answer Cancer Foundation) is about people helping people through inclusive virtual peer support that allows for widespread participation, especially to those geographically, physically or socially disadvantaged.

Pancreatic Cancer Awareness month is a time for reflection for me. It is a time for me to show gratitude and thanks-giving for the many personal milestones I have been able to share with my family over these 9+ years. I have been so lucky to celebrate births, b’nai mitzvahs, graduations, theater productions, marriages, science fairs, birthdays, bike rides, I am so lucky to have time.

Esther Lee Shares Her Pancreatic Cancer Journey

We are delighted to have Esther Lee, DPT, as our Honorary Starter for the 2021 LA Cancer Challenge Walk/Run. The LACC Honorary Starter is a special honor we bestow each year on a pancreatic cancer survivor who has shown great courage, strength and positivity throughout their cancer journey.

Diagnosed in July 2020 with stage IV **pancreatic neuroendocrine** tumor with metastasis, Esther faced a long and bumpy treatment journey that she is still on. Through it all she exemplifies grace and expresses gratitude every step of the way. In Esther’s own words, “I’ve truly learned to take it one day at a time, the greatest challenge being fully present in each day, moment by moment… this is the amazing place of peace and gratitude.”

Learn more about Esther in this short video

Esther is a source of joy and inspiration to everyone she meets, including her long-time client Serena Williams. The tennis icon and Esther’s dear friend shared a heartfelt video rallying support for Esther and her team.

Watch Serena’s video

Esther has the amazing support of her family, friends and her medical team at UCLA. On October 31, 2021, we rally for Esther and all those facing pancreatic cancer to walk for research, race towards a cure and never give up!

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!