

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.

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.

Finding Your Voice to Inspire, Motivate and Never Give Up

My name is James, I live in Los Angeles and my affiliation with the Hirshberg Foundation goes back 10 years now. In 2010, my son Christopher and a few friends participated in our first LA Cancer Challenge 5k Run.

How to Host a Virtual Fundraising Event

Give friends and family a fun night in, alleviate that cooped up feeling and serve a greater purpose – raising awareness for pancreatic cancer. All of these goals can be accomplished by hosting a virtual fundraising event online and we guarantee it will be an exciting and fulfilling experience. The big

difference between an in-person event and a virtual event is moving everything to a video conferencing platform and selecting an activity everyone can participate in – we've plenty of ideas and resources for you!

5 Steps to Get Started

1. Choose a Virtual Event Idea
2. Ask a Friend to Help Plan & Co-host
3. Create a Fundraising Page
4. Choose a Video Conferencing Platform
5. Follow our Virtual Event Checklist

Step 1: Choose a Virtual Event Idea You'll Enjoy

Make your virtual event interesting and memorable with a few fresh ideas. Here are some suggestions to get your imagination going! Give your event some purple pizzazz when you [order a Purple Spirit Box](#) and send them to attendees to share amongst their households.

- Scavenger hunt at home
- Game night (virtual card & board games)
- Wine & Cheese Tasting
- Pajama Brunch
- Holiday Trivia Party
- Simultaneous crafting projects
- Teach a yoga class

- Amateur Music concert
- Amateur a cupcake wars baking class
- Netflix Watch Party

- Costume party
- Pre-Thanksgiving Family Reunion
- Do crafts or a DIY project
- Video Game Competition

Example: A Virtual Scavenger Hunt is a game anyone can participate in right from home. Each household team can scour their home and the web for funny items or mysterious clues. Split your event attendees into teams and turn the hunt into a race, or you can award points based on the originality and absurdity of the answers. Prompts or theme ideas: Family photo gone wrong, terrible present, elaborate decoration, getting a stocking full of coal, pet dressed up in Christmas clothes, Drunken Santa and more!

Step 2: Ask a Friend to Help Plan & Co-Host

This is an optional step, but really, everything is more fun when you do it with friends. Brainstorm ideas, divide up tasks and spread the word together. And if you want to go it alone, that's fine too!

Step 3: Create a Fundraising Page

A fun event idea combined with a cause you care about will inspire people to not only attend your virtual event but also make a donation. Your online gathering will serve a greater purpose – raising awareness and funds for pancreatic cancer research and patients services. So, don't hold back, present a strong call to action to drive donations and attendance.

Fundraising is key but it can be kept simple. Two easy ways to collect donations are:

Event Fundraising Page

When you set up a fundraising page you'll have a link to direct donors and event attendees to give. Follow up each donor by sending them a link to access your event!

[Create an Event Fundraising Page »](#)

Facebook Fundraiser

When you start a Facebook Fundraiser, you can direct people to your Facebook Fundraising Page to give. Follow up each donor by sending them a link to access your event!

[Create Facebook Fundraiser »](#)

Step 4: Select a Video Conferencing Platform

Video conferencing tools have become a popular way for people to communicate with family, friends, and the organizations they care about. Around the world, people are getting creative in how they are using livestreaming thanks to inexpensive technology. New to hosting online events? Check out this collection of resources.

- **Zoom** – Allows free video meetings for three or more people for up to 40 minutes with their free plan. The next tier lets you set up video calls for up to 100 participants long.
- **Skype** – Up to 10 people can join a Skype group video call. Skype is free to download and works on phones, tablets and computers with webcams.
- **Google Hangouts** – If you have Gmail, that means you

already have a Google account you can use to set up Hangouts for free. Up to 25 people can join a video Hangout and up to 150 people can join a voice-only Hangout.

- **Houseparty App** – This app was made for up to eight participants can participate on a FaceTime-like call. It also features third-party games that can be played simultaneously throughout the call.
- **FaceTime** – You can set it up as a Group FaceTime with up to 32 people (requires newer devices and updated iOS).

Step 5: Follow our Virtual Event Planning Tips

This [virtual event checklist](#) will help guide you as you dig into the details of your virtual fundraising event. From start-to-finish, we're helping you set up your fundraising page, select an event idea, plan an event agenda, thank your attendees and more!

*Resources and articles

LA Times: [How to have Zoom parties that are actually fun](#)

LA Times: [Ultimate guide to hanging out with your friends online](#)

Style Caster: [How to Throw an Epic Zoom Party Your Friends Will Never Forget](#)

Team Building Blog: [32 Fun Virtual Holiday Party Ideas in 2020](#)

Your Virtual Fundraising Event Checklist

We've officially entered the age of the social video call for remote work, social events and family/friend gatherings. This virtual event checklist will help guide you as you dig into the details of your virtual fundraising event. From start-to-finish, we're helping you set up your fundraising page, select an event idea, plan an event agenda, thank your attendees and more! If hosting a virtual event online is new to you, make sure you read our 'How to Host a Virtual Event' instruction sheet first. We share 5 steps to get started, video platforms, resources available and more.

Select a Virtual Event Idea!

Before selecting an activity, check out the section below about partnering with a small business for an easy additional way to fundraise. Select an activity that you'll enjoy planning and isn't too complicated. Here are a few ideas to consider:

- Scavenger hunt at home
- Game night (virtual card & board games)
- Wine & Cheese tasting
- Holiday Trivia Party

- Amateur cupcake wars baking class
- Pre-Thanksgiving Family Reunion
- Do crafts or a DIY project
- Video Game Competition

□ **Ask a Friend or Family Member to Co-host**

Co-hosts can support each other through the planning process, learn how to set up the video call together and guide attendees through the online event.

□ **Create a Fundraising Page & Set a Goal**

A fun event idea combined with a cause you care about will inspire people to not only attend your virtual event but also donate! Don't hold back, present a strong call to action to drive donations and attendance. Fundraising is key but it can be kept simple. We suggest two easy ways to collection donations:

- Create an [Event Fundraising Page](#) to collection funds and follow up with each donation with a link to access your event.
- Create a Hirshberg Foundation [Facebook Fundraiser](#) to collect funds and follow up each donation with a link to access your event.

□ **Collect Donations or a Suggested Donation Entry Fee**

It's a fundraising event! In addition to collecting donations, if you partner with a business there may be a fee to purchase a product or service. If not, ask for a 'suggested donation admission fee' for an appropriate amount. Attendees donate to your fundraising page to cover the fee.

Create your guestlist

Virtual fundraising events can range from small to large-scale depending on the activity. Set a limit of attendees based on what you're comfortable with and the activity you choose.

Plan an Agenda

Set an agenda so people know what to expect and how long you'll dedicate to each part. For example: "We'll chat from 6 to 6:30ish, then at 6:35 we'll share the instructions for the activity, we begin the activity and at 8pm we wrap up by thanking everyone for participating and donating."

Provide a Virtual Background

Zoom video conferencing allows you to upload your own photos, so you can really go wild with this one or allow everyone to spice up their own lives by adding backgrounds to their screens.

Purple Décor

For pancreatic cancer awareness, add some purple accessories and decorations. The Hirshberg Foundation provides a [Purple Spirit Box](#) in our e-store that you can suggest or send to attendee households!

Keep it short

One-hour-to-90-minute range tends to be the sweet spot for most online gatherings. Give them too much and their brains will shut off, give them too little and they will get bored. Give attendees a chance to get up, walk around, and grab drink.

Keep it interactive but monitor noise

Even if your audience is not outspoken enough to ask questions, they typically will be willing to participate. Make sure you can mute everyone when the host needs to speak or if someone has to step away and there's background noise.

Play games

Tap into your attendees competitive side. Puzzles or riddles, crosswords, memory games, ordering tasks are all great ways to keep your attendees engaged and on-task. For added drama, impose a time limit. Try introducing a quick quiz and offer a small prize for the winner.

Offer reward or prizes

Attendees will be more motivated to participate You should also consider extra incentives such as a competition or small prizes. [Ask the Hirshberg Foundation](#) if we can provide a few fun items to offer!

Thank your donors and attendees!

As you finish your event, remember to thank your attendees for participating and giving. Let them know how they're making a difference and send a thank you email or note to people who donated but didn't attend.

Partner with a Local or Online Small Business

Before you decide on an event idea, consider whether a local small business would be interested in partnering with you. Do a little local research and you may find a business that provides a service or product to be the theme of your event. Many businesses are taking their in-person services and transitioning them to online while mailing products. Ask if they'll donate 20% of their sales towards your fundraising. Examples include: a yoga studio teaching a virtual class if you sell the tickets, they'll donate a portion of the proceeds; a wine bar that provides a cocktails/mocktails recipes or wine & cheese package and then offers an online tasting class; or a local baker willing to teach a pie making class online, provides a list of ingredients and offers a discounted pie for attendees for Thanksgiving. Get creative and simply ask. Small businesses are looking for exposure and community support and they recognize the value of supporting something their customers believe in and partnering with a charity!