

Pancreatic Cancer Awareness Month is my Milestone

I was diagnosed with inoperable pancreatic cancer in May of 2021. I was initially given six months to a year to live. My tumor is wrapped around the superior mesenteric artery, in the uncinate process of the pancreas. I have had 8 rounds of SBRT radiation, and 5 rounds of cyber knife radiation. Between the two, a portion of the tumor was removed. I have refused Chemotherapy infusion, opting instead for the oral Chemotherapy drug Xeloda. I was on Xeloda for 2 years but made the decision to stop taking it altogether because my feet and hands were cracked open and bleeding, and I had sores inside my mouth.

When I was first diagnosed, my mind worked overtime to try and grasp the fact that I was dying. I cried buckets of tears and had a million thoughts run through my mind. I am a grandma of 7 grandchildren, 4 boys and 3 girls. I was so looking forward to watching each one graduate high school, and I wanted to dance at each of their weddings! I looked forward to holding my great grandbabies in my arms. My husband, Dan and I had plans for his retirement that we looked forward to. Plans to go back to Scotland again and see more of my grandmother's ancestral home. Plans to do more hiking and camping in the remote wilderness of Alaska, where I was born and raised. So many plans, hopes and dreams that pancreatic cancer stole from me.

I kept asking myself, "Why me? How can I possibly cope with all I stood to lose and never accomplish? I felt overwhelmed with grief, and sorrow, and fear over saying my final goodbyes to my husband, our three sons and their families. I felt myself giving in, and giving up to cancer.

And then, I called upon my faith, my hope and my trust in God. I

placed my life and my future in God's hands. I made the decision to speak positively about my cancer, and to live every minute of every day to the fullest. I stopped focusing on the 'what ifs' of tomorrow. Nobody knows what tomorrow will bring. Instead, I live in the moment, giving thanks for every breath I take, for the joy and laughter my family and friends bring me. I look for ways to encourage others who have been diagnosed with cancer.

Today, I am three years and six months past my initial diagnosis of inoperable pancreatic cancer. I live for the day, focusing my time and energy on the positive aspects of my life. I have no idea how much longer I have on this Earth, but today I am alive and doing well, and that is sufficient for me. Pancreatic cancer does NOT define me but rather, I define IT!

November is Pancreatic Cancer Awareness Month and helps me draw attention to this deadly disease, and to get others to check if they have symptoms, early detection is so important! Pancreatic Cancer Awareness Month is my milestone; I have survived 3 years of Novembers. This November I want to encourage everyone to keep your focus on the positive aspects of your life. Be thankful for each breath you take, and do not let cancer define who you are!

YOU ARE BRAVE! YOU ARE STRONG! YOU ARE A CANCER WARRIOR!

Agi Hirshberg: Our Lady of Hope

PANCREAS SPOTLIGHT

By Shweta Lavania

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Selfless service in cancer research is the embodiment of compassion in action. It is through service that we truly connect with the world around us, leaving a legacy of love, generosity, and empathy. No one has understood this fact better than Agi Hirshberg. From finding inspiration through her tragic loss, Agi's unwavering commitment to the cause of supporting and advocating for Pancreatic Cancer patients is simply a tale of compassion, inspiration, and true labor of love. We, here at Pancreas are honored to celebrate the life and philanthropy of the remarkable Agi Hirshberg by featuring her in our inaugural Pancreas Spotlight series.

I spoke with Ms. Hirshberg on a sunny Fall afternoon to try and decode the secret sauce that flows through the veins of this impossibly sunny, vivacious, 78-year- (young!) old and came back inspired by her humility, her boundless optimism ("the cure is just so close now, I can feel it") and her love and support for the tiny but growing community of pancreatic cancer research that punches well above its weight in the fight for patients' lives!

Agi's inspiring life story which begins in 1946 has all the hallmarks of the upheaval of the Post World War era that forced her parents, Edmund, a Holocaust survivor, and Sarah Mandel, to leave Hungary and emigrate to the United States of America. Like all immigrants, America eventually embraced and assimilated this hardworking family with all its fervor and thus began little Agi's journey to a life of hard work and boundless optimism towards a better destiny. From Miami to eventually Los Angeles, armed with limited English, Agi set out to complete her education eventually receiving her bachelor's degree at Woodbury University in Business and Design. A career in creative designs

and marketing beckoned which eventually led to a chance encounter with a “handsome gentle giant”, who went on to change the course of her life, both personally and professionally. In 1986 Agi met, fell in love and eventually married the love of her life, Ronald Hirshberg, a “retail genius”. Together, they established a successful business by becoming the exclusive licensee for Adidas accessories, all over the world. Life was perfect until fate intervened. In 1997, Ron was diagnosed with Pancreatic Cancer which eventually led to his demise at the age of 54 after a hard-fought battle of 8 months and seven days. Those who are familiar with the ravages of this disease know the stealth nature by which it manifests in the form of innocuous symptoms which are often ignored until it is well too late to stage a successful therapeutic intervention. While losing one’s beloved husband in the prime of his life might have broken the spirits of a lesser mortal. Agi Hirshberg found new strength and a clarity of purpose that led to the establishment of the Hirshberg Foundation for Pancreatic Cancer Research a mere 6 weeks after Ronalds’s death.

One can say now, with hindsight, that the mission almost chose Agi way before she chose it herself. Her phenomenal instincts as an entrepreneur coupled with her unapparelled belief in the urgency of her mission led her to recruit and collaborate with some of the brightest minds in the field of Pancreatic cancer research to raise awareness, brainstorm new treatment guidelines and above all, place the needs of patients first and foremost, in any clinical and research scenario. Merely 6 months after Ron’s untimely loss, the Hirshberg Foundation was up and running at UCLA under the leadership of Dr. Howard Reber. Since its inception, the Hirshberg Foundation has touched the lives of countless patients by raising more than \$32 million in funding that is used for providing financial aid to patients, establishing the Seed grant program that provides critical

funding to support medical research in pancreatic cancer, establish research institutions that focus on pancreatic cancer pathobiology and treatment, establishing tissue data banks to support research, provide support for inter-disciplinary cancer research to spur new innovations and support professional research organizations such as the American Pancreatic Association (APA), Japan Pancreas Society, and the European Pancreatic Club's Annual Meetings to name a few. One might assume that Agi's legacy as a champion of Pancreatic Research is all but assured and she may well afford to relax as the years go by. One couldn't be more wrong because the messianic zeal which fuels Agi is far from diminished, and she continues to criss-cross across the world marshaling her phenomenal resources to bring together new collaborators, supporting new researchers, and throwing fundraisers and spending time with pancreatic cancer patients and supporting them through the tough journey that defines their destiny from diagnosis to treatment and management of symptoms. She is ably supported in this mission by her daughter, Ms. Lisa Manheim, Director of the Hirshberg Foundation for Pancreatic Cancer Research, who shares her mother's boundless optimism and passion for pancreatic cancer patient advocacy and research. Ms. Manheim has taken over the rigors of the day- to-day operations of the foundation while Ms. Hirshberg continues to draw up ambitious plans and alliance to thwart the march of pancreatic cancer.

Agi Hirshberg is one rare human being who has turned her personal loss into a cause that transcends her own pain and provides support and meaning to countless pancreatic cancer patients all over the world. Thank you for being a true friend & cheerleader of the Pancreas & the Pancreatic Cancer community!

Below are some of the excerpts from our meet-up session:

What is your opinion about the status of research in the field

and how close we are to finding a cure?

Agi: I almost think that with AI and all the new technology that we have now, we are as close as we can be to finding a cure. (On her optimistic outlook) Listen, I live with the word “we are going to beat it (Cancer)! Hope springs eternal.

Did you ever envision that your life’s work would ever involve establishing a foundation for the patient support, advocacy and fundraising for pancreatic cancer research?

Agi: Absolutely not! I am an immigrant, grew up in Hungary, arrived in US as an 11-year-old only child (tie breaker child!) with limited English. This humble start to life made me realize the importance of a strong work ethic and boundless optimism. After finishing my education, I started as a fashion designer and then I met the love of my life Ronnie and together we set up our business, I designed the Adidas products, and he built our global distribution business up and running and we were a successful team! Then Ronnie’s loss spurred me to approach Dr. Howard Reber at UCLA, and the Hirshberg Foundation came to life, and we have never looked back!

For someone who has spent 26 years working with pancreatic cancer patients and their loved ones, supporting them, and giving their suffering a voice and positive direction to inspire changes, please share some of your favorite memories of interactions.

Agi: I must tell you that while I am truly proud of all the efforts and resources that we (Hirshberg Foundation) have provided to the Basic and Clinical research community, what I am really focused on is providing support to the patients. I am proud of the network of support and services that we can call upon all over the country, best centers, best physicians, and staff to refer these patients for treatment and help them in

every possible way as they battle this dreaded disease. Providing these patients with all the support and help remains my primary focus to date. To celebrate their courage and to inspire other patients and survivors, I host Agi's Backyard Barbecue (see pictures), an annual get together where in 60-80 patients, their loved ones come over and share their stories. Every year it so happens that we have newly diagnosed patients that sit on one side and on the other side we get patients who are thriving even after 7, 18 and even 23 years post cancer diagnosis! This allows the "newbies" and the "veterans" to share their experiences and support one another and celebrate life. I can tell you no one wants to go home by the end of the night! That sort of energy is infectious and inspires me to do what I do.

Lastly, Tell us your secret Agi? At 78, you look like you've cracked the code to a life well lived!

Agi: You can't help but become sisters and brothers with the patient, so the emotion is always with the patient and that they have the long life. What else could I say? I am an eternal optimist, and I am sure that the cure is just out there, all we got to do is keep going. We can beat CANCER!

Turning Pain Into Purpose

In 2022, Whitney Goldin's mom, Karen, was diagnosed with pancreatic cancer, a disease Whitney has become too familiar with but never imagined would touch the life one parent, let alone two. The diagnosis came after the family's devastating losses of Whitney's father, grandfather, and great-grandfather

to the same disease. "My dad passed away in 2021 and then it was a shock for my mom to be diagnosed in 2022. I decided I'm just going to turn my sadness into action." Today, Whitney is ready to end the cycle of pancreatic cancer in her family. She's already turning that sadness into action by raising awareness and rallying her entire community in the Chicago area with her Purple Ribbon Event, [Pushing Back Against Pancreatic Cancer](#).

Whitney, a loving mother, dedicated daughter, and attorney has generously shared her family's remarkable story to help raise awareness since her mom's diagnosis. *"Getting to this path has been riddled with pain, seeing both of my parents go through what they've gone through,"* said Goldin. *"This devastating disease is impacting too many of my loved ones. Enough is enough, I'm done."* Whitney wouldn't sit idly by without taking their own action. By February of 2023, her mom was scheduled to have the Whipple surgery and Whitney was hosting a [Purple Ribbon Event](#) to benefit the Hirshberg Foundation. *"I have never planned an event before other than my kids birthday parties so I have zero event planning experience but I started doing some research. I called the Hirshberg Foundation for Pancreatic Cancer Research and I said, 'Listen, I'm going to plan an event and it's going to be in three months and I have no idea if anyone will even come, any money will be raised, but anything I raise I'm going to send to you.'"*

Hosted at Temple Sholom of Chicago, *Pushing Back Against Pancreatic Cancer* featured yoga, brunch provided by a variety of Chicago eateries, tequila mimosas, and a silent auction with items from top Chicago businesses. Whether you live in Chicago or any other city or town across the country, Whitney has demonstrated the importance of sometimes going outside your comfort zone when it comes to helping raise funds for pancreatic cancer research and patient programs, "I went into the event planning process trying to be as open minded as possible with

what I thought would attract the most people and raise the most awareness. The event evolved as more and more people registered and as more and more businesses donated. I took a deep breath of gratitude at every turn, and tried to remain as flexible as possible." By the end of the day on February 2nd, her community had helped raise over \$42,000! "The day of the event was more perfect than I could have ever imagined. The two-hour event passed by in the blink of an eye. But at the very end, I reminded myself to take a step back and to witness everything come to fruition. It was so touching to be surrounded by so many people- all with the communal goal of raising awareness." Whitney shared.

Throughout the planning process, Whitney continued raising awareness in her Chicago community through a televised segment with [Fox32 Chicago News](#), and an interview with [Chicago's Very Own WGN9](#). She has shown unwavering support throughout her mom's journey and continues to connect with other families by sharing her family's story, including a recent [podcast interview](#) on *Living Hope: Your Journey with Pancreatic Cancer*. Today, with the help of a committed medical team her mom is thriving. She continues her journey back to health one day at a time. Whitney is ready to create a new cancer-free path for her mother and family, "One day, there will be a cure, and I want to do everything I can to help us get there," she shares. She has found a new purpose in her life – to eradicate pancreatic cancer. "We're going to get closer and closer to a cure and I will do everything I can throughout my life and devote myself to getting closer to that," she said. "I can tell you that that is my new goal. Forever."

Marathon Goddess, Julie Weiss Raises One Million Dollars for Pancreatic Cancer Research

Ten years ago, Julie Weiss finished her journey of 52 marathons in 52 weeks, in a quest to raise one million dollars for pancreatic cancer research and became known as the *Marathon Goddess*. On Sunday, March 19th, Weiss will be celebrated by pancreatic cancer survivors and supporters everywhere as she crosses the Los Angeles Marathon finish line yet again, and at the Hirshberg Foundation's Purple People Party Cheer Station near Mile 21. The celebration will commemorate Weiss raising more than one million dollars for pancreatic cancer research over the past decade, and helping raise awareness about the disease that has the highest mortality rate of all major cancers.

MY BIGGEST FAN & INSPIRATION...

In 2010, following the death of her father to pancreatic cancer, Julie remained determined to make a difference, and running gave her a purpose. Just one week after he passed, she fulfilled their dream for her to qualify and run the Boston Marathon. He was, after all, her biggest fan. "I know he was there with me. He was the wind at my back and had the best seat in the house my heart after I ran the Boston Marathon in 2011," Julie shared. From there, she decided to turn her passion into a purpose and embarked on an incredible endeavor to raise hope, money and awareness for pancreatic cancer. In time, Julie chose the name Marathon Goddess, but is quick to point out its true meaning that it is not about her, it's a name that allows her to encourage others to embrace their passion and let it shine.

A \$1 MILLION DOLLAR GOAL...

Since 2010, Julie has made many ties in the pancreatic cancer community. She has witnessed the ups and downs of statistics and gotten to know the faces and journeys of countless survivors whom she has run in honor of. Through the ups and downs, her focus hasn't waivered: "When I began this journey, my objective was to raise a million dollars to find a cure for pancreatic cancer, the disease that took my father away from me, and to help others affected by this insidious disease," said Weiss. "Julie set out to achieve a lofty goal, at the grass roots level, and never wavered in her commitment to see it through," said Lisa Manheim, Executive Director of the Hirshberg Foundation. "In addition to being our partner in helping spotlight pancreatic cancer, the awareness and money she raised has helped fund much-needed research bringing us one step closer to finding a cure." Throughout the years, Weiss has received support and donations from corporate sponsors and running organizations, however, the majority of her fundraising has come from individuals and families that have been impacted by the disease and those she has inspired through her running.

PHILANTHROPIST & AMBASSADOR...

As a marathon runner, author, philanthropist, ambassador and advocate, Weiss keeps busy by sharing enduring stories of hope, empowerment, loss and resilience from patients and families fighting for their lives and the lives of their loved ones. She has remained a fervent supporter of the Hirshberg Foundation throughout her journey, motivating fellow runners on the Hirshberg Training Team each year, running the LA Cancer Challenge 5K and receiving the Never Give Up Award, leading a team at Tour de Pier, and inspiring communities across the country to Never Give Up hope. She has been a spokesperson for

the Hirshberg Foundation's successful fundraising campaign, *52 Races for 52 Faces*, a year-long, philanthropic crusade in which she competitively ran in marathons, half marathons, 10Ks and 5Ks in 52 cities throughout the U.S., and across the Pacific Ocean to shine a light on pancreatic cancer. The campaign started and ended with Weiss running the Los Angeles Marathon which also included the foundation's signature Halloween fundraiser, the L.A. Cancer Challenge.

Through running, Weiss hopes to show the world that pancreatic cancer is much more than devastating [statistics](#). There is a name and a face behind every survivor, and she is running for them. "Over a decade later, my mission to fight the good fight against pancreatic cancer has evolved to not only fundraise, but to be a voice for patients and to create awareness about the risks." She added, "Although we have seen progress, more needs to be done, and together, we can find a cure. We got this!"

AN EXTRAORDINARY FINISH...

Throughout this extraordinary journey, Julie has shared enduring stories of hope, empowerment, loss and resilience from patients and families fighting for their lives and the lives of their loved ones. She has crossed over 1,000 finish lines, whether she was completing her 52 Races for 52 Faces campaign or her most recent 12 races in 12 months to raise awareness about the 5-year survival rate that has increased two years in a row. The stories she has helped share will never be forgotten and thanks to the one and only Marathon Goddess, we are \$1 million dollars closer to a cure through research funding and patient programs. *"Running with a purpose to fight the good fight against pancreatic cancer has become my mission; I will not stop until we have found a cure."* We look forward to cheering her on as she leaps across her 116th marathon finish line!

New Podcast from Pancreatic Cancer Survivor Offers Hope

Since her diagnosis with an inoperable pancreatic tumor in 2002, [Roberta Luna](#) has embarked on many new adventures. From her first half-marathon, to her first tattoo to her first of many sky diving trips, Roberta has embraced living life to its fullest. As she said, “we tend to put off doing things we want to... because we think there’s plenty of time down the road.” So when the opportunity to host a podcast radio show on OC Talk Radio presented itself, Roberta, along with her husband and caregiver, Vic, began yet another first.

“Vic and I recently had the 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.](#)”

Through their podcast, Roberta and Vic hope to provide information and [resources](#), share [inspirational stories](#), give hope to those affected by pancreatic cancer. With new episodes available on Thursdays, Roberta is not only sharing her story, but stories from across the pancreatic cancer community. As she shared, “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.”

Roberta is a wife, mother, self-proclaimed thrill-seeker, tireless advocate and volunteer, and as of April 1, 2021, a 19-year pancreatic cancer survivor, with an inoperable tumor due to

artery & vein involvement.

Vic and Roberta hope to share the journeys of various patients, caregivers and advocates, including the good, bad and ugly of facing this disease. They aim educate, raise awareness, provide hope and spark inspiration in their audience. Together, the pancreatic cancer community can weather the storm with the support of loved ones, family, “the purple family” and the many people encountered along this often-difficult journey. We are happy to support Roberta and Vic on their latest endeavor!

Learn more and listen to their show → <https://livinghopepc.com/>
Follow along on their Facebook page → <https://www.facebook.com/LivingHope2055>

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)