

# You Can H.E.L.P. Fund Spotlight- Tyrone Buchheim Fund

*“A Surprise Birthday with an Unexpected Gift”*

By Tatjana Luethi

This January, a year after my father-in-law Tyrone passed away from pancreatic cancer, my husband Mark's 40<sup>th</sup> Birthday was quickly approaching. Mark's mother Meta, sister Debbie, and I wanted to do something to celebrate my husband's life and honor his father memory. So we set out to plan a surprise birthday party and raise funds to donate to The Hirshberg Foundation. This would be our gift to him. I wanted to support a foundation near us that was making a difference for patients and families affected by pancreatic cancer.

Our conspiracy was to keep Mark “busy” by our friends before his party. As it turned out Mark was and wasn't surprised! Invitation websites simply don't always work perfectly – oh well, lesson learned. However, by the end of the evening 65 of his close friends and family joined us and had a blast! He was genuinely touched by the fund we'd created and appreciative of all the contributions.

We're so grateful to all who generously participated in our fundraiser. They stood by us in support of research that will help families in the future in hopes of finding a way for early detection and new treatment options of this deadly disease! We did this as a tribute to Mark's dad. It hadn't been long since Tyrone passed away and I remember my husband's powerful reflection on his father's life, the time they spent together,

and some of their final memories. Mark wrote, “The last few months and days were both difficult and beautiful. My sister and I are his legacy. His beautiful grandchildren are his legacy. We are the gentle, giving, intelligent, and humorous children and adults we are today not in-spite of our experiences but because of them.”

Planning this unique gift turned into a wonderful experience and great collaboration with The Hirshberg Foundation. Mark’s surprise birthday party is a memory that will always stay with us.

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## **Doug C. Never Gives Up!**

Since Doug’s diagnosis he has been an avid supporter and participant in Hirshberg Foundation events and programs including the Annual symposium, the LA Cancer Challenge and hosting his Fishing for a Cure fundraising event. He continues to share his story with the community, advocating for patients and raising awareness. His passion for life and his determination to never give up continues to inspire us all!

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## **You Can H.E.L.P Fund Spotlight**

# – Koplow Fund

By Leslie Koplow

My Dad, Michael Koplow, was diagnosed in July 2010 with pancreatic cancer. They discovered that he had a large tumor in the head of the pancreas, which had not yet metastasized. In typical Dad fashion, he took a weekend to absorb and process the information on his own, before breaking the news to his wife and kids.

As a man of science, and a mechanical engineer by trade, Dad attacked his disease with his full arsenal of tools – his ability to tackle complex projects, his research skills, his scientific knowledge, his patience, his fortitude and stoicism, his charm, and his ability to just “get things done.” He knew from the beginning that the statistics were not in his favor, but he was determined to get the best treatment he could and extend his life as long as possible while maintaining the quality of life he required. Years of hockey, tennis and basketball and his wife’s excellent cooking had him in good shape for the battle. For 20 months, he was able to stave off most of the disease’s effects, undergoing a Whipple operation attempt, 17 rounds of Gemcitabine (chemotherapy) and 2 rounds of Cyberknife (radiation). During that time, he was able to accomplish many of his end-of-life goals with help from dear friends and family, by preparing he and his wife’s house for sale, buying and refinishing a new condominium apartment, visiting with all his children, grandchildren and great-grandchildren near and far, and managing his treatment with the help of his medical team.

Dad was treated at Beth Israel Deaconess Hospital in Boston. He kept meticulous notes of his symptoms and treatments, and charted his CA-19 levels against the tumor’s size. He never

showed any self-pity; his biggest worry was how his death would affect his family. It was only in the last two months, when his digestion became severely compromised by the tumor's growth that he experienced pain and real debilitation.

Once his options had run out for treatment, he quickly decided that he had no interest in lingering in an incapacitated state, and chose to withhold all measures that might extend his life. This is so in keeping with the man he was! He talked of his worry of "disrupting his children's lives for too long" as we and his grandchildren all gathered in Boston to help in any way we could and be with him during this incredibly difficult time. He died a mere eight days later, very peacefully at home, surrounded by his children, Paul, Leslie, Hilarie, and Jeff, his dear wife Dottie, and his daughter-in-law Kathy.

He had an excellent relationship with his oncologist, Dr. Andrea Bullock, and her colleague, Dr. Jamie Potossek of Beth Israel Deaconess, and fully comprehended the challenges of pancreatic cancer. Unlike many other cancers for which treatments have been developed, pancreatic cancer remains inevitably fatal and difficult to treat effectively. We decided to create a You Can Help Fund Page in memory of dad because Dr. Bullock's pancreatic cancer research was supported by the Hirshberg Foundation Seed Grant Program and thus Dad hoped that friends and family would contribute to this Fund in his memory and to help future patients diagnosed with this terrible disease.

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# Patient Programs Spotlight – Two Sisters Create Patient Symptom Management Workbook

*Editor's Note: Bellah Care Chronicles Patient Symptom Management Workbook was created by two sisters who were caretakers for their mom after her diagnosis of pancreatic cancer. Their books are a tool aimed to help patients and family members gain control over symptoms, side effects, nutrition, medication, appointments and blood and scan results. In collaboration with the Bellah Care Chronicles, we have created a customized, comprehensive and complete Patient Symptom Management Workbook for pancreatic cancer patients. Thanks to a generous educational grant, The Hirshberg Foundation for Pancreatic Cancer Research is gifting the notebook to newly-diagnosed patients. It is our hope that patients and families will be able to take control of their treatment and their well being and be able to focus on what really matters most to them. Below is their story.*

By Sarah and Carmella Banks

Our names are Sarah and Carmelle Banks. We are sisters, 2nd-generation caregivers, and cancer activists. In 2006, our lives took a dramatic turn when we became primary caregivers to our mom, Jane, who was diagnosed with pancreatic cancer at the young age of 57.

At the time, we lived on separate coasts, one of us living on the east coast and one on the west. When our mom told us she had cancer, we immediately returned home to live with her and put our heart and soul into taking care of her. While most people in their twenties are transitioning into careers and family life, we were getting ready to embark on the biggest role of our

lives, warriors against pancreatic cancer, with our mom leading the way. Our mom was a single parent, a registered nurse and health educator for 37 years. She taught us about being women of integrity by stressing the importance of service and helping others. She always made sure we were taken care of. Years later, as she was facing the biggest challenge of her life, it was our turn to make sure she was loved, supported, and was well taken care of.

Throughout treatment mom endured a variety of chemotherapy drugs, surgeries, integrative treatments and took many medications. In an effort to be better caregivers and understand how *her* body was handling treatments medications and new food regimens, I designed a book which would keep track of her daily needs and what we refer to as the "new normal". I created the book specifically so it was small enough to travel in a purse or bag back and forth to doctor appointments, but large enough to hold the pertinent information that your doctor may ask. The book also contains refillable pages with detailed charts for medication, daily food intake, symptoms, doctor's notes, phone numbers and other medical information.

Our mom fought courageously for 2 1/2 years overcoming the bleak statistics that gave her only six months to live. Today, though we can no longer fight this disease beside our mom, we continue to stand up for cancer by dedicating our lives to helping other families manage their cancer care. We've made it our mission to stand up for all patients, caregivers, and loved ones by spreading cancer awareness and helping to raise thousands of dollars for cancer research.

Our family was first introduced to the Hirshberg Foundation after going to one of their annual educational Symposiums at UCLA. We were eager to collaborate with them by creating a customized book for pancreatic cancer patients and their loved

ones. The Hirshberg Foundation helped to pioneer the first customized Symptom Management Workbook for people facing pancreatic cancer. Agi has shown her unyielding support for the book's launch and the entire Hirshberg Foundation family has supported the two of us as both caregivers and as an organization. We have high hopes of contributing to the cancer community using the Foundation as a guiding source of inspiration. We are so happy and proud to be a part of the Hirshberg family and their ongoing efforts to find a cure for pancreatic cancer. We know our mom would be too.

With the help of an educational grant, the Hirshberg Foundation is generously gifting the customized workbooks along with a re-stickable medication logs to individuals touched by pancreatic cancer. Helping other pancreatic cancer patients and caregivers manage their care better is a special way to honor our mom's memory, continue her legacy of love and generosity and help make a positive difference in the lives of other families, like o

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## **Patient Spotlight – Tyler Noesen**

By Tyler Noesen

It was July 5, 2006, I was 25 when I received the news. My life had been very full up to this point. I had recently been promoted at work, was looking forward to marrying the love of my life, Eva, I was playing sports and travelling when time allowed. Then one day I felt like I had tweaked muscle from playing soccer, but the hardness on the left side of my stomach

did not resolve. I went to the family doctor. After scans and an ultrasound with a fine needle aspiration, they found stage IV adenocarcinoma of the pancreas. Because there was a lesion on my liver, I was not a surgical candidate. I began chemotherapy almost immediately. Today I am a four year survivor! While riding through the ups and downs I have had some pretty amazing moments like going back to work, hiking from the south rim to the bottom of the Grand Canyon, spending a night at Phantom Ranch and hiking back out the next day, and finishing up my private pilot's license and passing my check ride.

I participated in my first LA Cancer Challenge after my diagnosis in 2006. Each year friends and family walk by my side as I participate in the 5K. Their positive energy is what carries me through. Last year we had quite a showing... seriously, everywhere you looked, you would see someone in a purple Team Tyler shirt. I started along the 5K route. It sure did feel like a long 3.1 miles. Not only did I finish, but my time was *seven minutes* faster than in 2009. We took the 5K Team title for the 4<sup>th</sup> year in a row! My friend Shannon came through fabulously with some awesome jerseys and Big Dennis and my dad made adorable kiddie Team Tyler shirts. Actually, I am pretty sure our edge was the few small children that were a part of the team – essential ingredients for any feel good story. I think it is safe to say that we were the most stylish team out there. We raised over \$8,000 which I found particularly impressive considering the current economic climate. This will certainly help in pushing research forward. Past donations that have come from the Hirshberg Foundation have led to UCLA being designated as a comprehensive pancreatic cancer center and have also funded a study performed by my endocrinologist which was published earlier this year. I think the highlight of the day for me was seeing so many old and new friends and getting to talk a bit with so many people. I also had the honor of starting the 10K



shot gun. It was a fun day. I treasure every fun day I get.

A lot has happened since the last race – foot drop, AF0s, strength improvement, extensive neuropathy, walker, wheelchair, walker, gradual improvement, a couple minor surgeries, more strength, and finally a cane- and I really didn't know if it was going to happen. My family and friends have helped to get me through my emotional and physical rollercoaster that I have been on. I would like to take a moment to truly thank all of you that have been a part of my life. I have been given an opportunity to fight this disease and spread awareness in the community. Please join me in that fight!

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## **Patient Spotlight – Nancy Amato**

By Nancy Amato

My name is Nancy Amato and I am a survivor of pancreatic cancer.

I will start my story from the beginning. In August, 2006, I had an episode of pancreatitis that would not respond to treatment. I had been having episodes of pancreatitis for about ten years but there was something different about this one so I was admitted to the hospital. All my scans were clean but I still wasn't feeling any better. It wasn't until I became jaundiced that everyone realized this was a serious problem. I was transferred to the Cleveland Clinic where I had a stent implanted which made me feel a little better, but still not great. An endoscopic ultrasound was performed which revealed a pancreatic mass, and I was referred to a wonderful, kind,

highly-skilled surgeon. After many tests and discussions, I was scheduled for a Whipple procedure. I'll spare you the gory details, but will tell you it's a huge surgery. . .some organs are removed and some are rearranged, but it was the best chance I had to fight this horrible disease. As they began the surgery, on October 5<sup>th</sup>, they found a lesion on my liver (making me a Stage 4 and not a candidate for the Whipple procedure). The lesion was biopsied and came back negative for cancer so they proceeded with the Whipple. Five days after surgery the surgeon came back and told me that the final pathology report on the liver lesion was actually cancer. I knew he had just saved my life.

After my surgery I began a regimen of chemotherapy and radiation at the University of Michigan before I was accepted into a vaccine study at Johns Hopkins, developed by Dr. Elizabeth Jaffee. Setting goals was an important part of my diagnosis and treatment. I wanted to attend my daughter's graduation. I also wanted to attend my son's, two years later. Once I reached both of these goals, I decided to take on my next challenge. All of my kids are in to marathons and triathlons so I decided to sign myself up and train for the LA Cancer Challenge 5K with the Hirshberg Foundation. On October 25, 2009, I completed my first 5K with over 30 family members and friends from all over the United States crossing the finish line with me. My sisters, nieces and co-workers surprised me when they flew in from out of town to join Team Nancy Pants.

In February, 2010, I received the good news that my 3  $\frac{1}{2}$  year scan was clean. As I look back over the years I have been very blessed. I have been married to my wonderful husband, Chris, for 29 years, we have four beautiful children, I've been a nurse anesthetist for almost 30 years and love my job, I am a 3  $\frac{1}{2}$  year pancreatic cancer survivor, and I am grateful for each day and

live life to the fullest. I don't want to be the miracle for pancreatic cancer. . .I want to be the norm!

In the beginning I was too scared to believe I could survive. With each day I get a little stronger and a little more vocal. Agi was one of the first people I spoke with early in my treatment. She personally returned my phone call and gave me tons of encouragement and advice. From the beginning Agi offered me hope when no one else would. I will always be grateful to the Hirshberg Foundation...they make me feel like a part of their "Foundation family". It is because of people like Agi and the Hirshberg Foundation that one day soon I will be the norm!