

Kosten

Pancreatic Cancer
Support

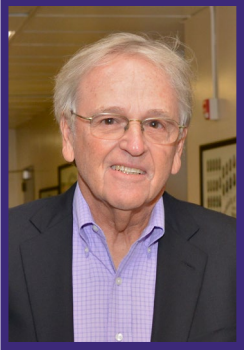
Research Advocacy Education Hope



Newsletter

Spring 2023

Working to find a cure in the fight against pancreatic cancer



A message from **Alan Kosten**

As stated in previous correspondence, when my brother, Herb, was diagnosed with Stage 4 pancreatic cancer (PC) seventeen years ago, support resources available in our area were abysmal. The information on the internet was horrifying, there was very little ongoing research, and there was no place to turn in this community to find someone – anyone – who had been similarly diagnosed to talk to, much less any support groups. For the most part, word had not spread to this community about PC and those who were diagnosed were isolated and alone in battling this devastating disease.

Herb bravely fought the disease until he passed away in June 2003, only 11 months after being diagnosed. Shortly following his death, several family members and friends gathered to find ways to honor his memory. For several years we raised funds through tennis tournaments and made donations to the Grizzlies' "Tickets For Kids" program (Herb loved both tennis and the Grizzlies.) Although the program was extremely worthwhile, we remained troubled about the difficulties Herb had experienced when battling the disease. As a result, in 2006 The Herb Kosten Pancreatic Cancer Charitable Fund was formed with the mission to raise awareness of PC and funds to help fight it, and also to provide support and counsel to those battling it.

Since that time, we have donated, approximately, \$2,500,000.00 for research and provided hundreds of people with various forms of support that were badly needed during very stressful times in the lives of patients and families coping with this deadly disease. Our Support Group continues to meet monthly in an effort to perform these services. In addition, we have raised community awareness at our annual 5K, which is our only major Fundraiser each year. We are very hopeful that this year we will be able to make meaningful Grants to research teams across the country in our continuing effort to find a cure for PC. As you are aware, research is the life blood of finding a cure! Accordingly, please consider KOSTEN FOUNDATION in your charitable donations.

We simply can't do it without you. Your support makes a real, lasting impact in the lives of those currently fighting, and those still to be diagnosed, with PC so one will never again have to fight this disease alone.

Sincerely,

HERB KOSTEN PANCREATIC CANCER CHARITABLE FUND

A handwritten signature in black ink that reads "Alan Kosten".

Alan L. Kosten
Chairman of the Board

*In memory of
all we have
lost in 2022*



Marilyn Kosten

*On February 11, 2022,
we lost Marilyn Kosten,
the wife of our namesake,
Herb Kosten. The Kosten
Foundation will forever
be grateful to Marilyn for
inspiring us all to wage
hope and continue the fight
against pancreatic cancer.*

*An incredible wife, mother,
and friend, her impact on
those around her leaves
an unforgettable legacy.*

Support Group Updates

The Kosten Foundation Pancreatic Cancer Support Group meets every 2nd Saturday of the month at the Cordova Public Library and via Zoom Meeting. The library's address is 8457 Trinity Road, Cordova, TN 38018. Those who chose to Zoom in to the meeting should check our website, kostenfoundation.com and click on Support Group for the Zoom link to the meeting. Our meetings are free and open to anyone affected by pancreatic cancer. This includes the patient, their caregiver and family members, friends and anyone interested in learning more about the disease.

During the pandemic, we met via Zoom as we felt it was not wise to be in a group. We started meeting at the library, for in-person meetings in 2022 and have enjoyed being together with those who feel comfortable in a small group. We have had about half of the group in-person and the other half via Zoom. Usually, the total attendance is between 12 and 18 individuals. We have welcomed several new support group members over the last few months.

The purpose of the support group is just what it sounds like. We gather as a community to support one another through our journeys with pancreatic cancer. We share our personal stories, discuss the many questions about what to expect and how to manage our experience with pancreatic cancer. Many in the group have had the opportunity to have surgery to remove the tumors. Others are not candidates for surgery depending on the location of the tumor and whether or not the cancer has metastasized to other organs. We have male and female patients, and patients who have been diagnosed as Stage 1, 2, 3 or 4. All ages can be affected by this disease. Almost all of us have gone through chemotherapy, immunotherapy and/or radiation. These treatments can have different side effects for different people. So those of us who have completed our surgeries and/or therapies, share what we have found that worked for us. We are told by support group members that it is encouraging and helpful to understand some of what to expect on their journey with pancreatic cancer. We talk about eating, getting exercise, resting and many more issues that we all face or have faced with pancreatic cancer. Caregivers find these meetings helpful as well as it is sometimes a difficult job to help someone who is in treatment, has new eating habits and the need to rest due to fatigue.

All in all, our aim is to offer support and hope to those affected by pancreatic cancer. The motto of the Kosten Foundation is "Research, Advocacy, Education and Hope." Please join us for a meeting soon.

The support group is led by volunteers Tom and Kathryn Gilbert Craig. Kathryn is a 10+ year pancreatic cancer survivor. You may contact Kathryn at kgilbertcraig@comcast.net or at [901-832-4782](tel:901-832-4782)



Survivor Highlight



Teresa Wright

I am thrilled to say that I am a five-year pancreatic cancer survivor—breathing rarefied air, as only 11% of those diagnosed can claim that status. I thank the Kosten Foundation and researchers across the country who are working to keep that percentage moving higher.

When I look back, I realize I was very lucky because pancreatic cancer symptoms are what I call “sneaky,” meaning they can easily be passed off as something else. For example, I started having mid-back pain in the Spring of 2017, which I attributed to just more arthritis in my back. The “stitch” in my side that I had been having, I thought, was probably caused by pulling a muscle at the gym. The biggest symptom that bothered me was a change in my stool. We had recently moved our mother-in-law from Washington D.C. to a facility close to us in Memphis and I figured the change in stool must be related as I was eating some of that soft, mushy, bland nursing home food when visiting her. When I started experiencing fairly constant abdominal discomfort, day and night, is when I decided it was time to call my gastroenterologist.

When they told me he couldn’t see me for three months, I said “NO! I NEED TO SEE SOMEONE RIGHT AWAY.” They didn’t like it, but I persisted and saw another doctor in the group within a week. We quickly ruled out a bowel infection and within 10 days I had a CT scan that showed a shadow on the pancreas. An endoscopic ultrasound a week later confirmed the diagnosis of adenocarcinoma on the head of the pancreas.

“When the doctor walked into the exam room and asked me what the problem was, I told him: “I want you to tell me I don’t have pancreatic cancer!” He said, “Oh no, I’m sure you don’t have pancreatic cancer—you don’t have jaundice. But we’ll definitely run some tests to rule it out.”

Dr. Kurt Tauer, my oncologist at West Cancer Center, and Dr. Paxton Dickson, my surgical oncologist at Methodist/UTHSC explained what a deadly disease this was and that they would do their best to help me fight it. I was extremely fortunate to be a candidate for the Whipple surgery. Six weeks after surgery, I started a three-month post-surgery chemotherapy regimen of Xeloda pills and Gemzar infusions.

For several years I had labs and scans every three months, always petrified that the cancer would return. After five years, I am now on a six-month check-up schedule. And while I know there is always a chance it could return, I thank the good Lord every day for my doctors, my good health, and for giving me each day to continue enjoying life with my sweet husband of 47 years.

For anyone reading this who has recently been diagnosed, I would urge you to take charge of your own healthcare journey. Keep a journal and write down your questions and the answers when you get them. Study your lab reports. Look at your trends and ask your doctor questions. Your doctors have hundreds of patients, so help them help you!

And most importantly, have hope, because every year there are new developments that are helping patient outcomes, such as tumor analysis for targeted therapies, among others. My prayer is that I will live to see the day when there is a common blood test or procedure to diagnose pancreatic cancer. And maybe by then, there will be better therapies to eradicate cancer that are easier on the body than the chemotherapies in place today. Nothing wrong with having big dreams!

Grant Updates

We were honored to donate \$144,000 to three great organizations working to create better treatment options for Pancreatic Cancer Patients.



Dr. Stephen Behrman on the right performing a Whipple procedure.

Dr. Stephen Behrman, General Surgeon and Medical Advisor to the Kosten Foundation



There are 4 cancers that occur in the area of the pancreas, including pancreatic cancer, cancer of the ampulla of Vater, distal bile duct cancer, and duodenal cancer. Removal of all of these cancers requires the same operation: pancreatoduodenectomy or a Whipple procedure which is a high-risk operation. By far, the most common lesion is pancreatic cancer, with ~60,000 new cases diagnosed annually in the United States. At the opposite end of the spectrum is duodenal cancer, with an annual incidence of 5,000 cases. All of these cancers remain highly aggressive and have a high risk of recurrence despite any treatment. The majority of research on treatment, appropriately, has focused on pancreatic cancer, with the other 3 cancers receiving much less attention due to their rarity. Pancreatic cancer can often be difficult to remove due to tumor relationships to surrounding organs and major blood vessels. In contrast, the other 3 cancers in this area are typically easier to remove, are frequently treated by immediate surgery, but unfortunately have a high recurrence rate.

It is now known that patients with pancreatic cancer, along with many other abdominal cancers, benefit from chemotherapy and sometimes radiation therapy before surgery to destroy potential "micrometastatic" disease and cancer tissue within the pancreas. Thus, in 2023, most patients with pancreatic cancer do not proceed to immediate surgery but begin their treatment with chemotherapy.

Because patients with the other 3 peripancreatic cancers are so much less common, it is unknown if they might benefit from a similar treatment strategy consisting of chemotherapy and radiation before surgical resection (neoadjuvant therapy).

Furthermore, while there has been extensive analysis of genetic mutations associated with pancreatic cancer, much less study has been directed at those with other peripancreatic cancers. This is important because our knowledge and development of "targeted" therapies or immunotherapy are rapidly expanding, allowing us to utilize our body's immune system to attack and destroy cancer.

Our work at Baptist Cancer Center, supported by the Kosten Foundation, has focused on a neoadjuvant treatment platform to attack cancers of the ampulla of Vater, distal bile duct, and the duodenum. Our preliminary results suggest that sequencing treatment in this manner leads to significant tumor destruction and better pathologic outcomes that we hope will lead to better survival. A secondary arm of our work had been to study the genetic aberrations associated with these 3 cancers that might lead toward advances in targeted therapy of these lesions. Indeed, a small subset of our patients has benefited from targeted therapy. This work has been submitted for publication in medical journals and presented at the Southwest Oncology Group – an arm of the National Cancer Institute, in consideration of an ultimate clinical trial.

These cancers represent a terrible burden in our community, and we will continue to work tirelessly for a cure going forward. The generous funding by the Kosten Foundation allows us to continue this important work.

Amanda Billings, Vice President for Development, UT Southwestern Medical Center

Report from June 2022

UT Southwestern
Harold C. Simmons
Comprehensive Cancer Center



I am pleased to share an update from Nisa Kubiliun, M.D., on the progress in the Pancreatic Cancer Prevention Program (PCPP). Since the program began, Dr. Kubiliun and her team have cared for more than 3,200 patients at increased risk of developing pancreatic cancer and collected nearly 600 serum samples to contribute to a deeper understanding of the pancreatic disease process. Over the last year, Dr. Kubiliun and her team have compared diagnostic performance of next-generation sequencing (NGS), an emerging adjunctive test performed on pancreatic cyst fluid with high sensitivity. The preliminary results demonstrate that NGS of pancreatic fluid is associated with pancreatic adenocarcinoma and high-grade dysplasia, and, therefore, may improve sensitivity over the current standard of care techniques. In addition, Dr. Kubiliun has received IRB approval to begin enrolling patients in a new, cross-sectional study. Its primary aim is to perform whole genome sequencing on collected biospecimens in order to better understand heritable traits that may explain the high propensity for developing pancreas cancer.



We are deeply grateful for your partnership in accelerating the world's understanding of this disease and preventing its occurrence. With your support, we are one step closer to transformational change in the way the world approaches pancreatic cancer prevention.

Dr. Kubiliun performing an endoscopy.

In the Media



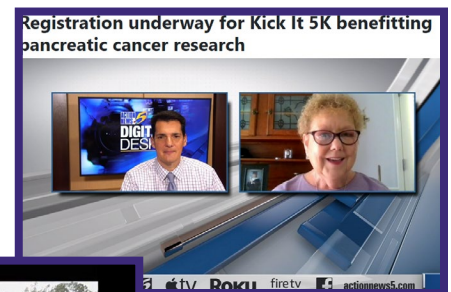
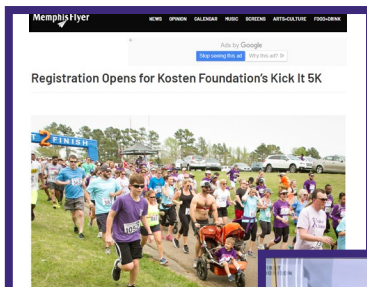
35
Mentions



\$67,500
Earned Media Value



1,780,175
Audience



Bluff City Life



ABC 24

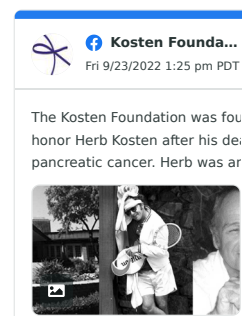
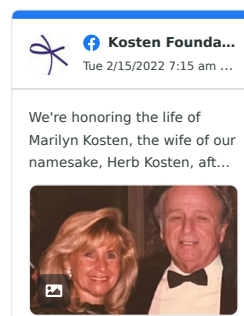
Social Media Stats



177,905
social media Impressions



4,527
social media engagements



2022 Event Recap

Captain's Reception – September 15, 2022



Our Kick It 5K team captains mean so much to us! They rally the troops every year helping us to raise great funds to help fund Pancreatic Cancer Research and continue our mission. To celebrate them and show appreciation for their hard work, we hosted a Kick It 5K Captain's Reception at Owen Brennan's! It was a wonderful event, and we look forward to celebrating our captains again in the months to come!

Kick It 5K – October 30, 2022



Over 600 runners, walkers, volunteers, pancreatic cancer survivors, and supporters showed up and helped raise more than \$140,000 for pancreatic cancer research and support in honor of the Kosten Foundation's 12th Annual Kick It 5K on Sunday, October 30.

Thank you so much to all of the teams that participated in the 2022 Kick It 5K. Our top raising teams included

1st Place **Boyers Warriors - \$6,474.99**

2nd Place **Purple Roses - \$5,432.51**

3rd Place **Jean's Quest - \$3,385.05**

Tribute at Twilight – November 17, 2022



In honor of Pancreatic Awareness Month, the Kosten Foundation hosted a "Tribute at Twilight" event. This event's purpose was to recognize pancreatic cancer survivors, caregivers, those lost to pancreatic cancer, and anyone affected by the disease. It took place at Cancer Survivors Park on Thursday, November 17.

The event was filled with members of the Kosten Foundation as well as others that came to show support and to remember those lost. Those who attended read names of those lost to pancreatic cancer, shared stories, and lit candles in a ceremony of remembrance.

2023 Upcoming Events

Support Groups

Support Group Dates

March 11, 2023
April 8, 2023
May 13, 2023
June 10, 2023
July 8, 2023
August 12, 2023

2nd Saturday of Each Month | In Person & via Zoom

Save the Date!

The 13th annual Kick It 5K is scheduled for October 29, 2023, at Shelby Farms Park.

The Kick It 5K is the Kosten Foundation's largest fundraiser for pancreatic cancer research and support. Last year's in-person and virtual event raised over \$140,000 with more than 600 participants.

The Kosten Foundation is currently accepting sponsors for the 2023 Kick It 5K. please contact Alan Kosten at 901-606-5330 or Jeffrey Goldberg at 901-606-7542 for more information.



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