Heroes Among High-Risk Groups Keep Fighting

Throughout April, as part of <u>National Minority Health Month</u>, the Hirshberg Foundation has shared an important message of unity while providing critical information for those disproportionately impacted by pancreatic cancer. We've touched on <u>genetics for Ashkenazi Jews</u> and the high risks associated with chronic health conditions like <u>diabetes for African Americans</u>. Even as this month comes to a close, we will know it's crucial that we continue to provide new information on this topic, discuss the <u>risk factors</u> and share personal stories to raise awareness year-round.

Together, we must be united in this fight because when pancreatic cancer impacts one group, it impacts us all. Share this information and resources with family, friends, neighbors and co-workers so that no one faces pancreatic cancer alone. Several fearless survivors, caregivers, family members, volunteers and event participants have also joined us in our efforts to elevate this conversation. They have generously shared their perspectives and stories to shine a light on this topic.



SURVIVOR Donald and Wife Carolyn

Read Story



SURVIVOR Dr. Norm and family

Read Story



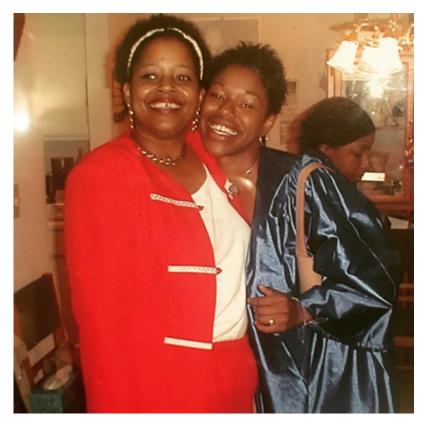
"My husband's pancreatic cancer was discovered by an Upper Endoscopic Ultrasound. I do not recall being informed or having a conversation that we may be at a higher risk because of our ethnic background. I think it's very important that it be discussed more. I would like to see it be part of a checklist and gently approached by asking or informing minorities who are at high risk for pancreatic cancer. My words of inspiration to communities, families and other survivors of color is to have hope and live one day at a time. Also, Be Persistent. My husband went to the Doctor with symptoms in February and was not

diagnosed until June after many tests and a hospitalization." -Addie



"After the loss of my mother I became more aware of the risk as an African American and how important it is to seek help. High blood pressure is prevalent in my family history. As well as different forms of cancer. I feel a need to express to people of color how pancreatic cancer can go undiagnosed if certain health issues are not presented to physicians. My mother decided to keep silent, and because of that it's truly been a loss and a deep hole missing from my heart. Her cancer could have been prevented."

-James LACC Team Captain



"I was 18 years old at the time my mom was diagnosed but I believe she was feeling sick for a while. Shining a light on the topic of high-risk groups is meaningful to me because maybe this information could have saved my mother's life 18 years ago. It could help save the life of someone who is battling pancreatic cancer and/or showing early symptoms now. I think healthcare professionals should be prepared to spend more time on marginalized groups and facilitate information for them. It's important to not just talk but act...this is a step in the right direction."

Alicia

HTT Member & LACC Team Captain

I am a SURVIVOR

My symptoms started back in 2008 when I felt tired all the time. I thought it was because I was working a lot of hours. It hit me

when I was driving home one day, and it took me 3 hours to get home. That's because I had pulled over and fell asleep. It took me weeks before I told my wife and that's when I went to the doctor.

Once I saw the doctor and tests were run, I was told I have cancer. However, my doctor doesn't specialize in cancer, so I was referred to another doctor who ran more tests and discovered I have Neuroendocrine Tumors (Carcinoid Cancer). That doctor didn't have a clue of what to do. As far as I was concerned the clock was ticking. With a lot of prayers and our own research we found a doctor who was a specialist in Carcinoid Cancer. He told me that I have the same cancer that Steve Jobs had, where it started on the tip of the pancreas and the tumors moved to my liver.

It was never said to me I was high risk because of my race but I was told many people are misdiagnosed. I think shining a light on this topic only once a month is not enough to help people no matter what their ethnicity. I look at all of us as God's children and iron sharpens iron. I'm also blessed to have a family who cares and pushes me to continue the fight.

I've met many people since my journey began. I've heard their stories and most people don't do any research for themselves and you know the results. There is a lot of information out there and people need to do their research and then reach out to organizations for help. I realize that health care is a major factor for cancer. I didn't do any research on genetics or ethnicity specifically because that really didn't matter after I was told I have cancer.

I've been to many meetings about pancreatic cancer and how it can branch out to other physical problems. I've felt like a raisin in a bowl of rice and I truly don't understand. I know

someone who had pancreatic cancer and they invited me to a luncheon for survivors and caregivers. It was very informative, so I've told others about Hirshberg Foundation. I've been to 2 affairs and just to hear other people talk about living with cancer is support to me. There is a lot of help and support out there and you have to drop your color barrier because cancer is like a bullet it has no name on it. We're all in this together.

A Nurses Guide to Pancreatic Cancer From Diagnosis to Treatment

We are dedicated to supporting our pancreatic cancer community, particularly as we all try to navigate the COVID-19 pandemic. We have launched a series of free webinars to provide virtual patient support and resources to our patients and their caregivers. We are pleased to share information about the third in our series which took place on Friday, May 1, 2020.

There are a multitude of concerns and emotions that a person experiences when diagnosed with pancreatic cancer. Patients and family members are immediately thrust into a world they often know little about while having to make important health care decisions in a timely manner. Having a road map to understanding what happens from pancreatic cancer diagnosis to treatment is ideal. We asked Lauren Damato, Nurse Practitioner of the <u>UCLA Agi Hirshberg Center for Pancreatic Diseases</u> and Megan Price, Oncology Nurse Practitioner with the <u>UCLA Jonsson Comprehensive Cancer Center</u>, to discuss how pancreatic cancer is diagnosed,

surgical resection and chemotherapy options. They discuss the benefits of patient care in an integrated practice unit utilizing a multidisciplinary approach as well as factors to consider when choosing a treatment plan.

Megan also shared valuable tips and resources, including the booklet by the National Cancer Institute (NCI) titled, Chemotherapy and You. This is a great guide to refer to during chemotherapy treatments, including information on how chemotherapy affects cancer cells, potential side effects and helpful questions for your doctor or nurse.

Watch Webinar

SPONSORS & SUPPORTERS

A very special thanks to our Sponsors & Supporters for helping ensure that these vital patient resources can be offered free-of-charge in place of our Annual Symposium.







California Community Foundation, Caroline Dockrell, Fineberg Foundation, Dr. Robert

Richter Foundation Fund, Sidney Stern Memorial Trust, Joanne & Ken Weinman in memory of Sylvia R. Weiner

Virtual Volunteers Needed for #GivingTuesdayNow

Become a Virtual Volunteer for #GivingTuesdayNow, a global day of giving and unity on Tuesday, May 5, 2020. This international campaign is aimed at driving an influx of grassroots generosity and action to support nonprofits, like ours, around the world. We can really use your help!

What does it mean to be a Virtual Volunteer? Here is a list of simple ways that you can make a difference on May 5th from the comfort of your home. Your support on #GivingTuesdayNow can be as simple as advocating for us on social media or by email, sharing our mission with a family member or friend. You can also make a small gift and encourage others to join you!

Raise Awareness on Social Media and in your community

- Encourage your community to support the Hirshberg Foundation on #GivingTuesdayNow, by emailing your friends & family and sharing why you support the Hirshberg Foundation.
- Post a purple picture on social media and share why you support our mission, make sure to tag us, so we can share.
- Add our Facebook photo frame to your profile pic from now through May 5th.

• Download our #GivingTuesdayNow_poster to help spread the word. You can print it and display it at home, perhaps on a window for your neighbors to see. You can also take a photo and post it on social media to help us spread awareness.

Fundraise on Social Media

- On **Facebook**, create a #GivingTuesdayNow Facebook Fundraiser to benefit the Hirshberg Foundation. Use this link to get it set up in seconds.
- On Instagram, use the Instagram Donation Sticker to help us raise money for our patient support programs. Create an Instagram Story, add a donation sticker and share with your friends. We've created a simple video to show you how.
- On Twitter, you can temporarily change your twitter display name for the day to show that you are supporting us #GivingTuesdayNow. Here's an example.

If you have any questions, please contact our Volunteer Coordinator at info@pancreatic.org.

Without volunteers who give their time and energy, we would not be able to continue with our mission to cure pancreatic cancer. Thank you in advance for your help!

Key Protein for Pancreatic

Cancer Cell Growth Discovered, May Provide Therapeutic Target

Pancreatic cancer is particularly deadly because it is often found in advanced stages when the tumor has grown too large and spread from the pancreas making removal impossible. In order to grow, cancer cells require molecular food — Dr. Wantong Yao's Seed Grant research investigated mechanisms to starve those cells as a therapeutic intervention for pancreatic cancer.

Almost 95% of human pancreatic cancers contain oncogenic mutations of the KRAS gene which drives the initiation, development, and progression of the disease. There is currently an effort to pharmacologically target genetic mutations in the KRAS gene and inhibit tumor growth, but that research is in early stages and may not be effective for all KRAS mutations.

It was previous shown that mutations in KRAS in pancreatic cancer initiates the cellular process of macropinocytosis, in which the cell surface membrane engulfs extracellular fluid and prioritizes signaling pathways that support their uncontrolled growth. By interrupting those pathways and blocking the food supply, there is the opportunity to target and prevent cancer cells from growing.

New research from Dr. Yao, conducted at MD Anderson Cancer Center, sought to identify ways to starve and kill cancer cells by understanding the mechanisms responsible for how mutations in KRAS drives macropinocytosis. This research focused on the proteins expressed at the surface of the cell, where macropinocytosis takes place. By studying changes in the proteins expressed at the cell surface when mutant KRAS was expressed in cancer cells, Dr. Yao's research was able to identify a link between mutant KRAS and activation of

macropinocytosis.

Through funding from a 2017 Seed Grant, Wantong Yao, MD, PhD, identified SDC1, a protein that was more abundant when mutant KRAS was expressed than in cells where there was no mutant KRAS. Their research confirmed that while SDC1 may be present in the cell, it is only when mutant KRAS is expressed that SDC1 is shuttled to the cell surface to drive macropinocytosis. Understanding that SDC1 acts under the control of mutant KRAS to fuel cell growth provides an opportunity to target SDC1 and inhibit tumor cell growth. Since SDC1 drives growth when it is on the surface of the cell, it may be more vulnerable to intervention. There is research underway targeting SDC1 using monoclonal antibodies in multiple myeloma patients, which may open the doors for similar therapies for pancreatic cancer.

An Inherited Predisposition to Pancreatic Cancer

This month, as part of National Minority Health Month, we are highlighting those communities at high-risk for pancreatic cancer. The Ashkenazi Jewish community, like African Americans, have been disproportionately impacted by pancreatic cancer. Increasing awareness in these communities includes sharing information and providing resources. These tools empower not only high-risk communities but the pancreatic cancer community as a whole. When pancreatic cancer impacts one group, it impacts us all.

For decades scientists have investigated the BRCA1 & BRCA2 gene

mutations and their connection to cancer. The Johns Hopkins National Familial Pancreas Tumor Registry (NFPTR) has gained a better understanding of how BRCA1 & BRCA2 gene mutations account for a portion of the increased risk for pancreatic cancer for Ashkenazi Jews. According to their research, "The increased risk of pancreatic cancer associated with inherited BRCA1 mutations is estimated to be about two-fold (about the same increased risk associated with cigarette smoking)". In addition, carriers of the BRCA2 gene mutations also have a ten-fold increased risk of developing pancreatic cancer.

The <u>National Comprehensive Cancer Network</u> (NCCN) recommends genetic counselling for all individuals diagnosed with pancreatic cancer. The Hirshberg Foundation provides resources to encourage families, especially those with a high-risk ancestry, to learn more about how genetics play a role. Watch this Hirshberg Symposium video <u>"Why Should I See A Genetic Counselor?"</u>, presented by Wendy Conlon, MS, a genetic counselor at UCLA. Whether you are of Ashkenazi Jewish ancestry or not, genetic testing unlocks some answers to pancreatic cancer and is a resource worth exploring.