

Genetic Counseling for Pancreatic Cancer Patients and Families: Review and Updates During COVID-19

Many of the ways in which patients are able to receive care have changed in light of COVID-19. In order to keep our pancreatic cancer community informed, we are providing virtual support and resources for our pancreatic cancer community.

Genetics plays an important role in the treatment of pancreatic cancer, and COVID-19 has brought about some important changes in regulations around telemedicine and genetic counseling. Individuals with an increased genetic risk may benefit from lifestyle modifications to prevent cancer or from early diagnosis, when treatment may provide a better outcome.

Wendy Conlon, MS, CGC, is a genetic counselor with UCLA. She oversees surveillance of patients and their family members, provides risk assessment, genetic counseling and genetic testing to individuals with pancreatic cancer and their at-risk relatives. She helps individuals and families navigate their treatment options, as well as other cancer prevention strategies. In light of COVID-19, access to genetic counseling and testing is easier and more convenient, and Wendy shares these updates. We learn about the benefits of genetic counseling and ask Wendy questions about this important topic!

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Dockrell, Fineberg Foundation, Dr. Robert**

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

Dr. Girgis Presents “Pancreatic Cancer: Advances in Research and Patient Care” for 2020

In response to the changing landscape of patient care brought on by COVID-19, we are providing a series of free webinars to provide virtual support and resources to our patients and their families. We are pleased to share information about the fourth in our series.

In an ever-changing world of advancements in the field of pancreatic cancer research we rely on our experts to keep us informed of breakthroughs and new medical guidelines. In 2017, Dr. Girgis provided an update on Advances in Pancreatic Cancer Surgery at our annual [Symposium](#). Now, three years later, he presents on “Pancreatic Cancer: Advances in Research and Patient Care” as part of our ongoing webinar series.

In 2019, the landscape of pancreatic cancer care has evolved. Studies are showing that improved [neoadjuvant](#) (prior to surgery) chemotherapies are helping make the disease resectable for more patients. In the metastatic setting, new targeted agents have been approved for use in certain patients. Finally, advances in

surgical technique are leading to improved preoperative outcomes. The webinar "Pancreatic Cancer: Advances in Research and Patient Care" focuses on these areas to provide a promising outlook for things to come.

Mark Girgis, MD, is an Assistant Professor of Surgery at the David Geffen School of Medicine at UCLA. His interests include robotic and minimally invasive approaches to surgical oncology and he is committed to the improvement of cancer care through innovative technological advancements.

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Heroes Among High-Risk Groups Keep Fighting

Throughout April, as part of [National Minority Health Month](#), 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 [genetics for Ashkenazi Jews](#) and the high risks associated with chronic health conditions like [diabetes for African Americans](#). 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 [risk factors](#) 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

LACC Team Captain



"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 [UCLA](#)

[Agi Hirshberg Center for Pancreatic Diseases](#) and Megan Price, Oncology Nurse Practitioner with the [UCLA Jonsson Comprehensive Cancer Center](#), 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.

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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!