# Early Detection Initiative for High-Risk Individuals

For those at high risk of pancreatic cancer, navigating the uncertainties of the disease can be a challenge. Whether due to a family history, genetic predispositions, or other risk factors, proactive measures and early detection are critical. The Pancreatic Cancer Early Detection (PRECEDE) Consortium offers a vision of collaborative excellence to transform how we approach these challenges and provide new hope to those at increased risk.

The PRECEDE project, spearheaded by Dr. Diane Simeone, represents a significant leap forward in early detection and patient support. This international consortium unites top experts and institutions with a shared goal: to elevate the 5-year survival rate for pancreatic cancer from 13% to 50% over the next decade. This ambitious target underscores a commitment to improving outcomes through advanced research and personalized care.

**How PRECEDE Supports High-Risk Individuals**

For individuals with a family history of pancreatic cancer, pathogenic gene mutations, or other high-risk factors, PRECEDE offers a valuable resource:

1. Personalized Monitoring: Through the PRECEDE study, participants receive tailored monitoring based on their specific risk factors. This includes regular blood tests every 6 to 12 months and additional imaging for those in particularly high-risk groups. This individualized approach aims to catch potential issues early, before symptoms arise.

2. Innovative Screening Techniques: The consortium is developing and refining advanced screening methods to enhance early detection. These efforts are focused on identifying pancreatic cancer at its most treatable stages, thereby improving the likelihood of successful interventions.

3. Comprehensive Risk Management: By studying individuals with known risk factors—such as chronic pancreatitis, pancreatic cysts, or genetic mutations—PRECEDE aims to deepen our understanding of the disease. This research is critical for developing effective early detection tests and comprehensive prevention strategies.

4. Longitudinal Follow-Up: Under the guidance of experts like UCLA's Dr. Donahue, the PRECEDE study will follow participants over time, providing ongoing support and monitoring. Dr. Donahue emphasizes the importance of early detection, stating, "Early detection would drastically change the trajectory of the disease and ultimately save thousands of lives."

If you or someone you know is at high risk for pancreatic cancer, consider enrolling in the PRECEDE study. Your participation can contribute to groundbreaking research and potentially save lives by advancing early detection and prevention methods.

For more information on how you can be part of this transformative study, visit PRECEDE Study.

To hear more from Dr. Diane Simeone about the PRECEDE project, watch her Symposium Speaker Spotlight.

By working together, we can advance towards a future where early detection and proactive prevention truly transform outcomes for those facing pancreatic cancer.

# Family Genetics in Pancreatic Cancer and High-Risk Individuals

Pancreatic cancer remains one of the most challenging cancers to detect and treat, with significant disparities affecting certain populations. The Hirshberg Foundation is dedicated to improving outcomes through research, awareness, and support, particularly focusing on family genetics, early detection and high-risk communities.

While most pancreatic cancers develop due to acquired gene mutations influenced by factors like smoking, obesity, age, and chronic pancreatitis, genetic predispositions can play a significant role.  Approximately 10% of pancreatic cancer cases are hereditary, linked to inherited gene mutations known as Familial Pancreatic Cancer (FPC). FPC refers to families with at least two immediate family members with pancreatic cancer but no known hereditary cancer syndrome.

If you have a first-degree relative diagnosed with pancreatic cancer, your risk of developing the disease may be increased. It is strongly advised that your family member undergo genetic testing for inherited mutations. If their test results are negative, you typically may not need genetic testing. However, if their results are positive or uncertain, or if multiple close relatives have cancer, it is recommended to consult with a genetic counselor to determine if you should undergo genetic testing for inherited cancer risks and consider monitoring options. The risk increases further if more family members are affected or if there is a history of certain familial cancers. About 10% of pancreatic cancer cases are due to inherited mutations.

Black Americans are disproportionately affected by pancreatic cancer, facing higher incidence rates and significant obstacles to early detection and treatment, exacerbated by socioeconomic disparities, racial discrimination in healthcare settings, and late-stage diagnoses. Additionally, Ashkenazi Jews also face a higher incidence, possibly due to mutations in the BRCA1 or BRCA2 genes, which are associated with hereditary cancer predisposition.

To help further understand these risk factors and monitor individuals with genetic risks, researchers have established pancreatic cancer tumor registries. These registries include:

- The Pancreatic Tumor Registry at Memorial Sloan Kettering Cancer Center (MSKCC)
- The National Familial Pancreatic Tumor Registry (NFPTR) at Johns Hopkins University
- The Cancer of the Pancreas Screening-5 (CAPS5) Study which is also a clinical trial currently conducted at 8 universities

These pancreatic cancer tumor registries collect valuable data that can lead to early detection and potentially life-saving interventions for high-risk individuals.

Addressing pancreatic cancer requires a multifaceted approach that includes understanding genetic risks, improving early detection, and ensuring equitable healthcare. The Hirshberg Foundation is committed to transforming outcomes for high-risk families and communities through research, education, and support.

**Resources:**

- Hirshberg Foundation – Paving the Way to Better Outcomes
- American Cancer Society – Health Disparities Research
- FDA – Racial and Ethnic Minorities in Clinical Trials
- National Institutes of Health – Clinical Trial List

Through research, education, and community support, we strive to make significant strides in the fight against pancreatic cancer, ensuring no one faces this disease alone.

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# Symposium Speaker Spotlight: Dr. Marcia Canto to discuss Pancreatic Cancer Screening and Surveillance in High-Risk Individuals

The Hirshberg Foundation is honored to announce that Dr. Canto will discuss screening and surveillance in individuals with a high-risk for pancreatic cancer at the 16th Annual Symposium on Pancreatic Cancer.

While participating in a pancreatic cancer screening program is not appropriate for everyone, it is an important consideration for individuals with known high-risk factors. For those with particular risk factors, including family history and certain genetic syndromes that increase susceptibility to pancreas cancer, it may be appropriate to participate in a research screening program. Surveillance may also be clinically recommended in instances such as a new diagnosis of a pancreas cyst or lesion. Many experts believe that individuals with a greater than fivefold risk of developing pancreatic cancer should undergo regular early detection tests to survey their pancreas. Regular surveillance uses medical imaging and endoscopic techniques to detect precancerous lesions or early pancreatic cancer that can be surgically removed. Screening and surveillance of high-risk individuals is a topic important to our pancreatic cancer community and we are happy to have an expert in the field present more information.

Marcia (Mimi) Canto, M.D., M.H.S. is a Professor of Medicine and Oncology at The Johns Hopkins University School of Medicine. She is also the Director of Clinical Research at the Johns Hopkins Division of Gastroenterology. Dr. Canto received her Bachelor of Science degree from the University of the Philippines in Manila in 1981 (summa cum laude). She received her Doctor of Medicine degree in 1985 from the University of the Philippines and completed her training in Internal Medicine from State University of New York Sciences Center in Brooklyn, Brooklyn, New York.

Dr. Canto completed a postdoctoral fellowship in Gastroenterology-Hepatology at The Johns Hopkins University School of Medicine and received a Master of Health Science in Clinical Epidemiology from The Johns Hopkins University School of Hygiene and Public Health. Dr. Canto came back to Johns Hopkins after advanced endoscopic training at the University Hospitals of Cleveland. Her primary clinical and research interests include endoscopy, particularly the use of endoscopic ultrasound (EUS) in detecting early pancreatic cancer and its precursors. She has shown that endoscopic ultrasound can be used to detect asymptomatic precancerous lesions in patients with a family history of pancreatic cancer, downstage pancreatic cancer screen-detected pancreatic cancer, and improve survival.

A subject that we are excited to learn more about from one of the top experts in this field, we welcome Dr. Canto to educate us on *Pancreatic Cancer Screening and Surveillance in High-Risk Individuals.*

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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

# Family Genetics

A core aspect of our mission is to be a reference source for the pancreatic cancer community, from patients and families to those at a higher risk for developing pancreatic diseases. The risk factors for developing pancreatic cancer include ones we can control, such as smoking and lifestyle, as well as those we have no control over, including family history. Knowing your family health history is important for learning about your cancer risk. Our Family Genetics section offers valuable tools to assist patients, families, and those with an increased risk for the disease. If you or your loved ones are at an increased risk due to environmental factors or family genetics, our resources are here to help guide you on a path to prevention. We are here to help, don’t hesitate to contact Patient Support for more information.
A brief overview of genetic counseling to help better understand how genetics play a role in one’s risk for developing pancreatic cancer. It is also recommended that all pancreatic cancer patients undergo genetic testing to guide treatment.
Genetic Testing

Learn more about the importance of family genetics, early detection, and high-risk tumor registries in addressing pancreatic cancer, particularly in high-risk individuals and communities.
High-Risk Individuals

The PRECEDE Consortium aims to revolutionize early detection and patient support for high-risk individuals through personalized monitoring and comprehensive risk management. Its goal is to increase the 5-year survival rate for pancreatic cancer to 50% over the next decade.

EARLY DETECTION

# Where to Begin: Guidelines for the Newly Diagnosed

The Hirshberg Foundation is committed to supporting pancreatic cancer patients throughout their journey. We often hear from newly diagnosed patients and families navigating a new landscape of healthcare decisions and terminology. A pancreatic cancer diagnosis raises many questions, and we are here to provide answers. **The following guidelines are intended to assist all newly diagnosed patients and their families.**

## LEARN ABOUT THE DISEASE

We have worked with the National Comprehensive Cancer Network (NCCN) to create a booklet for pancreatic cancer patients and their families. It has a glossary of terms, treatment options, info on staging and more. You can purchase the paperback version on Amazon or download the free digital version.

## KNOW WHAT TO ASK YOUR DOCTOR

Prepare for your doctor's appointments by knowing which questions to ask. Download and print our list of questions for your next visit. Consider bringing a support person to help and record the discussion for clarity. Your aim is to understand your diagnosis, treatment plan, multidisciplinary team, and make informed decisions about your health.

Watch A Nurse's Guide to Pancreatic Cancer: From Diagnosis to Treatment presented by two oncology nurses who offer helpful resources for understanding the treatment process and planning. Watch ‘Navigating from Diagnosis to Treatment’ , a presentation by Dr. Margaret Tempero, Director of the UCSF Pancreas Center, explaining what you need to know once diagnosed with pancreatic cancer.

## CONSIDER CLINICAL TRIALS AND SECOND OPINIONS

Once you have been diagnosed, you should consider participating in a clinical trial and seeking a second opinion.

**Clinical Trials:** We have compiled a list of resources and search tools on clinical trials. Early access to new treatments can lead to progress in research and better treatment options and outcomes for more patients.

**Second Opinions:** Seeking a second opinion is always recommended. New perspectives from doctors with expertise and experience ensures that all available treatment options have been offered and explained.

## CREATE YOUR TEAM

As you create your healthcare team, you will want to ensure that certain specialists are included to help you throughout treatment.

Registered Dietician**:** It’s important to meet with a registered dietician familiar with pancreatic cancer to create a nutrition plan to keep your body as strong as possible before, during, and after treatment.

Palliative Care Doctor: Palliative care is for people diagnosed with a serious illness. It provides relief from the symptoms, pain, and stress of an illness like pancreatic cancer. The goal is to improve the quality of life for you and your family. It provides an extra layer of support with your oncologist and can be used with curative treatment.

Psycho-Social Support Specialist: Studies have found a connection between social support, spiritual assistance, and more positive cancer outcomes. Patients are encouraged to ask their doctors about available resources within the cancer center to help them achieve a calmer and more peaceful state while navigating this challenging disease.

In addition to your oncologist, you will likely meet other medical specialists on your journey.

## UNDERSTAND YOUR GENETICS

Genetic Testing & Counseling: Once you receive a diagnosis of pancreatic cancer, your healthcare provider will order germline testing (inherited genes) and somatic testing (acquired mutations) of the tumor, using a sample. This will identify whether the cancer has mutations in specific genes and provide valuable information to help steer treatment decisions.

Surveillance & Screening: For those with particular risk factors, including family history and certain genetic syndromes that increase susceptibility to pancreas cancer, it may be appropriate to participate in a research screening program. Surveillance may also be clinically recommended in instances such as a new diagnosis of a pancreas cyst or lesion.

# KNOW YOU ARE NOT ALONE

We have a collection of videos featuring survivors and caregivers sharing their stories and perspectives. They offer great tips on how they coped and what helped them the most through treatment and beyond. Be inspired to hope. Watch the panel discussion Perspectives from Survivors and Caregivers , the heartfelt and funny Breaking Up with Pancreatic Cancer and the inspirational Conversation and Coaching with Pancreatic Cancer Survivors

Should you or a loved one need support navigating a pancreatic cancer diagnosis, please connect with our Director of Patient Programs, Amy Reiss. We are here for you, and there is hope.