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 <u>Dr. Diane Simeone</u>, 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 <u>Pancreatic Tumor Registry</u> at Memorial Sloan Kettering Cancer Center (MSKCC)
- The <u>National Familial Pancreatic Tumor Registry</u> (NFPTR) at Johns Hopkins University
- The <u>Cancer of the Pancreas Screening-5</u> (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 <u>Paving the Way to Better Outcomes</u>
- American Cancer Society <u>Health Disparities Research</u>
- FDA <u>Racial and Ethnic Minorities in Clinical Trials</u>
- 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.

Pancreatic Cancer Patient Support Groups

Living with pancreatic cancer can create an array of emotional and physical challenges. Fortunately, these new life difficulties can be greatly improved with the right support system in place. While family and friends can offer assistance there are many benefits to speaking with other pancreatic cancer patients and those with a shared experience. While not conventionally thought of as part of your medical team, support groups can provide a wealth of resources, tips and helpful information.

Participating in a support group online can make the difference between feeling alone and isolated versus feeling empowered and connected. Support groups can be beneficial for both the patient and the caregivers as it provides a safe space to connect with people going through comparable medical and psychological experiences. Not all support groups operate the same; some gather virtually while others are online forums where patients post questions, so take the time to find one that feels right for you.

Below are some of our partners and organizations that understand the importance of support groups for both pancreatic cancer patients and their loved ones.

- American Cancer Society provides free support services for anyone living with cancer and their loved ones. Search for support programs and services in your area.
- <u>CancerCare</u> provides free, professional support services for people living with cancer. They offer <u>counseling</u> with an oncology social worker to help cope with the emotional and practical challenges of pancreatic cancer. They also provide free <u>online support groups</u> for both pancreatic cancer patient and caregivers.
- Cancer Support Community offers a toll-free helpline and live web chat where anyone affected by cancer can speak with licensed counselors. Through MyLifeLine, you can create a private support webpage to stay connected with friends and family.
- WeSPARK offers an array of <u>free support groups</u>, from a caregivers group to a singles support group as well as intreatment and post-treatment groups. They also offer various supplemental programs such as acupuncture, reflexology and tai chi. They advise an <u>intake session</u> where they review your history to better recommend programs that may be a good fit.
- Pancreatic Cancer Connections is an online social community that provides a safe space for pancreatic cancer patients and their loved ones to share their experiences, get valuable coping resources, and support one another.
- If you're comfortable with social media, there's a Facebook group called the Whipple Surgery Survivor Group.

With patients from around the world, this vast community can be the right resource for those looking to connect with other patients on Facebook. This group does require you to have a Facebook account and posts may not be private.

- The <u>Smart Patients Pancreatic Cancer</u> discussion forum is an online support group for patients and caregivers dealing with pancreatic cancer. Members share help, advice and information about treatments, symptoms and side effects.
- <u>Cancer Support Community South Bay</u> offers a free, virtual group for pancreatic cancer patients, survivors, caregivers, and family members to build and maintain a support community from diagnosis through treatment and recovery. (Available for California residents only)
- If you're looking to connect with other patients and caregivers, <u>ANCAN</u> offers a virtual peer-to-peer support group with the mission to provide all pancreatic cancer patients with a better quality of life.
- Another virtual peer-to-peer group is led by long-term survivor Tom. Tom facilitates a space for patient and caregivers to share experiences, knowledge and support. Zoom calls are every Friday from 9:00am until 10:30am PST, contact Tom for more details.

If you are a patient or caregiver with questions, contact Patient & Family Support today.

Researchers receive \$4 million to advance immunotherapy treatment for pancreatic cancer

We are proud to share that our collaborative efforts with the UCLA Health Jonsson Comprehensive Cancer Center have led to a transformative \$4 million grant from the National Cancer Institute (NCI). This grant aims to advance immune-based therapies for pancreatic ductal adenocarcinoma (PDAC) to improve treatment and patient outcomes.

Immunotherapy employs drugs to boost the immune system's ability to identify and attack cancer cells. Under the guidance of Dr. Timothy Donahue, Director of the Agi Hirshberg Center for Pancreatic Diseases, Dr. Zev Wainberg, co-director of the UCLA Health GI Oncology Program, and Dr. Caius Radu, professor of molecular and medical pharmacology, a multidisciplinary team is delving deep into the role of adenosine in the immune suppression associated with pancreatic cancer. Their work seeks to understand how adenosine, a molecule in the body, affects the tumor environment and interactions between immune and cancer cells.

The grant will also fund a follow-up clinical trial examining a small molecule inhibitor combined with the existing combination of PD-1, an immunotherapy drug, and chemotherapy before surgery. Building on promising initial results, this trial seeks to diminish adenosine production within tumors, potentially boosting the immune system's ability to fight cancer more effectively. Previous Hirshberg Foundation Seed Grant Awardees, Dr. Thuc Le and Dr. Evan Abt, have also been working to study

adenosine.

"By introducing a small molecule inhibitor to the existing chemotherapy and PD-1 inhibition regimen, we hope to limit adenosine production in the tumor microenvironment, thereby enhancing the immune response against the cancer," said Donahue in the article published by UCLA Health. "We are hopeful this strategy will help the body's natural defenses fight the cancer more effectively, leading to better treatments for people with pancreatic cancer."

This substantial grant is a beacon of hope. We are optimistic that this research will uncover new therapeutic strategies that target adenosine, enhancing patient outcomes and leading to better treatments.

27th Annual LACC Honorary Starter is 9-Year Pancreatic Cancer Survivor, Tom Arai!

The Hirshberg Foundation is thrilled to introduce Tom, our Honorary Starter for this year's 27th Annual LA Cancer Challenge. Tom's story is one of remarkable resilience, determination, and hope—a true testament to the spirit of our pancreatic cancer community.

Nine years ago, at 65 years old, Tom received a diagnosis that would change his life: stage 4 pancreatic cancer. At that time, the five-year survival rate was less than 3%, so Tom focused on one day at a time, maintaining a remarkable attitude and calm

demeanor that inspired everyone around him.

Throughout his journey, Tom's wife, Toni, has been a pillar of support. Once diagnosed, she tirelessly researched to find a great medical oncologist, which led them to Dr. Tara Seery, who they deeply respect and admire.

Immediately after his diagnosis, Tom began a clinical trial that would ultimately change the course of his disease. Through his medical team's dedication and unwavering commitment to treatment, Tom achieved what many thought was impossible. Following the trial, he was considered to have no detectable cancer—a moment of triumph and hope for him and his loved ones. Today, at 74, Tom takes Lynparza, a maintenance chemotherapy drug. His youthful spirit and positivity have kept him strong and made him a beacon of hope for others facing similar battles.

Driven by the challenges he's experienced and inspired by the incredible support he's received; Tom has dedicated himself to giving back. Encouraged by his primary care physician, he started talking to other patients to offer insight, tips, and support. Before long, with another survivor, he founded a weekly Zoom support group for pancreatic cancer patients and caregivers across the U.S., creating a space for sharing experiences and building a community of strength and solidarity.

Before his diagnosis, Tom was an avid cyclist for 25 years, riding up to 20 miles daily. His passion for cycling kept him physically fit and mentally strong, preparing him for the battle ahead. In 2018, Tom took a leap of faith—literally—when he jumped out of an airplane with other pancreatic cancer survivors to celebrate their shared journey. Refusing to let pancreatic cancer take away their enjoyment of life and adventure, Tom and his fellow survivors went skydiving in Perris, California.

Before the LACC 5k race begins, Tom will take the stage to share

his journey, offering all participants words of wisdom and encouragement. His story is about surviving, thriving, and finding joy and purpose every day. He embodies the message that while cancer can change the course of our lives, it does not define who we are or limit what we can achieve.

We invite you to join us at the LA Cancer Challenge, not only to support pancreatic cancer research but also to be inspired by individuals like Tom. Whether you are running, walking, or cheering from the sidelines, your participation makes a difference in the fight against pancreatic cancer.

Tom's story is a beacon of hope and a testament to the progress in cancer research and treatment. Let his journey inspire you to push through your challenges and support those fighting theirs. See you at the starting line!

Our Summer Momentum Newsletter

As summer kicks into gear with family vacations, hot temps, and cool adventures, the Hirshberg Foundation looks forward to sharing the latest updates with our foundation family. Your efforts throughout the year, from fundraising to event participation, have ushered in another season of groundbreaking scientific advances and patient support. Soon researchers will submit proposals for our annual Seed Grant Program, as patients, caregivers, and families gather again for seasonal events that educate and energize our community. We thank you for your continued support as we raise awareness and Never Give Up in the fight for a cure!

A Pancreatic Cancer Progress Report

At our Annual Hirshberg Symposium on Pancreatic Cancer we had the pleasure of welcoming Dr. Eileen O'Reilly, a member of our Scientific Advisory Board from Memorial Sloan Kettering Cancer Center, to speak. She discussed the genetics of the disease and the latest developments in pancreatic cancer treatments, immunotherapy, and vaccine approaches currently in development. With a new FDA-approved drug for pancreatic cancer, targeted treatments, and other emerging approaches, Dr. O'Reilly shared, "You'll see that there's real progress happening, and we're on the cusp of important developments in this disease that hopefully will translate to improved outcomes."

Read Progress Report →

Supporting & Educating Patients in June

In June, we honored the courage of pancreatic cancer survivors around the world throughout National Cancer Survivors Month. Survivors, caregivers, and families impacted by this disease generously shared messages of hope and expressed support for patients and survivors setting out on a journey to wellness. This was on the heels of our spring Symposium and the release of educational videos that educate and empower both patients and caregivers. This year's Symposium included important topics such as improving patient care through a partnership with Canopy Cancer Collective, genetic testing, pancreatic enzyme education, survivorship in pancreatic cancer and PRECEDE, the international collaborative study to improve early detection. We encourage everyone to check out the wide array of topics, especially our inspiring panel discussion, where survivors and

caregivers share their experiences, wisdom, and hope.

Watch the videos now →

Esteemed Journal Shares Agi Hirshberg's Journey

In July, *Pancreas*, a scientific journal of pancreatic diseases, published a beautiful article spotlighting our founder Agi Hirshberg's story, and her unwavering commitment to cure pancreatic cancer. It is a story that all of us can connect with; every family's journey with pancreatic cancer is unique and yet so familiar. At the heart of these stories is a desire to empower loved ones, ensure that no one faces this disease alone, and ultimately, eradicate pancreatic cancer once and for all. In the article, titled <u>Our Lady of Hope</u>, writer Shweta Lavania shares "a tale of compassion, inspiration, and true labor of love." This interview will resonate with you, and we hope you'll check it out.

Read the Article →

Registration is Open for the 27th Annual LA Cancer Challenge

Our signature event, the <u>LA Cancer Challenge</u> 5K Walk/Run is coming up on October 27th and registration is officially open. This incredible event unites families, survivors, and the medical community for an extraordinary day raising awareness. The LACC is more than a 5K, this event will inspire you! Come participate in our Fit Family Expo, Candyland Kids Zone, Halloween costume contests, and much more. Join us <u>in-person</u> at

UCLA or <u>virtually</u> from wherever you are, and know that your participation brings us closer to a cure.

Register Today →

Make a Lasting Impact on Research for Make-A-Will Month

National Make-A-Will Month is coming up in August. In the spirit of supporting our mission and advancing pancreatic cancer research in the future, we invite you to learn more about estate planning. A gift in your will has the power to change patient outcomes and drive cancer research forward beyond your lifetime. Through FreeWill: a free online state planning tool, you can support your loved ones, protect your possessions, continue philanthropic efforts, and secure your legacy. We also encourage you to learn about other ways to give from matching event gifts to Donor Advised Funds. Thank you for your shared commitment to cure pancreatic cancer!

<u>Learn About Planned Giving</u> →

Tour De Pier Rides for Love and Raises \$1.5 Million

In its 12th year, <u>Tour De Pier</u> offers the ride of your life and a unique experience for participants. This year, we embraced our theme of "Ride for Love," and together, we packed more love into the day than we ever thought possible. Thanks to everyone who participated the outdoor stationary cycling fundraiser, our community raised a remarkable \$1.5 million and counting. TDP's success and our ability to support research and patient services

rely directly on supporters harnessing the power of their community. Together we ride for fun, ride for love, ride for hope, and ride to cure cancer. We can't wait to see you on May 18, 2025 for year 13!

Learn More →

2024 Upcoming Events

<u>Hirshberg Training Team 2025</u>: October 5, 2024 - March 16, 2025

LA Cancer Challenge: Sunday, October 27, 2024

Pancreatic Cancer Awareness Month: November 2024

World Pancreatic Cancer Day: November 21, 2024

Giving Tuesday: December 3, 2024<</pre>