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.

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.
- CancerCare provides free, professional support services for people living with cancer. They offer counseling with an oncology social worker to help cope with the emotional and practical challenges of pancreatic cancer. They also provide free online support groups 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 free support groups, from a caregivers group to a singles support group as well as in-treatment and post-treatment groups. They also offer various supplemental programs such as acupuncture, reflexology and tai chi. They advise an intake session 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 Smart Patients Pancreatic Cancer 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.
- Cancer Support Community South Bay 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, ANCAN 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.

Treatment Decisions: Questions to Ask Your Doctors

Ensuring your comfort with the cancer treatment you select is crucial. This process begins by engaging in open and candid discussions with your healthcare team. It’s common to struggle with which questions to ask or to forget them during appointments. The following set of questions, originally featured in the NCCN Guidelines for Patients, aims to empower you with information. Whether you use these or create your own, gaining clarity on your treatment goals and expectations is essential.

Questions about cancer testing

1. What tests will I have?
2. Do the tests have any risks?
3. Do I need to do anything to prepare for testing?
4. Should I bring someone with me to the appointments?
5. Where do I go for testing and how long will it take?
6. If any of the tests hurt, what will you do to make me comfortable?
7. How soon will I know the results, and who will explain them to me?
8. How can I get a copy of the pathology report and other test results?
9. Is there an online portal with my test results?

Questions about treatment options

1. What are my treatment options?
2. Is a clinical trial an option for me?

3. What will happen if I do nothing?
4. Are you suggesting options other than what NCCN recommends? If yes, why?
5. How do my age, sex, overall health, and other factors affect my symptoms?
6. What if I am pregnant or planning to become pregnant?
7. Does any option offer a cure or long-term cancer control?
8. What are the side effects of the treatments?
9. How do I get a second opinion?
10. How long do I have to decide about treatment and is there a social worker or someone who can help me decide?

Questions about what to expect

1. Does this hospital or cancer center offer the best treatment for me?
2. Do I have a choice of when to begin treatment?
3. How long will treatment last?
4. Whom should I contact with questions or concerns if the office is closed?
5. How will you know if treatment is working?
6. What are the chances of the cancer worsening or returning?
7. What follow up care is needed after treatment?
8. What happens if treatment stops working?

Questions about side effects

1. What are the possible complications and side effects of treatment?
2. Does the cancer itself cause any side effects?
3. Which side effects are most common and how long do they usually last?
4. Which side effects are serious or life-threatening?
5. Are there any long-term or permanent side effects?

6. What symptoms should I report right away and whom do I contact?
7. What can I do to prevent or relieve the side effects of treatment?
8. Do any medications worsen side effects?
9. Do any side effects lessen or worsen in severity overtime?
10. Will you stop or change treatment if there are serious side effects?

Questions about clinical trials

1. Do you recommend that I consider a clinical trial for treatment?
2. How do I find clinical trials in which I can participate?
3. What are the treatments used in the clinical trial?
4. Has the treatment been used for other types of cancer?
5. What are the risks and benefits of this treatment?
6. What side effects should I expect, and how will they be managed?
7. How long will I be in the clinical trial?
8. Will I be able to get other treatment if this doesn’t work?
9. How will you know if the treatment is working?
10. Will the clinical trial cost me anything?

Questions about your care team’s experience?

1. What is your experience, as well as your team’s experience, with treating my type of cancer?
2. How many patients like me (of the same age, gender, race) have you treated?
3. Will you be consulting with experts to discuss my care?

Whom will you consult?
4. Is this treatment (or procedure) a major part of your practice? How often have you done this treatment (or procedure) in the last year?
5. How many of your patients have had complications? What were the complications?

Questions about supportive care?

1. What supportive care and services are available to me and my caregiver?
2. Are there any programs to help pay for out-of-pocket costs of cancer care?
3. Does this center provide transportation to and from appointments? What about childcare during health care appointments?
4. Is there help for basic needs like food and housing?
5. Where can I get legal advice? Is my job legally protected if I take a leave from work?
6. Who can help me cope with stress? Is there a support group that would be a good fit for me?
7. Who can advise me and my family about end-of life concerns?

We are here to help. For more support throughout your cancer journey, please contact us.

Messages of Hope for Cancer

Survivors

June is National Cancer Survivor's Month and we are happy to share these heartfelt messages with all those facing cancer. All month long we celebrate survivorship and honor those in treatment as we work towards a cancer-free future.

Share your message of hope here. Together, let's provide support, hope and love with all those facing pancreatic cancer!

> *I am an 8 + year survivor of pancreatic cancer. I was diagnosed in 2012 and had a distal pancreatectomy in September, followed by chemo for six months. I am happy and blessed to say I am still here, cancer free, and thriving! There is hope and you can survive too!*
>
> *Barbara*
>
> *Be well informed but don't let anyone take away your hope. Hope gives us the power to endure what we think we can't, to heal. Remember to enjoy life, enjoy the little things. Be your own best advocate and keep fighting. It's ok to have bad days, to feel like you want to quit, but remember what or who you are fighting for and continue. Even the strongest of us get tired and need to lean on someone else for a bit, or have someone give us a hug and say it's okay.*
>
> *Roberta*
>
> *Thank you to all the researchers, the clinical trials, the doctors, pharmacists, scientists, oncologists and nurses working to cure pancreatic cancer patients each day.*

George

The greatest gift I have received from my recent stage IV pancreatic cancer diagnosis is the deeper appreciation of each day of life and the deeper connections I have with each person, object and experience in my life. It is the gratitude and connections that give me strength and purpose to get through each step of this journey. Life is so much more beautiful when I focus on the wonderful things I have and not on what I don't have.

I am so thankful for the treatment options available for me, only made possible by incredible foundations such as the wonderful team at Hirshberg Foundation, generous donations from supporters and believers in the amazing scientists and doctors working hard to give us reasons for greater hope each day.

Esther

I remember hearing that the tumor on my husband's pancreas could be cancer and that the 5-year survival rate less than 5%. Boom! He was 50, and our kids were still too young. When I told my hubby's brother that the survival rate was only 5% (and I was shaking) he said this to me,
"So, why can't he be in the 5% ?" HOPE. Those words let light in and we began the fight! We formed our team of family, medical experts, support people and HOPE was restored. That was 11 years ago. He was in that 5%!

In this pancreatic cancer journey, it's hard and scary and so sad. But I KNOW that hardwork is happening and progress is happening and numbers are changing in a better direction. I KNOW that there is HOPE to increase them further. I KNOW! And *so does my husband! Eleven years, what a gift! So thankful and full of gratitude and HOPE.*

Cyndy

We are all individuals. Focus on surviving and positive energy instead of looking at stats or educating yourself on survival. Educate yourself in health and what that means instead. Maybe explore Ayurveda or cannabis if you are looking for gentle plant medicine. I was diagnosed in 2010 and I am a survivor.

Christina

I am a 16 year survivor, Blessed Be! My motto was “leave no stone unturned.” I did everything the doctor told me to do, and everything meditative and spiritual my heart and hospice counselor suggested. Hospice was so supportive. I exercised and walked daily and ate healthy as much as I could. It was so long ago and I’m so healthy now, I can only thank heaven. I tell everyone who is interested about my story because there IS hope and there ARE angels.

Julie

Hang in there! Every new day brings a chance for hope, more treatments and cures. Thank you to the Hirshberg Foundation for all the information and support, you are so helpful and inspiring! Appreciate it all!

Joanne

Each morning is a new day- live, love, experience…cherish each moment!

Kevin

Hang in there, be strong, have resilience. You are not alone, relatives, patients and the pancreatic cancer community is here to support you.

Ana

Happy National Cancer Survivors Day! I would just like to celebrate all cancer survivors perseverance, strength, passion and enthusiasm in each day, your spirit inspires all of us! It's been an honor being able to support this amazing foundation and be around such a great atmosphere of people!

Brandon

I am a 1 year Pancreatic Cancer survivor! My journey has had so many different emotions of fear, tears, pain, the unknown, but most importantly HOPE! Knowing that my medical teams and organizations like Hirshberg are doing everything they can to keep this mean cancer away and that research continues to progress gives me hope that I will continue to live a beautiful life, cancer free! I will win and beat this cancer! I am Dawnie Strong!!!

Dawnie

I am a 7 1/2 year pancreatic cancer survivor! A positive attitude is key to your recovery with the love and support of those around you.

Barbara

I was diagnosed with pancreatic cancer in the year 2000. A state-of-the-art clinical trial saved my life. Twenty years later the treatments and therapies have advanced to such an extent that the protocol I received is seldom used. The past two decades of breathtaking research can truly bring hope to you who have been recently diagnosed.
Helping hands and hearts are waiting to help you. Be strong and know that you are not alone!

Lee

Never give up hope! There is ALWAYS reason to believe!

Margie

To all those fighting and surviving every day…this is a new day. We have significantly progressed in the search for a cure. Don't give up hope and keep fighting because there are people you don't even know praying for you, and prayer is enormous! God Bless you and keep you healthy. You were given this life because you are strong enough to live it!!!

Noël

We will never give up! You deserve to be celebrated every day!

Lisa

What a beautiful thing it is, to be able to stand tall and say; " I survived"

Rocio

Wishing you years of health, happiness and a cancer-free future spent with loved ones!

Sarah

With love and encouragement to all who are working and educating themselves about pancreatic cancer and everything being done to support those who are affected by pancreatic cancer. We need this now and on into future when there will finally be a cure! Never give up!!

Kelley

You are examples of strength and we honor you for that!

Matt

I am doing very well after my Whipple in April of 2020. New survivors should hold on to hope, no matter what happens. I am working with research doctors to update protocols by educating *both patients and doctors to signs, symptoms and risks of this cancer. Early detection is the goal! Please support my efforts by letting the associations associated with pancreatic cancer know you agree that this is important for future survivors. God bless you all!*

Laura

I am a 23+ years survivor of pancreatic cancer. I was diagnosed and had the Whipple surgery in January, 1998, followed by chemo and radiation therapy. I am happy to say that I am still here, cancer free, being checked by my original surgeon and oncologist at least once a year with scans and blood tests. So far, so good!!!

Ruth

Wishing everyone suffering from this horrible cancer the very best and always look at what options are available to you. I am so very thankful to have some more time and hoping it stays away. Glad I had doctors that were looking out for me and offered me options for the liver metastasis. Thankful for all the researchers and doctors and caregivers who are there for us.

Kay

What is Type 3c Diabetes?

Type 3c diabetes develops when the pancreas is damaged in ways that affect its ability to produce insulin. Conditions such as chronic pancreatitis, cystic fibrosis, and pancreas surgery, either complete or partial removal (pancreatectomy), can lead to pancreas damage that causes diabetes. Type 3c diabetes (also known as pancreatogenic diabetes) is diabetes that comes secondary to pancreas diseases, involving the exocrine and digestive functions of the pancreas.

Diabetes is a health condition that occurs when blood sugar, or glucose levels in the blood, are too high. This develops when the pancreas doesn’t make any or enough insulin (a hormone), or the body doesn’t respond to insulin properly and glucose levels rise in the blood.

The pancreas has two main functions in the body:

Exocrine function: Produces enzymes including amylase, proteases, and lipase that assist with the digestion of carbohydrates, proteins, and fats.

Endocrine function: Sends out hormones (mainly insulin and glucagon) that control the amount of sugar in the bloodstream.

Pancreas damage that leads to type 3c diabetes may also affect the pancreas’s ability to produce the enzymes that help with digestion and absorption of nutrients. This condition is called exocrine pancreatic insufficiency (EPI).

The difference between the various types of diabetes is what causes them. **Type 1 diabetes** is an autoimmune disease in which the immune system attacks and destroys insulin-producing cells in the pancreas for unknown reasons. Individuals with type 1 always need insulin to manage the condition. **Type 2 diabetes** develops when the body doesn’t make enough insulin and/or the body’s cells don’t respond normally to the insulin (insulin resistance). Individuals with type 2 diabetes may manage the condition with lifestyle changes, oral medication and/or insulin. **Type 3c diabetes** results from damage to the pancreas that isn’t autoimmune in nature. People with type 3c often also lack the ability to produce enough enzymes their pancreas makes for digestion and absorption of nutrients. In this form of diabetes, the amount of insulin being made by the pancreas can vary. Some individuals will need to take oral diabetes medications while others may also need insulin to manage the condition.

The worldwide prevalence of type 3c diabetes is unknown. It is often misdiagnosed and under recognized because there is not a universally accepted diagnostic criteria. The management of type 3c diabetes depends on the level of damage and what caused the damage to the pancreas but may include oral medications, insulin injections, and diet and lifestyle modifications.

If you or a loved one thinks you have type 3c diabetes, please speak with your healthcare team. We are here to help.