

# **An overview of Exocrine Pancreatic Insufficiency (EPI) and Pancreatic Enzyme Replacement Therapy (PERT)**

Exocrine Pancreatic Insufficiency (EPI), also referred to as pancreatic exocrine insufficiency (PEI) or exocrine pancreatic dysfunction (EPD) is a condition where the pancreas doesn't produce enough digestive enzymes, or the enzymes are not mixing properly with nutrients. This can happen because of certain diseases, including cancers of the pancreas, small intestine, and stomach, radiation therapy, and/or surgical resection of these organs.

The pancreas is an organ that makes three types of enzymes – lipase, protease, and amylase. These three enzymes are involved in fat, protein, and carbohydrate digestion and aid to digest food and absorb nutrients. When EPI is present, normal digestion and absorption of nutrients are impaired and may result in undesirable symptoms and undernutrition (malnutrition) over time.

## **Signs and symptoms of EPI & Patient Generated Screening**

Unfortunately, EPI presents in a variety of ways which can make diagnosing this condition difficult. In many cases, the symptoms of EPI can overlap with other medical conditions. A patient generated questionnaire below can be used to see if you should be evaluated for EPI.

# Patient Screen for Clinical Indicators of Pancreatic Exocrine Insufficiency

1. Are you experiencing any of the following symptoms? Check all that apply.

- ☐ Excessive gas (belching, flatulence, bloating, or abdominal fullness)
- ☐ Feel full quickly when eating
- ☐ Cramping or pain with meals
- ☐ Stomach makes excessive noise
- ☐ Gas that is foul or rotten smelling
- ☐ None of the above

2. Do any of the following describe your bowel movements? Check all that apply.

- ☐ Floating, fluffy, or puffy
- ☐ Loose or unformed
- ☐ Urgent
- ☐ More frequent than usual
- ☐ Large size
- ☐ Yellow or light-tan
- ☐ Oil visible in the toilet after a bowel movement
- ☐ Unusually foul or rotten smelling
- ☐ Cramping or pain with bowel movements
- ☐ None of the above

3. Are you avoiding certain foods or types of foods because they cause unpleasant digestive symptoms? Yes/No

4. Are you eating regular amounts of food but losing weight? Yes/No/Unsure

## Treatment for EPI

Pancreatic enzyme replacement therapy (PERT) is a prescription

medication which replaces the enzymes your body isn't making enough of to help digest and absorb nutrients. Your prescribing health care professional can help you find the right dose based on factors like your body weight and diet pattern, including how often and how much you eat with meals and snacks. Generally, you will need to take PERT with the first bite of food for all meals and snacks. It may take some time to figure out what dose works best for your body to help you digest and absorb nutrients.

There is an array of PERT capsules to choose from, some common ones being CREON, Pancreaze and Zenpep. There may be an adjustment period to find the correct enzyme for your body as well as the correct dosage. While these enzymes can often be expensive, many drug companies offer payment assistance programs that can help.

## Enzyme Assistance Programs

- [CREON® capsules](#)
  - [Pancreaze® capsules](#)
  - [Zenpep® capsules](#)
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## Pancreatic Cancer Patient Wig Resources

Hair loss is a possible side effect for patients in chemotherapy or radiation treatment for cancer. However, not all therapies cause hair loss. According to the National Cancer Institute (NCI), [alopecia from chemotherapy](#) is usually reversible. There are a wide range of options for managing hair loss, how to cope emotionally, and how to approach aftercare when your hair

resumes growth. For those experiencing hair loss and the complex emotions that accompany it, you are not alone. To help ease patients through this transition, the Hirshberg Foundation is sharing some important resources to address this side effect. We also encourage you to share your concerns with your healthcare team to determine the best choice for you.

## **Oncology Aesthetics & Wellness**

<https://shop.hairwithacause.com>

Oncology Aesthetics & Wellness, OAW, is a state-of-the-art all-inclusive center for women diagnosed with cancer. Tailored to restore an innate sense of beauty, OAW adopts a holistic ayurvedic approach to beauty, bridging the gap between aesthetics, wellness and healthcare through hair restoration and post-chemo hair extensions.

## **Look Good...Feel Better**

<https://lookgoodfeelbetter.org>

Look Good Feel Better is a public service program that teaches beauty techniques to people with cancer to help manage the appearance-related side effects of cancer treatment. The program offers complimentary group and virtual sessions that teach beauty techniques to help people with cancer face their diagnosis with greater confidence.

## **AngelHair, Inc.**

<https://angelhairforcancer.org/about>

Look Good Feel Better is a public service program that teaches beauty techniques to people with cancer to help manage the

appearance-related side effects of cancer treatment. The program offers complimentary group and virtual sessions that teach beauty techniques to help people with cancer face their diagnosis with greater confidence.

## National Wigs for Cancer Society

<https://wigsforcancer.org>

National Wigs for Cancer Society (NWFCS) helps provide you with a wig that makes you feel like you again. From wig selection to connecting you with a hairstylist, our supportive team guides you through the process of customizing your new hair, so it looks and feels natural to you. NWFCS works directly with your insurance provider.

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## Make a Will & Leave a Legacy that Never Gives Up

August is National Make-A-Will Month! This is the perfect time to safeguard your legacy and leave a future gift that will change the course of pancreatic cancer research. Nearly 67% of American adults do not have an up-to-date estate plan, and it's an essential life task that everyone should have access to. This month, the Hirshberg Foundation is sharing how you can protect your assets and estate using a free tool provided by our partners at FreeWill. ***By creating a will today, you will give your loved ones peace of mind and leave a legacy that will never give up in the fight against pancreatic cancer.***

Create a will today and make a lasting impact in our pursuit for a cure.

[Make a Will Today](#)

## Introduction to Planned Giving

Planned giving is the practice of leaving a future gift in your will or estate plan by designating your favorite charity as a beneficiary. Whether you are leaving a portion of your savings, a major gift, personal property or other assets, a gift in your will has the power to continue changing lives beyond your lifetime. Through the [Hirshberg Foundation's Planned Giving Program](#), you can leave a legacy that never gives up; a legacy that helps us eradicate pancreatic cancer once and for all.

## The FreeWill Tool

FreeWill's tool is 100% free to support you in completing this vital act of caring for your loved ones. The process streamlines writing your will in 20 minutes so you can plan for all you love. You can build a charitable legacy with an optional planned gift to the Hirshberg Foundation in your estate plan. Your legacy gift can plant a seed of hope and support in our mission to eradicate pancreatic cancer, and advocate for patients and families along the way.

## Why it's Important to Create a Will

A will provides peace of mind to you and loved ones, safeguards your assets, and has the power to advance pancreatic cancer research and critical programs in the future.

- **Security:** Creating your will and estate plan allows you to communicate important financial and healthcare decisions, so you're prepared for whatever the future may hold.
- **Peace of mind:** A will allows you to provide for the people and pets you love, so you know that no matter what, they will be supported.

- **Impact:** By including a legacy gift to the Hirshberg Foundation in your will, you can advance our search for a cure for pancreatic cancer.

If you have already established a will and have included a future gift for the Hirshberg Foundation, [let us know](#) so we can thank you for your generosity.

Learn more about our [Planned Giving Program](#) to create a will today. We also invite you to learn about [other ways to give](#). Thank you for sharing our commitment to cure pancreatic cancer and never give up!

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## 21-Year Pancreatic Cancer Survivor, Roberta Luna to be Honorary Starter for the 26th LA Cancer Challenge

As the Hirshberg Foundation brings our vibrant community of supporters and fundraisers together for the [26th LA Cancer Challenge](#), we are thrilled to share that this year's Honorary Starter will be 21-year pancreatic cancer survivor, Roberta Luna!

For two decades, Roberta and her beloved husband Vic have been on a crusade to give back to their community and to embrace patients and caregivers going through a journey that the Lunas know all too well. "Through my experience with this horrific disease, I believe I am here to help those who have also been

affected by pancreatic cancer, to hopefully inspire them and give them much needed hope.” Putting her beliefs into action, Roberta is a volunteer, activist, patient advocate, guest speaker at awareness events and survivor panelist at the Hirshberg Foundation’s Symposium for Pancreatic Cancer. This year we are thrilled to welcome her as our LACC Honorary Starter, and we invite you to [register and join us](#) too!

Over the years, Roberta has shared her harrowing story of how pancreatic cancer took her father, her mother and her uncle before impacting her own personal health by her early 40’s. “I decided then and there I wasn’t going to die; I was going to fight this with everything I had.” Every step of the way, Roberta has stood strong as an advocate for patients. Most recently, she has given a voice to fellow survivors through her podcast: [Living Hope; Your Journey with Pancreatic Cancer](#). Living Hope is a weekly podcast sharing the real-life journeys of those affected by this disease. Her goal is to educate, raise awareness, provide hope, and a spark of inspiration for survivors and caregivers. The [Living Hope](#) podcast is also a returning sponsor of the LA Cancer Challenge this year.

Today, Roberta instills hope in newly diagnosed patients and long-term survivors alike. “Hopefully, you find inspiration from my story about how, through the good, the bad and the ugly, we can weather the storm with the support of our loved ones, our family, ‘our purple family’ and the many people we meet along this often-difficult journey.”

We are honored and humbled to call her a friend of the Foundation. As the Hirshberg Foundation shares its LACC mantra to “Fight to the Finish,” there are no better words than a quote Roberta shared years ago. “As I lace up my purple boxing gloves for the 19th time, I challenge pancreatic cancer to put on its gloves and prepare for the next round...I am still standing and

I'm not giving up!"

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# Momentum Newsletter: Summer 2023

Summer is in full swing, and we have research updates to share plus great ways to get involved in making a difference for the pancreatic cancer community. Our events continue to unite a community passionate about a cancer-free future and ensure that we can continue to fund research that drives us towards that goal. As our [25th year](#) concludes, we remain steadfast in offering hope with the motto, "Never Give Up! Finding a cure is worth fighting for."

## UCLA Activity Summary Report

A true highlight from our UCLA program is that the [UCLA Agi Hirshberg Center for Pancreatic Diseases](#) is moving to a beautiful new space where patients and their loved ones can receive holistic, state-of-the-art care in one central location. This new space enhances a key pillar of our mission and we can't wait to share it with you! Our newest program at UCLA is the Nutrition for Safer Surgeries developed by [Shelby Yaceczko](#), a highly skilled dietician. The program provides patients with medical nutrition services to enhance quality of life during cancer treatment. The Robotic Surgery program is also of special interest. Led by Dr. Mark Girgis, a past Seed Grant recipient, the Robotic Surgery program continues to gain momentum. The minimally invasive technique improves long-term recovery

prospects and expands the patient population eligible for surgery. Together, these programs are improving patient outcomes and quality of life.

[Read the Report →](#)

## **New NCCN Guidelines for Pancreatic Cancer**

The National Comprehensive Cancer Network (NCCN) brings together top cancer centers across the United States to improve cancer care through their vast collection of Guidelines for Patients. The latest version of the [Guidelines for Patients: Pancreatic Cancer](#), sponsored by the Hirshberg Foundation, provides information to help patients and their families navigate a pancreatic cancer diagnosis in an empowered and informed way. The Hirshberg Foundation is proud to support this great work to ensure that all patients and caregivers receive the most up-to-date information to assist them through their cancer journey.

[Learn more and get your copy →](#)

## **UCLA Joins the Pancreatic Cancer Early Detection (PRECEDE) Consortium**

Dr. Timothy Donahue has joined the Pancreatic Cancer Early Detection (PRECEDE) Consortium as a Principal Investigator, allowing UCLA patients with a family history of pancreatic cancer or individuals who carry pathogenic genes to be able to enroll for longitudinal follow up. This [Consortium](#) brings together an international, multi-institutional collaborative group of experts with the aim to increase the 5-year survival

rate from 10% to 50% in the next 10 years. The Agi Hirshberg Center for Pancreatic Diseases and UCLA's involvement in this study will help maximize identification and advance early detection of pancreatic cancer. We are hopeful that this collaborative project will lead to great strides in early detection so that we may see a marked increase in survival rates.

[Read more about PRECEDE →](#)

## **The 26th LA Cancer Challenge 5K is October 22, 2023**

Our signature event, the [LA Cancer Challenge 5K Walk/Run](#) is on October 22nd and registration is now open. The LACC brings our mission pillar to “unite generations, young and old, through physical fitness to raise awareness for pancreatic cancer” to life. Each year we gather at UCLA and in communities across the globe to make a difference for those facing pancreatic cancer. Join us [in-person](#) at UCLA or [virtually](#) from wherever you are, and know that your participation helps us take strides towards a cure.

[Register Today →](#)

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## **UCLA Joins the Pancreatic**

# **Cancer Early Detection (PRECEDE) Consortium to Transform Early Detection and Survival Rates**

Dr. Timothy Donahue, Director of the UCLA Agi Hirshberg Center for Pancreatic Diseases and Garry Shandling Chair in Pancreatic Surgery at David Geffen School of Medicine at UCLA, has joined the Pancreatic Cancer Early Detection (PRECEDE) Consortium as a Principal Investigator. This Consortium brings together an international, multi-institutional collaborative group of experts with the aim to increase the 5-year survival rate from 10% to 50% in the next 10 years. With Dr. Donahue as a Principal Investigator, UCLA patients with a family history of pancreatic cancer or individuals who carry pathogenic genes will be able to enroll in the PRECEDE study for longitudinal follow up.

The PRECEDE Study is an observational long-term study of people with an increased risk for pancreatic cancer due to family history, a history of chronic pancreatitis or pancreatic cysts, or the presence of specific gene mutations linked to the disease. Study participants have blood work every 6 to 12 months with additional imaging collected for those in defined high-risk groups. This data-driven model integrates basic, translational and clinical research to greatly enhance our understanding of this disease and to drive early detection and prevention methods. The consortium aims to identify high-risk individuals, create an effective early detection test for pancreatic cancer, understand the risk factors, including susceptible genes, and develop a strategic pancreatic cancer prevention plan. As Dr. Donahue told us, “It is critical for high-risk individuals to

join this important study in order to maximize identification and advance early detection of pancreatic cancer. Early detection would drastically change the trajectory of the disease and ultimately save thousands of lives.”

The Agi Hirshberg Center for Pancreatic Diseases and UCLA’s involvement in this study will expand the population of high-risk individuals involved and allow family members of patients to participate in deepening our knowledge of pancreatic cancer risk factors. We are hopeful that this collaborative, multi-institution project will make early detection and prevention for pancreatic cancer accessible for all so that we may see a marked increase in survival rates.