

2023 CancerCare Summary on Financial Assistance for Patients

At the heart of the Hirshberg Foundation's [mission](#) is our commitment to provide [support for pancreatic cancer patients and their families](#) as they navigate this disease. In 1998, the Foundation established a partnership with [CancerCare](#), a national organization providing free, professional support services to help manage the emotional, practical and financial challenges of cancer. This longstanding relationship has allowed our organization to provide low-income patients with a one-time grant. Thanks to community fundraising and the generosity of our supporters, we have made a positive impact on thousands of survivors and loved ones thanks to this grant.

Each year, CancerCare provides the Hirshberg Foundation with a [report](#) on how these funds have been used to support patients and families thanks to our partnership. Below are details on the services provided.

2023 PROGRAM SUMMARY

In 2023, through the Hirshberg Foundation's grant program with Cancer Care, nearly 150 financial assistance grants were provided to pancreatic cancer patients. This grant helps to alleviate some of the hardship that can come with a cancer diagnosis and the devastating impact it can have on a patient's life. CancerCare was able to serve a diverse group of individuals impacted by pancreatic cancer throughout the country.

This year, the program served 67 women and 78 men with resources provided across 33 states including Florida, New Jersey,

Georgia, Pennsylvania, and California. Funds to help cover the cost of transportation to and from treatment continue to be the highest need for CancerCare clients; approximately 43% of grant funds disbursed over the course of the 12-month period were allocated to transportation. Copayment charges and treatment expenses were the second most needed type of assistance, at 28% of grant funds. The remaining financial assistance grants contributed to insurance premiums, imaging tests, home care, massage/acupuncture treatments, biopsies, and childcare.

LEARN MORE ABOUT THE CANCERCARE GRANT

To date, the Hirshberg Foundation has provided over \$1.2 million dollars for this patient program offering limited financial assistance associated with transportation to and from treatment, pain medication, childcare, home care, and beyond. Funds are provided to low-income patients for whom it has been a vital resource over the years. Patients and families can learn more about eligibility and program information today.

[CancerCare Program](#)
[Medicaid Eligibility](#)

CancerCare also offers a wealth of other resources free of charge including support groups, educational workshops, co-payment assistance, and case management. Counseling is available in English and Spanish and centers on the emotional and practical challenges that arise from cancer.

[More CancerCare Services](#)

HIRSHBERG FOUNDATION PATIENT

RESOURCES

Patients and families are not alone in this journey. We are here to help guide you through the initial steps of educating yourself and your family about this disease. Learn more about programs, events, and resources offered by the Hirshberg Foundation when you [watch this video](#) and review our [patient and caregiver support services](#) .

[Learn More](#)

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](#)

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>

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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.

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.

An Overview of the Updates to the NCCN Guidelines for Pancreatic Cancer

The National Comprehensive Cancer Network (NCCN) works 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 extensive guidelines include care options, treatment

protocols, quotes from patients, advice for how to discuss treatment with doctors, and much more. The Guidelines for Patients are based on the recommendations in the NCCN Clinical Practice Guidelines in Oncology available to [physicians](#). One of the most recent updates included for patients is the addition of a new first-line therapeutic option, liposomal irinotecan + 5-FU + leucovorin + oxaliplatin (known as NALIRIFOX). This new drug regime has shown promise in early-stage trials conducted by [Dr. Zev Wainberg](#), a member of the UCLA Agi Hirshberg Center for Pancreatic Diseases, Professor of Medicine at UCLA and co-director of the UCLA GI Oncology Program.

Another highlight of the updated version is the recommendation that all individuals diagnosed with pancreatic cancer have genetic testing for a range of inherited mutations. The advice is to screen beyond just *BRCA1* and *BRCA2* to look at an array of mutations that can assist with treatment planning. There is also an expanded section on biomarker profiling for advanced and metastatic pancreatic cancer which can provide a molecular profile of small yet important features of the cancer. Biomarkers detect abnormal changes in cancer cells' genes that occurred during your lifetime and may also help with treatment planning.

An update that we are excited to focus on is the whole-body approach to treatment that is emphasized in the latest Patient Guidelines. The Hirshberg Foundation has long advocated for a holistic method of treatment that takes into consideration the [mind-body connection](#). The newest updates include details on [supportive care](#) that is recommended from the point of diagnosis. Treatment options have also taken on the best-practice of a more individualized approach based on individual and cancer specific characteristics.

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. The NCCN Guidelines for Patients booklet is available for [digital download](#) or to purchase through [Amazon](#).

National Cancer Prevention Month: How to Create Your Personal Cancer Prevention Plan

As the Hirshberg Foundation funds invaluable [patient programs](#) and [research in prevention, early diagnosis, therapies and patient care](#), among these paths to eradicate pancreatic cancer, prevention is at the forefront. As shared by the CDC, [preventative care options](#) including blood tests, annual screenings, surveillance, and scans are all available for various cancers and diseases. The Hirshberg Foundation is eager to empower you and your loved ones with the tools you need to take control of your health and be proactive in your [cancer prevention plan](#). As National Cancer Prevention Month comes to a close, we encourage you and your loved ones, especially if you are at high risk, to use the resources we've provided to create a prevention plan that will allow you to thrive.

Begin your prevention journey by taking a personal inventory of your health. In 2021, the National Institutes for Health, discussed the importance of *Pancreatic cancer epidemiology: understanding the role of lifestyle and inherited risk factors*. [understanding the role of lifestyle and inherited risk factors](#).

Rethinking certain lifestyle choices, documenting your family history, and assessing your risk factors could help set a foundation for a healthier future. Tackling [modifiable risk factors](#) (smoking, obesity, diabetes and pancreatitis) are just that, *modifiable*. Making the decision to quit smoking, maintaining or losing weight, preventing type 2 diabetes or pancreatitis are significant steps. Speak with your doctor about how to begin addressing these important health issues.

Over time, we have found that some [communities are disproportionately affected](#) by pancreatic cancer while [genetics](#) play an important role for others. Both are at high-risk and raising awareness is only the first step in addressing the issue. Whether you are of [Ashkenazi Jewish ancestry](#) or have a family history of diabetes, pancreatitis, or pancreatic cancer, it's important that we address these diseases before they become life threatening. Progress continues to be made in the field of pancreatic cancer as diagnostic blood and [saliva tests](#) are in development, but our ultimate goal is to offer a cancer-free future. After 25 years of fighting this disease on many fronts and [sharing the facts](#), we remain confident that we are getting closer and closer to reaching this goal.

Learn [how you can support our efforts](#) and [make a donation](#) for cancer prevention today!

PANCREATIC CANCER PREVENTION RESOURCES

MODIFIABLE RISK FACTORS

- [Smoking](#)
- [Obesity, Nutrition and Exercise](#)
- [Stage-2 Diabetes](#)

- [High Risk Communities](#)
- [Risk Factors](#)

GENETIC COUNSELING & TESTING

- [Genetic Counseling](#)
- [Ashkenazi Jewish Ancestry](#)
- [BRCA1 & BRCA2 gene mutations](#)
- [Hereditary Pancreatitis](#)

EDUCATIONAL VIDEOS

- Dr. Marcia Canto, Johns Hopkins: [Pancreatic Cancer Screening and Surveillance in High-Risk Individuals](#)
- Wendy Conlon, UCLA: [Why Should I See a Genetic Counselor?](#)
- Dr. Zhoaping Li, UCLA: [Nutrition & Pancreatic Cancer – Food Matters!](#)
- UCLA Center for Nutrition: [Boosting your Immune System](#)