

Caring for Carcinoid Foundation

Turning a dream into reality

The Caring for Carcinoid Foundation (CFCF) is dedicated to discovering cures for carcinoid, pancreatic neuroendocrine, and related neuroendocrine cancers. Along with its focus on research, CFCF is committed to supporting patients, families, friends, and caregivers by providing them with complete and up-to-date information.

Nancy Lindholm, a metastatic carcinoid patient, founded CFCF in 2005 to address the lack of treatment options and information available to patients, as well as the need for increased scientific understanding of neuroendocrine cancers.

Since its inception, CFCF has awarded millions of dollars in research grants to leading scientists at renowned institutions worldwide.

For more information about CFCF or to support our research, please visit www.caringforcarcinoid.org or call **617-948-2514**.



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Imagine a world without cancer...

*personalized
medicine offers
hope for a cure*



bbb.org/charity



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Why do two people of the same age and gender, with the same form and stage of cancer, often respond differently to the same treatment?



For those diagnosed with carcinoid and related neuroendocrine cancers, this question holds particular relevance. The few treatments available can cause severe side-effects, and the results are often uncertain and disappointing. Even traditional chemotherapy is typically ineffective for this poorly understood form of cancer.

Imagine if doctors could know, in advance, which therapies would most effectively help each individual while causing the fewest side-effects. Although more research must be done before this dream of “personalized medicine” becomes reality, scientists have already made significant progress.

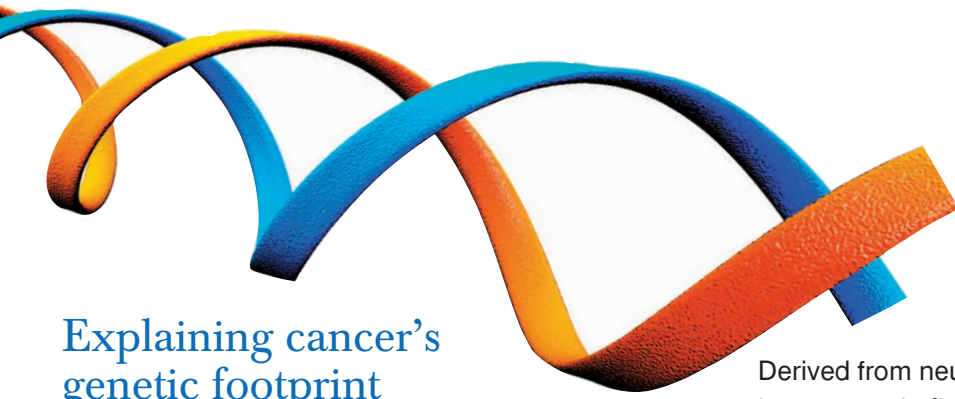
Cracking the genetic code: the key to effective treatments

In 2010, through a grant from the Caring for Carcinoid Foundation (CFCF), researchers at Johns Hopkins University made discoveries that could lead to a personalized approach to the treatment of neuroendocrine cancers.

Nickolas Papadopoulos, PhD, has uncovered several sets of genetic changes, or mutations, in the DNA of patients—a discovery that has led to a number of important conclusions.

“One of the most significant things we learned is that each patient with this kind of rare cancer has a unique genetic code that predicts how aggressive the disease is and how sensitive it is to specific treatments,” said Dr. Papadopoulos.

He and his team discovered mutations that may respond to an existing class of drugs called mTOR inhibitors. These drugs block the mTOR signaling pathway, which is involved in cell growth. The study, published in *Science*, provided scientific rationale for the May 2011 FDA approval of everolimus, an mTOR inhibitor treatment for patients with advanced pancreatic neuroendocrine tumors. This is the first new drug for these patients in 30 years, and a powerful example of personalized treatment for patients with specific types of genetic mutations.



Explaining cancer's genetic footprint

To understand why genetics are so vital to cancer treatment, it is important to understand how cancer develops. Each cell in our bodies contains many genes that control: how the cell grows and divides; our physical characteristics such as hair color and height; and even how likely we are to develop certain diseases such as cancer. Each gene is made up of molecules, called DNA, that carry genetic information and pass it from one generation to the next. DNA appears in a particular sequence or code that contains the instructions for a particular gene.

It is normal for our DNA to change over the course of our lives. Sometimes, changes are passed from parent to child, causing diseases to run in families. In other cases, changes are introduced because of damage to our DNA, from either environmental factors or errors that occur when a cell divides and fails to make an exact copy of its DNA. Fortunately, our cells have checkpoints at which mistakes are detected and repaired. However, sometimes our body's repair mechanism goes awry.

Cancer is the uncontrolled growth of abnormal cells caused by many changes (or mutations) within a cell's DNA. Abnormal growth of cells within the body can lead to the formation of a tumor. A tumor can be non-cancerous (benign) or cancerous (malignant).

A tumor is considered cancerous when it grows uncontrollably and can invade and destroy surrounding tissue. Malignant tumors can spread to other organs of the body.

Derived from neuroendocrine cells, neuroendocrine tumors most often arise in the gastrointestinal tract, lungs, appendix, rectum, and pancreas. Carcinoid and pancreatic neuroendocrine tumors are subtypes of this tumor. Today, approximately 100,000 Americans have neuroendocrine tumors, and this number is increasing annually.

A roadmap for hope: CFCF-funded research

With the help of a carefully planned research roadmap developed under the leadership of its Board of Scientific Advisors, the Caring for Carcinoid Foundation's mission is to bring us closer to the dream of personalized cancer treatment. To that end, CFCF-funded research focuses on three key areas:

- 1. Genetics**
GOAL: to discover cancer-causing mutations in DNA
- 2. Molecular Biology**
GOAL: to identify how neuroendocrine tumors spread in the body
- 3. Clinical**
GOAL: to develop genetically-targeted therapies to most effectively cure patients

For detailed information about research studies funded by CFCF, please visit our web site at www.caringforcarcinoid.org

Promising words from our researchers

“Taking a closer look at these tumors allows us to learn critical information about the genetic landscape of this disease. Our study could achieve a real impact on the care of carcinoid patients.”

*Matthew Meyerson, MD, PhD
Dana Farber Cancer Institute*

“By studying the Seneca Valley Virus, we hope to define a novel, targeted therapeutic strategy for patients with neuroendocrine cancers, in particular more aggressive neuroendocrine cancers such as atypical carcinoid.”

*Charles Rudin, MD, PhD
Johns Hopkins University*

“Through the clinical history, pathology, and blood samples of the Neuroendocrine Tumor Bioconsortium, I believe we will be able to identify genes and molecular markers as well as possibly unravel the mechanisms that lead to the development of neuroendocrine tumors. It is my hope that this information will enable us to identify new and better treatments for our patients.”

*Diane Reidy-Lagunes, MD
Memorial Sloan Kettering Cancer Center*

“Developing mouse models will provide us with a deeper understanding of neuroendocrine tumors and give us a much-needed model to test potential new treatments.”

*David Tuveson, MD, PhD
Cambridge Research Institute (UK)*



Unlocking the future of cancer research: personalized medicine

Researchers continue to make enormous progress in the quest for targeted cancer therapies, but there is still much more work to be done to achieve the goal of truly “personalized medicine.”

Personalized medicine relies on the discipline of “genomics”—the analysis of the complete DNA sequence of a patient’s cancer. By analyzing the patient’s tumor and comparing tumor cells to other cells in the body, researchers can identify mutations present only in the cancerous cells. These mutations become ideal targets for therapies designed to destroy cancer cells while leaving other cells unharmed.

For patients with carcinoid and related neuroendocrine cancers, a personalized approach means targeted therapies with the greatest chance of success and the fewest side-effects possible.

The promise of personalized medicine is closer today than ever before.