Caring for Carcinoid Foundation

Annual Report 2010

Dedicated to discovering cures for carcinoid, pancreatic neuroendocrine, and related neuroendocrine cancers
Caring for Carcinoid Foundation Leadership

Nancy Lindholm founded the Caring for Carcinoid Foundation the only carcinoid, pancreatic neuroendocrine, and related neuroendocrine cancer-focused foundation with the mission of discovering cures. A formal Board of Directors, a Board of Scientific Advisors, and a structured research road map support its mission.

The **Board of Directors** governs the Caring for Carcinoid Foundation by managing its strategic, scientific, and financial direction. The Board of Directors is comprised of highly distinguished community leaders. All members have diverse educational and professional backgrounds and share a commitment to CFCF’s mission.

The **Board of Scientific Advisors** provides scientific direction to the Caring for Carcinoid Foundation. The Board of Scientific Advisors comprises highly distinguished medical leaders who share a commitment to discovering cures for carcinoid, pancreatic neuroendocrine, and related neuroendocrine cancers. CFCF’s Board of Scientific Advisors developed CFCF’s Research Road Map to discover cures as quickly as possible.

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The Caring for Carcinoid Foundation

The mission of the Caring for Carcinoid Foundation (CFCF) is to discover cures for carcinoid, pancreatic neuroendocrine, and related neuroendocrine cancers. To achieve rapid discovery of a cure, CFCF directs 100% of all individual donations to fund breakthrough scientific research of neuroendocrine cancers. This is made possible by the generous support of its Board of Directors and Corporate Sponsors. Along with its focus on research, CFCF is committed to addressing the lack of treatment options for patients and supporting patients, families and caregivers by providing them with complete and up-to-date information.

Since its inception, CFCF has awarded over six million dollars in large-scale, multi-year research grants to leading scientists at renowned research institutions worldwide including Cancer Research UK, Dana-Farber Cancer Institute, Johns Hopkins University, MD Anderson Cancer Center, Massachusetts General Hospital, Memorial Sloan-Kettering Cancer Center, Stanford University Cancer Center, and the University of Massachusetts Medical School.

CFCF has established itself as the leading and most efficient not-for-profit funder of carcinoid, pancreatic neuroendocrine, and related neuroendocrine cancer research. CFCF has achieved this status through guidance from its Board of Directors, whose support allows CFCF to operate efficiently, and its Board of Scientific Advisors, whose members provide a clear Research Road Map and Research Action Plan. CFCF also organizes an annual state-of-the-science symposium dedicated to carcinoid, pancreatic neuroendocrine, and related neuroendocrine cancer research.

In addition to research, CFCF provides support to patients and their loved-ones through its award-winning website (www.caringforcarcinoid.org), E-Updates, patient education materials, phone support, and outreach programs. Through its website, CFCF also maintains its Clinical Trials Resources, a dynamic service to update patients about clinical trials and new treatment options. This resource consists of a dedicated phone line, electronic updates, and a website with a searchable database of trial listings and supportive information.

In 2009, CFCF launched its National Patient Education Series in Los Angeles, CA and Boston, MA. Since then, over 500 patients and supporters have attended our educational events nationwide.

CFCF supports all carcinoid, pancreatic neuroendocrine, and related neuroendocrine cancer patients, families, and friends!
About the Founder, Nancy Lindholm

Nancy Lindholm, a metastatic carcinoid cancer patient, founded the Caring for Carcinoid Foundation in 2005.

At age 29, Nancy collapsed while riding the subway to work. She was taken to the emergency room at Massachusetts General Hospital in Boston. There, she was diagnosed with extensive liver tumors that displaced the majority of her liver, as well as with innumerable bony tumors. The doctors were grim and gave her a few months to live.

Nancy is thankful to be alive, but greatly disappointed that there is no cure for carcinoid. She founded the Caring for Carcinoid Foundation to support leading scientists whose research will lead to a cure for carcinoid carcinoid cancer. She knows the lonely feeling of fighting an incurable cancer that receives little governmental research funding and little pharmaceutical company interest. She also knows that greater insight into neuroendocrine cancers will result in greater insight into other cancers and diseases such as diabetes, prostate cancer, and gastrointestinal cancer.

Currently, there are about 100,000 Americans diagnosed with neuroendocrine tumors and the incidence is rising for reasons not well-understood. Currently, between 11,000 and 12,000 carcinoid tumors are diagnosed each year in the United States, but the prevalence has been increasing by six percent annually.

In 2010, Nancy was honored at Massachusetts General Hospital (MGH) at its annual “one hundred” gala. This fundraising event celebrates 100 individuals and groups whose diligence and discoveries, philanthropy and passion have helped advance the fight against cancer.

Nancy’s courageous story was also profiled in a March 2010 article in Self magazine entitled, “Becoming Your Own Best Hope.” Her passion to discover cures for carcinoid, pancreatic neuroendocrine, and related neuroendocrine cancers continues to inspire the work done at CFCF.
Research Progress in 2010

The Caring for Carcinoid Foundation holds research symposia in order to discuss the latest findings from our research grants and to update and review our Research Action Plan and Research Road Map. In 2010, the symposium took place May 6-7 at the Novartis Institutes in Cambridge, MA. Arnold J. Levine, Ph.D., and Evan Vosburgh, M.D., served as scientific organizers of the event, which was sponsored by CFCF and the Raymond and Beverly Sackler Foundation. The Verto Institute provided additional support. Over 70 distinguished researchers, physicians, and patient advocates attended the symposium.

In 2010, the Caring for Carcinoid Foundation awarded 1.4 million dollars to launch high-impact research initiatives across all three steps of our Research Road Map.

Mouse Model Project

Internationally established researcher David Tuveson, M.D., Ph.D., (pictured) is using his laboratory's expertise in forward genetics and mouse cancer modeling to generate models of neuroendocrine tumors and simultaneously identify genes and pathways that promote neuroendocrine tumor formation.

This study at Cancer Research UK Cambridge Research Institute will uncover critical genetic alterations and pathways that regulate the development of neuroendocrine tumors. Once identified, these genetic events will be used to generate mouse models of neuroendocrine tumors. These genetic events may also represent novel therapeutic targets in neuroendocrine cancers.

*The development of more effective treatment regimens for patients with carcinoid metastasis and carcinoid syndrome has been hampered by the lack of effective in vivo models, which recapitulate the disease process in humans.* - Dr. David Tuveson

The lack of model systems that accurately recapitulate the behavior of neuroendocrine cancers has long been a significant hurdle to developing targeted treatments for patients. This project has the promise to create faithful animal models; therefore, eliminating one of the barriers to treatment development.

2010 Grant Partnership with AACR for Carcinoid and Pancreatic
Neuroendocrine Tumor Research

In 2011, two grants – each totaling $250,000 over the span of 2 years – will be awarded to junior and senior investigators pursuing innovative ideas and approaches that have a direct application and relevance to carcinoid cancer, pancreatic neuroendocrine, and related neuroendocrine cancers. These funding opportunities are possible thanks to a collaboration between the Caring for Carcinoid Foundation and the American Association for Cancer Research (AACR).

The AACR is an international organization whose mission is to prevent and cure cancer through research, education, communication and collaboration. AACR is the oldest and largest scientific organization in the world focused on every aspect of high-quality innovative cancer research. Its reputation for scientific excellence have attracted over 28,000 premier researchers as members and roughly 17,000 participants at its Annual Meeting each year.

AACR’s accomplishments include awarding and administering the innovative Stand up to Cancer Research Grants, which awarded over $100 million in 2009. The organization also publishes six-peer-reviewed scientific journals as well as convening numerous topical scientific conferences each year. AACR collaborates with cancer survivors, raises public awareness of the progress and cause for hope in cancer research, and advocates for strong federal research funding.

"The AACR is thrilled to partner with The Caring for Carcinoid Foundation and the Raymond and Beverly Sackler Fund for the Arts and Sciences," said Margaret Foti, Ph.D., M.D. (h.c.), CEO of the American Association for Cancer Research. "We share the vision of these two incredible organizations to move the science forward to combat carcinoid tumors."

Through this exciting joint effort, CFCF and AACR seek to increase the understanding of neuroendocrine tumor biology, elucidate the mechanisms of currently available therapies, and identify new treatment targets for carcinoid and pancreatic neuroendocrine tumors.

Pancreatic Neuroendocrine Tumor Genome Project

Nickolas Papadopoulos, Ph.D. (pictured) and his collaborators are sequencing pancreatic neuroendocrine tumors to identify the genetic changes underlying development of pancreatic neuroendocrine tumors with the long-term objective of using
this information to develop diagnostics and novel targeted therapies.

Dr. Papadopoulos’ laboratory is uniquely qualified to uncover the genes involved in the development of pancreatic neuroendocrine tumors; the team possesses a collection of well-characterized tumor samples and has sequenced the genes of four tumor types in previous investigations. Dr. Papadopoulos is an Associate Professor of Oncology and Director of Translational Genetics at the Johns Hopkins University School of Medicine. His collaborators include world-class experts in pancreatic cancer, sequencing, and data analysis. Members of his team have successfully executed several large-scale DNA sequencing efforts, including the genetic sequencing of pancreatic adenocarcinomas.

Ultimately, this study may lead to new therapies “personalized” to each patient’s specific mutations as well as new diagnostic tools and strategies for prevention. For more information on genomics research please visit: www.caringforcarcinoid.org

Serotonin-Expressing Intestinal Endocrine Cells Project

Andrew Leiter, M.D., Ph.D., received another year of funding for his project on serotonin-expressing intestinal endocrine cells. Gastrointestinal carcinoid tumors express serotonin and therefore are thought to arise from serotonin-expressing intestinal endocrine cells. At present, relatively little genetic information is available to support this theory. Dr. Leiter’s laboratory at the University of Massachusetts Medical Center aims to identify how serotonin cells become specialized to produce this hormone and to examine their potential to form carcinoid tumors in mice. Understanding how normal cells give rise to carcinoid cancer cells will be important for identifying new therapeutic targets for treating neuroendocrine cancers.
Advocating for Change

Founder and Director, Nancy Lindholm

In 2010, Nancy Lindholm served on the Neuroendocrine Task Force of the National Cancer Institute (NCI) Gastrointestinal Steering Committee. The NCI Gastrointestinal Cancer Steering Committee’s role is to harmonize an efficient, cost-effective, science-driven and transparent process that will identify and promote the “Best Science” in gastrointestinal cancer clinical research.

The NCI Gastrointestinal Cancer Steering Committee is designed to provide comprehensive analysis of proposed clinical trial concepts and facilitate the sharing of ideas among a broad range of clinical, basic and translational scientists, NCI staff, community oncologists and patient advocates in the development of those concepts.

Executive Director, Lauren Erb

On June 29, 2010, Lauren Erb was invited to speak on behalf of neuroendocrine cancer patients at the Food and Drug Administration’s public hearing on "Considerations Regarding Food and Drug Administration Review and Regulation of Articles for the Treatment of Rare Diseases." Lauren addressed the difficulties in bringing drugs to markets for patients with rare diseases like neuroendocrine tumors. She described the specific needs of patients with neuroendocrine cancers, challenges in bringing drugs to market for these patients, and how these challenges necessitate novel approaches to the way potential treatments for rare diseases are approved and regulated.
Supporting the Community

In 2010, the Caring for Carcinoid Foundation launched a new and improved website. This user-friendly site features a plethora of patient resources, including Patient Education Conference Materials, a Video Gallery, and a Newly Diagnosed Patients section.

In 2010, the Caring for Carcinoid Foundation also expanded its Patient Education series to include conferences in Houston, TX, and Palo Alto, CA in addition to Los Angeles, CA. CFCF’s Patient Education Seminars bring together our extensive community of leading clinicians and scientists in the fields of oncology, liver transplant, primary care, surgery, endocrinology, genomics, and research. Patients and supporters attending these events are able to learn about the latest breakthroughs in neuroendocrine cancer research, as well as learn about innovative ways to manage their disease.

Raising Funds for Research and Creating Awareness

The Caring for Carcinoid Foundation brings the neuroendocrine cancer community together through a series of highly visible athletic events across the nation. Team members, including patients, caregivers, physicians and friends, run, bike, walk, and swim to a cure. These events benefit patients by empowering them to go out into their communities and advocate and fight for increased awareness of their disease. Athletic events also facilitate growth and development of communities, as they are so often dedicated in honor and/or in memory of loved ones.

In 2010, over four hundred members of “Team CFCF” participated in athletic events across the country.

- Bank of America Chicago Marathon in Chicago, IL;
- Bolder Boulder in Boulder, CO;
- Breezy Point Triathlon in Norfolk, VA;
- Country Music Marathon in Nashville, TN;
- Cure Carcinoid Golf Tournament in Tenafly, NJ;
- Cycle for Survival in New York, NY;
- Great Race of Agoura Hills in Agoura Hills, LA;
- Jimmy Fund Walk in Boston, MA;
- Marine Corps Marathon in Washington, DC;
- MD Anderson SCOPE 5K and 1K Run/Walk in Houston, TX;
- Palo Alto Moonlight Walk and Run in Palo Alto, CA;
- Pan-Mass Challenge in Massachusetts;
- Run for Hope 2 in Missoula, MT;
- Run for Hope in Fort Collins, CO;
- Swim Across America Boston Harbor Swim in Boston, MA.
2010 Audited Financial statements are currently in process. To receive information regarding the Caring for Carcinoid Foundation’s financial performance or to receive copies of the Caring for Carcinoid Foundation’s Audited Financial Statements as soon as they are available, please call 617-948-2514. In the interim, please see the Audited Financial Statements for 2009 at: http://www.caringforcarcinoid.org/sites/default/files/documents/2009Audit.pdf

CFCF is committed to transparency and accountability, and is happy to provide accurate information as it becomes available.
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