

# Caring for Carcinoid Foundation

## "Dedicated to discovering a cure for carcinoid"

E-Update: Number 4, 2007

### **CFCF Donations**

- Until June, All Donations to CFCF Matched by Stephen and Caroline Kaufer Fund for Neuroendocrine Research - Donate Now!

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- The "E" Team Joins CFCF Sunflower Squad - "Caring, Giving, Fighting for a Cure"
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## **CFCF in the Media**

- Nancy O'Hagan Interviewed on "Jordan Rich Show"

## **Nancy's Blog**

- Nancy O'Hagan Posts New Entry to Blog: "Commitment to Our Future--The Time Is Now"

## **CFCF Donations**

### **Until June, All Donations to CFCF Matched by Stephen and Caroline Kaufer Fund for Neuroendocrine Research - Donate Now!**

All donations to the Caring for Carcinoid Foundation (CFCF) are now matched dollar-for-dollar by the Stephen and Caroline Kaufer Fund for Neuroendocrine Research. [Donate today](#), and your contribution will help twice as much! 100% of your donation supports carcinoid research.

This matching offer lasts until June 30, 2007.

[Donate now!](#)

## **CFCF Fundraising**

### **Team CFCF Enters 2007 The LaSalle Bank Chicago Marathon - Join Now!**

The Caring for Carcinoid Foundation (CFCF) has proudly entered [2007 The LaSalle Bank Chicago Marathon](#) on Oct 7, 2007.

The LaSalle Bank Chicago Marathon is one of the world's leading marathons. In 2006, 60 charities collectively raised over \$9.5 million with 5,000 runners participating. This fundraising success shattered The LaSalle Bank Chicago Marathon record, representing a 30% increase over 2005.

Kathleen Effler is captain of Team CFCF. The fundraising minimum per team members is \$1,000. As a team member, you will enjoy many benefits:

- Training programs
- Training runs
- Fundraising tools
- Option to run marathon with team members
- And freebies!
  - Singlet
  - Sunflower
  - Photos at marathon finish (available for free download)

We are grateful to our dedicated team members! They are working very hard to help cure carcinoid.

Show your support! Please visit their personal fundraising pages:

- [Boone, Byron](#)
- [Effler, Kathleen](#)
- [Miller, Keri](#)
- [Miller, Lance](#)
- Morrison, Jay
- [O'Hagan, Patrick](#)
- [Setness, Christine](#)
- [Weiss, Joanna](#)

[Join Team CFCF!](#)

## **The "E" Team Joins CFCF Sunflower Squad - "Caring, Giving, Fighting for a Cure"**

The "E" Team joined the Caring for Carcinoid Foundation (CFCF) [Sunflower Squad](#) to help cure carcinoid.

The "E" Team's fundraising drive is entitled, ["Caring, Giving, Fighting for a Cure"](#):

"Thank you for visiting The "E" Team's fundraising page!

In 2006, our lives were forever changed when we learned of Eva Donoghue's diagnosis of Carcinoid Cancer. Eva has shown us that she is fighting this disease through Education, Empowerment and Empathy.

By Eva's courage and determination, we have learned what Carcinoid is all about. As a family, we wanted to provide support not only to Eva, but to others struggling with Carcinoid as well. We have formed The "E" Team, whose mission is...Caring...Giving...Fighting for a Cure.

The "E" Team will be holding several fundraisers throughout the year to raise money for the Caring for Carcinoid Foundation. Please check this website for upcoming events. However, the purpose of this website is to provide an opportunity to donate funds at anytime. As a member on the [Board of Patient Advisors](#) for the Caring for Carcinoid Foundation, Eva has stated in her [Survivor Story](#), "Every step forward is crucial, no matter how small." That is why we are asking for your support."

We welcome The "E" Team to our Sunflower Squad.

If you want to help cure carcinoid, join our Sunflower Squad today! Fundraising is easy, and it takes less than 10 minutes to start. [Join Sunflower Squad!](#)

## **Diane Newland Joins CFCF Sunflower Squad - "Cure Carcinoid Now"**

Diane Newland joined the Caring for Carcinoid Foundation (CFCF) [Sunflower Squad](#) to help cure carcinoid.

Diane's fundraising drive is entitled, "[Cure Carcinoid Now](#)":

"My mom, Sarah L'Heureux, suffered with this rare disease and passed away on Dec. 8th, 2004. She was only 67 years old and was loved by all who knew her. My daughter was named after my mom and misses her terribly. I would like to help other families in the future to be spared of the sadness my family feels every day over the loss of my mom. Please help the doctors find a cure, so that others do not have to stand by and helplessly watch their loved one suffer and lose the battle against carcinoid."

We welcome Diane to our Sunflower Squad.

If you want to help cure carcinoid, join our Sunflower Squad today! Fundraising is easy, and it takes less than 10 minutes to start. [Join Sunflower Squad!](#)

## **CFCF Research**

### **CFCF Joins with NCI to Host Unprecedented Carcinoid Research Summit on Sep 12-13, 2007**

The Caring for Carcinoid Foundation (CFCF) joins with the National Cancer Institute (NCI) to host the first ever Carcinoid Research Summit on Sep 12-13, 2007 in Washington, DC.

Hosting this Carcinoid Research Summit is Action #1 of our [2007 Research Action Plan](#).

CFCF is grateful to the NCI leaders for making this summit a priority. They have shown tremendous dedication to planning the 2007 Carcinoid Research Summit and listening to key input provided by the Caring for Carcinoid Foundation.

Thank you to the carcinoid community for achieving this success! Each of you who wrote a letter to Congress during our "[Move Toward a Cure](#)" campaign should feel proud that your voice was heard.

CFCF will provide additional updates on the 2007 Carcinoid Research Summit throughout the year.

[Visit 2007 Research Action Plan](#)

### **CFCF Posts 2006 Research Progress Report by Dr. Matthew Kulke**

The Caring for Carcinoid Foundation (CFCF) posts all research progress reports by our funded scientists. This policy is based on our commitment to transparency and accountability.

Dr. Matthew Kulke at Dana-Farber Cancer Institute presented his 2006 Progress Report on two lines of research:

- Clinical Trials of Novel Agents in Patients with Neuroendocrine Tumors
- Translational Research in Carcinoid Tumors

The goal of Dr. Kulke's research is the following:

"Carcinoid cancer research and the application of carcinoid biology to clinical practice is a major focus of our research program. With support from Caring for Carcinoid Foundation, we have initiated a multi-faceted approach to aid in our understanding and treatment of neuroendocrine tumors. Translational research and clinical trial components work in tandem; our approach is designed to facilitate the flow of results and information from one experimental track to another in real time."

[Read Dr. Kulke's 2006 Progress Report](#)

### **CFCF Posts 2006 Research Progress Report by Dr. Ramesh Shivdasani**

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Dr. Ramesh Shivdasani at Dana-Farber Cancer Institute presented his 2006 Progress Report on research of carcinoid tumor biology.

Specifically, Dr. Shivdasani focused on two areas of research:

- High-resolution analysis of chromosomal copy number alterations (CNAs) in human carcinoid tumor samples
- Study of gastrointestinal development to address fundamental questions about the origin and diversity of endocrine cells in the gut

[Read Dr. Shivdasani's 2006 Progress Report](#)

### **CFCF Posts 2006 Research Progress Report by Dr. Daniel Chung**

The Caring for Carcinoid Foundation (CFCF) posts all research progress reports by our funded scientists. This policy is based on our commitment to transparency and accountability.

Dr. Daniel Chung at Massachusetts General Hospital presented to CFCF his 2006 Progress Report on "Proteomic analysis of GI neuroendocrine tumors."

The goal of Dr. Chung's research is the following:

"The overall goal of this project is to determine whether there are unique protein expression patterns in gastrointestinal (GI) neuroendocrine tumors that can provide novel insights into disease pathogenesis. Through this approach, we hope to identify specific therapeutic targets that have been previously unrecognized. This strategy has never been undertaken in the study of GI

neuroendocrine tumors and is a powerful, unbiased way to identify some of the key proteins involved in tumor development."

[Read Dr. Chung's 2006 Progress Report](#)

## **CFCF to Announce Research Request for Proposal (RFP) in June 2007**

The Caring for Carcinoid Foundation (CFCF) issues a [Request for Proposal](#) (RFP) prior to awarding research grants. Our RFP are open to all scientists who undertake cutting-edge, genetically-based carcinoid / NET research.

CFCF will announce the next RFP in June 2007.

## **CFCF Community**

### **Read 5 New "Survivor Stories"**

The Caring for Carcinoid Foundation (CFCF) is honored to present 5 new "Survivor Stories." They reflect remarkable courage and determination:

- [Christine O'Connor \(New York - USA\)](#)
- [Jessica \(New York - USA\)](#)
- [Philip Bailey \(England\)](#)
- [Rebecca Orchard \(Arkansas - USA\)](#)
- [Steve Rose \(Montana - USA\)](#)

[Survivor Stories](#) are submitted by carcinoid / NET patients who are surviving cancer and fighting each day for a cure. These patients live around the world. See our [global map](#)!

We encourage you to care for the community, too. [Share your Survivor Story](#) and inspire others!

### **Listen to "Expert Interview" with Dr. Gary Jacob - Chief Executive Officer and Chief Scientific Officer, Callisto Pharmaceuticals**

The Caring for Carcinoid Foundation (CFCF) offers "Expert Interviews" to provide the carcinoid / NET community with cutting-edge knowledge directly from leading experts.

Listen to the new "Expert Interview" with Dr. Gary Jacob, Chief Executive Officer and Chief Scientific Officer of Callisto Pharmaceuticals. Dr. Jacob is interviewed by [Nancy O'Hagan](#) on the topic of Atiprimod.

[Listen to Dr. Gary Jacob interview](#)

### **Listen to "Expert Interview" with Carol Lundin - Founder, Reach Beyond Healing Programs**

The Caring for Carcinoid Foundation (CFCF) offers "Expert Interviews" to provide the carcinoid / NET

community with cutting-edge knowledge directly from leading experts.

Listen to the new "Expert Interview" with Carol Lundin, Founder of Reach Beyond Healing Programs. Carol is interviewed by [Nancy O'Hagan](#) on the topic of fighting cancer through adventure and activity.

[Listen to Carol Lundin interview](#)

## **CFCF Board of Directors**

### **Sandra Brockman-Lee Joins CFCF Board of Directors**

The Caring for Carcinoid Foundation (CFCF) is honored to announce that Sandra Brockman-Lee has joined our Board of Directors.

Sandra brings a strong commitment to discovering a cure for carcinoid:

"While carcinoid cancer is an incurable and fatal disease, I believe it can be beaten if we focus resources and researchers on the problem. The Caring for Carcinoid Foundation is a catalyst to achieving this goal.

As a former Leukemia Society of America fellow, I am keenly aware of the dedication and effort required on the part of researchers and funding foundations to develop treatments and cures for cancer. With its ambitious strategic plan, the Caring for Carcinoid Foundation has already had a significant positive impact on our understanding of carcinoid and the drive to find treatments and cures for the disease. I want to do whatever I can to ensure the success of the Caring for Carcinoid Foundation's goal of finding a cure for carcinoid."

[View Sandra Brockman-Lee's bio](#)

### **Marsha Kessler Joins CFCF Board of Directors**

The Caring for Carcinoid Foundation (CFCF) is honored to announce that Marsha Kessler has joined our Board of Directors.

Marsha brings a strong commitment to discovering a cure for carcinoid:

"When I met Nancy, I was inspired by her courage, passion and strength. When I started to talk with her about the Caring for Carcinoid Foundation, I became equally inspired by the quality and commitment of the organization. From my background in project management and organizational improvement, I am impressed with the structured approach, strong leadership and consistent dedication to finding a cure for carcinoid and helping to move forward research in diabetes and related neuroendocrine cancers. I am greatly honored to participate in this important work."

[View Marsha Kessler's bio](#)

## **CFCF Board of Scientific Advisors**

### **David Lee, Ph.D., Joins CFCF Board of Scientific Advisors**

The Caring for Carcinoid Foundation (CFCF) is honored to announce that [David Lee, Ph.D.](#), has joined our Board of Scientific Advisors.

#### **Profession**

- Assistant Professor of Chemistry, Tufts University
- Adjunct Assistant Professor of Biomedical Engineering, Tufts University

#### **Education**

- Ph.D., Scripps Research Institute
- B.Sc., University of Manitoba

We are grateful for Dr. Lee's dedication to helping us discover a cure for carcinoid.

[View Dr. Lee's bio](#)

## **CFCF Sunflower Memorials**

### **CFCF Cherishes and Honors the Memory of Steve Goyen**

CFCF cherishes and honors the memory of Steve Goyen with a Sunflower Memorial:

"Steve Goyen, 39, passed away peacefully at home on February 25, 2007. Born January 27, 1968, in Los Angeles, California, Steve was a 1985 graduate of Pater Noster High School and a 1989 graduate of UCLA. After many years in the U.S. Army Reserve, Steve became a first grade school teacher at Hobart Blvd. Elementary School in Los Angeles.

He is survived by his wife, Sarah, of Azusa; his parents Robert and Cristy Sanchez-Goyen, his sister Gabrielle Sanchez-Goyen and grandmother Rosa Krikorian, all of Sylmar. Steve also leaves his beloved dogs, Ripley, Daphne, and Duke."

[Visit Steve's Sunflower Memorial](#)

### **CFCF Cherishes and Honors the Memory of Bradford Monks**

CFCF cherishes and honors the memory of Bradford Monks with a Sunflower Memorial:

"Brad Monks grew up in the suburbs of Detroit. He was a graduate of Cranbrook School and a *cum laude* graduate of Duke University. After several years in the business world, he attended Vanderbilt University School of Law where he earned his J.D.

Brad came to New York where he practiced law for seven years at the firm of Orrick, Herrington & Sutcliffe. He then collaborated with Barry Silbert in the establishment of Restricted Stock Partners.

Brad was diagnosed in November 2004 with Carcinoid Cancer and died on February 17, 2007 at the age of 40 at Mt. Sinai Hospital in New York City.

He was greatly loved by his family and friends. Brad is survived by his mother, Eleanor Monks, sister and brother-in-law, Julie and David Zvara, and brother, Dave."

[Visit Bradford's Sunflower Memorial](#)

## CFCF QuickPoll

### **CFCF QuickPoll #11 Closed: "Carcinoid / NET patients: Do you have any heart complications?"**

CFCF QuickPoll #11 is now closed: "Carcinoid / NET patients: Do you have any heart complications?" The results are:

- Yes: 32%
- No: 68%

[View graph of CFCF QuickPoll #11 results](#)

### **CFCF QuickPoll #12 Open: "Carcinoid / NET patients: Do you have any bone metastases?"**

CFCF QuickPoll #12 is now open: "Carcinoid / NET patients: Do you have any bone metastases?"

- Yes
- No

[Vote in CFCF QuickPoll #12](#)

## CFCF Events

### **Nancy O'Hagan and Lance Miller Present at SEA4Carcinoid Event - "The drive to find the cure...what we, as patients, can do!"**

[Nancy O'Hagan](#), CFCF Founder and President, and [Lance Miller](#), CFCF Director, presented at the [SEA4Carcinoid](#) event, "The drive to find the cure...what we, as patients, can do!".

As carcinoid patients, Nancy and Lance discussed their personal experiences battling carcinoid cancer. Lance delivered an impressive presentation which contained a thorough recommendation for how to choose a carcinoid clinician and surgeon, among other insights. Nancy outlined her vision to discover a cure for

carcinoid. Nancy founded the Caring for Carcinoid Foundation (CFCF) to pursue this mission. In her presentation, Nancy shared with the SEA4 carcinoid patient audience the significant progress that CFCF has made toward achieving this mission.

CFCF is grateful to Nickolette Way and SEA4Carcinoid for inviting Nancy and Lance to attend this special meeting.

[View 2007 events calendar](#)

## **CFCF in the Media**

### **Nancy O'Hagan Interviewed on "Jordan Rich Show"**

[Nancy O'Hagan](#), CFCF Founder and President, was interviewed on the "[Jordan Rich Show](#)". This show appears on WBZ NewsRadio 1030 in Boston and attracts a national audience.

The extensive, one-on-one interview with Jordan Rich covers a broad range of carcinoid topics, focusing on the CFCF mission to discover a cure.

[Listen to Nancy's interview](#)

## **Nancy's Blog**

### **Nancy O'Hagan Posts New Entry to Blog: "Commitment to Our Future--The Time Is Now"**

[Nancy O'Hagan](#), CFCF Founder and President, writes a blog to communicate with the carcinoid / NET community. Nancy posted a new entry entitled, "Commitment to Our Future--The Time Is Now".

[Read Nancy's blog](#)

## **Links to CFCF Website**

- [CFCF Donor List](#)
- [CFCF Research Action Plan](#)
- [CFCF Breaking News](#)
- [CFCF Home Page](#)