

Caring for Carcinoid Foundation

"Dedicated to discovering a cure for carcinoid"

E-Update: Number 3, 2007

CFCF Board of Patient Advisors

- CFCF Launches Board of Patient Advisors with 5 Founding Members

CFCF Board of Scientific Advisors

- Benjamin Cravatt, Ph.D., Joins CFCF Board of Scientific Advisors

CFCF Community

- CFCF Launches "Expert Interviews" - 3 Audio Interviews with Carcinoid / NET Experts Already Available!
- CFCF Joins Research!America to Increase National Advocacy for Carcinoid / NET Research
- Read 4 New "Survivor Stories"

CFCF Fundraising

- Join Team CFCF (35 Riders and Growing!) in the 2007 Pan-Mass Challenge - Registration Is Closing Fast!
- Kathleen Effler Joins CFCF Sunflower Squad - "Mount Monadnock Moonlight Hike"

CFCF Sunflower Memorial

- CFCF Cherishes and Honors the Memory of Payton Farnell Graeber

CFCF QuickPoll

- CFCF QuickPoll #10 Closed: "Carcinoid / NET patients: Do you also have a blood relative with carcinoid / NET?"
- CFCF QuickPoll #11 Open: "Carcinoid / NET patients: Do you have any heart complications?"

CFCF Board of Patient Advisors

CFCF Launches Board of Patient Advisors with 5 Founding Members

The Caring for Carcinoid Foundation (CFCF) launched a [Board of Patient Advisors](#) with 5 founding members.

The Board of Patient Advisors provides CFCF with advice about how to support patients and partner in the fight against carcinoid.

All members of the Board of Patient Advisors are:

- Carcinoid / NET survivors
- Dedicated to supporting the carcinoid community
- Dedicated to achieving CFCF's mission

The Board of Patient Advisors comprises highly distinguished community leaders who share a commitment to discovering a cure for carcinoid.

[Duane Collie](#)

"In a very short time period, I went from being diagnosed with the rare cancer we call carcinoid, to being told I was a doomed man. And I didn't even feel sick! By nature I'm a scrapper, and I am was not going down without a fight. I fired my doctors and went in search of a smarter physician. My results paid off, and I am now cancer-free.

I believe in what Nancy and Patrick are trying to accomplish, and their philosophy in running the Caring for Carcinoid Foundation. I am on the Board of Patient Advisors to help others in their quest to rid themselves of this disease and promote awareness and education of this cancer. Knowledge is Power."

[Duane's Survivor Story](#)

[Kimberly Condon](#)

"I pray that by our meeting together, that we collectively will find a cure for carcinoid. We must strive to improve the lives of us all and know that a cure is within our reach.

I am excited about being on a team, part of an organization that is dedicated 100% to this cause. As a survivor myself, this is one of the most important things I have done in my life and am excited about the future."

[Kimberly's Survivor Story](#)

[Eva Donoghue](#)

"I am honored to be serving the Caring for Carcinoid Foundation via the Board of Patient Advisors. What an extraordinary opportunity to be part of the foundation of this cutting-edge organization, immersed in science and research and dedicated to finding a cure for this disease which is so often misunderstood, misdiagnosed and miserable.

What we do here gives us the opportunity to bring hope to ourselves and to others while sharing strengths and experiences and building community."

[Eva's Survivor Story](#)

[Bill Evans](#)

"My primary reason for supporting and helping the Caring for Carcinoid Foundation is that it brings hope to so many who have felt they were in a hopeless situation.

A cure can be found and will be found through the dedicated efforts of the true warriors that guide this foundation.

As a carcinoid patient, I believe this disease can be beaten. We are told it is treatable but not curable. That may be true at present but not for long with the proper research.

It has been proven many times over that when good folks gather together and unite in an effort, they are usually victorious.

Well, here and now is a coming together of many different walks of life, cultures, and backgrounds, all dedicated to a common cause. Together we will overcome.

I am adding my one small voice to the growing chorus of others so we can assure future generations they can live free of this disease."

[Bill's Survivor Story](#)

[Jan Peine](#)

"I have been impressed by the professionalism and intense focus of the Caring for Carcinoid Foundation since I became aware of them in 2005. I share in their vision of finding a cure for carcinoid.

Patient input is one more useful element in finding that cure, and I hope that I can assist in that capacity as a member of the Board of Patient Advisors."

[Jan's Survivor Story](#)

[Visit CFCF Board of Patient Advisors](#)

CFCF Board of Scientific Advisors

Benjamin Cravatt, Ph.D., Joins CFCF Board of Scientific Advisors

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

Profession

- Professor, Department of Cell Biology, The Scripps Research Institute
- Professor, Department of Chemistry, Skaggs Institute for Chemical Biology
- Co-Founder, ActivX Biosciences, Inc.

Education

- Ph.D., The Scripps Research Institute
- B.S., Stanford University
- B.A., Stanford University

Accomplishments

"Dr. Cravatt is a nationally recognized leader in the fields of bioorganic chemistry and enzymology. His research group has a broad range of experimental expertise, ranging from synthetic chemistry to molecular biology to mammalian physiology. His group has obtained fundamental insights into the chemical, biochemical, and physiological workings of several important mammalian serine hydrolases, including enzymes involved in the neurobiology of pain and in proteases associated with tumor progression."

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

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

CFCF Community

CFCF Launches "Expert Interviews" - 3 Audio Interviews with Carcinoid / NET Experts Already Available!

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

Expert Interviews cover the most important topics and questions requested by the carcinoid / NET community. Therefore, Expert Interviews provide a unique opportunity to hear directly from leading experts about the issues that concern you.

CFCF is deeply grateful to all the leading experts for sharing their insights and answering follow-up questions from the carcinoid / NET community.

We are fighting together as one team!

- [Listen to Expert Interviews](#)
- [Cardiology: Dr. Heidi Connolly - Mayo Clinic](#)
 - Topic: Carcinoid Heart Disease
- [Counseling: Dr. Paula Rauch - Massachusetts General Hospital](#)
 - Topic: Parenting with Cancer
- [Surgery: Dr. Michael Choti - Johns Hopkins](#)

- Topic: Carcinoid / NET Surgery
- [Contact Us](#)
 - [Ask a Follow-Up Question](#)
 - [Recommend an Expert](#)
 - [Suggest Topics and Questions](#)

CFCF Joins Research!America to Increase National Advocacy for Carcinoid / NET Research

The Caring for Carcinoid Foundation (CFCF) joined [Research!America](#) to increase national advocacy for carcinoid / NET research.

CFCF is proud to be the first and only carcinoid / NET organization to join Research!America.

Together with Research!America, CFCF is advocating for increased carcinoid / NET research funding to help discover a cure.

About Research!America

"Research!America is the nation's largest not-for-profit public education and advocacy alliance working to make research to improve health a higher national priority. Founded in 1989, Research!America is supported by more than 500 member organizations that represent the voices of more than 125 million Americans. Our public opinion polls, advocacy programs and publications reach the public and decision makers to help advance medical and health research."

About Mary Woolley - President

"Mary Woolley is the President of Research!America. Under her leadership, Research!America's membership has more than quadrupled as it has earned the attention and respect of research, media, and community leaders with its signature public opinion surveys and advocacy resource materials.

Woolley is an elected member of the Institute of Medicine and a fellow of the American Association for the Advancement of Science (AAAS). She serves on several boards and committees, including the Institute of Medicine Health Sciences Policy Board, the National Council for Johns Hopkins Nursing, the Board of Overseers of the Harvard School of Public Health, and the Children's Research Institute of Children's National Medical Center. She is a Founding Member of the Board of Associates of the Whitehead Institute for Biomedical Research. Woolley has served as president of the Association of Independent Research Institutes (AIRI), as editor of the *Journal of the Society of Research Administrators*, as a reviewer for the National Institutes of Health and National Science Foundation, and as a consultant to several research organizations.

Woolley has a twenty-five year editorial and publication history on science advocacy and research related topics. Her op-eds and letters to the editor are published in newspapers and magazines from coast to coast and she has been published in *Science*, *Nature*, *Issues in Science and Technology*, *The New England Journal of Medicine*, *The Journal of the American Medical Association*, *The Scientist*, and other research-oriented periodicals. She is a sought-after speaker

and is frequently interviewed by science, news and policy journalists."

Research!America Tools

- [Advocacy Center](#)

"Our goal is to make it easy for you to communicate effectively with your elected officials."

- [Outreach](#)

"Our outreach framework, the 435 Project®, includes programs, polling and initiatives that provide advocates across the nation with messages and tools that build a unified voice for research."

- [Poll Data](#)

"Research!America has been commissioning public opinion polls regarding health-related research since 1992."

[Visit Research!America](#)

[Visit CFCF "Advocate for Change"](#)

Read 4 New "Survivor Stories"

The Caring for Carcinoid Foundation is honored to present 4 new "Survivor Stories." They reflect remarkable courage and determination:

- [Kaylynn C](#) (Oregon - USA)
- [Alice Helms](#) (Indiana - USA)
- [Jan Peine](#) (Texas - USA)
- [Karen Rodman](#) (Massachusetts - 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!

CFCF Fundraising

Join Team CFCF (35 Riders and Growing!) in the 2007 Pan-Mass Challenge - Registration Is Closing Fast!

Team Caring for Carcinoid Foundation will ride in the 2007 Pan-Mass Challenge:

- [Captain](#): Anne Doyle

- **Riders:** 35 and growing!
- **Fundraising Goal:** \$250,000
- **Fundraising Purpose:** To fund cutting-edge carcinoid research (100% of every dollar received by the Caring for Carcinoid Foundation will fund research)

Registration is closing fast! [Join Team CFCF!](#)

Please note, you can also join Team CFCF as a "Virtual Rider":

- **Virtual Riders:** People who are passionate about curing carcinoid but cannot ride in the PMC event
- **Who Qualifies:** Everyone
- **Fundraising Minimum:** None
- **Join Team CFCF as a Virtual Rider:** pmc@caringforcarcinoid.org

Kathleen Effler Joins CFCF Sunflower Squad - "Mount Monadnock Moonlight Hike"

Kathleen Effler joined the Caring for Carcinoid Foundation's [Sunflower Squad](#) to help cure carcinoid.

Kathleen's fundraising drive is entitled, "[Mount Monadnock Moonlight Hike](#)". Kathleen writes:

"Join me for a moonlight hike up Mount Monadnock, a 3,165-foot peak in southwestern New Hampshire. Be one of the 125,000 hikers who summit yearly!

The hike on June 30th will show an incredible full summer moon and views of New Hampshire.

Experienced climbers will lead the hike. Hikers of all abilities can join the fun (especially novices!). Transportation, food and beverages will all be provided. Please bring your own water.

Suggested donation is \$40-50 per person. Additional donations (from hikers and non-hikers) are welcome.

Thank you for visiting my fundraising page!"

We welcome Kathleen to our CFCF Sunflower Squad. Our team members are:

- [Blackwood Family - "Catherine Blackwood's Ten Children Team Up Against Carcinoid"](#)
- [Kimberly Condon - "Give Up Something You Love For One Month"](#)
- [Kathleen Effler - "Mount Monadnock Moonlight Hike"](#)
- [Liz Potter - "Fundraising Drive to Celebrate 35"](#)
- [Gayla Preston - "Hope Through Giving"](#)
- [Lindy Rex - "RexArt for Cancer"](#)

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 Sunflower Memorial

CFCF Cherishes and Honors the Memory of Payton Farnell Graeber

CFCF cherishes and honors the memory of Payton Farnell Graeber with a Sunflower Memorial:

"Mrs. Payton Farnell Graeber, 29, of Greensboro, died Tuesday, January 23, 2007, at Moses Cone Memorial Hospital.

Payton was born in Elizabeth City, and was a 1995 graduate of Bourne High School of Cape Cod, Mass. She was a 1999 graduate of The University of North Carolina Greensboro with a degree in Business Administration. She was the owner and operator of her own business, Vivid Marketing and Design. Payton loved to read, go to the movies, vacation at the beach, and travel. She also had a very special love for her cat, Lily.

Payton is survived by her husband of 7 years, Brent Graeber of the home; one sister, Sarah Rhodes Farnell of Nashville, Tenn.; parents, Samuel and Penny Farnell of Chapel Hill; in-laws, Jim and Dianne Graeber of Lenoir; brother-in-law, Bryon Graeber of Asheville; grandmother, Pearl Rhodes of Chapel Hill; and two uncles, Victor and Jeff Rhodes of Chapel Hill; one aunt, Alletta Farnell of Jacksonville; and one uncle, Edward Farnell of Hubert."

[Visit Payton's Sunflower Memorial](#)

CFCF QuickPoll

CFCF QuickPoll #10 Closed: "Carcinoid / NET patients: Do you also have a blood relative with carcinoid / NET?"

CFCF QuickPoll #10 is now closed: "Carcinoid / NET patients: Do you also have a blood relative with carcinoid / NET?" The results are:

- Yes: 16%
- No: 84%

[View graph of CFCF QuickPoll #10 results](#)

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

CFCF QuickPoll #11 is now open: "Carcinoid / NET patients: Do you have any heart complications?"

- Yes
- No

[Vote in CFCF QuickPoll #11](#)

Links to CFCF Website

Caring for Carcinoid Foundation

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