



THE CARCINOID CANCER FOUNDATION, INC.

333 Mamaroneck Avenue #492 • White Plains, NY 10605 • (888) 722-3132 • (914) 683-1001 • Fax (914) 683-0183



Claire



Jean



Pamela

HOPE IS IN YOUR HANDS: YOU CAN MAKE THE DIFFERENCE

Dear CCF Friend and Supporter,

Carcinoid and other NET cancers have affected each of our lives and the lives of our loved ones. We know you understand because your life has been touched too by NET cancer. We are turning to you as fellow fighters in the war against carcinoid and neuroendocrine tumors.

Imagine a time in the future when carcinoid and NET cancers no longer exist. It is a goal we all hope to attain. But first we must work together to change the statistics – that no carcinoid/NET patient has to wait 5 years or more for a proper diagnosis and treatment. We want to ensure that patients no longer receive misdiagnoses such as Crohn's disease, irritable bowel syndrome, asthma, or rosacea, among others.

Our goal, and this is the mission of the Carcinoid Cancer Foundation, is to bring about greater awareness of carcinoid and NET cancers, to educate medical professionals to look for and diagnose these cancers early, before they spread and the disease progresses, the symptoms intensify, pain worsens, and our prognosis becomes less positive. Early treatment can result in a cure – we wish that could be the case for all carcinoid, pancreatic NET, MEN, and even more rare NET patients.

www.carcinoid.org

If you don't suspect it, you can't detect it.



THE CARCINOID CANCER FOUNDATION, INC.

333 Mamaroneck Avenue #492 • White Plains, NY 10605 • (888) 722-3132 • (914) 683-1001 • Fax (914) 683-0183

We are the lucky ones because our NET cancers have been diagnosed and treated and we are being followed by knowledgeable and caring physicians. There are many more patients who are still seeking a diagnosis. With about 11,000 new cases yearly in our country, we want to be sure each and every patient who has a NET is properly diagnosed.

We are sharing our stories with you so you can see how we were diagnosed and have lived with our disease. It hasn't always been easy. We've turned to those we love, our family and friends, caregivers, and colleagues, for help and support. We've also turned to the Carcinoid Cancer Foundation and found an extraordinary resource. The Foundation provides an enormous amount of information – whether you are newly diagnosed or have been living with a NET for many years. We can call or write to the Foundation and have our questions answered. We've found specialists who can direct our care through the Foundation, support groups, and the knowledge that even with this rare cancer, we are not alone.

Please help the Carcinoid Cancer Foundation to reach out even more broadly, to have an even greater impact. The Carcinoid Cancer Foundation has been there for us when we needed them, please give generously so we can ensure that the Foundation can continue to expand on its mission of education, awareness, support, and advocacy. This is truly a gift that will continue to give hope to you, to your friends, neighbors, family, and people across the globe. Thank you for your most thoughtful consideration. We send you our best wishes for a joyous Holiday Season and a bright New Year.

Sincerely,

Pamela and Brett Cosor

Claire J. Flynn

Jean A. Pignatelli

Tax-deductible contributions to The Carcinoid Cancer Foundation can be made by check (mail to The Carcinoid Cancer Foundation, 333 Mamaroneck Avenue #492, White Plains, NY 10605), online at <https://npo.networkforgood.org/Donate/Donate.aspx?npoSubscriptionId=6395> or by phone (using Visa, MasterCard, or American Express) at 888-722-3132.

www.carcinoid.org

If you don't suspect it, you can't detect it.

Claire J. Flynn

My journey with carcinoid cancer began when abdominal pain caused me to visit the emergency room of our local hospital one chilly October evening in 2000. I imagined that I would be examined and diagnosed with something a prescription medication would cure. Even when the doctor sent me to radiology for an abdominal sonogram, I never suspected anything serious. That all changed when the doctor told me there were “masses” on my liver. The possible significance of the findings registered on the face of my interpreter. As a profoundly Deaf person who uses American Sign Language, signs, eye contact and facial expression all correspond to the speaker’s words. Knowing what I know now...carcinoid cancer had been silently working on changing my life for years.

The next month included a battery of tests to determine what the “masses” on my liver might be. These were to see if I had a metastasis from a melanoma, breast cancer, uterine or ovarian cancer. One week after having a liver biopsy, my interpreter and I sat in front of a gastroenterologist who said I had carcinoid cancer and that, since it had already spread to my liver, I had a short time to live.

Weeks of countless phone calls were spent seeking out a specialist who might be able to provide some hope to hold onto, some treatment, something to stop these feelings of fear and shattering helplessness. Finally, a nurse on a hospital hotline told me about a doctor associated with Mount Sinai Hospital who worked with carcinoid cancer patients. His name was Dr. Richard Warner. There are no words to express my infinite gratitude to Dr. Warner and the Carcinoid Cancer Foundation. It is because of Dr. Warner and the plan of treatment he prescribed that I am here today.

The Carcinoid Cancer Foundation has been like a beacon in a storm for me for more than 11 years. CCF has been, and continues to be, that for countless other patients all over the world. The care, compassion and fidelity to research, patient support and access to information is invaluable and unequalled.

Carcinoid cancer and other neuroendocrine tumors are often referred to as “Orphan Diseases,” which leaves those who suffer from neuroendocrine cancers feeling marginalized from mainstream medical research. The Carcinoid Cancer Foundation has committed decades to making these diseases the sole focus of its efforts, and for that, I am eternally grateful, as are all patients for whom CCF is a source of hope.

Jean Pignatelli

Pay attention to your symptoms . . . I didn’t realize that my wheezing, flushing, and gastrointestinal issues were all signs of carcinoid until after I was diagnosed in September 2007. The heavy feeling on my chest and the fact that I couldn’t breathe properly turned out to be a tumor the size of an orange on my right lung. It took more than a year for me to be correctly diagnosed. I went from doctor to doctor and was diagnosed with everything from thyroiditis to anxiety. I asked one doctor for a chest X-ray and he wouldn’t do one, saying that I was young, hadn’t smoked, and had no family history. But I knew something was wrong.

Finally, at Columbia University Medical Center, I had a chest X-ray and the doctor saw a tumor. On November 1, 2007 I had surgery and, because the carcinoid tumor had spread to the pericardium, they had to remove my right lung. About three years after my surgery, I experienced postpneumonectomy syndrome, a rare complication, where my organs shifted all the way to the right. In January of 2011 I had corrective, repositioning surgery.

These have been extremely challenging times for me – I felt ill, I was scared, I had a lot of pain following my surgeries, and now I have finally found a personal trainer who is knowledgeable about all of my issues and can help me with my recovery.

Turning to the Carcinoid Cancer Foundation I found a really wonderful resource. I knew nothing about carcinoid and CCF provided me with information and support. I watched a video of a carcinoid patient and that gave me hope. I attended the Foundation's conference in New York City and it was very valuable for me to hear from the carcinoid specialists and to learn more from other people's stories.

Going to the Carcinoid Cancer Foundation's website and becoming more aware is critical. I didn't give up and I hope that my story helps someone else not to be scared, to be sure to go to the doctor when something isn't right, and to get the word out about carcinoid. Although carcinoid is rare, it doesn't mean you are alone. What I have been through has made me really strong. A special thank you to the Carcinoid Cancer Foundation for giving me the knowledge, support, and hope to keep looking forward.

Pamela and Brett Cosor

Pamela Cosor, my wife, is a retired flight attendant who had never had a health problem in her life. Like many carcinoid patients, her diagnosis came from an ultrasound looking for something else. I will never forget standing next to the doctor hearing him tell Pam that she has cancer in her liver. That was the instant that changed our lives forever.

Our family doctor in Maryland, Rupinder Singh, became our partner as we searched for the magic doctor who would pull Pam from the jaws of this nightmare. We found a "carcinoid specialist" at a prestigious teaching hospital. More scans and tests later, the specialist, who was a surgeon, pronounced Pam inoperable. "Too many tumors, too many places, forget about the primary tumor, if we can't get the ones in the liver it is a waste of time." We will start with chemoembolization, he passed us on to his interventional radiologist and that was the last time we heard from him.

I began researching this procedure only to find out that it has serious risks associated with it and rules out other, future treatments in the event that it does not produce the desired results. Dr. Singh agreed with me and I began a search for the doctor who would have the right approach for Pam. My deal with Pam, I do the research, have it validated by Dr. Singh, and then you make all the decisions.

I found the Carcinoid Cancer Foundation's website with its list of carcinoid specialists and tremendous amount of information. I literally spent weeks on the internet watching videos of doctors speaking a language that, over time, become less arcane, reading medical publications with words that I had never seen but was determined to understand. Dr. Singh made our choice of a specialist easy: find the doctors who are in a leadership position and clinical researchers at teaching hospitals and that hospital has to have a dedicated institute for neuroendocrine tumors.

I called Dr. Richard Warner at Mount Sinai because he was the closest. We drove to his office in New York where Pam and Dr. Warner spoke for three hours. Dr. Warner sprang into action and called the other members of his team. Research shows that patient outcome is markedly improved when doctors work together as a team with the patient at the center.

Since diagnosed in December of 2009, Pam has undergone major surgery to remove the primary tumors and 3.5 feet of her small intestine, resection of tumors in her liver, zapping others with radio frequency ablation, and vaporizing surface tumors with an argon beam. She also had Sirtex SIRT Spheres treatment and has been on long-acting Sandostatin for over a year now. Pam has been through six courses of treatment with the oral chemotherapy combination of Xeloda and Temodar without significant side effects.

That is why we support the Carcinoid Cancer Foundation. Their people have made measurable headway against NETs. To Dr. Warner and his team we will always be grateful.