

Survivor Stories

Many blogs and personal websites contain additional valuable information about carcinoid and related neuroendocrine tumors, survivor stories, medical information, support group schedules, patient conference schedules, treatment tips, newsletters, reports from patient conferences, lecture



transcripts, videos, and much more.

These websites include personal and support group sites, both national and international.

United States

- ["My Carcinoid Story"](#) by **Susan Anderson**

La Grande Dame de Carcinoid

Created in 1997, this is the first and oldest online personal website. Susan is a carcinoid patient and awareness advocate. Her website has a wealth of information and should be one of the first personal websites you should visit. She is a longtime carcinoid and breast cancer survivor with an aggressive approach to maintaining an active and lifestyle.



"I was diagnosed with Infiltrative Ductal Carcinoma (IDC) Breast Cancer on June 18, 1999. There is NO connection to Carcinoid, this is completely different! I had a lumpectomy, and did 33 sessions of radiation, but no chemo. I went for mammogram every 6 months for 5 years and now go each year. All is well. Getting those mammograms is very important, do it gals! More on my web site www.carcinoidinfo.info. I am a 10 plus year survivor, but I do not like the word survivor,

how about winner!"

"Lead a full and active life while LIVING with Cancer" is Susan's motto. On her website you will find information and links to medical/drug databases, support groups, humor, books, music, prayer lists, travel, political issues, cowboy poetry, and much more!

READ MORE on Susan's blog: <http://www.azcentral.com/members/Blog/sunnysusan/50634?&wired>

- **[Emily Wilkinson's Story: An 8-Year-Old Carcinoid Survivor Triumphs!](#)**

After nearly a year of being sick, with many visits to doctors, the ER and possible diagnoses of Crohn's disease, IBS, indigestion, acid reflux, and a ruptured appendix, Emily was finally properly diagnosed as having a neuroendocrine tumor. Read more about this amazing carcinoid survivor [here](#).



- **[Glass Half Full or Half Empty? Ronny Allan's Journey](#)**

When Ronny was diagnosed with carcinoid in 2010, he experienced a whole range of emotions from shock, disbelief and anger followed by grudging acceptance. However, those emotions were quickly followed by what he describes as "determination, tenacity, strength of character and rock solid willpower" to face what was in front of him. Ronny shares his experience with neuroendocrine cancer as well as his amazing trek along Hadrian's Wall in northern England in his blog, **Ronny Allan - My Journey to Fitness and Good Health**. [Read more](#)



- **[Jess Gockley: Celebrate Every Accomplishment](#)**

What I want everyone to take away from my story is to take the time to celebrate every accomplishment you have along your road to recovery. It doesn't matter if it's being able to get out of bed or the chair without assistance, walking from the couch to the fridge without getting out of breath, getting full range of motion and strength back in your arm after surgery, walking around your neighborhood or running your first 5k. It's important for all of us after surgery to celebrate the small things so that when the hurdles come...we can jump over them too without too much pain and disappointment. Keep in mind that every roadblock you may encounter, may be an opportunity to open a new door elsewhere. _

[Read more](#)



- [Jackie's Journey: From Desperation to a Renewed Belief in the Human Spirit](#)

Meet Jackie who was diagnosed with carcinoid in 2009 after surgery to remove a mass in her mesentery. Years of “watching and waiting” led to a very difficult day in July 2013 which turned around when Jackie found a NET cancer team to treat and follow her. Jackie’s journey, shared by her husband, Jeff, is one of “hope, desperation, and a renewed belief in the human spirit.”

[Read more.](#)



- [Cara's Carcinoid Story](#)

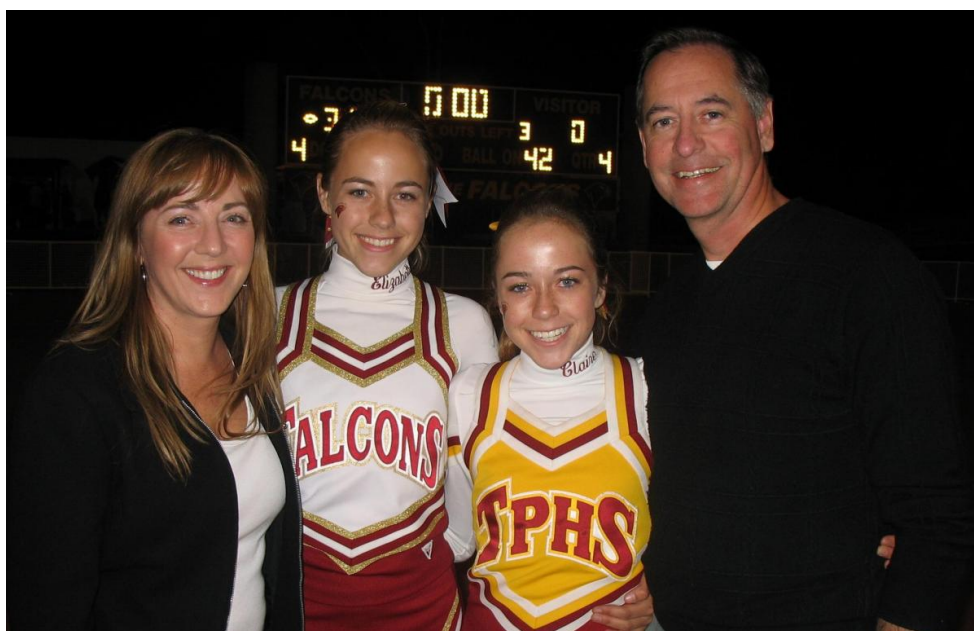
I am 43 years old, live in Illinois with my husband, and work as a college professor. I have always had good health – I run, do yoga and Pilates, and eat a fish and vegetable diet (with occasional handfuls of peanut M&M's). In mid-March of 2012, I got chronic diarrhea that lasted about 3 weeks. Because this was very unusual for me, and because I have a history of Crohn's and colitis in my family, I went to the doctor. After determining that it wasn't the result of anything more acute, she agreed that with my family history I should be referred for a colonoscopy. [Read more](#)



- [A Roller Coaster Ride: Chris Lindsey's Carcinoid Journey](#)

We were on summer vacation on the shores of Lake Michigan in the summer of '98. One night I started having incredible pain in my gut. I was literally writhing on the floor in pain. My wife went to the store and brought back all the stomach relief medicine she could find. It didn't help. Gradually the pain subsided. What we didn't know at the time was that I had a Carcinoid tumor in my intestine.

[Read more](#)



- [Taking Back My Life: Carolyn Francis' Story](#)

Survivor Stories

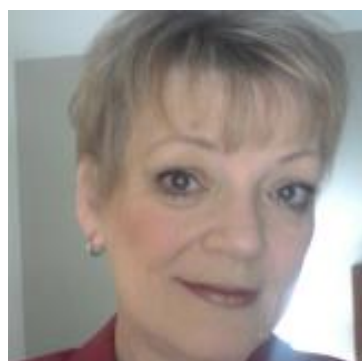
Published on The Carcinoid Cancer Foundation (<http://www.carcinoid.org>)

I was diagnosed with bronchial carcinoids when I was 29 years old. I was newly married and on a business trip in Europe when I got pneumonia. Six months later, I was finally diagnosed with carcinoid. I had the lower two lobes of my right lung removed and began the long, uncomfortable road to recovery. I was given a very ambiguous diagnosis; no one seemed to know what to tell me!

[Read more](#)



- [Beyond Life's Challenges: Coral Levang's Blog](#)



After an emergency room visit in April 2012, Coral “was sent on a journey of scans, a biopsy, tests and a crash course in medical terminology that would rival cramming for any university exam. On May 15th, it was given a name: Stage IV Gastrointestinal Carcinoid Syndrome, which has metastasized to the liver.” But this did not deter a woman who spent 15 years in the military. She says she has hope and an incredible support system of friends and family. “And may I always remember that my purpose has been set in this life – to inspire others to see beyond the challenges they face in this lifetime.” [Read Coral's blog here](#) and check out an article in the *Northwest Guardian* about Coral, [“Courageous ACAP Worker Defines ‘Selfless’.”](#) Coral works as a Transition Assistance Program workshop facilitator at the Joint Base Lewis-McChord Army Career and Alumni Program center. She speaks to transitioning and retiring soldiers and families.

- [Let's Cure Neuroendocrine Cancer: Catherine Cooling Davis' Blog](#)

Newly married, working on her MBA during the evening, feeling that everything in her life had come together perfectly, Catherine was given the news that she has carcinoid cancer following the discovery of a tumor in her small intestine during a routine gastroenterological exam on August 10, 2012. As she prepares for surgery, Catherine has become an extraordinary advocate for the

[iCancer campaign](#), seeking to raise funds for the [Uppsala University Oncolytic Virus Fund](#). She says, "There is one thing that gives me hope, and it is a cure." Read more at [Catherine's blog](#).



• [Brian's Carcinoid Battle](#)

Brian Bowe was diagnosed with carcinoid in 2005, after years of not feeling well. In his blog, Brian says he has "a wonderful and supportive family, incredible friends," a terrific career, and he enjoys life. "My hope is that my journey will not only benefit me, but that it might also help pave the way for others to get the critical treatments necessary to extend their quality of life." Pictured are Brian and his wife, Kathy. Read more about Brian and his journey here <http://fightcarcinoid.com/>



- [Ann Can! Ann's Journey with Carcinoid Cancer](#)

Ann was diagnosed with carcinoid cancer in February 2012 with a 5 cm tumor in her right lung. Since then she has learned that her cancer has spread throughout her body. Ann says that she is in "very good company with this rare cancer. Many of you have heard of Steve Jobs' battle over the last 10 years with Pancreatic Cancer. Most of you are unaware that he actually had Neuroendocrine Islet Cell Tumor which is very different from the more familiar pancreatic cancer that took Patrick



Swazye's life. Another familiar figure to lose his battle not too long ago was Dave Thomas of Wendy's hamburgers. It was listed as Liver Cancer. I stand amongst Giants!" Read Ann's blog here: <http://www.anncan.net/>.

- [Tick, Tock . . . Time of My Life](#)

Derek Wilson, editor of the Larkspur-Corte Madera Patch in California, writes a column most Mondays where talks about his own battle with carcinoid cancer and about cancer issues. "Switching From Patient To Caregiver -- When someone who has eased your pain is suffering, you'll do what you can to return the favor" is a column from August. "My wife and I have been making back-and-forth trips to the hospital lately, but this time I'm just as worried about her as she has been about me." Read the complete

column: <http://larkspurcortemadera.patch.com/articles/switching-from-patient-to-caregiver>. Check out Derek's column, **Tick Tock . . . Time of My Life**, in the **Larkspur-Corte Madera Patch** on a regular basis, [CLICK HERE](#). Pictured are Derek and his wife Tracy.



- [Investigational: Isabel Call's Blog](#)

Meet **Isabel Call**, a young social scientist whose cancer journey began



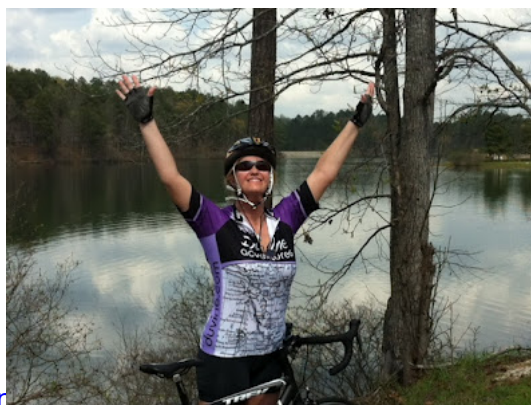
in the fall of 2011 when she was diagnosed with a paraganglioma in her neck. This rare NET has led Isabel to fight her insurance company – and win! -- in order to be treated with proton radiation beam therapy. Read more about Isabel and her insurance appeal in this Sacramento Bee article, [UC Davis student wins coverage fight for 'investigational' cancer treatment](#). And follow her [blog](#) as she uses her “investigational spirit” to fight her cancer.

- [Pureed Pzazz: LaVonne Levar's Blog](#)

Why pureed foods? As a result of living with pancreatic neuroendocrine



cancer since 1998, LaVonne experiences intestinal tract blockages if food is not prepared in an easily digestible manner. In her [blog](#), LaVonne shares recipes for pureed foods that are healthy and delicious. “I hope this blog will inspire others to discover that food and life can still be full of Pzazz even when faced with challenges.” Her recipes include beautiful photographs, ingredient lists, how to prepare each dish, and nutritional content. All illustrations for the blog were created by LaVonne’s son, Dan Levar – and they are terrific!



- [Juliet Haikes, Living with Carcinoid Cancer](#)

Juliet Haikes was diagnosed with carcinoid on October 21, 2011. She writes in her [blog](#), "On March 21, 2012, I am in remission from carcinoid cancer. Remission to me...It feels like freedom. It feels like water, when you're so thirsty. It feels like fresh clean air, when you need a deep breath. It feels like sun that warms you on a cool day. . .it's that warm blanket from the dryer when you're cold. It's a revival of the human spirit . . .to make you want life back. . .to fight even harder for it. . .to never give up. . .never give in."

- [Cy Ball: A Blog about Music and Cancer](#)



Cy is a retired computer software developer, an enthusiastic fly fisherman, bicyclist and music producer. His blog, [Cy Ball – Music](#), chronicles his journey as a carcinoid survivor and shares his incredible compositions. Be sure to listen to all of his works, especially [“Carcinoid,”](#) a piece composed when he was undergoing chemoembolization.

- [Tracy Krulik’s Journey: I Have Cancer. And I’ve Never Felt Better.](#)



Tracy was formerly a fundraiser and musician, now she describes herself as “the CEO of my health.” She spends her time “fighting cancer, writing, teaching, practicing Pilates, putting ridiculous amounts of miles on my road bike, growing vegetables and cooking fresh, plant-based meals.” A pancreatic NET survivor, Tracy was diagnosed in 2007

Survivor Stories

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after many years of pain and illness. Read more about her journey in her [blog](#). Be sure to visit the ["About Me"](#) section and read the articles that have been written by and about Tracy.

- [Two Lung Carcinoid Survivors Inspire and Lead the Way](#)



Imagine the strength, endurance, and determination it takes to run races and marathons. Now consider running with only one lung. This is an inspirational story about two lung carcinoid survivors: **Deirdre Durant** and **Kenneth Todd**.

- [Channeling Jackie-O: Marlena Johnston's Blog](#)



"Everybody needs a hero; for me, it's Jacqueline Kennedy Onassis, affectionately known as Jackie-O. For as long as I can remember, when things became difficult, my mother would always tell me to think of Jackie-O and how she would handle the situation - with perfect grace. That is the purpose of this blog, to allow me to channel some of Jackie-O's intangible grace and dignity in meeting my latest challenge: surviving carcinoid cancer."

- [Knock on Wood . . . Kristin vs. Carcinoid](#)



"My carcinoid cancer journey, like most carcinoid journeys, is a long and winding one," writes Kristin. Join her as she chronicles her "adventures" from a trip to the ER to testing, diagnosis, surgery, and weighing different treatment options.

Survivor Stories

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- **Roger Wood**, son of DGW, created this amazing blog, documenting step-by-step his father's trials and tribulations living with carcinoid. A true educational voyage for both patients and caregivers.

dgwhealthnews.blogspot.com



- **Lucy Wiley's Blog** -- [my profile](#), [my blog](#)



Lucy's blog, started in October 2008, covers everything from a video on how to mix black raspberry powder; PRRT; travel tips for carcinoid patients in Europe; and the nanoknife procedure for carcinoid tumors. We recommend Lucy's blog for an extraordinary amount of practical and varied information for carcinoid survivors.



- [Welcome to My Story](#)

[Kari Houston Jones](#)

This website has been created to share with you my story. It's a story about being diagnosed with cancer. But not just any cancer - a rare form of cancer, one that is normally diagnosed in people twice my age. Many people have never heard of it, most doctors are confused by it, and survivors are just looking for a way to beat it. This is my story about my ongoing battle with Carcinoid Cancer.

An incredibly inspiring video created to bring about greater awareness of carcinoid and NET (neuroendocrine tumor) cancer. Humor, strength, adventure, hope -- this is Kari's story. Watch the video below or to see it in a larger size click on the YouTube icon on the bottom right of the video screen.

- [Larry Chinnery's Home Page](#)

June 2006. We mourn the departure of Larry from this earth.

Larry, a long time Noid survivor, published an amazing website. One of the goals with this website was to provide direction to those searching for useful information about carcinoid cancer and carcinoid syndrome.

- [Carrie Snelgrove's Carcinoid Story](#)

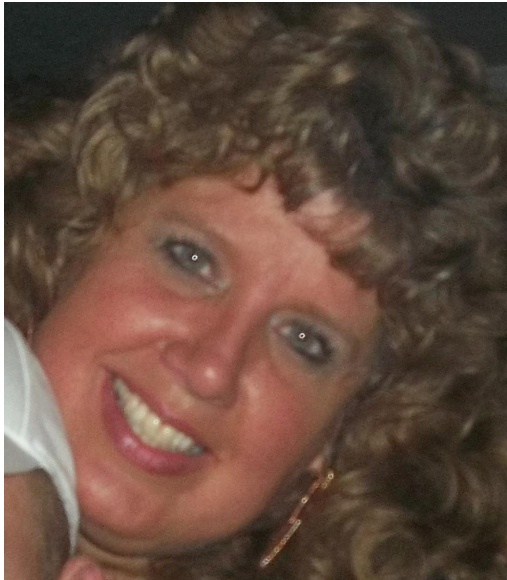
Good Evening Ya'll. Just wanted to let everyone know that I have updated my Caring Bridge website.

NEW SURVIVOR STORIES

- **Hilary's Carcinoid Journey: Never Take a Breath of Air for Granted** (posted December 30, 2013)

Four years ago I came down with a cough that I just couldn't shake. I was a single mother of a son which was a senior and just kept pushing ahead instead of going to the doctor. Having no insurance

did not help the situation either. [Read more](#)

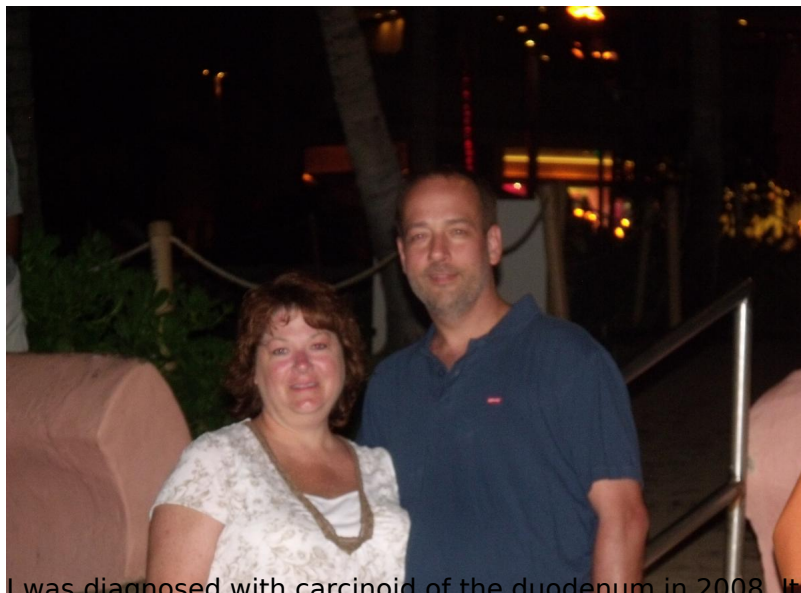


- **Jan Eisner's Story: Run for the Stripes** (posted July 30, 2013)

"I am so thankful I can run," writes Jan. Running has given her health benefits, time to mediate, time to enjoy nature, and the opportunity to meet supportive friends. She was diagnosed with neuroendocrine cancer in 1999 when she was 37 years old, married, and had two very young sons. [Read more](#)



- **Kelly Andersen's Carcinoid Story** (posted November 28, 2012)



I was diagnosed with carcinoid of the duodenum in 2008. It was a very small tumor, but still serious. I had a partial small intestine resection which was a very serious surgery that required the surgeon to cut me open from breastbone to bellybutton. [READ MORE](#)

- **Anna's Carcinoid Story** (posted October 18, 2012)



Hi, my name is Anna. I am a 25 year old girl who was recently diagnosed with Carcinoid Cancer this past August 2012. In August, I awoke in the middle of the night with severe pain in my lower belly. The pain was so severe that I went to an Urgent Care where the doctor diagnosed me with appendicitis and told me I would have to go right to the ER. [READ MORE](#)

- **Dave Smyth's Story** (posted September 5, 2012)

I know cancer is not a pain of itself but it does cause it. Over the years I have been living with a pain



that I hid from a lot of people including myself. It wasn't until July of 2008 that I could not take it anymore. Was I scared, was I stupid, was I selfish, or was I just in plain denial? Why would I have cancer? No one in my family had it. I was expecting some type of other problems over the years like a stroke or a heart attack, but never cancer. [READ MORE](#)

• **Jeanne Lambert's Story** (posted July 2, 2012)

We are only five weeks from the [Run for Hope 5k](#), I just want to share with you the passion behind this event in our Colorado city of Fort Collins and the blessing Carcinoid Cancer is in my life. As founder and director of the **Run for Hope 5k** for the past 8 years, I am reminded that we have much much to do...there is still not a cure, there are still those that don't know they are not alone and many who have no HOPE! [READ MORE](#)



[HOME](#) [REGISTER](#) [CARCINOID CANCER](#) [RACE INFO](#) [PAST RACE RESULTS](#)

• **Harriet R. Hannigan's Story** (posted January 4, 2012)



I have Metastatic Carcinoid Syndrome. My symptoms started in March 1981 and being a Nurse, I looked up everything and came to the conclusion that I had Carcinoid Cancer. I asked many doctors who never agreed. I was getting sicker as I grew older, changed doctors and was still told I had Irritable Bowel. I knew better, I had read volumes of literature, particularly Dr. Warrens in NY, and I could not find a doctor who would listen. In October 2000, with my daughters encouragement, I went to a Lahey Clinic MD and after many tests, they diagnosed me with Metastatic Carcinoid Syndrome in Nov. 2000! I have had a small bowel resection and ovaries removed and receive 40 mg. of Octreotide every 28 days (since Jan.2001) and **now feel better at 80 years of age than I did at 50**. I now have Carcinoid Heart Disease but am doing well. I still play golf and bowl and am more active now than when I was younger. You can live with this disease if you find the right doctors. I believe that many doctors have heard about it but know very little about it. Thank you

- **Master Sergeant Aki Summer's Story** (posted November 20, 2011)

I'm Aki A. Summers and currently serving Active Duty Military with the US Air Force for 18.5 years. I have written 2 articles below and would like to share them with other survivors. I am 9 months into remission.



<http://www.pacaf.af.mil/news/story.asp?id=123277009>

<http://www.scribd.com/doc/70621315/mcw-thisweek>

- **Carolyn Woolman's Story** (posted November 20, 2011)

In 1992 I was diagnosed with metastatic pancreatic cancer. I was at the time an ER Nursing

Manager. I was told I had 3-6 months to live. After two years on chemo I requested another biopsy and was told it was carcinoid. I went to a large teaching university hospital and was told they could supply support but no treatment was known. In 1998 I contacted Dr. Richard Warner at Mt. Sinai in NY and was told the only doctor in CA he would recommend was Dr. Edward Wolin at Cedars Sinai. Dr. Wolin told me he was going to go after the carcinoid with aggressive treatment. I had lots of tests and scans and three chemo embolizations. I had no untoward effects from them. I was sent to a liver surgeon. A central line was placed in my arm and I was given chemotherapy. In eight months it was felt that surgery could now be performed. I had remained very active until this time without any real side effects from any of the treatments. The carcinoid was in the liver, stomach, and small bowel. They also found a renal cell tumor while doing a pre-op work up. In October of that same year I underwent extensive surgery. They removed my kidney, part of my stomach, part of my small bowel and 80% of my liver. Over three days I had 24 hours of surgery. I developed two infections and had lots of antibiotics. The hospital stay was kind of a blur. I honestly do not remember any pain. After 3 weeks I was discharged. It took a couple of months before I was really recovered. It is now 2011 and I remain cancer free. Since that time I got to see my son and my daughter both graduate from college and both married. I have a 9 year old granddaughter and a 7 year old grandson. To say that I am blessed to have found Dr. Wolin would be such an understatement. He not only saved my life but has given me years to make memories with my friends and family. I never thought I would live to see 40 and now I am 66. I am active in my grandkids' school and try to appreciate every day. I pray for anyone reading this that you will recover from this disease. I cannot believe how far the treatment has progressed and the new treatments just on the horizon. My only advice would be to make sure you go to someone who is actually a carcinoid specialist. Many doctors will say that they know how to treat this disease but as I found out at the university hospital, they did not. It would have cost me my life had I stayed with that facility. I don't know if my email will be shown but if it is please feel free to contact me if you have questions and may God bless you. cjwoolman@hotmail.com

- **A Breath of Hope, Lisa Pawlak's Story** (posted October 17, 2011)

Lisa also shares her journey in the May/June 2013 issue of **Coping with Cancer** magazine. Read the article [here](#).

It's easy to get caught up in the hype of "back-to-school" season.

I understand this, because I've been there.



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Published on The Carcinoid Cancer Foundation (<http://www.carcinoid.org>)

The month before Joshua (pictured with mom, Lisa, above) started Kindergarten – even though I was working a part-time job at a non-profit, shuttling my two small boys around town to their various activities, and managing our unmanageable household -- I deemed it necessary to spend hours upon hours shopping for the perfect little backpack for Joshua's grand entrance into academia. [Read more](#)

• A Carcinoid Soldier's Survival Story (posted February 1, 2011)

When **Staff Sergeant Daniel Barber** of **D Company 1-106th AVN in the Missouri National Guard** was first diagnosed with carcinoid cancer in 2009 he experienced feelings of shock, despair, anger, fear and frustration. But he was also relieved because he knew the symptoms he had been experiencing for over a year were not all in his head, as had been suggested to him. From that moment on the Missouri native, who describes himself as “having a little mule in me,” began a journey that is both typical and unusual for a carcinoid patient. [Read more](#)



• Theresa Conroy (posted January 23, 2011)

I am a seventy nine year old woman, diagnosed with midgut carcinoid syndrome, February 2010. Stage four, c.s. was diagnosed. The bone marrow biopsy was positive, as were the octreotide scan, and the lab values were elevated CgA 272, and 5H1AA 24. I was started on Sandostatin, IM monthly, and the diarrhea and hot flashes have gone. So far my liver and kidneys are not involved. My biggest problems at this time are weakness and almost twenty pound weight gain. I actually worked as a clinical nurse three in a neonatal unit for 34 years and retired after my diagnosis. At this point I am not in pain, and I am grateful for that. When I read about food I should stay away from that includes most of my diet. Because my symptoms are not surfacing at this time, should I be excluding milk, high fiber bread, and cheese from my diet? I know if I eat walnuts or avocado, it has an effect on me, so I do stay away from them. I do have a positive attitude. My husband of sixty years is having a difficult time. I keep reminding him it's slow growth, but it is hard to forget the tumors are traveling through my blood. My doctor has never seen carcinoid in the bone marrow. Does anyone

out there have any info about this? It was good for me to sit down and write about my cancer. Whoever reads this I appreciate your input. Thank you. Theresa Conroy

- **Richard Smith** (posted December 9, 2010)



"Severe gut pain" 2/88. The beginning.

Moved to NC from NJ 12/90.

DX Primary Liver Cancer 2/2000 given six months to live.

Moved back to NJ 4/2000.

DX Carcinoid Syndrome by BX 5/2000.

Visited Daniel Haller, MD prof of Onco U. Penn

11/2000. He advised Octreotide.

Received computer 12/2000 for holiday.

Found Carcinoid Cancer Foundation site.

Studied here and elsewhere to find out all I could about the "enemy."

Started Octreotide with out a scan 11/2001

'Been doing good (sub q.) Titrating dose myself.

Also a v

Thanks for belief in God and a refusal to give up, I'm still here

going in (cancer is all over, I fight like hell!) Never surrender to it!



Aust

[Eric's Story of his journey through the carcinoid maze](#)

Eric has been diagnosed and treated for a rare form of cancer called "Carcinoid Cancer". His personal website chronicles the saga of Eric's trials and tribulations on his journey from the day of diagnosis. This website is updated very frequently. He has finished his 4th and final Lu-177 treatment as part of the study conducted by Prof Harvey Turner at Fremantle Hospital WA with reasonable good results.

Photo: Eric & Leonie Gully

Singapore



NEW [CNETS of Singapore](#)

Carcinoid & Neuroendocrine Tumor Society is an association of patients, caregivers and physicians,

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promoting better understanding of carcinoid and neuroendocrine cancer, a relatively rare disease which is poorly understood and is often misdiagnosed.

About CNETS Singapore

The association was formally registered on 9 April 2009 (ROS Number 2039/2009). The founders of the association are Dr. Paul Ho, Lam Wei Choong, and William Claxton. Founding members include local and foreign patients, and many prominent Carcinoid NETs specialist physicians in Singapore.

Sweden

- [Carpa](#)

This Swedish carcinoid support group site contains many easily understood articles by some of the world's foremost carcinoid/NET specialists.

[Diagnosis midgut carcinoid by Agneta H-Franzén](#) (A patient's perspective)



[support.jpg](#)

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