



TELL YOUR STORY: Gary Murfin, PhD

Fall 2008: I had a colonoscopy and was diagnosed as carcinoid of the Ileum with mets to nearby lymph nodes, mets to my liver and to my sacral bone. I had no symptoms and no clue what this meant, but soon began to find out. I was age 66 at that time and had just retired. One month later: I had surgery to resect my primary and the lymph mets, but I had nothing done about the 8-10 mets originally suspected in my liver and the one suspected lesion on my sacral bone. My goal at that time was to learn more about this cancer.

I most likely started my journey with an advantage over many NETS patients since immediately after earning my PhD in (1975), I started a career in cancer research. The cancers I researched were the most conventional ones - colon, breast, lung - but my cancer research experience and the fact that I grew up in a family of doctors (dad, grandfather, great grandfather, uncle) gave me the tools to better understand and interpret research design and results AND to speak "Doctor."

I began researching my cancer so that I could develop a long-term treatment plan. I learned that many doctors knew very little about NETs or how to treat it. My first oncologist preferred the "wait and see" what happens approach and wasn't happy that I came to appointments armed with questions. I am not a "wait and see" kind of patient, so we had a mutually agreeable parting. Through my NET support group, I found a new oncologist who was not a NET specialist, but a smart, collaborative doctor who became a partner in my journey.

Spring 2009: I consulted with a noted liver surgeon specialist who was treating NETS patients in Omaha and another well-known NETS specialist from down New Orleans way. The treatment options presented to me by these doctors (more surgery and Y-90 spheres) were not bad, but they just did not seem to be the right choice for me since I had NETS outside my liver that would not have been treated. So I continued looking for the best long-term option.

Summer 2009: I found information about Peptide Receptor Radionuclide Therapy (PRRT), a treatment that had been available to NETS patients at various medical centers in Europe for nearly 20 years. The more I read, the more I thought this might be the right treatment for me since it was a systemic treatment that would deal with my sacral bone lesion AND my liver mets.

After evaluating the most active centers in Europe offering PRRT, I decided that Bad Berka, Germany was the best place for me because of the personalized medicine approach to treatment that tailors isotope therapy to the scope of a patient's cancer in terms of the size, number and location of the NETs.

July 2009: My wife and I consulted by phone with Dr. Richard Baum at the Zentralklinik in Bad Berka, Germany. Dr. Baum reviewed my case history and agreed that I was a candidate for PRRT, pending the outcome of a scan that was only available in Europe at that time. I secured a treatment date in mid-September for the Gallium-68 PET/CT and for the expected PRRT. This was done as a self-referral, but with the cooperation and support of my oncologist in Seattle. Since then, my wife and I have traveled to Bad Berka 5 times for the Gallium-68 PET/CT scan and evaluation. I have only needed one additional treatment in September 2011. At this time, we return annually and feel very fortunate that I am doing so well.

June 2010: I had the good fortune to attend a CNETS-Canada NETS conference in Vancouver, BC. This was an excellent conference with the likes of Dr. Warner from NY, Dr. Woltering from Louisiana, Drs. Odorisio from Iowa, Dr. Wolin from California (now in Kentucky), Dr. Pommier from Oregon, Dr. Granberg from Sweden and many other well-known Docs in the field. Among the presenters was a young Doc from Tennessee who was just making a name for himself in the NETS world, by the name of Dr. Eric Liu.

Based on Dr. Liu's presentations and my brief conversations with him at the Vancouver conference, it was very clear to me that this was a doctor with enormous talent and passion who was going to have much to offer to the NETS community as it continued to evolve. Following the Vancouver conference, my wife and I stayed in touch with Eric Liu even though I did not need NETS surgery. We saw him again at another CNETS-Canada conference in Ottawa in May of 2012. Once again a good number of distinguished NETS doctors, including Dr. Liu, gave presentations on many facets of the diagnosis and treatment options available and in the pipeline for NETS patients. It was clear that Eric Liu, a talented, smart and very likeable doctor, was headed for leadership among NET physicians.

Spring 2013: I saw Eric Liu as a patient. As part of the normal monitoring of my tumors, I was able to have a Gallium-68 PET/CT as part of the clinical trial – the first in the US - that Dr. Liu started at Vanderbilt. Unlike my Ga-68 in Germany in 2012, there was some progression in my liver tumors and my sacral bone tumor remained stable. I was very appreciative of the opportunity to be part of the trial and receive the professional opinion of Dr. Liu as part of my evaluation. Even though there was some progression, Dr. Liu and my oncologist concluded that I didn't need another treatment. They were absolutely right.

Spring 2014: I returned to Germany for restaging and evaluation with a sixth Gallium-68 PET/CT. The images from 2013 had identified 12-15 tumors in the liver. The 2014 scan could only find 4 tumors left in the liver. The 2013 and 2014 scans reported that my sacral bone tumor continued to be stable. So the basic conclusion from the 2014 Ga-68 scan was that I was

stable with some regression. That continues today. **As of October 2014 based on MRIs, there was more regression in the 4 liver tumors and the sacral bone lesion couldn't be found.** I have never been on Sando LAR or Lanreotide. Maybe someday I will be advised to take one of these meds, but for now I seem to be doing well and probably better than what would be expected for a 72 year old man with two cancers...Yes, in 2013 I was diagnosed with prostate cancer too and was treated in Seattle with beam radiation therapy. As I write this, It appears that the treatment was successful. This now leaves me free to focus on dealing with my carcinoid cancer.

It is my hope that Dr. Liu and the team at The Healing Net Foundation can make a big difference for NETS patients in their pursuit for meaningful information and contacts relevant to the diagnosis and treatment of Neuroendocrine cancers. There aren't enough experts in this field in the US and he is definitely one with a wonderful ability to relate to patients as a person as well as a professional. We've become friends, as well as partners in NETs. A last note, another NETs patient (Josh Mailman) and I collaborated on a website with information about PRRT, the Gallium-68 PET/CT scan and the ABCs of having PRRT at the Zentralklinik in Bad Berka, Germany. The URL for this site is prrtinfo.org.

The above story stopped in the spring of 2014. Since that time I had an MRI in the fall of that year. It found no progression and all was stable. In April of 2015, I returned to Germany for another restaging. The outcome of that Ga-68 PET/CT scan was no new tumors, target lesions were stable and some lesions in the liver had shrunk and some could not be found. The lesion on my sacral bone was hard to visualize.

The follow up to the Germany scan in April was an MRI in the fall of 2015. That scan result was the same as the Ga-68 scan – no new tumors, some tumors could not be found and some had shrunk. The report stated no evidence of bone metastases. I will get another MRI or check my bio-markers the spring/summer of 2016 and then return to Germany in September of 2016 for another Gallium scan. So far I am at 53 months out since my last treatment and counting.

Summer of 2016 - Did not get MRI, but instead did blood bio-marker tests for pancreastatin, CgA, 5-HIAA plasma and serotonin. All were somewhat elevated and showed upward trend, but not dramatic increases.

September of 2016 - Was restaged in Bad Berka with Ga-68 PET/CT scan. Results showed mild progression with some lymph node mets in area of sternum and in lower abdominal wall. Mets not large enough or widespread enough to warrant PRRT. Good news was that mets in liver are stable and some older mets could not be found on scan or on ultrasound. The one met on my sacral bone remained stable. I will be re-staged in Germany in September of 2017. I will do MRI to monitor situation in spring of 2017. As of now, I am over 5 years out since my last (#2) PRRT in 2011.

--Gary Murfin, PhD

Editor Note: Gary has is a member of the Healing NET Foundation Board of Directors and hopes to help our efforts to help educate primary physicians, oncologists, and other medical personnel on the front lines of cancer care about NETs.