

Lee Curtis

My personal odyssey through carcinoid began on April 30th 2001 when I went to my family physician, Dr. George Valley, to determine why I had a persistent red face with no apparent cause. My doctor gave me a few possible explanations, but suggested I see Dr. Paul Sayers, a dermatologist.

The dermatologist asked a lot of questions and finally suggested a 5HIAA test. It came back positive. I then returned to my GP to find out what it meant. He said I had “carcinoid”. He and his nurse were very solicitous. I thought, this sounds like carcinoma.

“Is this cancer?” I said. He replied that it was. He told me to see an oncologist immediately. I was on my way.

I met with my new oncologist, Dr. Robert Marschke, a few days later and learned he had only seen a handful of carcinoid patients in 25 years of practicing oncology. He told me I needed to consult with the experts at the world famous Mayo Clinic. I was off to see “The Wizard”.

A few weeks later, my wife and I were winging our way to Rochester, MN to see Dr. Joseph Rubin at Mayo. After what seemed like every medical test known to man, we asked the hardest question.

“Can you help me?” I asked. “I don’t know,” he said. “It will be up to the surgeon to decide.”

The following day, we met with Dr. David Nagorney a professor of surgery at the Mayo Medical School. Around Mayo, they call him “The Wizard”.

“It’s borderline,” he said, “but I’ll try.”

The next day, he removed most of my liver and a large piece of my small bowel which both had metastatic carcinoid cancer, along with my gall bladder and appendix, to which it often spreads. This, however, was just the start. A few days later I developed peritonitis, which required opening me up again. Then I developed a blocked liver duct, requiring a specialist to conduct an ERCP procedure at another MAYO hospital facility. I ended up spending 21 days in the hospital, much of which I fortunately can’t remember. After 30 days at Mayo, I came home to recuperate.

Unfortunately, after 6 months my disease progressed both in my liver and then to my bones. Dr. Marschke started me on interferon injections three times a week and two large sandostatin injections every month. The tumors and markers progressed slowly for four years with this treatment, under the care of oncologist, Dr. Diana Medgyesy, as Dr. Marshke had moved to Scottsdale AZ. During this time I also underwent six weeks of radiation treatments, twice a week, on my throat, which had also developed a dangerous lesion.

Through the carcinoid website, and with doctor Medgyesy’s help, we learned of Dr. Eugene Woltering, in New Orleans, a pioneering carcinoid researcher. We met with him in 2005; just 2

weeks before Hurricane Katrina destroyed his clinic and the hospital in which it was located. Again, after multiple scans and tests, we asked the question, “Can you help us?”,

“I don’t think so” he said, “but there might be someone in Houston who can.”

Houston? “Yes,” The only place in the country where this treatment is available.

He referred me to a colleague of his who had just started treating carcinoid patients with a new isotope called Induim 111, pentatretotide. In October 2005, after dodging Hurricane Rita, I arrived at Excel Diagnostic Imaging Clinic in Houston and met Dr. Ibrahim Delpassand. After 5 solid days of scans and tests, Dr Delpassand agreed I was a candidate for the isotope. Five days later I had the six-hour infusion. It was around this time that I realized how new this treatment is. I was only the fourth patient to have it since it’s approval by the FDA.

“Come back in three months and we’ll repeat the scans to look for any improvement and see if a second dose is warranted.” They said. In February 2006 we were back in Houston. Mixed results but at least encouraging enough to repeat the dose.

As this is being written, (mid March 2006) I am “stable”. We will repeat the tests in three months and hope. There is no third dose.

When I first began this journey, I was told my life expectancy was 2-5 years. I am now at 5 years and counting....and counting.

Lee Curtis, age 58

Ft. Collins, CO