



JAMES ALTON THOMAS INTERVIEW

*By David Caldwell
Clinical Research Communications Specialist
Benaroya Research Institute at Virginia Mason*

For many people, the path to joining a clinical research study begins with a startling diagnosis followed by a series of very heavy decisions. Fear, anxiety, disbelief and sadness are perfectly reasonable emotions to feel when faced with the reality of an incurable condition.

However, to hear James Alton Thomas describe his experience, one might think they were listening to the memories of a proud parent rather than a cancer patient. He consistently uses the words *grateful*, *love*, and *magic* when reflecting on his journey. “As a child I always thought I’d make a wonderful spokesperson,” laughs James. “Of course, I didn’t know it would be for clinical research. But here I am. And I was right.” He erupts into laughter and then adds, “I am thankful every single day for having cancer. And I am here because of a clinical trial.”

James’ journey from patient to clinical research advocate began thirty years ago when, at the age of 24, he was diagnosed with HIV. As a young man in Monterey, CA, he witnessed numerous friends bear the same diagnosis in addition to the often-unpleasant side effects of AZT, the only available treatment then.

“I declined AZT after watching my friends get really sick,” James says. He then adds, “I endured a lot of abuse in my life. And I learned that responding with anger only allows an abuser to retaliate against you. So, I told HIV, “We need to take this journey together,” and I decided to love it and invite it in.” He says among that original group of friends he is the only one still alive.

For decades James was the picture of health. He became a hair dresser and, in 1996, followed a lover to New York. He earned a degree in Horticultural Science and took a job with an Orchard near his current home in Greenville Township. However, all of that changed in 2014.

For about a year, James had suffered from a series of stomach aches which his doctor attributed to H. Pylori, a gastrointestinal bacterial infection. “I just thought I was just going through a new phase in my life,” he jokes dismissively. By May of 2014, the treatments, however, weren’t working and James’ condition worsened to the point he was unable to eat any food without vomiting. “At that point,” he says, “I knew what it was.”

An endoscopy at Memorial Sloan Kettering confirmed James’ intuition: a tumor in his abdomen applying significant pressure on his stomach. The final diagnosis was diffuse large B Cell Non-Hodgkin Lymphoma.

As David Aboulafia, MD, Hematologist/Oncologist at Virginia Mason in Seattle and a Principal Investigator with the AIDS Malignancy Consortium (AMC) explains, James’ diagnosis was not entirely unexpected. “Advances in treatment of HIV/AIDS have multiplied in an unprecedented and truly remarkable fashion,” says Dr. Aboulafia. “With effective antiviral medications people living with HIV are now living a normal lifespan yet they are still susceptible to certain cancers. Cancer of the lymph nodes, also called lymphoma, is the most common cancer to be diagnosed in this group.”

James’ lymphoma specialist was Ariela Noy, MD. Her goal was to provide him with the most effective treatment which included the opportunity to participate in an AMC clinical study for patients with HIV-related lymphoma.

James began a complex treatment regimen in which he received intravenous chemotherapy infusions in combination with the drug vorinostat. Because treatment for cancer does not work well without treating the HIV infection, he had to begin treating his HIV for the first time. During the study, James was treated in an outpatient infusion center for five consecutive days at a time - a schedule that was repeated every three weeks. The treatment restructured his life, yet he continued to work up to 80 hours a week at the orchard whenever he was able.

In a rare moment of somber reflection, James admits the process wasn't always easy. "So many patients were frustrated and angry. I saw people become smaller lashing out against their cancer, even calling it names. I saw patients having to take care of their partners who were also angry from their lack of control."

James' own partner struggled to be present during the treatments. "I didn't need to burden him with this," James offers, kindly. Though difficult, the process allowed them both to grow deeper into their relationship.

"As a cancer patient, you come to represent other people's mortality" James offers. "That can be very scary. It can be uncomfortable. But breathe into that discomfort. Ask yourself 'what is there to learn from this?'" Through a soft laugh he says, "Remember what I said about anger?"

After four very intense months James completed his study. Yet five months later, during a routine follow up visit, he discovered his lymphoma had returned.

"The truth is," James says, "You can never know the outcome of your cancer treatment. But as a study participant, you have so many more people coming to care about you than you would as a standard patient. Everyone wants to help you get to the other side. It's incredible."

With the support of his care team, James enrolled onto a second clinical study. James remembers Dr. Noy calling him from atop a mountain while on a skiing vacation to tell him he had qualified for the study. He exclaims, "It was like getting a golden ticket!" Each new treatment involved three days of inpatient chemotherapy in addition to radiation and an oral drug called Ibrutinib. After another four months of chemotherapy James completed the study. His lymphoma was finally gone.

"I am so lucky" James reflects.

Today, James is choosing to live his life "like a leaf in a stream." He plans to work with sick people helping them connect with their spirit through dance yoga. "Everyone is a dancer," he says. There's even talk of writing a children's book about cancer. "Cancer can help you find that secret power within you."

When asked what advice he would give someone considering clinical research, James takes a deep breath and pauses. "Clinical trials are like dreams for both patients and researchers. If you are willing to step into your critical role as a participant, you can help manifest these dreams into reality. This may be the only time in your life that it is all about you. So, receive the love being sent to you - even from total strangers. Believe in the experience. Surrender control. Allow room for magic and let the miracles happen."



For more information on HIV-related cancer clinical research, please visit the [AMC website](#) and www.ClinicalTrials.gov.