

Seabury Road

Fred Thaler

Some of you know me as Aaron's dad, some as Uncle Fred, Doctor Thaler, Doc or Fred. But nothing beats being known as a Badass Mofo.

Alalia and I feel that it is important for Aaron's friends and family, and our friends, and our coworkers and our neighbors to know how bravely Aaron lived his life and how he died with dignity, surrounded by much love in the privacy of our home.

The story of this journey will be presented in 5 acts. This is the story:

Before the curtain opens, Aaron, a free spirited 20-year-old Wesleyan student is seen in the neurologist's office in South Africa where he is studying post- Apartheid politics. Dr. Staub, who Aaron described to me as a very sweet and most diminutive gentleman, tells him that his seizures are due to an inoperable brain tumor.

In Act One we meet the Wizard. This role is played by Dr. Cosgrove, a neurosurgeon at Massachusetts General Hospital. Aaron hits it off with this frank speaking doctor right from the start when it is quickly established that they are both avid sports fans. The Wizard says that he had already reviewed the MRI images that were sent over from South Africa and that he has booked Aaron for surgery the following week. When he sees my disbelief, he replies that the tumor is indeed inoperable for most surgeons. But that he is the one person in the world who can handle it.

In Scene 2 The Wizard is hailed for his mastery by the MGH Tumor Board. Aaron has a brilliant recovery. Dr. Batchelor, Aaron's neuro-oncologist, deems the surgery a "tour de force".

(I remember thinking that I finally got some use out of high school French.)

Aaron subsequently undergoes 36 radiation treatments. Meanwhile, Aaron participates in an experimental oral chemotherapy program that continues for a full year. Aaron misses the second semester of his junior year. He attends Boston University summer school and returns for his senior year at Wesleyan, all the while continuing treatments.

I am pretty certain that few of Aaron's friends knew what he had gone through. Partly because Aaron never wanted to be defined by the illness and partly because many juniors had been abroad while he was receiving treatment in Boston.

In Act Two, Aaron graduates with his class. After graduation, he travels with family and friends for 7 months. He goes to Africa, Ecuador, Israel, and all over America. On Valentine's Day, 2006, Aaron moves in with my dear friend Mary Birdie in the Bay Area before launching an independent life in San Francisco that continued until just 2 months ago.

In San Francisco, Dr. Butowski monitors Aaron's tumor at the University of California San Francisco Medical Center. Aaron worked for Lutheran Social Services as a case manager for disabled HIV/Aids adults. I was his invited guest at the annual Christmas dinner and met his clients who absolutely adored him. It would be an understatement to say that many of Aaron's clients were profoundly down on their luck. He actively volunteered for the SF Jazz festival, played in a soccer league, played guitar, learned to cook and relished the great variety of ethnic cuisine in the thriving Mission District where he lived.

There were days over this 3 and a half-year period where things seemed pretty normal.

However, in September of 2009 the Wizard reappears, this time in the guise of another brash neuro-surgeon, Dr. Berger at UCSF. Although Aaron is feeling well, there are concerns that the tumor is growing toward his language center. Dr. Berger delicately and successfully removes more tumor tissue while assessing Aaron's language function using advanced brain monitoring equipment.

I was so incredibly impressed by the number of friends who visited Aaron in the hospital on the evening following his surgery. This reaffirmed for me that Aaron had a strong network of support on the West Coast. First and foremost among his friends was Colin, who often went to Aaron's doctor visits.

Act Three literally starts with a ferocious storm on June 22nd of last year. On the East Coast of America, our property on Seabury Road is devastated by a microburst that punches two holes in the roof and nearly totals my truck. Alalia stopped tallying when the downed tree count reached 50. On the very same day on the West Coast, Aaron receives the devastating news that the tumor is growing again. We were literally off the grid for a day. It was the first and it was the only time that we felt that we were not there for Aaron.

Subsequently, Aaron underwent a variety of chemotherapy treatments including an experimental program for which he willingly volunteered, but tolerated very poorly.

In January of this year, Aaron was told that he had less than 4 months to live. Aaron told me that he knew that it would be best for him to come home to Maine.

At this point we are well into Act 4 when Dr. Cosgrove from Act 1 reappears as a flashback. This time he is not playing the role of the Wizard, but rather he appears as the Soothsayer.

I remember Dr. Cosgrove's words from 2003. He said that the tumor was "a bad actor" and that Aaron would have just 7 years to live.

And then, at this point in the Story, Dr. Cosgrove is transformed one last time. This time he appears as the Sage.

His last words to us in the MGH post-op waiting area went something like this: the key for Aaron was for him to find a way to live his life with meaning, purpose and caring. And for him to show people how to lead a dignified life when faced with an overwhelming medical condition.

And, as I look out and see his friends and family, and as Alalia and I read all the kind words from people from all corners of his life, we know that Aaron did succeed.

And now....and now.....we are in Act Five of our story.

In this last act, Aaron is back in Maine for 2 months. He travels to New York to see my dad one last time, he stays with Eric and Robyn and attends Doro's brother's engagement party and Peter's wedding. He reconnects with his East Coast friends from college and high school. He travels to Vermont to spend time with the Johnsons. He continues palliative chemotherapy up until a week before he dies. He gets visits to the house from Colin, Aileen, Jesse, Anjana, Ben, Bos, Kara, Larry, Joan, Taylor, James and our dear friends Chris and Alex.

In the last scenes of this last act, there are no Wizards. There is just his family, friends and the family dogs: Rico, Izzy and Sadie Mae.

Alalia and I decided that we would care for Aaron at home. At one point I asked Alalia if we were capable of doing this alone. I remember her looking up from the sink, saying matter of factly, "Freddie, if we can't do this, no one can." Yes, as Aaron said, his Mom is a Jersey Girl.

During the last week of his life, Aaron and I went to Fenway Park to see the Sox play (thank you Aunt Lizzie!). Thereafter, we went for daily drives and stayed in contact via texts with Colin and Bos. Aaron felt weaker and weaker and experienced language and memory difficulties that did frustrate him. We have since learned that he told his friends that he sensed that the end was fast approaching.

On the day before he died, Aaron showered on his own. I did help him floss his teeth but after doing the top row, he stopped me and said, "Dad, I'm good." He had Sushi for lunch. He watched the NBA play offs with his longtime friends, Taylor, James, Joan and Larry. He spoke with Colin and the other guys at the bachelor party in New Orleans and told them that he was sorry he had not been able to make it down.

And then he said that he was tired.

While we watched the ball game he marveled at Dice-K's skills after such an abysmal start to his season. Earlier in the morning he and Sasha had talked about her successful running of the Boston Marathon on Patriot's Day. Yes, Aaron maintained clear cognition throughout his life.

Before Aaron went into a coma, I asked him if he was good. He gave me a hearty thumbs-up and squeezed his Mom's hand.

Allowing Jesse, Sasha, Alalia, and me the opportunity to care for him was his final gift to us. He had one more gift to give, however.

After Aaron passed away at 9 AM on Easter Sunday, we bathed him and sat with him for 2 hours. We dressed him in a RemDawg tee shirt, jeans and super warm and colorful socks. Jeff Pelkey

took him back to Mass General one more time so that Aaron's last gift could be granted: Aaron donated his brain for research purposes.

And so, here we are.

For me, Aaron's illness and untimely death come as a cruel irony. 30 years ago, my life long friends and I lost a member of our inner circle, Vinny. Alalia and I stayed in touch with Vinny's dad until his passing several years ago. Mr. Vito enjoyed hearing about our careers, meeting our children, and reliving memories of his son.

Alalia and I hope that Aaron's closest friends will think of us throughout your life journies.

You are always welcome at our home on Seabury Road.

And now, I would like to introduce Aaron's brother, to you. Jesse is the pure intellect in the family. He is a theoretical physicist and professor at MIT. His field is High Energy Particles Physics and he dabbles Cosmology, the study of the whole universe.

Aaron jokingly referred to Jesse's field as "Theoretical Cosmetology."

Give it up for Aaron's brother, Jesse.