Behind the Fibrolamellar Foundation is a Family's Tragic Loss

By Kris Herndon

Last month, when First Selectman Fred Camillo designated February 26 as Rare Disease Awareness Day in Greenwich, he presented the official proclamation to John Hopper, the President of the Fibrolamellar Cancer Foundation (FCF).

The FCF is based here in Greenwich, and Hopper says that Greenwich resident Marna Davis is a driving force behind it. Davis's late son, Tucker Davis, founded the organization just before he passed away in 2010 at the age of 28, after battling the disease for 18 months.

Fibrolamellar carcinonoma, also known as fibrolamellar hepatocellular cancer (FLC), is a rare liver cancer. Often asymptomatic in its early stages, FLC can escape detection until after it has spread. This, combined with its rarity and its tendency to afflict adolescents and young adults without clear risk factors, makes it deadly.

Marna Davis, in other words, is uniquely aware of the challenges that face patients and caregivers confronted with a rare-disease diagnosis. And, like many who have survived a painful loss, Davis is determined to provide help, guidance, and resources to others facing the same struggle.

In a recent conversation, Davis described the FCF's mission: "To raise money, to fund research, to educate and to spread the word about fibrolamellar. To get the word out that there is work going on, the medical community wants to help patients and caregivers." FCF's website provides links to treatment options, updates on the latest research, a list of resources and support groups for patients and caregivers, and a list of ongoing clinical trials. There is also a link to donate and support the FCF's work.

Rare Disease Awareness Day underscores the paradox that while any given rare disease may affect only a handful of patients, there is strength in numbers. Twenty-five percent of all cancers are rare, and every pediatric cancer is rare. Yet an astounding one in ten Americans suffers from a rare disease.

The day that Tucker was diagnosed, he and his family first encountered one of the signature difficulties of fighting a rare disease: "There is no standard of care," Davis says. "Doctors cannot tell you, this is the treatment and this is what you can expect."

That can be bewildering, as patients and their families face high-stakes decisions about treatments.

"The day that things started to go awry for Tucker, we immediately went to a doctor and he said, you've got to go to the hospital," Davis recalls. "And over the course of that day, it was determined that we were dealing with a liver cancer."

The Davis Family. Photo credit: The Fibrolamellar Cancer Foundation

"He said, 'Mom, I hope we find a cure in my lifetime, but if we don't, you've got to find it for me.' And I said: ' We will.'"

Soon they were headed to Sloan-Kettering: "In Greenwich, we are so fortunate to be close to New York," Davis says now. "We're close to a major medical center, and our doctors knew that and sent us there."

In Tucker's case, that first day presented a decision whether to have a filter placed in his kidney to treat a blood clot that had been causing problem. That was the first of many twists and turns, all made more challenging by the dearth of information about this rare condition.

"There was a boy whose cancer seemed to go into remission with this combination of drugs," Davis recalls now. "But there were no clinical trials, you know, and there was no data. This was a one-off situation."

Making matters worse, one medical team wasn't comfortable giving Tucker that treatment due to the toxicity of the combination of drugs, while the Sloan-Kettering team was. "They said they'd monitor him closely," Davis recalls.

It's a dilemma many, if not most, cancer patients have faced: "There's always that balance between toxicity and treatment: how much can a body take? Is the chemo going to kill you, or is the cancer going to kill you? There's always that question with all cancers," says Davis.

Such decisions can be made based on data, trials, and comparing the outcomes of similar cases. But, in Tucker's case, there were only a handful of cases worldwide to compare.

Fibrolamellar often attacks the young. Tucker was no exception: "He was 26 when he was diagnosed, 28 when he passed away." All pediatric cancers are rare, and even when they do present symptoms, doctors may not think of screening for cancers in young patients. "You think, they don't get cancer," Davis says. "But they do."

"I have found in this whole journey -- we now know doctors all over the country. We know where the doctors are who think outside of the box and are willing to go the extra distance with a patient to try and help them "

"We really want to come up with a standard of care right now," Davis says. "Surgery can be curative. But that's if you get it before it spreads."

When Davis speaks about the work FCF has made possible, her voice lifts, and you can sense her optimism: "We have two clinical trials that have just started, this year, during a pandemic. Wow!" Davis says. "We have so many research papers written in top tier medical journals from the last ten years. We insist on collaboration, because collaboration speeds results. We are kind of like the mouse that roared; we put fibrolamellar on the medical map."

Davis says FCF's struggle is the same as other rare disease charities: "We all have some similar issues, being small. Some of these rare disease foundations are just a few people, all volunteer. There is a lot of talent locally, a lot of support and a caring community."

"He said, 'Mom, I hope we find a cure in my lifetime, but if we don't, you've got to find it for me.' And I said: 'We will.'"

For more information on FCF, please visit www.fibrofoundation.org.