‘We’re here!’

Connecticut Brain Tumor Alliance wants to help patients and caregivers

by Lynn Woike
Editor

Courtesy photos

Danbury Mayor Mark Boughton conducts a roll call of brain tumor survivors at this year’s 5th Annual Path of Hope presented by Saint Francis Hospital and Medical Center.

Two women, both diagnosed with brain tumors within seven months of each other, along with five of their family members who took care of them, formed an alliance that now provides the support that wasn’t there for them 12 years ago.

Tracey Gamer-Fanning of West Hartford was 35 in 2006 when she was diagnosed with a malignant brain tumor, underwent brain surgery and was told she had a three- to five-year life expectancy. When she came out, paralyzed, she expected to be embraced by a supportive, loving community of others who had brain cancer, much the same way those with breast cancer or heart disease are supported.

Jennifer Pace of Simsbury was diagnosed several months earlier with an anaplastic astrocytoma brain tumor. Her surgery was followed by radiation and chemotherapy.

The mother of her neighbor, Stacey Mairano, was diagnosed with Stage IV glioblastoma in 2003 and died 11 months later. Mairano and her sister, Kim Hodnett, had cared for their mother and had met Gamer-Fanning. They introduced her to Pace.

Together with Pace’s husband, Andy, and Mairano’s husband, Ron, they founded the Connecticut Brain Tumor Alliance Inc. in 2007, a 501(c)(3) to provide hope and support to the brain tumor community.

“There’s a lot of different organizations around the country, but I think we’re the only one completely formed by patients. Our original board was all patients and caregivers,” Pace said.

Ron donated office space at his business, Paragon Insurance Holdings in Avon, while a post office box in West Hartford became the mailing address.

The group’s first event was a golf tournament.

Since then, they have raised more than $2 million with a wine dinner at the Mark Twain House, a comedy night, trivia events, a gala and Path of Hope, a 5K walk, run and family-fun event in Fairfield begun five years ago. The event, which draws about 2,000 participants and supporters was held September 29 this year and raised more than $165,000.

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There have also been donations from others, including a nurse affected by brain tumors in New Haven who raised $3,000 with a raffle, and two sisters from West Hartford whose father was bass guitarist Dan Valente; they collected $1,600 with a performance by his fellow musicians to commemorate what would have been his 65th birthday.

The money raised has been used in various ways, including funding brain tumor research and nurse navigator positions to guide patients through this diagnosis, to purchasing equipment for hospitals, and setting up patient assistance funds at hospitals throughout the state to pay for things such as basic living expenses to transportation to receive treatments so that patients and their caregivers can focus on receiving the care they need. “We can’t help people financially directly. They need to seek out the patient assistant funds at hospitals,” said Hodnett, the organization’s secretary.

“I think we’ve done a good job,” said Pace, board president. “I’m sure there’s always going to be more need than we can meet, but we’ve done a really good job to allocate enough funds to sustain the programs.”

While the money is important, CTBTA offers something perhaps even more valuable: real life experience from brain tumor and brain cancer survivors and their caregivers.

“Most people who are involved in the CTBTA have been affected as a patient or indirectly as a caregiver or family member. I think only one or

Nearly all members of the board of directors of the Connecticut Brain Tumor Alliance are survivors or their caretakers.

two people now have not been affected at all," said Gregory Shimer, who serves as the organization's co-secretary.

"The key thing about it is they've continually stepped up. They've kept stepping up. They don't just write a check and walk away. They help other patients. They talk to other caregivers," he said.

Executive Director Christopher Cusano said, "We've all been touched by this in some form or another. We are intimately connected to this cause and are very passionate about it, which is unlike other nonprofits and groups that dedicate themselves to doing what we do – raising awareness and research dollars."

In 2008, he had three surgeries for a brain tumor, one in 2012, radiation in 2013 and a fifth surgery in 2015. "Although mine was benign, I was left with severe cognitive difficulties. I was in law school at the time. I was told, 'You're not going back to law school. You will not graduate law school. You'll be reading Dr. Seuss books for the rest of your life.'

"They were wrong, thank God," he said.

"It was through severe persistence and perseverance that I was able to overcome all that adversity and get back to the point of graduating law school. I took the bar three times, but didn't pass. I worked for a law firm for 17 years until I came here. I felt a desire to give back and

Susan and David Lemkuil spend a moment with Dr. Michael Twohig and his wife, Marybeth Twohig, at the Gala of Hope in May 2017.

help others and then this opportunity presented itself and there was no better job. I wouldn't have had it any other way. This has all been a blessing in disguise for me," said Cusano, who began in July.

"So when someone's diagnosed and they pick up the phone like I did, [wondering], 'Who do I turn to and where do I go?' We want people to know that we're here to help them. That they can call us and we will guide them through this journey,"he said.

"The first family we helped were the Lemkuils out of West Hartford, and then they joined," Shimer said, adding, "They've been invaluable."

Susan Lemkuil, a brain cancer survivor, is on the board of directors. Her daughter, Emily, organizes Teen Trivia Night at Kingswood Oxford School. Previously, Emily's two brothers conducted the trivia events at the school.

A Gray Ribbon Club was begun in 2016 for those with a brain tumor and those who love them.

"One just got her ability to speak back and to drive. We're talking about a woman who was down, down, down. She's pulled herself back up and now she's pulling other people back up with her. And that's so super important. I think that's honestly what makes us so different," Shimer said.

Pace said, "Our main thing is for people to understand they're not alone. We're here to help."

"Whether you're diagnosed with brain tumors or brain cancer, we're all inclusive. We're here to help. Both malignant and benign, pediatric also," Cusano said.

"Cancer itself is intimidating. It's an intimidating cancer because there is little to no progress. There is little to no difference. It is stupid scary. There are survivors of breast cancer. There are survivors of lung cancer. There are survivors of all types of cancer. There are rarely survivors of brain cancer," Shimer said.

"It's not easy to lick. As it grows, it affects your emotions, it affects your cognition, it affects your ability to move, it affects your ability to move your bowels. … Even if it's a small, little sucker, it still affects you in major ways. It all depends on where it is. My wife's is around her motor stem, so she's lost all her movement in her left side."

Location matters, Hodnett agreed, explaining, "My mother's was millimeters from her brain stem. … Your brain does everything for you. It took her before it took her."

Pace said the standard care for brain tumors is surgery. If it's cancerous, then radiation and chemotherapy are used as treatments.

"It's been that way since 2004. So here we are in 2018 and they haven't made any major advancements in standard of care treatment for a really invasive brain tumor," Pace said. "We want Connecticut to become a center of excellence for brain tumor care. In our efforts to do that, we have partnered with hospitals throughout the state."

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It's difficult to develop a drug to combat brain cancer because it would be expensive and only a small percentage of people need it, she said.

"Even though they say there's a smaller percentage of people who have brain tumors, to those that have them, it's a challenge to survive and to live."

Hodnett said, "We started because we wanted to help those people" and the people who love them.

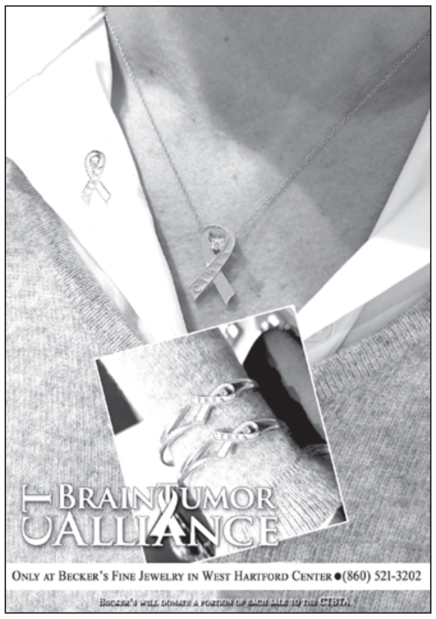
Shimer noted there are 13 ambassadors around the state loosely connected to the alliance.

"It's not easy for us to get down to Mystic. We have a group down there acting in our behalf. We have people in Vernon, Torrington, Hamden, Fairfield County," he said, adding, "We're always looking for more."

Soon those diagnosed with a brain tumor will be wrapped in comfort, as Gamer-Fanning wished she was 12 years ago.

"A recent $2,500 grant from the Newman Foundation is funding an important new piece of our patient outreach program," Cusano said. "Three hundred soft gray blankets, embroidered with the CTBTA logo and gray ribbon for brain tumor awareness and community, will be made available to medical teams to give to brain tumor patients, along with a brochure about the alliance, at the time of diagnosis, at the first follow-up consult or at a later appointment.

Sarah Quirk, whose father died of a brain tumor, made this gray ribbon cookie. Gray is the color of brain tumor awareness.



Becker's Jewelry designed a bracelet, necklace and pin specifically for the Connecticut Brain Tumor Alliance, which receives 20 percent of the gross proceeds from sales.

"The intent is to embrace the patient – literally and figuratively – with the warmth and support of the CTBTA, and provide something they can use again for comfort during treatment." **WHL**

For more information, call 860-264-5776, email info@ctbta.org or visit ctbta.org.