

Searching for a cure



Jody Desserich with granddaughter Elena Desserich, shortly before Elena's death.

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Elena water skis on Tellico Lake during a visit to her grandparents. At top, Elena at the Yacht Club.

Local couple, Tellico clubs, work to eradicate deadly childhood cancer

BY VICKY NEWMAN
FEATURES EDITOR

For Loudon County residents Jody and Dennis Desserich, becoming grandparents truly was a grand, joy-filled and life-altering experience.

Grandparenthood soon coincided with that point in life — retirement — when they would have plenty of time and energy to love, nurture and spoil their grandchildren.

When the Dessericks moved from Ohio to Tellico Village in 2006, they looked forward to having their grandchildren come from Cincinnati, Ohio to visit.

They had no inkling that their first grandchild, an adorable girl named Elena Desserich, would be making a “bucket list” by the time she was 6 years old. They could not anticipate that before Elena reached 7, she would be gone.

And, although Elena would inhabit the world a comparatively brief time, they could not imagine the enduring impact that their small grandchild would make on the entire world.

“It is amazing what this little girl started,” says Jody Desserich. “It’s what we call the Elena Effect,” Dennis adds.

It had started suddenly and unexpectedly. Two days after Thanksgiving, 2006, Elena began having headaches and difficulty speaking. The next day, she could not lift her right arm.

The phone call from their son, Keith, brought devastating news. Elena had been diagnosed with an incurable brain tumor on the center of the brain stem.

Instead of making holiday preparations, the Dessericks headed back to Ohio. They would spend much of the next seven months waiting for updates, driving to children’s hospitals for radiation treatments and trying to make their granddaughter’s final wishes come true.

Several unplanned and unexpected things happened during that six-month period that would change everything and bring a lasting impact.

First, son Keith started a blog to keep family members apprised of what was going on in the family’s lives, and to help Elena’s younger sister Gracie remember her sister.

Secondly, the Dessericks reluctantly became lay experts on oncology. They learned that the type of cancer Elena suffered was called DIPG, or Diffuse Intrinsic Pontine Glioma, the worst brain cancer monster that exists. A high-grade, malignant, tumor, it arises in the glial (supportive) tissue of the lowest, stem-like part of the brain, which controls many vital functions. Diffuse pontine gliomas account for 10-15 percent of all childhood central nervous system tumors.

They also learned that funding for pediatric cancer research has decreased every year since 2003, and currently is at \$26.4 million, compared to \$584 million in 2006 for breast cancer.

“The trouble with this disease is it affects the youngest,” Jody says. “We want a cure, and researchers think if they find a cure for this one, they will be able to cure not just brain cancer, but all kinds of cancer.”

Less than 10 percent of children with DIPG live longer than 18 months past diagnosis.

“We did not accept that. We were in denial,” Jody says. “We knew Elena would be the exception, the one who beat it. We had to have that hope.”

While Jody and Dennis Desserich never accepted that the disease would claim their granddaughter’s life, they watched as it progressed, and eventually robbed Elena of the ability to speak.

Elena, attempting to entertain herself, drew and painted pictures. She spent hours penning little notes to each member of her family, and hiding them in places where they would be discovered later.

When Elena no longer could walk, sister Gracie would become complicit, helping her hide them — between stacks of sheets

and towels in the linen closet, in sock drawers, or at the bottom of jewelry boxes.

Jody Desserich treasures the notes Elena left behind for her.

The hope for healing was eventually replaced by desire that Elena would no longer suffer.

She died in August 2007.

The notes and Keith’s journaled blog entries were compiled into a book about Elena, called, “Notes Left Behind.” Harper Collins published the book in paperback Nov. 1, 2007, and sales quickly skyrocketed. “Over a half-million copies worldwide sold,” Jody says. “It was huge.”

“Notes Left Behind” was a best-seller in Japan, China, and Australia.

Inspired by the things they learned about DIPG and the lack of funding for pediatric cancer, Keith and wife Brooke decided to start a foundation, a 501 (c) (3) not-for-profit, called The Cure Starts Now. The proceeds from “Notes Left Behind” go to the foundation.

Soon The Cure Stops Now jumped the ocean. There are now 19 chapters worldwide, working together to find a cure for pediatric brain cancer, and eventually, all cancer.

So far, the foundation has raised about \$1 million in funding for research, and any protocols showing promise will be considered as a candidate for grants.

The success of The Cure Starts Now is just another indication of what Dennis Desserich calls The Elena Effect.

“This is not a memorial or a tribute to Elena, but for all children who are suffering,” Jody says. “She was the inspiration.... We can’t let this go unanswered; we have to fight this, and pick ourselves up. We have a purpose. We want people to become educated and understand this disease. We want awareness, and it has been an amazing phenomenon.”

Elena’s story strikes a chord with many people, and many fundraising events have been staged. Elena’s art work has hung in a Cincinnati Art Muse-

um next to a Pablo Picasso painting.

A specialty limited edition ice cream flavor, Graeter’s “Elena’s Blueberry Pie,” for which a portion of proceeds is donated to The Cure Starts Now, became one of the company’s more popular flavors. Its sale continues. “You can buy this ice cream in Maryville,” Jody says.

Shortly before her death, Elena visited Tellico Village and fulfilled some wishes for things she wanted to do.

Now, two Tellico Village clubs, Tellico Riders and Village Vettes have joined forces in the battle to find a cure for pediatric brain cancer.

For the second year in a row, the club members contributed their best recipes to publish a cookbook.

The “Taste of Tellico Volume 2” will feature all types of main dishes. The cookbook is the second in a series of cookbooks. The first “Taste of Tellico” appetizer cookbook, was published in 2009 and was a tremendous success, Jody says.

The cookbooks went on sale Sept. 1 and are available through any member of the clubs, or by e-mail: jody.desserich@thecure-startsnow.org.

The books also will be available in October and November at the Yacht Club lobby prior to various club meetings, just in time for holiday gift giving.

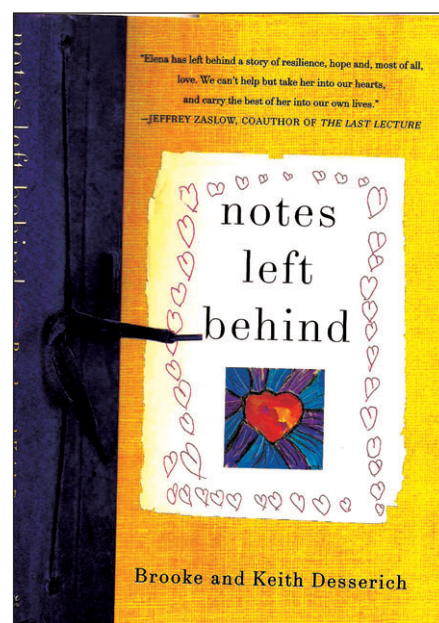
The proceeds from the sale of cookbooks will be donated to The Cure Starts Now Foundation.

Local sponsors Granite Transformations, The Grove Wine and Spirits and 72 Wine and Spirits have underwritten the printing costs, allowing 100 percent of book sales to go directly to the charity.

Over the past three years, Tellico residents have raised more than \$20,000 for The Cure Starts Now Foundation.

The cookbook’s recipes stand alone, representing the best of some fabulous cooks, Jody Desserich says.

But those involved believe the sweetest taste — that of success — will be the curing of pediatric cancer.

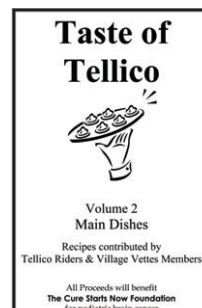


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The cover of “Notes Left Behind.” See www.notesleftbehind.com



At left, a note left by Elena for her grandmother.



Taste of Tellico, Volume 2, will be available at the Yacht Club in October and November. All proceeds benefit The Cure Starts Now.