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Section: Main

Page: A1

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Boy and hero are ready for the fight

Ben Stowell, 6, finds courage in cartoon ally as he faces rare cancer

By Anne Miller

Staff Writer

COLONIE - The stick figures on construction paper tell of an epic battle.

Our hero, Green Drakkoman, regularly vanquishes Evil Alien, explains creator Ben Stowell, 6, as he lays out the multicolored pages on his kitchen table.

In the latest installment, written just this fall, Evil Alien has returned to seek revenge on the Green Drakkoman's closest ally: Ben himself.

The line between fact and fiction blurs as Ben continues telling the story, running his hands across the pictures to explain the drawings, stepping back to personally demonstrate fighting poses (and barely missing the kitchen counter).

He doesn't like talking about the disease Evil Alien stands for - the bone cancer, excruciatingly rare in one so young, found in Ben's right arm the first month of first grade.

Speaking through comics helps Ben cope with the very real monsters invading him. Between 400 and 600 American children are diagnosed with osteosarcoma, a cancer of the bone, every year. Maybe six are under the age of 8. One of those is Ben, who was diagnosed this fall.

After three months of chemotherapy, Ben has surgery scheduled at Ellis Hospital Tuesday to remove the tumor and receive a new bone in his upper arm. He is the youngest patient his physician there, Dr. Matthew DiCaprio, sees. His parents call the medical team his weapons in this fight.

The power of Green Drakkoman has spread. All of Latham, it seems, is cheering for the hero and his grade-school buddy. More than \$45,000 has been raised to fund the fight. With any leftovers, Ben's parents hope to start a charity fund. They already have a name: the Green Drakkoman Foundation.

"Ben, and who his family is, and all these people - it's really unearthed an incredible beauty in our community," said Annette Trapini, Ben's principal at Blue Creek Elementary school.

Ben and his twin brother James were born after a struggle. Their parents, Stacey Gerard and Tim Stowell, needed in vitro fertilization to conceive. She stays home. He handles data and telecommunications for corporate firms.

This summer, Ben was just another comic-crazy kid.

"Captain Underpants is very popular in our house," said Stowell, referring to the kids book series.

But the week before Labor Day, at a cottage in Vermont, Ben fell out of bed every night.

The evening before starting first grade, his mom tried to help him into his pajamas. He couldn't lift his arm.

They visited the emergency room. The doctor saw nothing on the X-rays. A few days later, a radiologist who routinely reviews X-rays examined the films and had concerns.

Within two weeks Ben started chemotherapy.

"It's such an aggressive cancer, and for a 6-year-old to have it - that's unheard of," Gerard said.

And so Green Drakkoman found his latest nemesis.

The superhero and his pal are in for a heck of a fight.

Sarcomas affect the connective tissue - bones, muscle, fat - with osteosarcoma the most common, DiCaprio explained. Commonality is relative, though.

"It's really almost a one in a million or two in a million chance," DiCaprio said. He will perform Ben's surgery at Ellis Hospital in Schenectady.

In Ben's case, the operation will remove about 80 percent of his humerus bone in the upper arm. First, DiCaprio will remove the tumor, plus surrounding healthy tissue

for security. Next, he will take a human bone and ligaments from a donor and re place Ben's from just above the elbow to the shoulder.

The bone comes from the Musculoskeletal Transplant Foundation, which harvests bones from dead donors. Unlike vital organs such as a liver or heart, bones can be frozen for months, perhaps up to two years, DiCaprio said. For transplants, doctors request X-rays of available bones from the foundation and pick the best match, which is sent about a week ahead of surgery.

"It's easy in Ben's case - you just ask for the smallest one," he said.

Few children donate bones. The smallest, typically, is a petite female, DiCaprio said. Ben's new bone is already in a freezer at Ellis.

But the surgery is just one battle in a larger war facing the Green Drakkoman's army.

Ben will probably have six more months of chemotherapy, his arm in a sling for months, physical therapy. He might have to wait a year or two before joining his brother for soccer again. "There's a lot of his childhood taken away by this treatment," DiCaprio said.

DiCaprio said 80 percent of osteosarcoma patients live at least five years - a good prognosis.

"This is the best reconstruction for Ben to get back to the most normal lifestyle he can, and that's the goal," DiCaprio said.

The surgery is expected to leave him with a permanently shortened right arm.

"He'll be like Nemo, that little special fin on the side," his mother said.

When James wanted to cheer up his hospitalized brother, he donned a pirate scarf, a Stormtrooper costume and buck teeth, carried a whoopee cushion. At home, Ben scarfed yogurt and argued with his brother, about what only they knew - "yes I am", "no you're not," "yes I am." The only sign of illness was Ben's bald head.

At first, the family was reluctant to accept help. Ben's care wouldn't bankrupt the family. Tim Stowell wanted to say no.

But one morning, he read an article about strangers giving money to the families of Amish girls involved in a school-house shooting. A community leader said they do not

accept charity - but if strangers are so determined to help, he can do nothing but humbly accept.

At that moment a friend arrived to discuss a fundraiser.

Stowell stopped declining.

Last Sunday, 1,700 people bought dinner from Carrabba's Italian Grill, with all proceeds going to the Ben Fund.

On a family blog, Stowell details the latest exploits of Green Drakkoman, Ben, and his weapons in this monumental fight.

Fans fill a virtual guest book. Like the women's water polo team from Siena College, who met Ben in the hospital. A friend of a player wrote: "My uncle is also being attacked by an evil alien - his alien is attacking his lungs, so I'm really glad to hear about the Green Drakkoman and all the great work he's doing."

Factbox:

How to help

Information about the Musculoskeletal Transplant Foundation, including how to become a donor, is available at <http://www.mtf.org>.

Further adventures of the Green Drakkoman, as told to Tim Stowell by Ben Stowell, appear at <http://www.greendrakkoman.com>.

Donations for Ben can be sent to: The Ben Fund, c/o Blue Creek School PTA, 100 Clinton Road, Latham, NY 12110