

TOMMY STRONG

DOWNTOWN

Ramsey

A
GRIDIRON
STORY
HANNAH
NOKES

THE
**FITZPATRICK
FAMILY** Strength,
Courage &
Grateful Hearts

**POWER
PLAYER**
Devils' TV Voice
**STEVE
CANGIALOSI**

DECEMBER 2017



#TOMMSTRONG

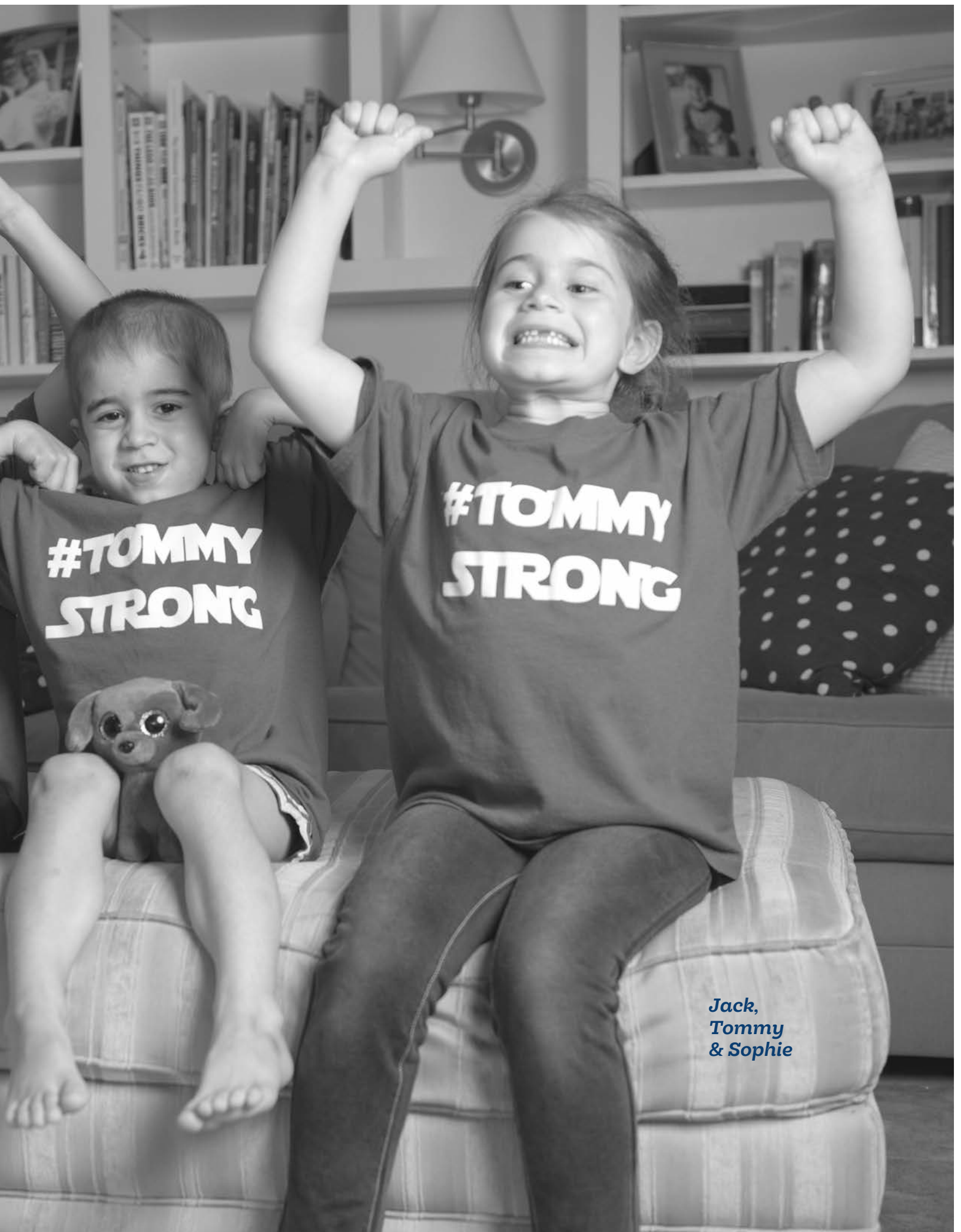
Little Tommy Fitzpatrick has endured a year of surgeries and chemotherapy, but the love and support of his parents and siblings, and the entire Ramsey community, has provided uncommon strength.

INTERVIEW
Lauren
DePaul
Schreiber



Kat
Yannalfo





*Jack,
Tommy
& Sophie*



WHEN 2017 BEGAN,

the FitzPatricks had no idea they were about to find out the unimaginable—the youngest member of the family, four-year-old Tommy, had a rare and aggressive brain tumor. Now, Christine and Andrew FitzPatrick, and little Tommy and his siblings Jack (8) and Sophie (6), have invited us into their Ramsey home to tell their story, to reflect on the past year and to express their gratitude for the tremendous support they have received along the way.

DOWNTOWN RAMSEY: When did you first realize something was wrong?

ANDREW: It all began last January, right after Tommy turned four. He had two vomiting episodes over the course of a few weeks. It was the winter—the time of year everyone is sick—so we didn't think too much of it. He recovered quickly and went back to school. The third time it happened was on a weekend. He started complaining of neck pain and that he had a headache. We had been in touch with our pediatrician throughout these episodes and he told us to go to Hackensack Hospital to see what was going on. That was Saturday, Feb. 18.

What happened when you got to the hospital?

ANDREW: They decided to do a CAT scan because Tommy kept saying his neck hurt. As soon as they came out and looked at us, we knew the news

FROM THERE WE WENT STRAIGHT UP TO BOSTON CHILDREN'S HOSPITAL.

was bad. Within 15 minutes, the pediatric neurosurgeon was there. The CAT scan showed that there was a mass on Tommy's brain, but the doctors couldn't tell how extensive it was. The mass was obstructing the way the fluid was supposed to drain from his brain. The pressure was building and the situation had become very dangerous. We were told he needed to go in for emergency surgery.

It must have been terrifying.

ANDREW: It all happened so quickly. We didn't even have time to ask any questions. After the surgery relieved the pressure with a shunt, and while Tommy was still under anesthesia, the doctors sent him right for an MRI to get a better look at what was going on in his brain. The news got worse. They saw a tumor that was much more massive than they had first thought. The tumor started in the back of his head, by his brain stem, and went all the way to the front. The Hackensack team was amazing, but they told us Tommy should go someplace that specializes in these kinds of complex pediatric cases. Tommy spent a week in the Hackensack ICU and from there, we went straight up to Boston Children's Hospital. Dr. Liliana Goumnerova, a renowned pediatric neurosurgeon, was going to take Tommy's case. We hadn't been home since we took Tommy to the hospital on Feb. 18, and we wouldn't be back home again for a while.

While you were with Tommy, what was going on at home?

CHRISTINE: Everyone stepped in to help. Our family was amazing. My mom came to stay with Jack and Sophie so that they could keep going to school. We hadn't lived in Ramsey that long at that point, and Jack had just started at Hubbard School. Sophie was in preschool at St. Elizabeth's in Wyckoff. People from both schools rallied to help Jack and Sophie get to and from school every day, and get back and forth to all their activities. Our friends, and even some people we had only met a few times, stepped in to help anyway they could. It was a community effort from the very beginning.

Meanwhile, what was happening up at Boston Children's Hospital?

ANDREW: Dr. Goumnerova said the best course of action would be to try to resect the tumor as much as she could with surgery. Tommy's first surgery lasted about 12 hours and it focused on the portion of the tumor located on the brain stem. She was able to remove about 50% of that tumor. A week later, she went back in to try to get the tumor that was in the front. After about five hours, she came out to tell us that she did all that she could. She told us that tumor was wrapped around nerves in such a way that his ability to function would be compromised if she kept going. It would have left him with deficiencies from which he might not recover. The next course of action would be chemotherapy to try to shrink it, then more surgery. In the meantime, we waited for the pathology reports to come back.

What were the results?

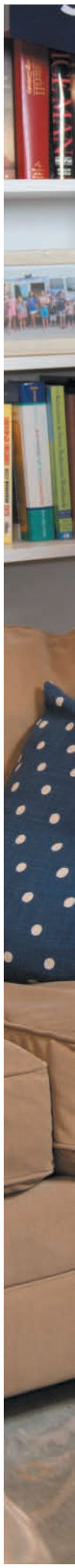
CHRISTINE: We found out that the tumor was an Ependymoma Grade III, which unfortunately was very aggressive and rare. The results were shocking to everyone. The tumor had been growing in an area of the brain that affects balance, fine motor skills and cognitive ability. And yet, there were no red flags in any of these areas. He was behaving like a typical four-year-old boy. There was no other way of knowing what was happening in his head.

Were you in the hospital with Tommy all day long, every day?

ANDREW: Yes, we would be at the hospital all day with Tommy. The neurosurgery team would come in every day at 6 a.m., and all day long doctors would be in and out doing tests. We had a hotel room across the street, just so we could run back and forth to shower, and not have to go far. We didn't want to be more than a few minutes away. This was downtown Boston and the hotel we were staying in was very expensive. When it came time for us to check out, we found out our room had been paid for. We learned later that a "dads" group from St. Elizabeth School, of which I was a part, paid for the room. They did it without us knowing.

What an unbelievably kind gesture. What happened next?

ANDREW: At that point in time, after so much surgery and time in the hospital bed, Tommy





IT WAS TIME FOR A NEW PLAN. THE CHEMOTHERAPY WASN'T WORKING

could barely stand. The doctors felt he needed some time to heal and make his body stronger before starting chemotherapy. We were moved to Spalding Rehabilitation Center in Charleston for psychical therapy, to help get Tommy up and walking again. The surgery also impacted Tommy's ability to swallow so he went through speech therapy, too. When we were done there, we went home to New Jersey. It was the first week of April. Our team at Boston Children's Hospital worked with the oncologists at Hackensack to make a plan for his chemo treatment.

You must have been happy to be back in New Jersey but, of course, not looking forward to chemotherapy.

CHRISTINE: The first round of chemo was very hard on him. He was very sick and lost his hair. It just really wore him down. He was so lethargic. Three weeks later, we went back in for the second round. On the first day, we noticed his breathing was irregular. By chance, our pediatrician was at Hackensack doing his rounds. He came by to see Tommy and he knew that something wasn't right. The results of the CAT scan showed that the hydrocephalus had returned and that the tumor started to grow again.

ANDREW: It was time for a new plan. The chemotherapy wasn't working. It was determined that Tommy should go for proton radiation therapy. There are only a few places in the country that do this. So, we went back up to Boston, to Massachusetts General Hospital. The advantage of proton therapy is that the physician can control where the proton releases the bulk of its cancer-fighting energy. It's targeted only at the cancer cells and doesn't affect as many healthy cells. Tommy would go for this therapy for 10-15 minutes a day, for 30 days.

It must have been close to the end of school for Jack and Sophie at that point. Did you all go?

CHRISTINE: Yes. We all moved into an apartment in Christopher's Haven, which is a home for kids and their families to live in while they battle cancer. This was a large community and support system that turned out to be a very special place;

it was invaluable to us. And Tommy was feeling pretty good during this treatment, so our family made the most of our summer up in Boston. We went to Faneuil Hall, the aquarium and the museums. We saw the July 4th fireworks over the Charles River. Tommy saw his first baseball game at Fenway Park. And having the whole family there together really helped us get through it so much better. Ultimately, Jack and Sophie are Tommy's best medicine. We stayed until his treatment ended.

When did you finally get home?

ANDREW: It was July 27. Unbeknownst to us, our neighbors, the McLaughlin family, had "Tommy Strong" signs made up for our entire street, Manor Drive. The signs were on display on all the front lawns. As we drove into the neighborhood—we'll never forget this—Tommy climbed up on the arm rest because he started to see his name all over the place. He couldn't believe all the signs. He counted how many times he saw his name. When we reached our house, our entire family was in our driveway with a big "#tommystrong" sign. The driveway was all chalked up with the words "welcome home." It was awesome!

Tell us about #tommystrong.

ANDREW: It was started by friends as a way to help us through the rough days in the beginning. People would take pictures holding makeshift #tommystrong signs and post them on social media. That way, Tommy knew people from everywhere were thinking about him. We even printed up T-shirts. Tommy is obsessed with Star Wars, so the font we use is the same as the Star Wars font. A lot of people started asking where they could get the shirts, so we decided to turn it into a fundraiser for Tackle Kids Cancer. We have sold over 500 of them. Some members of the Red Sox, Yankees and Mets have worn them. We've joked that only Tommy has the ability to get these three teams to agree on something. [Laughs]

Tell us more about Tackle Kids Cancer.

ANDREW: The Children's Cancer Institute at Hackensack University Medical Center started an initiative to raise funds and awareness for pediatric cancer patients called Tackle Kids Cancer. [Every dollar] of all donations made to Tackle Kids Cancer benefits the essential clinical care, unique support services and groundbreaking cancer



research needed to find a cure. New York Giants Quarterback Eli Manning has agreed to match contributions, one-to-one. Some of the statistics about pediatric cancer funding are absolutely staggering.

Give us some of them.

CHRISTINE: Government funding to support pediatric cancer research is lacking, with approximately just 4% of the National Cancer Institute's budget dedicated to childhood cancer. And it's estimated that more than 40,000 children are treated for cancer annually nationwide. During the last 20 years, there have been only three cancer medications specifically developed for children, and 20% percent of pediatric cancers are still without a cure. There are so many truly gifted people out there devoting their lives to finding a cure. They just need the support. It's our hope that the people who read this story are inspired to help. We have seen so much incredible generosity come out of this.

What's next for Tommy?

ANDREW: Right now, Tommy is feeling great and attending school part-time. He's playing with his siblings and friends while he continues treatment. We had good news from a recent MRI that the tumor remains stable. We're exploring clinical trials at the moment.

What have you learned about yourselves this year?

ANDREW: We learned about Tommy's extraordinary courage and resiliency, and also about the level of compassion shown by his brother and sister. We also spent a lot of time away from home this year. Being together as a family gives us the strength to make the best of any situation.

CHRISTINE: We just remain focused on doing whatever needs to be done to make Tommy better. And that's the advice we would give people: don't lose hope. Focus on the steps you need to take to get the best care possible. Be grateful. Find the good and happy stories that come out of hardship. There are lots of people and resources out there who want to help, and in ways you would never expect or imagine—friends and family, for sure, doctors and experts, and sometimes total strangers. Don't hesitate to accept that help.

Ramsey stepped up for you all. Others did too.

ANDREW: How do we thank hundreds of people? There were meals, gifts, cards, prayers. We've had kids in town show up on our doorstep with their allowance or lemonade sale money to donate for cancer research. Hubbard School, St. Elizabeth School and the Ramsey Juniors have all held fundraisers for Tommy. The list goes on and on. We got dealt a really bad hand. But it has brought out so much good in people. We are very blessed and for that we are truly grateful. ∞

