MAKING HEADWAY SPECIAL FAMILY EDITION
Families tell their stories about pediatric brain tumors and how Making Headway impacted their lives.

www.makingheadway.org
REAL FAMILIES  REAL IMPACT

A LIFEBOAT OFF THE ISLAND

By Ed Dodd

There are images you don’t forget when your child is diagnosed with a brain tumor. The look on your wife’s face as a doctor explains to her that, no, your son is not OK and won’t be going home from the hospital. The supernatural glow the tumor has when you look at that first image of his brain. The way a doctor idly twists a phone cord during a family meeting, sighs in a way that is so far from hopeful it doesn’t even feel in the same state as despair, and says, “So. Second opinions…”

Making Headway was a lifeboat off our lonely island of hopelessness. Our lives were changed irreversibly when Owen was diagnosed. But so, too, were they when NYU Neurosurgeon Dr. Jeffrey Wisoff said he thought he could remove the tumor. And when the incredibly kind staff at Hassenfeld and Making Headway walked us through the resources at our disposal post-surgery. And when “Snowen” met Looney Lenny for the first time after surgery. And when we went to our first Family Fun Day on Father’s Day, 2009. And when we snapped a picture of Owen with Dr. Wisoff as he celebrated 10 years cancer-free.

We’re honored to be a part of the Making Headway community—a family of fighters, survivors, and angels. I’m not sure we would have made it off the island if not for them. “Thank you” seems inadequate to the task of expressing our gratitude.

Let’s support each other in this challenging, frightening, and lonely time. Be kind to those around you who are going through similar struggles. And most of all, be patient with yourself. You are doing the best you can, and that is enough.

You will be challenged. You will be scared. You will be angry. You will feel alone. There is no avoiding that. But know there is a whole community—our family, the NYU and Hassenfeld staff, and so many Making Headway families and friends—who are here to help: to support, to provide services, to listen, to love, and to bring joy.

Read the family stories that follow and get to know them.

Fall/Winter 2019 Newsletter

www.makingheadway.org
MAKING HEADWAY’S FAMILY STORIES

THE SUPPORT WE NEEDED
When my son Cairo was diagnosed with learning difficulties I was overwhelmed. Trying to navigate “the system” and receive help for my son left me confused and feeling helpless. I knew my son could receive services provided by the Department of Education, even though I chose to send him to a private school. But when services began I didn’t know if he was receiving all that he needed in order to have a successful educational experience. I had no one to speak to or ask questions of. I felt like I was imposing on my son’s school because they are not a school designed for special education. When I became connected with Making Headway’s Education Advocate Patty Weiner, I felt a weight lift off my shoulders. Patty has been an invaluable resource. She has a tremendous amount of experience and connections and has helped me not only with the DOE (obtaining testing for my son and understanding the results) but also with my son’s school. Whereas in the past I would sit back and hope that the services my son were receiving were “good enough,” I now know that I have someone looking out for my son’s best interests and who will make sure that he is receiving all the services he is entitled to. I can’t thank Making Headway enough for providing this valuable resource to our family.
—Kelley Archer

MAKING HEADWAY MAKING A DIFFERENCE!
Words cannot express how grateful we are for the support that Making Headway Foundation is providing to our family during this challenging time. As a medical social worker, I have seen firsthand how a family member’s illness can impact an entire family system. Making Headway is helping my children and our entire family access the highest quality support and expertise to guide us through the brain cancer diagnosis and treatment. We feel incredibly lucky to be connected to such a special organization that goes above and beyond for the families they serve.
—Rachel J.

ONE LIFE
By Fazl Shaikh and Jacob Ellen

One Life is a student-run organization at Middlebury College that raises money for the Making Headway Foundation. We are Fazl Shaikh and Jacob Ellen, the two co-presidents of the organization, and we are passionately driven to support Making Headway’s mission due to our own personal experiences with childhood brain cancer.

We have been motivated by the fact that pediatric cancer research receives only 4% of total federal cancer research funding and a similarly small share of funding from pharmaceutical companies. Since its inception at Scarsdale High School in the fall of 2012, One Life has raised over $45,000 for Making Headway with the goal of playing some part in fixing this disparity. Most recently, One Life at Middlebury College held a “spin-a-thon” event where they partnered with the campus’s spinning studio to hold paid classes all day, with all the proceeds going to One Life.

Obviously, one small organization is not going to fully solve the gap in cancer research funding, but One Life is confident that our fundraising efforts have helped pediatric cancer patients and their families navigate their disease with Making Headway’s support. We both plan to continue our efforts to fundraise and spread awareness for pediatric central nervous system tumors after graduating from Middlebury College in May 2020.

Fazl’s best friend in middle school, Jack Reyna, tragically passed away from a brain tumor in 2012. Jack and his family received support and services from the Making Headway Foundation throughout his treatment cycle.

Jacob was diagnosed with a brain tumor during his freshman year of high school, and was treated at the Hassenfeld Center at NYU, one of the treatment centers Making Headway supports.

One Life visits the Making Headway PreClinical Core at the NYU Medical Center. From left to right Daniel Muldoon (Research Technician), Jacob Ellen, Fazl Shaikh, and Dr. Guisheng Zhao (Lead Research Scientist).

Fall/Winter 2019 Newsletter
MAKING HEADWAY’S FAMILY STORIES

SURVIVORS REUNITED

By Julia Procopio with Christine Kiernan

When I was four and a half months old, I was diagnosed with a low-grade optic pathway glioma. My parents took me to NYU hospital where they met Dr. Epstein and Dr. Wisoff. They were confident that my tumor would be able to be treated through surgery and then chemotherapy. Eighteen and a half months later, with the grace of God and medicine I was able to overcome my brain tumor. Unfortunately, I did suffer vision loss in my right eye and am visually impaired in my left eye.

Growing up in school was a challenge, to say the least, for me. The other children did not understand what it was like for me to have a disability. They would tease me about my vision and surgical scars to the point where I was bullied all the way through middle school. There were times that the teachers did not know what to do or how to help me to succeed in my work. At times, it felt impossible to get through school, but my family lifted me up, were always there for me, and told me to never give up. Years later, while I was at Caldwell University, my life had changed for the better. I began to pursue my degree in communications and vocal performance. It was at Caldwell that the most amazing thing happened...

Julia and Christine Together Again

We were both in the same school where we had met one night in the music wing of the college. What we did not know was that we had met before, twenty-two years ago. One day, we just began talking and I mentioned to her that I was visually impaired from a brain tumor. At that point, Christine informed me that she had a brain tumor as a baby, as well. I asked her where she went for treatment, she said, “NYU.” I asked, “Do you know Dr. Allen?” She nodded her head and asked, “Maya?” We began to cry and called our parents. My mother was at work when I asked, “Hey Mom, do you know a Christine from when I was at NYU?” She responded, “Yes! You girls were roommates in chemotherapy...! She was having a bagel and you were having your bottle!” I said, “Oh my god! We both go to Caldwell U!” It just felt like something out of a movie! I mean, how often does a miracle happen in a lifetime? I survived a brain tumor that was almost impossible to overcome and I made a great friend who knows what this feels like. I really do believe that God puts you through things for a reason.

CHILDREN WITH SPECIAL HEALTHCARE NEEDS IN SCHOOL

By Patricia Weiner, Making Headway Educational Advocate

Brain and spinal cord tumors are the second most common types of childhood cancer, affecting approximately 2,500 children each year in the United States. Today, they are often treated as chronic illnesses similar to arthritis, diabetes, or asthma. Although these illnesses can be serious and require being treated in the hospital at times, they may be managed in an ongoing way as special healthcare needs to minimize disruptions to a child’s education and family life.

Children diagnosed with brain and spinal cord tumors have special healthcare needs that must be communicated clearly to their schools. The medical care and educational plans can be connected seamlessly through an Individual Health Care Plan (IHP). Many children diagnosed with brain and spinal cord tumors need accommodations such as modified gym schedules, flexible attendance schedules, or medication to be given during the school day. Often they might have an Individual Education Plan (IEP) or a 504 accommodation plan already in place.

Filing an IHP with a child’s school nurse is considered best practice, but it is not legally mandated. A well-crafted IHP makes returning to school better for everyone: parents, child, and school staff. Visit www.MakingHeadway.org/IEP, where you can learn more about Individual Healthcare Plans and download a parent-developed template, to be filled out in partnership with your child’s doctors and healthcare team. You can also read and download additional information including a confidentiality statement, references, and an article with more information about children with special health care needs in school.
Making Headway is honored and grateful to be the beneficiary of online donation campaigns from the following supporters. We can’t thank you enough.

Tiffany Nott Adams
Adam Auslander
Willie Birkett
Deanna Nicole Carey
Mary Church
Alexandra Cristina
Fred DeCaprio
Docu Family
Kendall Ecker
Patty Egan
Tiffany Gentile
Anthony Golaszewski
Stella Greenbaum
Andrew Jacob
Ann Kennedy
Susie Kenny
Shelly Kindler
Hannah Klitsberg
Ashley Kummer

Sara Zaloom Lipinski
Chantal Klugmann LoPiccolo
Mary Lynn Martin
Chris Meyer
Helen Schrull Nott
Lina Orfanos-Belabbas
Janaki Rao
Andrew Rappaport
Roxy RoRo
Serenity Rose
Susan Rubin
Laurie Rubino
Marie Savickas
Aazum Shaikh
Jessie Sherrow
Karen O’Callahan-Stokes
Ian Patrick Sullivan
Caren and Bob Tucker

As many of you know, Making Headway Foundation has a dear place in my heart (and mind). If you wish to support my birthday this year, please donate to my fundraiser. Any amount is perfect, and will help those children in need. Thank you for taking the time to read this. —Lina Orfanos-Belabbas

We have personally seen the positive impact Making Headway has had on so many families including our own.

It’s been over 13 years since Ryan’s diagnosis and we are so grateful to have had the amazing support of this organization helping us navigate diagnosis, treatment and now thankfully survivorship...

Smaller foundations like Making Headway don’t get the kind of publicity that larger charities do, but the work they do is invaluable to the families impacted by brain and spinal cord tumors.

Please consider making a donation to this great organization. —Caren Carder Tucker

There are many important causes and worthwhile organizations, but there are none that mean more to my family than the Making Headway Foundation. They provide incredible help and care to children with brain tumors and their families. They fund medical research, give college scholarships, provide education advocacy and mental health support. As I celebrate my birthday and my daughter’s college graduation, I think back to eleven years ago, when she was first diagnosed with a brain tumor. For all those years and still to this day I have been able to count on Making Headway to provide us with help and support whenever we needed it. For my birthday this year, I’m asking for donations to the Making Headway Foundation. —Chantal Klugmann LoPiccolo

Thank you so so much!! You have no idea how happy your donations make me feel. Children who are pediatric cancer patients or survivors will be very thankful and appreciative for your donations because this organization helps them recover from this debilitating medical problem. This organization helped me and millions of other children recover from cancer. —Hannah Klitsberg

Thanks everyone for contributing to my “Fundraiser for Making Headway Foundation!” Alexa Wilding and I are indebted to Making Headway Foundation for their care and support, especially now that we are seeing our son, Lou through treatment a second time. I am happy to honor them for my birthday goal. Peace y’all. —Ian Patrick Sullivan
I remember well the first time we met Maya in the playroom at the Institute for Neurology and Neurosurgery at Beth Israel North. Our local pediatric neurosurgeon out on Long Island had referred my youngest daughter, Johanna, for consultation with Dr. Jeffrey Allen and the late Dr. Fred Epstein. We were newly seasoned parents; Johanna having had six brain surgeries before she turned a year old, the first one to resect a brainstem mass when she was a 12-week old infant. She needed a shunt placed before she was four months old.

That first year, November 1996-97, was a blur as we balanced raising three older children (3, 6 and 9) and caring for our critically ill baby. The kids loved our trips to NYC the best. The patients and families, nurses and some doctors came and went, but one of the constant joys in this walk has been Maya's smiling face in the playroom and the wonderful support we've received from Making Headway Foundation.

Founders and friends, Maya and Edward Manley, are among the most gracious and caring people I have ever met. Through the years, our family has participated in field trips like the cruise, theater performances, parties and fundraisers, which all helped to connect us to others who were on a similar journey. The families, the Manleys, the staff, and volunteers of Making Headway all made us feel normal and welcomed, reminding us that we were not alone.

Over twenty years and a hundred surgeries later, Making Headway is still making a difference in our lives. As the gap widens between Johanna's chronological and developmental age, there are a few things that remain the same. Maya's fun projects and caring presence (and chocolate!) are among our sweetest consolations. And then there is always—Maya's smile.

Thank you, Making Headway and Maya and Edward Manley!
For over a decade, Making Headway Foundation has forged a special partnership with the NYU Langone Medical Center, in particular the NYU Stephen D. Hassenfeld Children’s Center for Cancer & Blood Disorders. Making Headway’s goal is to help create the world’s best hospital to care for families impacted by childhood brain or spinal cord tumors. Over the years, Making Headway has awarded over 80 grants, totaling over $10 million to NYU. These grants meet specific needs of families and explore cutting-edge research. Previous grants have included funding for research coordinators, clinical trials, family wellness, massage therapy, playroom equipment, psychological care, many specific research projects, and more. For 2019-2020, below is a partial list of the many grants that we approved.

**Pediatric Brain and Nervous System Tumor Research Registry and Tissue Bank**
This program enables the collection of rare and valuable specimens and clinical data from children with brain tumors for distribution to leading researchers. This supports novel work of understanding the pathogenesis of these malignancies, leading to treatments that will impact the lives of affected young people. In 2020, the tissue bank will start collaborating with the Children’s Brain Tumor Tissue Consortium. The overall goal of this new partnership is to make NYU research samples more available to the worldwide research community, thus increasing Making Headway Foundation’s impact and the odds of identifying better treatments.

**DNA Methylation Profiling**
NYU doctor Matija Snuderl has developed a new tool to accurately diagnose pediatric brain tumors. This is the first clinical test ever approved for utilizing whole genome DNA methylation and machine learning for diagnostics in the laboratory—vitally important because Dr. Snuderl’s research has shown that tumors diagnosed through traditional methods arrived at the wrong diagnosis 12-14% of the time. By providing funding that will cover the costs of testing every child with a brain tumor at NYU, Making Headway is also helping to provide the data necessary for insurance companies to cover this test in the future. Our next step is to raise funds to expand this testing to ten times as many children throughout the U.S.

**Clinical Trials Research Manager and Research Nurse**
Access to clinical trials is often the best chance for a child with a brain or spinal cord to recover or even survive. However, each clinical trial requires extensive infrastructure, monitoring, and support. With funding from Making Headway, Hassenfeld Children’s Center’s Clinical Trials Manager oversees 80 active research projects for children with cancer. Making Headway wants to ensure that families can participate in the trials they need and that they are cared for during the process.

**Pediatric Neurosurgeon—Dr. Teresa Hidalgo**
There are only a handful of doctors in the world that excel as pediatric neurosurgeons. When Making Headway learned that NYU needed support to retain one of the brightest, most talented young pediatric neurosurgeons they had ever seen, we understood the importance of stepping in. Dr. Eveline Teresa Hidalgo has already distinguished herself as a vital part of NYU’s clinical and research efforts, as well as a future leader in the field. Making Headway is proud to support her efforts to provide world-class care to hundreds of families each year.

**The Making Headway Preclinical Core**
The Making Headway Brain Tumor Preclinical Core, a laboratory that is the first of its kind in the country, will generate models of pediatric tumors; these models are urgently needed by the research community. The facility will be used by local and national researchers, industry partners, and other academic institutions to test novel agents in the hope of bringing new therapies to patients. It aims to provide testable models of every type (and sub-type) of pediatric brain tumor.

**Pediatric Neuro-oncology Fellowship**
The study of pediatric neuro-oncology is extremely complicated and it requires extraordinary training to become proficient. In order to attract and train the most qualified next generation of pediatric neuro-oncologists, Making Headway has, for the ninth time, funded a fellowship that emphasizes clinical management skills and knowledge, familiarity with radiation therapy and chemotherapy administration, and exposure to the rigors of following—and eventually composing—clinical trials. After a rigorous search, Dr. Sheetal Phadnis has been selected for the 2019-20 Making Headway Pediatric Neuro-oncology Fellowship.
Mary* was an 8-year-old girl, newly diagnosed with a pineoblastoma and associated hydrocephalus who had just undergone a surgical resection to remove the tumor from the pineal gland of her brain. Most children who undergo this type of surgery encounter a variety of side effects, including ones that affect both motor and mental functions. Neuropsychologist Dr. Kate McGee (whose position is funded by Making Headway) was asked to consult with the family due to concerns regarding her language, processing, and communication following her surgery.

Through an assessment battery which was individually-tailored to account for Mary’s hearing loss, Dr. McGee was able to discern that she was, in fact, cognitively intact and did not have cognitive or expressive language deficits, despite initial concerns to the contrary. In fact, Mary was very bright, with important areas of neurocognitive strength that were being masked by her newly acquired hearing deficits. Furthermore, in attempting to compensate for her hearing loss, Mary was relying entirely on alternative strategies for communication. Dr. McGee’s consultation helped to inform Mary’s physical, occupational, and speech and language therapies, highlighting that in order to communicate effectively, Mary required direct eye contact to enhance her ability for lip reading. Thereafter, Mary was far better able to communicate interpersonally and express her needs with both her treatment team and her parents.

Fortunately, as her medical situation stabilized, discussion was able to shift to her return to school and associated educational needs in the context of her medical history and hearing impairment. Educational Coordinator at Hassenfeld, Julia Gomez, met with Mary’s family and communicated with her school to ensure appropriate support and accommodations were put in place in anticipation of her return to the classroom. With the support of Making Headway and the NYU Hassenfeld Center, Mary’s future looks bright.

*Name has been changed to maintain confidentiality.
In 2019, Making Headway awarded $5,000 college scholarships to each of fourteen inspiring survivors of brain or spinal cord tumors. The Scott J. Reisser Memorial Scholarship Fund was established by Fritz and Joanne Reisser to honor the memory of their 22-year-old son, who succumbed to a brain tumor just short of achieving his dream of college graduation.

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<th>NAME</th>
<th>COLLEGE</th>
<th>DIAGNOSIS</th>
<th>CAREER</th>
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<td>Rashell Burrus</td>
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<td>Child Life Specialist</td>
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<td>Ithaca College</td>
<td>Astroblastoma at age 2</td>
<td>Journalism</td>
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<td>University of Chicago</td>
<td>Anaplastic Oligodendroglioma at age 6</td>
<td>Healthcare</td>
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<td>Babson College</td>
<td>Hypothalamic Glioma at age 5</td>
<td>Business/Finance</td>
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<td>Manhattanville College</td>
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<td>Environmental Sciences</td>
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<td>Stonehill College</td>
<td>Glioblastoma Multiforme at age 3</td>
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<td>University of Hartford</td>
<td>Germinoma at age 16</td>
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STANDING UP
My parents told me I swung my four-year-old feet to the side of the bed. I watched my legs dangle, while they held my IV tubes to follow me. Although I had been recuperating from emergency surgery (due to a complication during my radiation therapy), it was time to see if I could walk by myself. My parents said I had become weaker, trembling as they supported me, but I stood up.

My recovery has been long and often threatened. I understand how healing from brain cancer requires hope and help. Someone had once given me a little card with the poem “Footprints in the Sand.” I read it, probably like anyone reads it for the first time, and was surprised by the ending—because you do not see it coming when you read it for the first time. As a glioblastoma brain tumor survivor, I have many challenges. We all need to be carried sometimes, but on occasion, we have the ability to stand up and carry others.

Making Headway exists because it has understood this all along. When I trace my cancer journey, I see how Making Headway has been there to comfort, to educate, to encourage, and to celebrate everyone walking this particular journey. To make progress, you need to walk forward, but to make headway, you need others.

I have remained in remission since my treatment in 2005. However, I have suffered cognitive and physical deficits, including mild hemiparesis, from the trauma of this diagnosis. By surviving, my responsibility is to reveal my purpose, with gratitude.

Now eighteen, I am so appreciative and excited to be attending college. I have much to accomplish, so I am using my inner strength and gratitude to ensure that I can land on my feet—because when I do stand up, my diligence delivers, my tenacity triumphs, and I rise to overcome my challenges. Grateful for how Making Headway has carried me through, I smile knowing that sometimes I can feel sand under my feet.

—Michael Holtz

“Footprints in the Sand”
One night I dreamed a dream. As I was walking along the beach with my Lord. Across the dark sky flashed scenes from my life. For each scene, I noticed two sets of footprints in the sand, One belonging to me and one to my Lord. After the last scene of my life flashed before me, I looked back at the footprints in the sand. I noticed that at many times along the path of my life, especially at the very lowest and saddest times, there was only one set of footprints. This really troubled me, so I asked the Lord about it.

“Lord, you said once I decided to follow you, You’d walk with me all the way. But I noticed that during the saddest and most troublesome times of my life, there was only one set of footprints. I don’t understand why, when I needed You the most, You would leave me.”
He whispered, “My precious child, I love you and will never leave you. Never, ever, during your trials and testings. When you saw only one set of footprints, It was then that I carried you.”

BROADWAY SHOW: MAGIC SHADOWS
This is Making Headway Foundation’s once-a-year fundraiser to provide Care, Comfort, and a Cure to children with a brain or spinal cord tumor.

Animated by the dancers’ shadows, every cinematic scene is a kaleidoscope of colorful storytelling that will awe and astound you.

THE NEW VICTORY THEATER
209 West 42nd St., between 7th/8th Ave.
New York City

SUNDAY, APRIL 5TH, 2020 AT 12:00PM

To purchase tickets or make donations online, please visit: www.makingheadway.org/magic

www.makingheadway.org
On Sunday, September 22, Making Headway welcomed hundreds of family members to our 17th annual Family Yacht Cruise around Manhattan. Each fall, the much-anticipated event brings together families who have had a child diagnosed with a brain or spinal cord tumor for an afternoon of fun activities, delicious food, and breathtaking views aboard the majestic Skyline Princess. All in all, it was a beautiful day of community, well-being, and joy. We are also extremely grateful to Richard and Marisa Stadtmauer for sponsoring the cruise each year.
YOU’VE COME A LONG WAY, BABY
A Message from Clint and Elisa Greenbaum

Clint is a Making Headway Founder and Treasurer. Elisa is Vice Chair.

The slogan—from a cigarette ad in the 70s—is now, thank goodness, very much outdated. But it can be used in a different context. Our son, Jake, has come a long way from when he was a 3-month-old baby in 1990 with a rare malignant brain tumor, to where he is today as a 30-year-old man. Yes, he has never spoken, and he is significantly developmentally delayed, but he has overcome many obstacles that most take for granted. Plus, he is the happiest person we have ever met.

We will never forget meeting the late Dr. Fred Epstein, Jake’s surgeon. Leaning back in his chair with his cowboy boots on his desk, Fred confidently told us that he would likely be able to remove Jake’s tumor. Meeting Dr. Jeffrey Allen was also unforgettable. He laid out the facts. Jeff, despite all his experience, had only treated three kids with Jake’s tumor: one had passed, one was ok, and the other was somewhere in between. (Making Headway originated when Dr. Epstein, along with Dr. Allen, began the Institute for Neurology and Neurosurgery.)

Jake was often a patient at NYU Hospital. The halls and rooms then were dingy. But that was where we met Maya Manley. She warmly greeted us and then suggested that we attend a meeting. That was the beginning of our partnership with Maya and Ed.

Over the past 30 years, advances have been made in the treatment of pediatric brain and spinal cords tumors—but baby, we still have a long way to go.

Today, there are more than 28,000 children living with a brain or spinal cord tumor. Over 2,500 children are diagnosed every year (seven every day), and they are currently the leading cause of death among all childhood cancers! Pediatric brain and spinal cord tumor achievements have not kept pace with other areas of oncology, where great strides have been made.

Every day when we are with Jake, we are reminded how lucky we are! We want many more children and their families to feel as lucky (and even luckier). While Jake was never able to go to college, how great is it that among the myriad things that Making Headway funds, we grant college scholarships for brain tumor survivors. Who knows, maybe one of them will become a leading scientist or philanthropist in this fight. In the meantime, help us now, by contributing to Making Headway. It would be the best possible 30th birthday present for Jake (and us).