Pediatric brain tumors are the most common and most deadly childhood disease.

In 2022, 6,000 moms and dads will hear “your child has a brain tumor.”

28,000 children in the U.S. are currently living with a diagnosis of a primary brain or spinal cord tumor.
**LETTER FROM OUR CHAIR**

**Making My Rounds**
I am not a doctor (and I don’t play one on TV), but I am happy to report that over a year since my two leg surgeries after my bike accident, I am so much more mobile, and I’ve been making the rounds. Here are some recent things I’ve gone to:

I was privileged to attend a presentation by Dr. Matija Snuderl, a brilliant neuropathologist at NYU Langone Health. Dr. Snuderl updated our Making Headway team on his current work diagnosing pediatric brain tumors. Dr. Snuderl’s goal is for every patient to receive a rapid and accurate diagnosis, that would result in better treatments and outcomes. Making Headway funds the NYU tissue bank that provided the samples needed for Dr. Snuderl’s breakthrough research into DNA methylation profiling.

I attended Making Headway’s Family Fun Day at the Bronx Zoo. It was our first Family Fun Day in two years (because of COVID-19). It was wonderful to see the smiles on the faces of the children, who got to just be regular kids for the day.

Along with other Making Headway Board Members, I met with senior physicians at NYU Langone Health to get an update on their pediatric neuro-oncology program and to discuss the partnership with Making Headway. Again because of COVID-19, we had not had any in-person meetings since I became Board Chair. It was great to hear from and speak with doctors Elizabeth Raetz, Catherine Manno, and William Carroll and to know that we are all on the same page.

At the end of November, I met two professionals whom Making Headway funds: Dr. Jess Clymer, the new Marguerite and Otto Manley Director of Pediatric Neurosurgery at NYU Langone Health, and Sarah Coughlin, RN, the Pediatric Neuro-Oncology Clinical Family Coordinator at NYU Langone Health. Great things to come.

Finally, we all had a blast at the Eat, Drink, & Karaoke fundraiser in memory of our son, Jake Greenbaum, and Board member Susan Rubin’s son, Andy Ecker. Thanks to the generosity of our friend and longtime Making Headway supporter Joe Sprung and his Bear Givers, who underwrote the event, everything we made that evening went directly to Making Headway.

I am not a doctor, but I prescribe a donation to Making Headway to help you feel as best as possible!

*Stay well,*

*Elisa Greenbaum*

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**FROM THE FOUNDERS**

Maya and I love the title of “Emeritus,” but we want our friends to know that we’re certainly not retired from the exciting developments at Making Headway. On the contrary, both of us are still deeply involved in age-appropriate ways! There is still so much to be done to help the children and their families. Besides that, many parents whom Maya has counseled through the years still want the calming presence of her gentle voice and understanding spirit. And of course, because we want the foundation to continue providing all the services so critical to the children, we are actively seeking contributions for special programs. To that end, we will be sending out over 600 invitations for the upcoming winter event. So yes, we plan to stay actively involved as long as we are able. Rest assured that the children of Making Headway, together with their families, will always be first in our hearts.

*Maya and Edward*
PUSHING THROUGH “SCANXIETY”

By Alexa Wilding

My 9-year-old son, Lou, is a two-time pediatric brain and spinal cord cancer survivor. He was first diagnosed with choroid plexus carcinoma at one year old. Every three months, we drive down from our home in Hudson, NY, and return to NYU Langone for scans and a check-up with Dr. Gardner. I am always amazed at how excited Lou is for scans. He literally counts the days until he can see his friends at Hassenfeld again, a testament to the compassionate care he continues to receive there. While my husband, Ian, and I of course share Lou’s deep love for his team, I wish we shared his enthusiasm for scan day. No matter how much time goes by, scans push us to the limits of patience, grace, and courage every time.

It’s hard for people who haven’t been touched by cancer to understand why “scanxiety” affects even the most seasoned cancer parents. While we’re waiting for the results, my family’s long journey flashes before me: the endless days in the hospital and the sleepless nights. Will I have to pack a suitcase again? What will I tell Lou’s twin brother, West? When I can’t stay present or catch my breath, I lean on a Sanskrit prayer I came across during Lou’s recurrence:

“May creatures everywhere be happy, healthy, and free.” This prayer has become my tried-and-true tool for pushing through fear. It opens my heavy heart, much in the way doing crafts with Maya and the children at Hassenfeld used to calm me down. Or sharing coffee with the other parents late at night in the hospital warmed me up. In those fleeting moments, I felt less alone in the story none of us chose.

I’ve come to realize that my son Lou looks forward to scans because visiting Hassenfeld reminds him he’s not alone either. It’s the one place where he’s no different from any other child. No matter the results, our visit is a reminder of the immense bravery of all families who have walked this path. And when I remember that good feeling, I’m able to knock fear down and meet the moment. I think that’s what resilience is. I don’t get it right every time. But there’s always the next scan.

INAUGURAL MAKING HEADWAY FAMILY CARE AWARD WINNER: TRUNZ FAMILY

Making Headway is awarding our first ever Family Care Award to Greg and Jeannie Trunz and their family for their enduring commitment to helping children who have been diagnosed with a brain or spinal cord tumor.

The Trunz family has been part of our Making Headway family since 1996 when their beautiful daughter, Allison, was diagnosed, at age 3, with a large supratentorial primitive neuroectodermal tumor. After a year of treatments, the tumor metastasized to her spine. Her family searched for answers, but came to understand that even the best treatments, ones that showed so much promise, were just not working. It was time to begin focusing on how to spend the rest of her days. On August 12, 1997, after naming in a clear voice all the people and pets she loved and singing “You Are My Sunshine” to her parents, Allison died quietly at home.

As they mourned their daughter, Greg and Jeannie considered what they could do to honor her memory. Their family chose to raise money so that other children could be helped by Making Headway, and increase awareness of this terrible disease. With the support of their family and the community, they launched the ALL-IS-ONe Tulip Festival Dinner, which they generously hosted at The Swan Club for the next 17 years. The event included not just dinner but a silent auction, raffles, and a printed journal that took a tremendous effort to organize, year after year. Ultimately, the Trunz family raised over $1,500,000 from over 3,000 donations; and personally and generously donated more than 100 times.

Those of us lucky enough to have known Allison will always remember her, and we thank Greg and Jeannie for being such wonderful parents and role models.

Photo by Yumi Matsuo

Lou (left), with his mom and twin brother West.

Photo by Alexa Wilding

Greg and Jeannie Trunz.
FAMILY FUN DAY

On August 21, Making Headway hosted Family Fun Day for families who have had a child diagnosed with a brain or spinal cord tumor. Over 400 guests attended for a day of free fun, food, music, adventures, and VIP Bronx Zoo admissions. The pandemic shut down this event for two years, but Family Fun Day came back this year and was better than ever!

Photos by Todd Shapera Photography
By Sabine Mueller, MD, PhD

Finding better treatments and a cure for pediatric brain tumors requires a worldwide effort. During the past decade, the international scientific community has collaborated in unprecedented ways, leading to remarkable advances in our understanding of the molecular alterations that contribute to specific pediatric brain cancers. To address the urgent need for rapid identification of clinically relevant drug therapies, teams are working together to advance research across several critical fronts.

In 2019, the University Children’s Hospital Zürich became the first European member of the Pacific Pediatric Neuro-Oncology Consortium (PNOC), a U.S.-based clinical trial consortium dedicated to offering innovative therapies to children and young adults with brain tumors. To address the urgent need for rapid identification of clinically relevant drug therapies, teams are working together to advance research across several critical fronts.

One specific example of this reach involves PNOC clinical trials to treat Diffuse Midline Glioma (DMG)/Diffuse Intrinsic Pontine Glioma (DIPG). Children diagnosed with DMG often have less than a year to live. Given the molecular complexity of DMGs/DIPGs, combination strategies that complement candidate drugs are needed to identify an effective treatment. With this urgent need in mind, over 60 scientists and eight institutions from Australia, Europe, and the United States are collaborating on a DMG- multi-arm Adaptive and Combinatorial Trial (DMG-ACT). The DMG-ACT aims to implement a highly innovative clinical trial design of combinatorial arms for patients with DMG at all disease stages. The team shares data and resources in real-time and collaborates across regional and institutional boundaries. This group, led by doctors Javad Nazarian, Carl Koschman, and me, is working to rapidly identify and validate promising drugs and drug combinations for clinical use, as well as biomarkers predictive of additional promising drugs.

A few years ago, a DMG/DIPG Center launched in Zurich, where Dr. Javad Nazarian and I introduced a new clinical standard for patients with these tumors: Each patient receives a biopsy, detailed tumor tissue profiling and—when sufficient tissue is available—patient-specific cell lines that can be used for drug testing. The center is also responsible for tissue acquisition/processing for all DMG/DIPG patients undergoing a tumor biopsy. To date, 26 patients have undergone a stereotactic tumor biopsy and received tumor biology analysis. Hundreds of patients, from all around the world, have worked with the center to receive interdisciplinary medical analyses and therapeutic advice. As always, the goal is to identify better treatments for this terrible disease.

Through my work at the University of California San Francisco, PNOC, the DMG/DIPG Center, and the Children’s Brain Tumor Network (CBTN), I have come to understand the power of international collaboration on medical research. Thanks to these efforts, I have every confidence we will find a cure.

Sabine Mueller is a board-certified neurologist and a pediatric neuro-oncologist with a world-renowned research program focused on novel therapies for pediatric brain tumors and also on late effects in survivors of childhood brain tumors. She also leads the Pediatric Brain Tumor Program at UCSF and the Pacific Pediatric Neuro-Onco-logy Consortium (PNOC).

As an Executive Council member of CBTN, and as an organization that funds a grant to make all PNOC clinical trials available to children at NYU Langone, Making Headway is very proud to collaborate with Dr. Mueller and her amazing team.
WHEN MY 8-YEAR-OLD DAUGHTER, Nora, started losing her sight, I didn’t even notice. My mom came to visit and, after reading with my daughter, pulled me aside and asked, “Do you know that she can’t see anything? She’s holding the book right in front of her face and can’t make out the words.”

Because my daughter has neurofibromatosis, a genetic condition frequently associated with optic nerve gliomas, I immediately contacted her neurologist, who sent us directly to an ophthalmologist. Her eyesight had deteriorated to 20/200, meaning that the average person sees from 200 feet, she could only see from 20. The fact that the lenses didn’t help made them suspect a brain tumor, which an MRI confirmed.

In the days leading up to our appointment with the oncologist, I was consumed with guilt and worry. How many eye exams had we missed during the pandemic? Is it malignant? What if she goes blind? I gave her the disease that spawned this tumor; it’s all my fault. Could we lose her? How would we survive if we lost her?

While the tumor was larger than they expected, they didn’t think it was malignant, though it was too risky to do a biopsy to confirm this. The oncologist laid out two treatment options for us: a traditional carbo/vincristine chemotherapy or a second option which was a clinical trial for a MEK inhibitor called Selumetinib. MEK inhibitors block proteins MEK1 and MEK2, which help control cell growth and survival. A week earlier, our biggest choice was having s’mores or ice cream for dessert, and now we needed to make a critical treatment decision with minimal medical knowledge.

After calling every human we knew with a connection to medicine, we decided we wanted “the MEK.” While there’s less known about its efficacy or durability, it had promising early results and would give her a better chance of being able to attend school, which was crucial for the mental health of my extroverted child who’d already suffered greatly from pandemic isolation. But since it was only available through clinical trial, we’d need to get randomly assigned to it. The day we were supposed to find out, I gripped my phone the whole day, afraid I’d miss the call. When it finally rang, I could barely answer because my hands were shaking so bad. When the doctor said we’d gotten the MEK, I slid down the wall, sobbing, then laughed because it was almost absurd to be so happy about getting the poison behind Door Number Two.

In the beginning, we referred to Nora’s tumor as a “bump in the brain” because that’s the way the doctor had talked about it, but instead of making it easier for Nora and her brother to wrap their heads around (no pun intended), it made it harder. My big-headed kids had had more bumps on the head than most football players and this was clearly different. We started with brain tumor, then accidentally progressed to cancer because once when our coughing cab driver repeatedly refused to put his mask on, I blurted out, “Please, my daughter has cancer!” to which Nora responded, “What? I have cancer?”

**WHAT? I HAVE CANCER?**

By Heather Osterman

In the days leading up to our appointment with the oncologist, I was consumed with guilt and worry.
Joseph was nervous but optimistic. “I don’t believe in statistics,” he told his older sister. Thirty rounds of radiation and not one single complaint, his sisters rooting him on the entire time. Then Make a Wish gave us a call, and my heart sank; that organization is for sick kids! I scoured the internet for answers—I knew the odds but didn’t have to accept them.

Our strategy was to stay three steps ahead and never look back. We worked to get him into all the right trials. A CED trial stalled the progress of the tumor, but only temporarily. An ONC-201 trial at NYU with twice-a-day chemotherapy pills exhausted him. As he sat by his computer to take his AP exam, he couldn’t keep his eyes open. He got sad, depressed, and angry but he never said, “Why me?” He accepted the fact that he’d have to attend John Jay College remotely for the time being and that getting a driver’s license, playing soccer, going running were all on hold. Instead he took his vitamins and his medicine, did his physical and occupational therapy, underwent his tests, and dealt with everything else that comes with cancer. We had honest discussions, but we fought every day to keep him happy and busy and just not thinking about the fact that he had cancer, to focus on how much we loved him. During this time, Making Headway Foundation provided care for our family through their Ongoing Care Team of psychiatrists and therapists.

Joseph passed on November 21, 2021. He was my hero and still is. He is missed by many, and as long as I’m alive, I will keep his name alive. I have so many people and organizations to thank. I want to thank Making Headway for recognizing my son and for continuing to reach out to us, and the DIPG Parent Chat, which gave me some comfort, and all the other organizations that helped me through this fight. And, of course, I must thank his friends who remembered and visited him, his sisters for trying to keep me strong, my boyfriend who helped me when no one else could, and my family—especially my older sister—who helped me stay positive, helped research upcoming trials, and stayed on the phone with me during doctor visits. One day I will do a fundraiser in my son’s name, and one day maybe they will find a cure.

Discovering my son, Jahsiah, had a brain tumor at the age of 10 broke my heart. Who would have thought his headaches and tiredness were the symptoms of a brain tumor? I honestly thought my son was going to die. He was a very fragile child, and I remember how nervous I felt when I was initially told he had brain cancer by a tech at Doshi Diagnostic. It felt like I was hit in my chest with a bowling ball. This diagnosis has taught me to love and cherish life more than ever before because at the blink of an eye, your life can change. —Jani Cauthen
The mission of Making Headway Foundation can only truly be achieved when we work in partnership with the children and families we serve. For the vast majority of our history, this was done face-to-face, at NYU Hassenfeld, or at one of our many events. After more than two years away, due to the pandemic, I was so relieved to finally see everyone again at Family Fun Day 2022. This was our first in-person event since 2019, and it renewed the commitment that Making Headway makes to every family we work with. Other recent events, including our teen and young adult activities and professional baseball games (see page 9), also served to provide our families with a greater sense of community and support. There is nothing like talking to someone face-to-face to truly understand their unique needs, circumstances, and perspective. Making Headway certainly learned from the challenges families faced during COVID-19, but we are all so grateful to return to the in-person programs and services that are critical to so many. Time with these families is not only precious but completely necessary for our work.

Since I joined Making Headway Foundation in 2016, I have had to redefine my perceptions of time. It is only through the experiences families have shared with me, about the short period of time after a family learns their child has a brain or spinal cord tumor, that I understand how a single day can change your life and can seem to last forever.

The questions each family faces, the trauma they endure, and the life-changing decisions they have to make—often within 24 hours—are overwhelming. Then there are the inevitable and unbearably vague timeframes, such as “6-12 months to live,” “18-24 months of rehabilitation,” or perhaps “a lifetime of challenges.” Within this world, there are also single moments of time, occasionally joyous, but often profoundly tragic.

At Making Headway, I have learned to treasure any positive and beautiful moments the world gives us and use them to remain strong when things look their darkest. We can all learn from our experiences, and I have learned to treat time as the world’s most precious commodity. Like anything else, it can be treasured or it can be wasted. At Making Headway, we revere time, appreciate and understand it, and aim to help our families cherish every moment like it was their last—because, sadly, sometimes it is.

Making Headway Foundation is dedicated to providing every child with individualized care and love. With your continued support, we will make every year, month, day, and minute count.

“There’s only one thing more precious than our time, and that’s who we spend it on.” —Leo Christopher

Daniel Lipka, Executive Director

SAVE THE DATE
MAKING HEADWAY WINTER BROADWAY SHOW IS BACK!

After several years without a show, Making Headway is back in a big way. Join us **Sunday, February 26th**, at 2:00 p.m. for a special presentation of the award-winning Broadway show “Wicked” at the Gershwin Theatre in New York City. We’ll be inviting Making Headway families to take a day off from their cares and enjoy this event for free; for everyone else, your ticket purchase or donation directly supports Making Headway’s programs and services. Don’t miss this opportunity to join us for Making Headway’s biggest fundraiser of the year. Visit makingheadway.org/wicked for more information or to donate.

“Wicked” is a vivid reimagining of the classic “Wizard of Oz”. It spotlights the untold stories of Oz’s most famous (or infamous) characters: the Wicked Witch of the West and her unlikely friend, Glinda the Good Witch. The show follows green-skinned Elphaba from birth to college and through the life-changing events that eventually earn her the label “wicked.” Meet spoiled rich girl Glinda, local prince and heartthrob Fiyero, and even the Wizard, himself. Elphaba—a passionate political activist if there ever was one—fights injustice and seeks to undo the mistakes of the past. The show explores the dark secrets and personal tragedies that shape the history of Oz. This show is dedicated to everyone who has ever passed away from a brain tumor, including the theater’s namesake, George Gershwin.
Since the summer of 2022, Making Headway has received donations of over 592 seats from Tickets for Kids. Through our partnership with this unique organization, on whose board our co-founder and Vice Chair, Clint Greenbaum, serves, Making Headway was able to send our families to Mets, Yankees, and New Jersey Devils games, five Broadway shows (including “Aladdin”), and Cirque du Soleil. These are amazing opportunities for our kids, most of whom have never had the opportunity for this type of experience before.

All tickets received by Making Headway are free, courtesy of Tickets for Kids.

Did you know that the home team is 7-0 in games that Making Headway families attended?

- Aug. 26: The Mets win 7-6 on a game winning, 9th inning hit by Pete Alonso.
- Sept. 21: The Yankees crush the Pirates 14-2
- Sept. 28: The Mets win 5-4 thanks to an extra-inning, game-winning hit.
- Oct. 5: The Mets win 9-2 in their regular season finale.
- Oct. 17: The Yankees beat the Guardians to advance to the next round of the playoffs.
- Oct. 22: The Devils win 2-1 as Dawson Mercer scores the game-winning goal.
- Nov. 10: The Devils win 4-3, scoring with 33 seconds left in overtime.

Seeing “Wicked” with my dad was extra special! I’ve loved the show’s soundtrack for a couple of years now, so this opportunity made it full circle. —Marcella Borgenicht

I brought my kids last night and they LOVED it. First baseball game for both of them. And they immediately begged to go back every day! —Parisa Sahay

It was an offer too good to refuse! Thank you, Bear Givers, and to its president Michel Mirman, and its founder Joe Sprung, for underwriting the Eat, Drink, & Karaoke Fundraiser at Sid Gold’s Request Room in New York City on November 3. What a night it was! The food was delicious and plentiful, the open bar drinks flowed, and the singing was—well, enthusiastic.

The event was in celebration and in memory of the lives of Andy Ecker and Jake Greenbaum.

Andy would be beaming knowing his friends were proudly singing the Michigan fight song in his honor. Andy sadly lost his brave fight against brain cancer in July 2015. Besides being a Michigan fan, he was a mathematical genius, a board game champion, a welcoming and loyal friend, a loving big brother, an amazing son, and an all-around remarkable man. Appropriately, given the event, Andy knew all the words to every song in the “Pitch Perfect” movie.

Although Jake literally couldn’t sing (or talk), because of a brain tumor diagnosed at 3 months old, he, too, would have loved to have been at the event. He would have given all the karaoke singers his trademark standing ovations and shrieks of joy! Jake was a brain tumor survivor for 30 years, but another aggressive cancer took his life in August 2020.

Thank you to everyone who bought tickets, those who sang, and those who couldn’t attend but still donated. Overall, the evening raised $57,000, with 100% of proceeds supporting Making Headway Foundation and its mission to help children with brain or spinal cord tumors. The event proved that despite the horrific nature of the disease of pediatric brain and spinal cord tumors, those touched by it can still find solace by celebrating those who have survived, those who have passed, and those who are currently fighting the battle by singing “I Will Survive.”
ENSURING EVERY CHILD GETS THE EDUCATION THEY DESERVE

“I love working with families and school teams to individualize learning programs and provide education on how to best accommodate our patients in the classroom. It’s wonderful to connect our kids with their school community, as this provides comfort and a sense of normalcy throughout treatment. It is a privilege to facilitate these connections and encourage active engagement in one’s education; it has such a positive impact on our patients’ overall well-being.”
—Julia Gomez.

Julia Gomez, who received an MA in general and special education from NYU, continues to develop and enhance the role of Education Coordinator as a member of the psychosocial team at NYU Stephen D. Hassenfeld Center for five years. The Education Coordinator’s role is to provide ongoing vital interventions and improve standards of care to address each child’s educational, social-emotional, and developmental progress, lessening the substantial burdens often associated with medical treatment during childhood. In 2022-23, Making Headway will once again fund 50% of Julia’s salary, bringing this critical service to children with brain tumors.

Julia in Action

Henry was only 9 years old in 2014, when he was diagnosed with a rare malignant (cancerous) brain tumor known as choroid plexus carcinoma. Treatments for this disease (surgery, radiation, and chemotherapy) can cause many problems, including physical and/or mental disabilities. In conjunction with his medical care, Henry was treated by NYU Hassenfeld’s psychology team, which evaluated his neurocognitive abilities and provided therapy to support his anxiety over his illness. At the time, Henry’s family also engaged with Julia, who arranged for home instruction while he was on treatment.

Following Henry’s treatment, his family moved out of New York City. Julia continued to work with them to secure services, especially once Henry returned to in-person schooling after the COVID-19 lockdown. In consultation, Julia recognized that Henry was starting to struggle in his new school placement; she subsequently referred him to NYU Hassenfeld’s neuropsychology services. Neuropsychologist Dr. Sarah Powell (also partially funded by Making Headway) undertook a full evaluation that found Henry had some weaknesses in learning new information and would benefit from extra time and smaller workgroups.

With Dr. Powell’s evaluation completed, Julia was able to help Henry’s family secure all the services they needed for him to be successful in school, including 1:1 classroom support and much-needed additional accommodations, including a reduced homework load, extra time on exams, and specialized instruction, all of which have had a significant impact on his schooling.

This support has made a huge difference: Henry and his family tell us that he is doing well and enjoying school once again, and looking forward to the upcoming school year.

Since Making Headway started funding the Education Coordinator position at NYU, Julia Gomez has provided comprehensive educational support and advocacy services over 1,000 times to children in need.

Educational Consultation Encounters

Since 2018, Julia has provided educational assistance 1,148 times.
*Julia was away on maternity leave during part of 2021-22.

This program is only one of many grants that Making Headway is currently funding to support patients and medical research. Other programs include an NYU Care Coordinator, an NYU Clinical Trials Manager, an NYU Brain Tumor Registry and Tissue Bank, a research project at Memorial Sloan Kettering studying long-term cognition of brain tumor survivors, and the Children’s Brain Tumor Network (CBTN).
MY MAKING HEADWAY PEDIATRIC NEURO-ONCOLOGY FELLOWSHIP

By Dr. Robyn Borsuk

My work completing the Making Headway Pediatric Neuro-Oncology Fellowship at the NYU Stephen D. Hassenfeld Children’s Center has been an invaluable educational experience that has prepared me for a career dedicated to helping children with brain and spinal cord tumors. The technical and interpersonal skills I’ve learned throughout my fellowship have allowed me to provide superior care and treatment to my patients and their families.

During my 2021-22 fellowship, I have had the opportunity to play a critical role in the diagnosis and treatment of pediatric patients with CNS (central nervous system) tumors, and have also been an instrumental part in managing relapses and helping families to anticipate long-term complications of their treatment regimens. Through the advanced molecular testing available to the patients of NYU Langone, I have garnered an in-depth understanding of the contributions of genetic mutations to the development of tumors as well as to the targeted approach to their treatment.

The Making Headway Fellowship also gave me the opportunity to rotate with the adult neuro-oncology, neuroradiology, and neuropathology teams. Each of these rotations provided the chance to expand my knowledge base in these very distinct areas, further improving my neurology examination skills, understanding of various tumor types, ability to interpret patient MRIs, and recognition of histological patterns. Additionally, being able to practice within the nation’s largest neurofibromatosis center has provided me with experience working with a unique population unavailable at any other facility.

Throughout my time at NYU, I have been able to appreciate and draw from the experience and different approaches of my mentors, Dr. Segal, Dr. Nicolaides, and Dr. Gardner. Through their leadership, I am now much more comfortable in leading my patients and their families through the process of diagnosis and management of CNS tumors.

This fellowship has inspired me to pursue a career dedicated to helping children with CNS tumors. To continue this work, I have joined the faculty of SUNY Upstate Golisano Children’s Hospital as a pediatric neuro-oncologist.

Overall, I am incredibly grateful for the opportunity and support Making Headway Foundation has given me. It has made me a stronger and more well-rounded pediatric neuro-oncologist.

Dr. Borsuk was the 11th Making Headway Pediatric Neuro-Oncology Fellow. Previous Fellows continue to help children all around the world.

KICKS FOR CANCER

This past October, the Hauppauge Girls Varsity Soccer Team hosted its 15th Annual Kicks for Cancer community event in memory of Courtney Tomkin. Representing Making Headway at the event once again was Greg Trunz.

At the very first Kicks for Cancer in 2008, we were all blessed to have Courtney still with us, and she ran on the field like a true champion. The community raised over $30,000 that day, greatly exceeding expectations. Tragically, just two months later, Courtney passed away from her aggressive brain cancer.

The day Courtney died, fellow students signed her desk, and Kicks for Cancer co-founder Alexis Gonzalez brought it to the steps of Courtney’s house that night. There stood most of the Hauppauge community; they held candles and sang “Silent Night.”

Today, Kicks for Cancer is organized each year by Courtney’s coach, Jessica Kulesa, and it has become one of Hauppauge’s biggest fundraising events, raising critical dollars for cancer research. This very special night is full of entertainment, with food trucks, bouncy houses, raffle tables, fun goods for sale, and—of course—two varsity soccer games. In support of cancer awareness, the teams wear pink and play with a pink soccer ball. The players are the heart and soul of this effort: they decorate the school, participate in spirit week, help fundraise, sell merchandise, and more.

Over the past 15 years, Kicks for Cancer has raised over $500,000 to support pediatric cancer research. Proceeds benefited Making Headway Foundation (over $250,00), the American Cancer Society, Make-A-Wish Foundation, the Courtney Tomkin Scholarship fund, and other wonderful charities.

Courtney was an inspiration to so many. We will not forget her and will continue to honor her memory with Kicks for Cancer every year.
Despite the horrible start, using medical terminology demystified the language for our kids. And while positivity is important, we’ve also found outlets for being angry and silly. From screaming in a closet to naming her tumor “Octopoop” because it looked a bit like an octopus, to writing songs for “Tumor the Musical,” featuring hits such as “It’s MRI day, wish it was pie day!” we’ve embraced the idea that no emotions are taboo and there’s no shame associated with her illness.

Having a child with a brain tumor can be isolating. Connecting to the brain tumor community was a game changer, especially Making Headway...

The unique way Making Headway is structured also allowed Dr. Donnelly to meet with my son and chat with my daughter, and in a world that can change drastically from week to week, not needing a strict appointment is a blessing.

Fifteen months into a two-year clinical trial, Nora’s tumor has shrunk by 50% and she’s regained a significant amount of vision, which surprised the doctors. We’re trying to live in the joy of the progress instead of focusing on what might happen when we stop the medication. As for my daughter, she’s determined to be the first person to completely get rid of her type of tumor.

What? I have Cancer?
By Heather Osterman
Continued from page 6

Connecting to the brain tumor community was a game changer, especially Making Headway...

Making Headway Foundation provides care and comfort for children with brain and spinal cord tumors, while funding medical research geared to better treatments and a cure.

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Making Headway services are available to all pediatric brain and spinal cord tumor patients and their families throughout the tri-state area.

This newsletter is dedicated to our donors and supporters, whom we celebrate every day.

Managing Editor
Robin Hardman

Making Headway is a 501(c)(3) non-profit organization. EIN# 13-3906297.