



making headway
foundation

A Foundation Dedicated to the Care, Comfort, and Cure
of Children with Brain and Spinal Cord Tumors

makingnews

Summer 2025

HIGHLIGHTS

FAMILY STORIES • LETTERS FROM MAKING HEADWAY • THE IMPORTANCE OF SURVIVORSHIP PROGRAM • UNFORGETTABLE CARE • PROGRAM TIMELINES • MAKING HEADWAY CARE AWARD • FAMILY EVENTS AND FUNDRAISERS • THE IMPACT OF FEDERAL RESEARCH • IN THE NEWS • REAL FAMILIES REAL IMPACT



Photo Credit: Vlad Kolesnikov

Rauri and his friend Aiden at Making Headway's 2025 Family Fun Day. Rauri (red shirt, age 6) was diagnosed with a brain tumor called ependymoma when he was three years old.

www.makingheadway.org

LETTER FROM OUR CHAIR



Elisa and Jake Greenbaum

Tumor Envy

When our baby son, Jake, was being treated for his brain tumor, there were times when we were in a doctor's waiting room with other parents in a comparable situation. We would hear about the different types of pediatric brain tumors, and then the probability of death (it was never the probability of survival). Jake's tumor was particularly rare and malignant. Dr. Jeff Allen (now a Making Headway Board member) said that he had only treated three children with Jake's diagnosis, even though he was a pioneer in the pediatric neuro-oncology field and had seen lots of patients. Dr. Allen said that of the three, one had died, one was ok, and the other was somewhere in-between. That was not a big sample, so we were desperate to learn from others. We were encouraged when we would hear other parents say that their child's probability of death was low. The waiting room lingo for this was "tumor envy"—parents felt envious of the type of brain tumor your child

had, if it had a lower probability of death than the type of brain tumor that their child had. But we learned that even low probability of death brain tumors sometimes turned into tragedy for the child and their family.

Survivorship in the world of pediatric brain tumors is different from most other illnesses or accidents. You can imagine how traumatic it is for a child to lose a limb due to cancer, but it can save their life. For a child with a brain tumor, amputation is not an option. For the doctor to cure a child's brain cancer, surgery, chemotherapy, and radiation are the standard methods of treatment. Yet the affected area is the most fragile area of the entire body. The collateral damage caused by these treatments is significant, but acceptable if it saves the life of a child.

Because the parents and the doctors on our Foundation's Board have experience going through this ordeal, Making Headway understands that when one of "our kids" leaves the hospital, even if they are cancer-free, they and their

families will likely require much more support than other children who have been discharged. This is why we have created our unique Ongoing Care Team Program, which has two major components: Psychological Counseling and Educational Advocacy.

When there is a brain tumor diagnosis, imagine the emotional strains put on the child, the parents, and the siblings. Making Headway has a team of psychotherapists we contract with on an on-demand basis to help those in need, at no charge to the family. And realizing that dramatic educational disruptions occur as the child is being treated, Making Headway has a team of educational advocates who work to make sure that the child, who could emerge from treatment with very different needs and capabilities, receives the appropriate school-based services so that they can reach their academic potential.

Thankfully, medical advances have led to more pediatric brain tumor survivors. But the disease is still the number-one killer of children. That is why Making Headway also offers bereavement support, as well as financial assistance, when needed, for a burial.

No brain tumor is to be envied. Making Headway is here to make a bad situation as good as possible. Please help us with your generous donations, so that we may help more children and their families.

Stay well,
Elisa Greenbaum



FROM THE FOUNDERS

Dear Friends,

The results from Magic City, our recent fundraising event, were a record, exceeding every past year in which we had a winter show. We are amazed at this achievement. We can now not only continue to fund our comprehensive array of existing services, but add new ones, such as our recently implemented legal consulting services for immigrant families. We send our heartfelt thanks to all of you who donated so generously.

Edward P. Manley *Marya*

A LETTER FROM OUR EXECUTIVE DIRECTOR



Purpose

There are moments in the life of every person when a deep and quiet voice stirs within. It is the voice of conscience, of calling, of purpose. And in those moments, we are reminded of a critical question—not about ourselves, but about what we are actually doing for others in need.

Every day at Making Headway, our staff works with real heroes who provide life-saving and sustaining services for children with brain tumors. We sincerely recognize the nurses and doctors who care for and treat patients; researchers who are looking for better treatments; and the social workers, therapists, and care coordinators who directly and indirectly provide critical support.

At Making Headway, our impact is not always simple. It is in our extensive set of programs, services, events, scholarships, and grants. But it is also

in our long hours, in sharing difficult news, and in holding very personal spaces for both sorrow and for strength. Sometimes, it is just a smile for a family so they can feel—if only for a moment—that they are not alone.

For me, the answer to this question is to work in service of children battling brain tumors, not merely as a profession but as a holistic and personal commitment: A commitment to hope in the face of hardship. A commitment to compassion when pain is overwhelming. And a commitment to the belief that every child—no matter how small, how sick, or how scared—deserves the world's best possible care.

It may not be easy to find your own answer, but you can start by looking into your heart and imagining what it would be like if your child was diagnosed with a brain or spinal cord tumor.

In doing so, let us walk boldly together, hearts open and hands steady, knowing that we are not

alone. We are bound by purpose and lifted by the sacred truth that, in serving others, we become a family, and the very best of ourselves.

Together, we believe that love (when backed by meaningful action) is a force mightier than disease. We believe that even in the valley of uncertainty, there is a way forward, lit by the unwavering light of human goodness and hard work.

This is not just our job.
This is our mission.
This is our legacy.

Daniel Lipka, Executive Director

If you want to learn more about pediatric brain tumors and our work at Making Headway, please call me at (914) 238-8384. If you would like to support our mission financially, visit www.MakingHeadway.org/donate.

WHY SURVIVORSHIP MATTERS

Each year, thousands of kids are diagnosed with brain tumors—the leading cause of cancer-related death in children. Fortunately, advances in medical treatment have greatly improved these children’s chances of survival. Yet the need for healing does not end when treatment is over. As more children survive their initial diagnosis, the focus must shift from short-term outcomes to long-term survivorship care. Making Headway understands how survivorship

programs play a critical role in ensuring these children receive the support they need to thrive into adulthood.

Pediatric brain tumors are often treated aggressively, targeting the disease with surgery, chemotherapy, and radiation. While these treatments save lives, they can also cause long-term complications, including learning disabilities and memory problems, hormonal imbalances and growth delays, seizures, vision or hearing loss, emotional and mental health challenges, secondary cancers, and chronic illnesses. Survivors also may face difficulty returning to school, forming relationships, or entering the workforce. Many continue to struggle in

silence, often falling through the cracks once the hospital visits stop.

Survivorship programs are designed to address the myriad challenges pediatric cancer survivors may face. Yet despite their proven value, these programs often operate with limited funding. Many families do not have access to specialized follow-up care due to geographic, institutional, or financial limitations. When you support Making Headway and our long-term survivorship programs, you’re doing more than funding care—you’re giving survivors the tools they need to live full, meaningful lives. You’re helping a child walk not just out of the hospital, but into a future filled with potential.

20 YEARS AND COUNTING

By Trudy Perkins

When you first hear the word “cancer”—especially when it’s about your child—it changes everything in an instant. You feel hopeless, lost, and terrified. I remember crying hysterically when I got the diagnosis. The doctor told me, “Cry, scream, punch a wall if you need to—but then be strong for Jimmy. He needs you now more than ever.”

For our family, November 24, 2004 was the day our lives changed forever. My 15-year-old son, Jimmy, had been showing strange symptoms for weeks: vomiting, excessive thirst, talking nonsense, and falling asleep constantly. I went to multiple doctors, but no one had answers. One told me just to put him on antibiotics. Another said he needed to “hold his pee.” But I knew something was wrong. I trusted my gut and pushed for more. Finally, his neurologist ordered an emergency MRI, and that’s when they found the tumor on his pituitary gland.

They told me, “Go home, pack your bags, and head to NYU.” I was terrified, but in a way I was also relieved to finally have answers (and later grateful we ended up at the right hospital with the right doctors). Jimmy underwent chemo, radiation, and surgery. The side effects were brutal—hallucinations, anger, and confusion. It took three months of hospital therapy, and a full year of outpatient therapy, to get my son on the path to recovery.

Throughout that terrible ordeal, I leaned on every resource available—social workers, therapists, friends—but one of the greatest gifts was finding Maya and the entire team at Making Headway. Maya’s daughter had battled the same tumor. Her compassion, strength, and guidance helped me get through the darkest times. Making Headway became a light for us in the most difficult period of our lives.

Today, my son is a survivor, but long-term survivorship hasn’t been easy, and it never will be. Jimmy has faced decades of physical, cognitive, and emotional challenges that impact every aspect of our lives together. During this time, Making Headway has remained a constant source

of support. When Jimmy was in school, Making Headway’s educational advocates made sure he received all the services he needed. Making Headway’s team of psychologists also provided expert advice and counselling. Jimmy and I have also attended over 25 Making Headway family events, allowing us to connect with other pediatric brain tumor survivors and their families. Maya, Edward, and the whole Making Headway team remain a great resource to provide help for our family, from day 1 to day 7,538.

Jimmy made it through everything, and so did I. And while life changed dramatically in an instant, I’ve learned what truly matters: love, strength, and not sweating the small stuff.



Jimmy was first diagnosed in 2004 and is a long-term pediatric brain tumor survivor.

CARE AWARD

PRESENTED TO DR. JEAN DONNELLY



Making Headway is delighted to announce Dr. Jean Donnelly as the fifth recipient of our annual Care Award. This honor is

given to a professional who exemplifies Making Headway's mission and our dedication to children with brain or spinal cord tumors. Over the past 27 years, as a staff member at the Institute for Neurology and Neurosurgery and as a member of our Ongoing Care Team, she has provided thousands of hours of compassionate psychological care and healing directly to Making Headway families. Her unwavering dedication has eased the pain of countless families during life's most difficult moments. With deep gratitude, we honor her extraordinary impact. We asked Dr. Donnelly to tell us her story:

All of us who become seriously ill quickly learn that we will need to change our plans. If illness comes when we are young, it is especially hard to have our lives go off the track we had expected to follow. We wait so long to be able to do the

things that most people do ordinarily, like going to school or work. Getting cancer as a young woman delayed many things I had wanted; but finally, after finishing my training at Memorial Sloan-Kettering, I could work. Because of Making Headway, at the age of 50, I got the job of my dreams.

My own experience was that the psychological recovery from cancer was even more difficult than the physical recovery. I wanted some good to come out of all I had gone through: to help others, especially children, cope with illness. When Making Headway was just starting, their founders shared this vision and they were committed to staffing a full-time, dedicated child psychologist to help children getting treatment for brain tumors. I was the lucky person to get that job.

The almost 27 years that I have worked with Making Headway have enriched my life immeasurably. The families who travel the treacherous road through illness are inspiring: children who endure misfortune with strength and grace, parents who model selfless dedication. They have convinced me that there is more good in this world than most of us

could ever imagine. For the last several years before his recent death, I took care of my husband, who had Alzheimer's Disease. Many ask me how I could stand the physical and emotional demands of caring for someone around the clock, day after day, night after often sleepless night. For me, a large part of the answer is clear: For years, I had been working with parents who cared for their children with a dedication that defied the limits of their exhaustion, their sadness, and their fear. Complete devotion was, and is, and will be the norm. At my most difficult times as a caregiver, the thought of these parents kept me going.

Complete devotion to those who need them is also the principle that guides Making Headway. Just trying to get healthcare can cause frustration and anxiety. Getting psychological care is even harder. Making Headway provides a range of help, so that the hours on the phone with insurance companies and social service agencies can be dramatically reduced, to say nothing of the expense. But, for the people who lead and support Making Headway, the bottom line is always about care. I am grateful to them beyond words.

COLLABORATION AND RESEARCH



For pediatric brain tumor researchers and clinicians, the annual meeting of the Pediatric Society for Neuro-

Oncology (Peds SNO) is one of the most important gatherings of the year. This conference provides a platform for the sharing of novel ideas and results, fostering new collaborations and offering attendees a state-of-the-art update in the field of pediatric brain tumor research. In 2025, Making Headway Foundation sponsored Dr.

Ammar Naqvi to attend and present at this event. Dr. Naqvi is a bioinformatics scientist at Center for Data Driven Discovery in Biomedicine (D³b) and the Children's Brain Tumor Network (CBTN). At D³b, he utilizes machine learning and predictive modeling combined with traditional molecular biology to gain an understanding of basic molecular mechanisms underlying tumorigenesis.

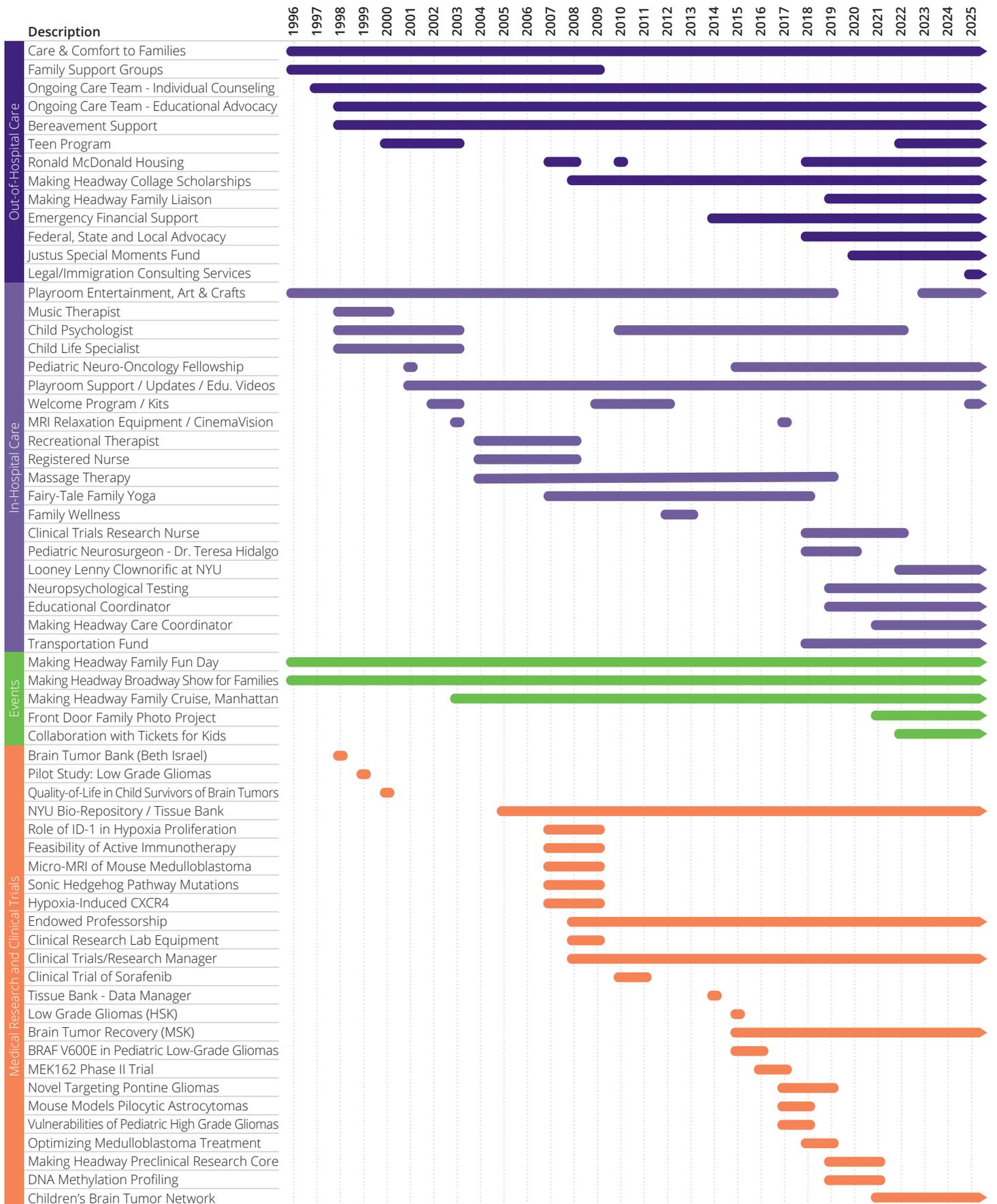
At Peds SNO, Dr. Naqvi presented on integrating splicing and proteomic data into pediatric brain cancer research. Sessions on extrachromosomal DNA (ecDNA) sparked new questions and strategies for multimodal data integration—highlighting how CBTN datasets could be further leveraged.

He also connected with potential collaborators to explore validation of microRNA biomarkers and to discuss future data-sharing opportunities.

"The conference emphasized the need to consider multiple data angles simultaneously—genomic, transcriptomic, epigenetic, and proteomic. It encouraged me to rethink how we structure our pipelines... Attending conferences like Peds SNO is absolutely critical to advancing our research. These gatherings are more than just presentations—they're opportunities to gain insider knowledge, troubleshoot challenges, and spark entirely new ideas."

—Ammar Naqvi

29 YEAR TIMELINE OF MAKING HEADWAY



IN AWE OF DR. JESSICA CLYMER'S UNFORGETTABLE CARE FOR BRANDON

By Steve Marder

Writing about Dr. Jessica Clymer is something we've wanted to do for some time. While we've only known Jess (as she immediately becomes known to her patients/families) for about a year, it's as if we've spent over a decade together while she was caring for Brandon, our beloved 12-and-a-half year old whom we lost in March 2025: the strongest, sweetest and "true best" the world has ever seen. That's why talking and writing about how truly special and wonderful Jess is as a person and physician is so natural and necessary, even and especially through the true worst of times.

When you are handed a diagnosis for your child as world-shattering as a secondary pediatric brain tumor, reality immediately enters another dimension from which there is no going back. Everything you thought you knew about time, priorities, and fear shifts in an instant—exponentially so, even in comparison to a primary pediatric cancer diagnosis. In the middle of the turbulence resulting from Brandon's August 2023 diagnosis, we were fortunate enough to wind up in the care of Dr. Jessica Clymer, with whom we were connected by the remarkable and extraordinary Dan Lipka and Making Headway. Jess is a physician and now close friend whose name we now say with reverence and deep gratitude. What she has given to our Son (yes, always capitalized), Brandon, and to us as a family, was/is way more than medical care. Much of it is definitely not taught in medical school. Part of what Jess brings includes presence, precision, hope, bravery, grit and heart—along with the prerequisite medical brilliance—a combination not often encountered, even in pediatric oncology.

From our very first telehealth meeting, Jess brought clarity to chaos and was clear on her intention to let Brandon lead us all. She didn't just show up in a formulaic manner—she faced us with compassion, knowledge, courage, and the rare ability to speak to us not just as a doctor but as a welcoming human being that jumped through the computer screen. Jess made eye contact like what you might normally experience in person with your dearest friend. She asked the questions that really mattered to give Brandon the very best care. She listened not just to our answers but to our silences. And somehow, without minimizing the seriousness of the situation, she helped reaffirm our belief (yet not with false hope) that we could navigate this and would give it our collective all, for a child that deserves both none of this and so many times more than the effort we could ever collectively provide. (And yes, it's absolutely not lost on me that that describes every single pediatric oncology patient, at any and every stage.)

We landed in the Pediatric Intensive Care Unit (PICU) at NYU, truly where we needed to be to best help our Sweet Boy, Bran. There we were lucky enough to overlap extensively with Dr. Gwynne Latimer, an attending physician who is sort of the yin to Jess' yang. With a compassion and skill—combined with the constant level-headedness of a fighter pilot in an active dogfight—Gwynne single-handedly orchestrated and personally performed life-saving care for Brandon over many months and multiple visits, long and short. In the most critical moments—in the face of truly critical emergencies, impossible decisions, new scans, and the dreaded wait times between test and result—Jess and Gwynne were always a steadying force, checking in on us even remotely if one or both were off-duty and



Dr. Gwynne Latimer (left) and Dr. Jessica Clymer (right).

even abroad ("stalking the chart" 24/7 as they do), often coming in during their off-time to be there for us, first as friends, and a close second as the world's most top-notch doctors. Their explanations were never rushed, but their attention was always immediate. Their tone: always calm and direct, hopeful but not delusional. Even when the news was difficult or worse, we trusted them completely, particularly if we had to debate or make a decision that is normally not recommended—because of the way they respected Brandon and respected us.

Even now, as we move forward, Jess' impact lingers every day. Our family talks about her daily. She gave us language when we had none. She gave us a plan when we had only fear and fight, especially when other institutions and teams had long since said they simply wouldn't and couldn't help. And in a system that can often feel impersonal, overwhelming, and isolating, she gave us care that felt deeply personal and exactly right.

I don't know if she realizes how rare that is—or how deeply it's appreciated. But I hope this note helps convey it. For the benefit of future fighters and their families, Dr. Jessica Clymer is more than a remarkable physician. She's a healer, a protector, and a light during the darkest times. Our family will always keep her close as we try to turn pain into purpose to help others in similar situations.

A GAZILLION SMILES

Earlier this spring, Making Headway Foundation treated 17 of our families to a special performance of the Gazillion Bubble Show in NYC. It was a spectacular event and the families had

a wonderful time. As a special bonus, all our kids got to go on stage with the star of the show, Guinness World Record holder Fan Yang. This special event was made possible through support from the Justus Special Moments Fund at Making Headway. If you are interested in raising funds to host an event like this, just call us at (914) 238-8384.



Making Headway Kids with Broadway star Fan Yang.

A MAGICAL BROADWAY EVENT

Besides being our largest fundraiser, Making Headway's Annual Spring Broadway show is also one of our biggest family events. On April 6, Making Headway welcomed over 400 guests to a special showing of *The Magic City* at the New Victory Theater. It was a fascinating, one-of-a-kind experience. The audience watched the back of the stage as the cast performed a live show

with puppetry and shadow play that was projected onto a video screen. The plot involved the fantastical adventures of two step-siblings in a "magic city" that they created. Themes dealing with adapting to life's changes made it especially poignant and thought-provoking. It was wildly creative and our guests—especially the kids—loved it. As an extra bonus, the New Victory Theater offered free arts and crafts activities before and after the show. Making Headway is so grateful to all our donors who sponsored tickets for families to be part of this wonderful afternoon. Thank you!



Making Headway's co-founders, staff, and families get together after seeing *The Magic City*.

GAINS FOR BRAINS

The annual Making Headway Gains for Brains Lacrosse Tournament was held this past April. Known as the premier high school girls' lacrosse showcase in the country, Gains for Brains featured 20 teams, including four of the top 10-ranked teams in the nation. In one of the most exciting matches of the day, the #1 ranked team, St. Anthony's,

made a dramatic comeback to win after trailing 5-0 in the first quarter.

Since this event started in 2016, Gains for Brains has raised over \$85,000 for Making Headway. We are so grateful for the ongoing support from the many teams, players, and volunteers who make the event possible. It's not too late to join in—if you want to support Gains for Brains, you can still donate at <http://weblink.donorperfect.com/gains>.



National #1, St. Anthony's High School, headlined this year's Gains for Brains.

FAMILY FUN DAY

On June 8, 2025, Making Headway Foundation hosted its 30th annual Family Fun Day. The event, held at Dave & Buster's in Brooklyn, welcomed over 400 attendees, including survivors, siblings, parents, caregivers, and volunteers, for a much-needed day of laughter, play, and community. Guests enjoyed unlimited access to video games, participated in arts and crafts, had their faces painted, laughed at the antics of our clowns, and shared a delicious lunch. Thanks to the generosity of our partners—Spin Master, Adidas, and LeSportsac—families also took home exciting gifts and toys. Family Fun Day is one of many ways Making Headway supports families affected by childhood brain and spinal cord tumors. It's a chance for everyone to come together outside of hospitals to simply enjoy each other's company in a joyful, supportive environment.



Photo Credit: Vlad Kolesnikov

"I wanted to take a moment to express my deepest gratitude for organizing such an incredible Family Day! It was truly a blessing to meet and connect with so many other uniquely abled families who understand and share our journey. Your kindness, support, and dedication to creating a sense of community and belonging for families like mine are truly inspiring. I'm so grateful for the opportunity to be part of this community and for all that you do to make a difference in our lives. Thank you again for an unforgettable experience!" —Tracey Jackson (mother of Tristian)

SAVE THE DATE: YACHT CRUISE

Making Headway Family Yacht Cruise to the Statue of Liberty

Sunday, September 14, 2025

Boarding at noon:
World's Fair Marina, 1 World's Fair Marina, Flushing Queens, NY 11368

This event is open to any family that has a child diagnosed with a brain or spinal cord tumor. Space is limited. Registration will open soon at www.MakingHeadway.org/cruise.



THE IMPORTANCE OF FEDERAL RESEARCH AND ADVOCACY



The US National Institutes of Health (NIH) and the National Cancer Institute (NCI) are, by far, the largest funders of pediatric brain tumor research in the world. They directly conduct research and fund grants aimed at finding better treatments and a cure. These federally funded agencies also run clinical trials, host collaborative groups, maintain critical research infrastructure like biobanks and datasets, train the next generation of pediatric brain tumor researchers, and much more. Discoveries are still rare, but without these investments, they would be virtually impossible. However, funding to these organizations is not always guaranteed.

Head To The Hill

Each year, Making Headway sponsors pediatric brain tumor survivors and advocates to attend Head to the Hill, an advocacy event organized by the National Brain Tumor Society (NBTS) in Washington, DC. We join hundreds of others from around the country to make our voices heard and tell Congress about the legislative priorities of the brain tumor community. This year Making Headway sponsored five families to travel to the event and advocate for maintaining federal research funds, as well as for specific legislation, like the BRAIN Act (a bill that would strengthen

research efforts, accelerate the quest for cures, improve access to cutting-edge treatments, and innovate the way health care is delivered for patients and survivors of brain tumors).

Federal Funding: From the Lab to the Clinic

2024-25 provided many real-world and concrete examples of how the NIH and NCI have directly benefited actual patients. For decades, there were only a handful of drugs approved to treat pediatric brain tumors. But over the last year, several new drugs were approved and hit the market. These novel treatments offer patients with specific types of brain tumors targeted treatment plans for the first time. Here are two examples:

The original studies to identify Ojemda (tovorafenib) as a potential treatment for pediatric low-grade gliomas were supported by three different NIH/NCI funding programs. In trials, this treatment had a clinical benefit rate in which 93% of patients had tumor shrinkage and disease stabilization. On April 23, 2024, the Food and Drug Administration (FDA)

granted accelerated approval for Ojemda for patients 6 months old and older with this type of brain tumor.

The genetic mutations that Voranigo (vorasidenib) targets were first discovered in brain tumors and published in a 2008 paper citing funding from eight different NIH grants. A follow-up study in 2009, funded with 11 different NIH grants, further illustrated how pervasive these mutations were. In Phase 3 trials, Voranigo showed a 61% reduction in the risk of disease progression or death (compared to a placebo). On August 6, 2024 the FDA approved Voranigo for pediatric and adult patients (12 years and older) with Grade 2 astrocytoma or oligodendroglioma.

For a variety of reasons, pharmaceutical companies rarely invest in treatments to help children with brain tumors. Realistically, it is only through funding from the NIH and NCI that improved new treatments will become a reality. To learn more or get involved visit makingheadway.org/advocacy/ or call us at (914) 238-8384.

“It was so heartwarming and uplifting to be with a group of people affected by brain tumors, training and advocating together in DC. We use our strength to make a difference for other cancer and brain tumor patients, even in the most uncertain of times. NBTS and Making Headway are champions for hope in this nation and the brain tumor community needs more of it.” —Greg Licciardi, pediatric brain tumor survivor and Making Headway supporter



PRESS RELEASE



Hassenfeld Children’s Hospital at NYU Langone Joins the Children’s Brain Tumor Network to Accelerate Pediatric Research

Children’s Brain Tumor Network (CBTN) welcomes Hassenfeld Children’s Hospital at NYU Langone as a new member institution. Dr. Jessica Clymer, a pediatric oncologist at NYU Langone, will serve as CBTN principal investigator.

“Hassenfeld Children’s Hospital is excited to join with other CBTN institutions as we work together to advance pediatric brain tumor research and provide the best care for our patients,” said Dr. Clymer. As part of CBTN, Hassenfeld Children’s Hospital contributes consented pediatric brain tissue and biospecimens to improve understanding of brain tumor biology. Collaboration through CBTN is critical, as no single institution can gather enough samples on its own to make meaningful progress in pediatric brain tumor research.

Hassenfeld Children’s Hospital at NYU Langone is located on the NYU Langone Health campus in Manhattan and is one of the oldest pediatric tumor centers in New York City. Since 2005, NYU’s pediatric brain tumor research efforts have received support from Making Headway Foundation to store pediatric brain tissue. In 2019, Making Headway Foundation set out to formalize a partnership between NYU and CBTN by funding a CBTN Care Coordinator to oversee pediatric brain tumor sample management at NYU.

“We are so proud to play an important part in this collaboration, as it directly connects to our mission of providing care and comfort for children with brain and spinal cord tumors while funding medical research geared to better treatments and a cure,” said Daniel Lipka, Executive Director of Making Headway Foundation.

Jena Lilly, Executive Director of the Children’s Brain Tumor Network said, “We’re thrilled to welcome Hassenfeld Children’s Hospital at NYU Langone to the Children’s Brain Tumor Network. Together, we are amplifying our efforts to advance pediatric brain tumor research and bring renewed hope to children and families in need of better treatments and brighter futures.”

About Children’s Brain Tumor Network

Children’s Brain Tumor Network is a global research initiative that accelerates pediatric brain tumor treatments. With 34 member institutions, CBTN has collected over 82,000 biospecimens and enrolled 7,900 participants, creating one of the largest childhood brain tumor data repositories in the world. Its advanced platforms enable real-time collaboration to improve outcomes for children with brain tumors. Learn more at cbtn.org.

ONE YEAR SINCE OUR HEARTS SHATTERED

By the Bonet Family

A day after our baby boy turned 6 months, a routine appointment became an emergency room visit where we learned our son, Nico, had pediatric brain cancer. In the year since, he’s endured five surgeries, countless treatments, and unimaginable challenges—all with a smile. His bravery has shown us what true courage looks like.

And through it all, our sweet dog Minnie has been his protector and cheerleader. She comforts Nico when he cries, motivates him during therapies, and showers him with unconditional love. She’s been the best big sister. Sharing the joy she brings us with others on social media has also become a therapeutic bit of lightness for us. Maybe she can do the same for you – www.instagram.com/minniepennyb.

For the 1st anniversary of Nico’s diagnosis, we’ve shared our story to raise awareness and support organizations like Making Headway, who have supported us through this fight.



Nico and Minnie share a special bond.

They’ve provided us with resources, comfort, and hope, and we want to pay it forward. In honor of Nico’s milestone, we ask that you consider donating to this incredible organization at www.MakingHeadway.org/donate. Thank you for standing with us.



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 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.



SEEING THE UNSEEN

By Max Chwatko

To most people, things like feathers, rainbows, or objects found on the street are ordinary. But to me, they can carry a different kind of meaning. Six years ago, when I was ten, I lost my younger sister Scarlett to brain cancer. She was only eight, and she was my best friend. Her absence left a silence I didn't know how to fill. At the time, I leaned on logic to make sense of what had happened. So when my mom said certain things were "signs" from Scarlett, I felt frustrated. It seemed like wishful thinking, and I didn't understand how something so painful could be comforted by small, random moments.

But over time something shifted. Now, I notice the little things. A rainbow reflection in the form of the letter M

just before my SAT. A butterfly landing on me on her birthday. A tiny Eiffel Tower charm beneath my foot while visiting the college I hope to attend, (Scarlett had always dreamed of going to Paris). Bright feathers often appear during walks with my dog, standing out like they were left there for a reason. My dog herself came to us quite by accident, through an unbelievable and inexplicable series of luck and mishaps, arriving on Scarlett's birthday, our first without her. None of these moments are loud or dramatic, but they no longer feel like coincidences either.

I used to think believing in signs meant refusing to accept reality. Now, I believe it means choosing to see beauty in it. These reminders of Scarlett bring me peace. They help me carry her with me, not just in memory, but in motion. She may not be here the way she once was, but in these small, quiet ways, I know she still is.