Summer 2026

makingnews

Highlights

Letters from Making Headway • Family Stories • New Investment in Medical Research • Family Fun Day • New Family Liaison • 30 Years of Making Headway • Care Award • Events • Legislative and Advocacy Achievements • CBTN Updates • Real Families Real Impact

Making Headway launches new legal services for families. See page 5 to learn more.

30th Anniversary Edition

Calvin and his little brother Max at Making Headway's 2026 Family Fun Day, held at Nickelodeon Universe. Calvin, age 3, who was diagnosed with medulloblastoma last year, had a wonderful day alongside over 550 of our guests. More on this event on page 10.

making headway foundation

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

www.makingheadway.org

Letter From Our Chair

Questions

How old is he? This question is innocent enough, unless your child has a brain tumor. When my husband Clint and I were asked about our son Jake's age, we'd state his then current age (which was older than both his appearance and his actions/abilities). Then Clint would always add, "But he laughs at an advanced level!"

Joyful Jake celebrating his 30th Birthday. We had no idea it would be his last.

More questions: How come he doesn't talk? Is he autistic? Can he hear? Does he understand you? It's tough to handle questions like these. Imagine if you are a sibling of a child being treated for a brain tumor who gets asked: Why is your sister bald? Where are your parents? (Usually taking care of the sick sibling.) Imagine having to be the kid with the brain tumor, having to field these questions directly (if they even can).

With this in mind, it should be easy to understand that for the sick child, the siblings, and the parents, the collateral damage caused by a child's brain tumor includes the psychological challenges that can affect each member of the family. And a child's illness or death can lead to many types of additional stresses, including marital. Some need help understanding or working through difficult and painful feelings. Others have a hard time finding the language to articulate their feelings or concerns.

To help ease this mental strain, Making Headway offers individual, free-of-charge short-term counseling sessions, conducted in person or by phone. These professionals are licensed local psychologists and social workers, each with specialized training to address the unique issues faced by the sick child, their parents, and their siblings. Expert mental health care like this is almost as important as medical care.

Finally, the crusher questions: Is your child going to die? Although most will never directly ask this question, the eyes and actions relay the thought of the person who is full of pity. And the toughest question for us since Jake died: How many children do you have? Note the present tense of have. This question is really difficult for the parents of a deceased child. Clint and I know firsthand.

Stay well,

Elisa Greenbaum

As Chair of Making Headway, I have a question for you, the reader: After reading the rest of this newsletter, how can you possibly put it down without wanting to help? In order to have received this, you must have some connection to a child with a brain tumor. You know the answer as to how you can help: make a donation today in honor/memory of your connected person, or in honor of Making Headway's 30th Anniversary, so that we can continue doing what we are doing. Thank you!

Making Headway Research Grant

Developing a Novel Ultrasensitive Pan-CNS Cancer Liquid Biopsy Assay

Diagnosing and monitoring brain tumors can be enormously challenging. Many tumors are located in delicate areas of the brain where surgery is risky or even impossible. Even after treatment begins, doctors often struggle to determine whether scans indicate that a tumor is growing again or are simply showing inflammation or the effects of treatment. Currently, in order to effectively diagnose and treat children, doctors must perform brain surgery (when possible) in order to collect tumor samples.

Instead of relying on potentially dangerous procedures, imagine if doctors could get all the tumor information they needed from a small sample of cerebrospinal fluid (CSF).

Dr. Matija Snuderl, Professor, Department of Pathology at NYU Grossman School of Medicine; Director, Molecular Pathology

This is known as a "liquid biopsy" and researchers led by Dr. Matija Snuderl at NYU Langone are using an advanced new technique to explore making this technology a reality. Dr. Snuderl is a

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From the Founders

"Why is everything on the menu listed twice?" This was the question posed by our daughter Cynthia in 1981 while vacationing out west with our family. She was experiencing double vision, and we knew immediately that something was wrong. Upon returning home, and after many tests, we were given the diagnosis of a brain tumor. The tumor, pressing on her optic nerve, had caused the noticeable disturbances to her vision. And so started our difficult journey with surgery, chemo, and radiation, turning what had been an "idyllic" family life upside down.

Due to good insurance, we were able to get Cynthia the best care available. We were also fortunate enough to be able to afford the many services we needed after she left the hospital, including therapists, educational consultants, and tutors. But that got us wondering; what do other, less fortunate, families do?

That was the main reason we established Making Headway in 1996, and since then have dedicated our efforts to making the journey easier for families in a similar situation. The past 30 years have been extremely satisfying for us, starting a foundation from scratch and building an organization that is able to assist so many families each year in a multitude of ways. As you read this newsletter, we hope you will learn more about our mission, our successes, and how you can help us continue on our path.

With warm regards,

Edward Maya

Maya and Edward Manley

Making Headway and Juliana, Both Turning 30 Years Old

By Chantal LoPiccolo

Can it really be 30 years? Yup, it has been 30 years since our beautiful, bright daughter Juliana was born. It has also been almost 20 years since Juliana was diagnosed with a tectal plate glioma and severe hydrocephalus. I still remember that day: when Juliana briefly lost her short-term memory, which was the latest and scariest of a series of odd symptoms that no doctor had yet properly diagnosed. That day was one day before her 10th birthday party.

Juliana Diamond-LoPiccolo with her baby boy.

Juliana's pediatrician said to take her immediately to the nearest hospital emergency room. When we got there, Juliana was her usual chatty vivacious self, telling the triage nurse with dramatic effect, "I lost my memory! I forgot that my birthday party is tomorrow." We were eventually seen by a young intern who noticed what no other doctor had recognized: Juliana's very pretty head was larger than is typical. A scan revealed severe hydrocephalus and Juliana was immediately admitted to the ICU. We soon learned that Juliana had a brain tumor. Needless to say, we were terrified.

Fortunately, we were transferred to NYU Medical Center where the wonderful pediatric neurosurgeon, Dr. David Harter, operated on her. The surgery, a third ventriculostomy, relieved the pressure caused by the hydrocephalus. The brain tumor remained, but most of her symptoms disappeared and she eventually had her birthday party!

The good fortune of being treated at NYU meant that Dr. Jeffrey Allen became Juliana's neurologist, and he introduced us to the absolutely beyond-awesome Making Headway Foundation. In those early days, seeing Maya at the Hassenfeld Center made the visits feel less scary. In fact, every time over the last twenty years that I've had the pleasure of being in Maya's presence I've immediately felt a sense of calm. With Making Headway's help, we learned to advocate for Juliana over the symptoms that remained and, over time, Juliana learned how to advocate for herself.

The ways in which Making Headway has helped our family over the last 20 years are numerous and blessings beyond all measure. And when I reflect on Juliana's almost 30 years, I think of how awe-inspiring, complicated, anxiety-provoking, life-affirming, and joyous these years have been. Juliana is doing incredibly well. She's now a lawyer, married, and gave birth last year to a healthy baby boy. Thank you Making Headway!! You've been there for her every step of the way.

Making Headway's New Family Liaison

I am so excited to be a part of the Making Headway family. It is an honor, and a serious responsibility, to support children and families who have been, and continue to be, affected by devastating diagnoses and medical crises.

I am a pediatric brain cancer survivor. I was diagnosed with an Anaplastic Astrocytoma and treated when I was 13 years old. Since that time, it has been my mission to work alongside youth and families navigating all the challenges that come with cancer treatments and the uncertainty and loss that accompany these experiences. I am enthusiastic to have the opportunity to truly fulfill this mission at Making Headway. Joining this team allows me to help families navigate difficult systems, find support, and build meaningful connections with others who truly understand their journey.

As Making Headway's new Family Liaison, I am also excited to work with our incredible Ongoing Care Team of psychologists, psychiatrists, social workers, educational advocates, and legal experts. I know firsthand how important a strong support system can be. Without my own care team, my life could have turned out very differently. I fully appreciate how overwhelming and life-changing a diagnosis can be, and I want families to know they do not have to face it alone.

At Making Headway, my goal is to be someone families can turn to for support, guidance, and thoughtful empathy. I will connect families with the resources and services available through our wonderful Ongoing Care Team, as well as services throughout their community. I will always be a compassionate source of encouragement and care, even (and especially) during the most difficult of times.

In addition to being a pediatric brain tumor survivor, I am a mother of two young children, so I also recognize the importance of family, togetherness, and having support during life's unexpected challenges. By tapping into these personal experiences, I will do everything possible to be a source of comfort and support for those dealing with anxiety, sadness, loss, and uncertainty. I understand, on a personal level, how overwhelming and life-changing a brain tumor can be, and I want families to know they do not have to face it alone.

As we are going to press on this newsletter, I was so excited to attend my first Making Headway Family Fun Day, meet the children and families, hear about their experiences, and introduce myself in person. Moving forward, I will do my very best for every family who I have the privilege of connecting with.

Tangi Walker-Rennalls, LMSW
Making Headway Family Liaison
family@MakingHeadway.org, (914) 354-0264

30 Years

By Eileen Benthal

This year marks a very big milestone in my daughter Johanna's life. Like Making Headway, she will be turning 30 later this year. Some days it seems like yesterday when I held my three-month-old baby in my arms as my husband and I looked at the CT image of her brain drowning in cerebrospinal fluid. As the neurologist pointed to a large mass compressing her brain stem, I held my baby closer to my breast hoping she wouldn't notice my racing heart.

Jo was rushed to the operating room that night to have an external catheter placed in her tiny brain until plans for a tumor resection could be finalized. Eighteen months and six brain surgeries later, it was Jo's neurosurgeon on Long Island who sent us to the Institute for Neurology and Neurosurgery (INN) at Beth Israel. Here, Drs. Jeffrey Allen and Fred Epstein discussed the brainstem tumor which was already growing back in my baby's brain. At the INN, Maya greeted our entire family in the playroom and kept our older children busy while my husband and I met with the doctors. We were met with faith, hope, and love: faith that a greater story was being written than we knew, hope that even in our darkest hours we were surrounded by light and love.

Making Headway's support in the playroom and in the integrative therapies of music, movement, and laughter they've provided, inpatient and out, have been an integral part of our family's journey. Thirty years feels like yesterday. While most of our friends are moving toward retirement, we are still reading treasured children's books and playing games with Jo. But even though some things are childlike, Jo's wisdom is way beyond her years.

Making Headway, most especially Maya and Edward, have always reminded us that we do not walk this journey alone. My prayer is that Jo live a long and fruitful life and I live just a little bit longer. I'm certain Making Headway will outlive us all because it is powered by more than financial donations. Making Headway is powered by people with visions of faith, hope, and love.

Happy 30th birthday to Jo and to Making Headway. Our family is eternally grateful to you both.

Making Headway Free Legal Services Program for Families Is Now Available

When a child is diagnosed with a brain tumor, families are suddenly forced to navigate not only overwhelming medical decisions, but also a complex web of potential legal issues. Parents may need help securing insurance coverage, accessing disability benefits, protecting employment rights while taking time off for caregiving, arranging guardianship or estate planning, and ensuring appropriate school accommodations during treatment and recovery. At a time when families should be focused entirely on their child's health and well-being, the burden of these legal issues can create additional stress and uncertainty. Access to compassionate, knowledgeable legal services is essential to help families protect their rights, maintain stability, and concentrate on what matters most: their child's care.

Making Headway Foundation is now offering free legal support services through a partnership with LegalHealth, a division of the New York Legal Assistance Group (NYLAG). As the country's largest medical-legal partnership, LegalHealth has been providing legal services to patients for 25 years, currently in 38 hospitals and community-based health centers in New York City, Long Island, and Westchester County.

To learn more about scheduling a free and confidential legal consultation, you can register online at makingheadway.org/register, email us at family@makingheadway.org or call (914) 238-8384. Please note that meeting with Making Headway's LegalHealth attorney does not guarantee legal representation.

If your child has been diagnosed with a brain or spinal cord tumor, you may be eligible for free legal support relating to any of the following concerns:

- **Securing Government Benefits:** Medicaid, SSDI, home care and long-term care benefit assistance, disability-related benefits, advocacy, etc.
- **Housing Problems:** Eviction prevention, housing preservation referrals, accommodations related to disability or illness, etc.
- **Immigration:** Comprehensive immigration screenings to determine whether you have pathways to regularize your immigration status, family preparedness for parents concerned about deportation/ detention, work authorization issues, naturalization, replacement green cards, etc.
- **Planning Ahead:** Wills, health care proxies, powers of attorney, and 17A guardianship
- **Medical Insurance:** Denials of medical claims, prescription coverage, denial or disputes involving short- or long-term disability benefits, etc.
- **Employment/Income:** Employment advice connected to illness/ disability, workplace leave issues and job/income protection

Thank You, Volunteers!

These past 30 years have been defined not only by the needs of the families we serve, but also by the extraordinary response of the people who chose to stand beside them. At Making Headway Foundation, we are profoundly grateful to the countless volunteers whose time, energy, and compassion have strengthened every part of our work. We are sincerely grateful to our volunteers who have organized family events, lent professional expertise, stuffed envelopes, helped behind the scenes, and stepped in wherever they were needed most.

What makes our community so powerful is not just what gets done, but how it gets done. Every act of service is grounded in empathy for children facing brain and spinal cord tumors. Each of our volunteers has helped with specific tangible tasks, and has done so with warmth, energy, and enthusiasm. Their commitment allows Making Headway Foundation to extend its reach further and to respond more fully to the needs that arise each day.

There are literally too many volunteers to name here, but you know who you are. Making Headway is honored to work alongside each of you. All our volunteers remind us that progress is never made alone, but it is built together, day by day and person by person.

If you are interested in volunteering at Making Headway Foundation, please contact Dan Lipka at dan@makingheadway.org or (914) 238-8384. Thank you.

A Generation of Change:

Pediatric Brain Tumors, Then and Now

When Making Headway was started 30 years ago, a diagnosis of a pediatric brain tumor came with far more uncertainty than hope. In the early 1990s, overall five-year survival rates for children with brain tumors hovered around 55–60%. Treatments were often aggressive and imprecise, and for many families the unknowns were as overwhelming as the disease itself.

Today, that landscape is profoundly different. Overall survival has risen to roughly 70–75%, and for some tumors, like low-grade gliomas, survival rates now exceed 90%. These numbers represent not just scientific progress, but thousands more children living longer, fuller lives.

We can now see these tumors with extraordinary clarity. Advanced imaging reveals not just where a tumor is, but how it behaves. Surgeons operate with a level of precision that was once unimaginable, guided by real-time imaging and brain mapping that help protect the parts of a child's brain responsible for speech, movement, and memory. What was once high-risk has become safer, more controlled, and more hopeful.

But the most powerful shift has happened at a deeper level. We no longer define pediatric brain tumors simply by how they look, but understand them by what they are. The discovery of their genetic and molecular identities has changed everything. Tumors that once seemed identical are now recognized as fundamentally different diseases, each with its own risks and, increasingly, its own treatment path.

This transformation has led to more tailored therapies, and in some cases, a reduced need for potentially toxic treatment. For example, many children with standard-risk medulloblastoma now achieve survival rates of 80–85% with carefully balanced therapy designed to reduce long-term harm. At the same time, emerging targeted treatments and immunotherapies are beginning to reshape outcomes for certain subgroups.

Just as importantly, survival is no longer the only measure of success. Nearly two-thirds of survivors experience some long-term effects from treatment, including cognitive or developmental challenges. In response, modern care has shifted to reduce these burdens—refining radiation doses, delaying or avoiding therapy in very young children, and expanding long-term support.

And yet, for all this progress, the story is not finished. Some of the most aggressive tumors remain devastating. Diffuse midline gliomas, for example, still have a median survival of less than one year, a statistic that has changed little in decades.

What has changed is the momentum. Across the world, collaboration has accelerated discovery, with more children enrolled in clinical trials than ever before. Breakthroughs in genomics, drug development, and precision medicine are building on one another at a rapid pace.

There is still work to do. But for the first time in a generation, the numbers, and the children behind them, are moving in the right direction.

1996: Dr. Fred Epstein, shown here with Mikey Schwartz, said "The caring support that Making Headway makes possible is a valued part of the care we provide."

2006: Making Headway Co-Founder, Maya Manley, at the NYU Hassenfeld Center playroom.

2016: The first annual Race for Ace, held in loving memory of Andy Ecker.

2026: Making Headway Chair and Vice Chair, Elisa and Clint Greenbaum, pictured here with Brittany and Ellie Cogan.

Making Headway Accomplishments: 1996–2026 by the Numbers

For the past 30 years, Making Headway has touched the lives of thousands of families. While we strive to capture our impact through surveys and patient stories, reviewing the numbers can also help showcase many aspects of our work. Below are some of our key measurable achievements.

Direct or indirect support to over
2,344
families

8,600+
hours of educational advocacy services

17,500+
hours of individual and family counseling

87%
of all donations have gone directly to programs and services

More than
90
events for families

Invested over
$30M
in grants, services, programs, and events for families impacted by a childhood brain or spinal cord tumor

Over
70
published research papers as a direct result of our grants

201
college scholarships

10
fully funded neuro-oncology fellowships

Funded over
176
research and quality-of-life programs at local hospitals

88,000+
donations, from more than
27,000
unique households

For 30 years, individual donors have been the heart of our sustainability, providing over 95% of the funding that makes our work possible. Every program, every service, and every moment of support offered to children with brain and spinal cord tumors and their families has been strengthened by the compassion and generosity of people who chose to make a difference. We are profoundly grateful to those who have stood beside us throughout the years. As we look ahead, the commitment of both current and future donors will be critical to ensuring that no family faces this journey alone and that hope, care, and support remain available for years to come.

makingheadway.org/donate

Making Headway Family Care Award:

Presented to Dr. Jeffrey Allen

On behalf of the Making Headway Board of Directors, and the thousands of families we have worked with, we are honored to award a special 30th Anniversary Care Award to Dr. Jeffrey Allen. Dr. Allen's 50 years of service are a model of compassionate medicine, visionary leadership, and unwavering dedication to children and families facing some of life's hardest challenges. Over his distinguished career, Dr. Allen has earned national recognition as one of the country's leading pediatric neurologists and pediatric neuro-oncologists, while never losing sight of the human side of care. Families navigating frightening diagnoses of their children have consistently found him to be a physician who listens carefully, explains clearly, and treats each child with dignity and kindness. Dr. Allen has tried to provide a more hopeful alternative for countless children diagnosed with brain and spinal cord tumors. His well-earned reputation has been built not only on clinical excellence, but on the trust he inspires.

Dr. Allen altered his professional goals early in his career following his two-and-a-half year old son's diagnosis of a malignant soft tissue sarcoma—sadly, he died four years later. By then, Dr. Allen had joined the Memorial Sloan Kettering (MSK) medical staff as a pediatric neurology consultant, one of the first pediatric neurologists in the country to specialize in caring for children with cancer.

While his initial responsibility was to help pediatric oncologists at MSK manage neurological complications of pediatric cancers such as leukemia and solid tumors, he soon expanded his work to include the comprehensive oncologic and neurologic care of a relatively neglected group of pediatric patients with brain and spinal cord tumors. Under the prevailing treatment of surgery and radiation therapy, many of these patients had a limited life expectancy.

In 1979, Dr. Allen created the first comprehensive pediatric neuro-oncology program in the New York metro area, and possibly the U.S. Together with his colleagues at MSK he conducted a series of phase 2 clinical trials that confirmed the activity of chemotherapy in several types of malignant CNS tumors. He had a national leadership role in advancing research of primary CNS tumors in large federally funded clinical trials groups and organized one of the first training programs for pediatric neuro-oncology fellows who would ultimately lead programs in other hospitals.

In 1986, Dr. Allen moved to NYU Medical Center to collaborate with an inspiring pediatric neurosurgeon, Dr. Fred Epstein. Together they created one of the largest comprehensive pediatric neuro-oncology programs in the country, recruiting a diverse team of medical specialists to provide for the complex psychological and physical needs of their patients. They also established a pediatric brain tumor bank funded by the Making Headway Foundation to preserve and distribute operative brain tumor specimens to investigators world-wide. This resource has helped establish a refinement of the classification of primary pediatric CNS tumors using their unique molecular signatures. The additional identification of the molecular drivers of specific cancers is leading to safer and more precise therapies.

Dr. Allen has always valued collaborating with his patients' families. He was an early advocate for establishing the Making Headway Foundation (MHF) which was conceived in 1996 by several families including Maya and Ed Manley, Elisa and Clint Greenbaum, and Mindy and Sam Schwartz. MHF has prospered ever since. It has raised over $13 million to fund over 100 grants at NYU and other regional pediatric neuro-oncology centers. MHF now also raises funds to support non-reimbursable outpatient services such as patient and family counseling, transportation to the clinic, and burial expenses, as well as many programmatic needs at NYU, such as fellowship training and clinical and translational research. Dr. Allen led the Pediatric Neuro-oncology Program at NYU for over 35 years, in addition to starting a new program in Neurofibromatosis, before he retired in 2021. He now continues to offer his expertise and advice to MHF as a member of the Board.

Dr. Allen and his colleagues improved the quality and duration of survival for thousands of children with primary CNS tumors through a steadfast and compassionate commitment to patients and their families. MHF is very proud to present him with our 2026 Care Award.

Dr. Allen with two of his patients, Jacob Krawitz and Stephanie Mejia, both brain tumor survivors.

Letter from the Executive Director

As Making Headway Foundation celebrates its 30th Anniversary, I realize that 2026 will also mark my 10th year at the foundation. Early in my life, I came to believe that helping others is the main reason for our existence. To that end, my professional life has led me to champion the causes of refugees, work toward economic and social improvement in local communities, help victims of domestic violence find paths of safety and renewal, and now, to focus on children diagnosed with a brain or spinal cord tumor. I have worked for some truly wonderful agencies and yet nothing matches the positive impact on individuals that I see every day at Making Headway.

From the moment I started as Executive Director, I recognized that this organization was extraordinary; not only because of the services it provides, but because of the people who lead it. Nearly every member of our Board of Directors has personally experienced the trauma and challenges of having their own child diagnosed with this disease. That perspective has shaped Making Headway into a unique organization, one that understands that the experiences families face extend far beyond medical treatment. Together, this has led to programs, services, and grants that support the emotional, financial, educational, medical, and day-to-day needs of patients, their siblings, and their loved ones.

It is an honor and a privilege to serve as Executive Director and to help advance a mission that impacts so many lives. At Making Headway, we stand beside families through every stage of their journey, from the moments of fear and uncertainty, to the hard-fought victories and heartbreaking losses. To be trusted by families during the most difficult times in their lives is both a profound responsibility and a lasting source of inspiration. We celebrate their triumphs as our own, carry their grief in our hearts, and remain committed to ensuring that no child or family ever feels alone. I hope you also feel honored to be part of our team and mission.

If we are to continue our work, we will need you. Individually, as a donor, volunteer, or champion of our cause, we have a passion to make a difference in the lives of children with brain tumors. Together, we have true purpose and a mission that is 30 years in the making: *To provide care and comfort for children with brain and spinal cord tumors while funding medical research geared to better treatments and a cure.*

Daniel Lipka, Executive Director

More Special Events for Our Families

Over the past year, Making Headway Foundation has made a concerted effort to increase the number of free, fun events for our families. Most recently, this has included special tickets to see amazing favorites including *& Juliet* on Broadway, *The Paper Bag Players*, as well as Jim Henson's *Fraggle Rock Live*.

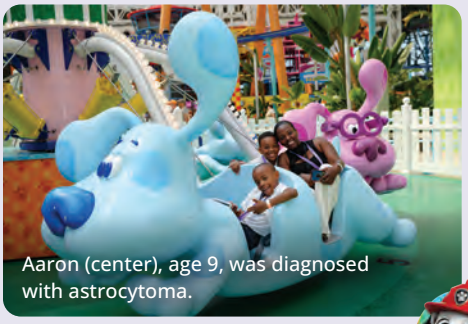
350 Making Headway guests give a standing ovation after the finale of *& Juliet* on Broadway.

Prior to seeing Fraggle Rock Live, Lily Wong enjoys arts and crafts activities at the New Victory Theater.

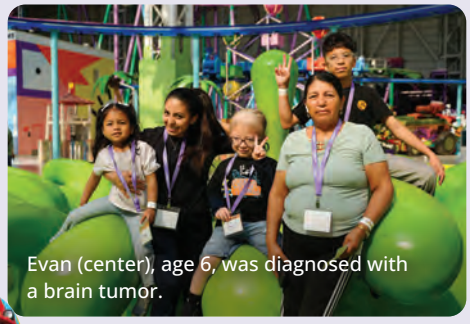
Family Fun Day 2026

For 30 years, Making Headway has hosted a free Family Fun Day for families of children diagnosed with a brain or spinal cord tumor. In 2026, over 550 children and their families joined us for a special anniversary event at Nickelodeon Universe, the largest indoor theme park in the Western Hemisphere. Our families had exclusive use of the park in the morning, including access to a "sensory-friendly" environment designed especially for guests with special needs.

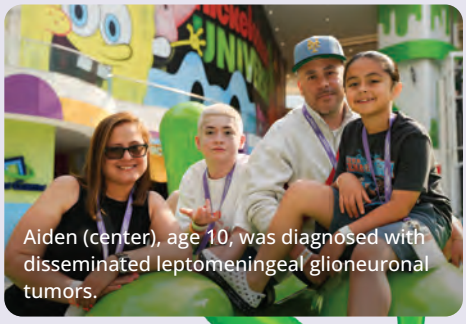
Thank you to Spin Master, LeSportsac, and Nickelodeon for their donations and sponsorship. Special thanks to international soccer star Gio Reyna and his team at Adidas for their wonderful donations and for helping our families enjoy and remember Family Fun Day.



Aaron (center), age 9, was diagnosed with astrocytoma.



Evan (center), age 6, was diagnosed with a brain tumor.



Aiden (center), age 10, was diagnosed with disseminated leptomeningeal glioneuronal tumors.

"Thank you so much for an amazing Family Fun Day at Nickelodeon Universe! Jaeden and Kenny had an absolute blast on their favorite rides, laughing over the Slime Time and meeting new friends. We truly enjoyed this wonderful event and will cherish the memories from this day always!" —*Xiomara Mitchell-Prince*

"This was our 1st event and it was very helpful and easing knowing other people and parents are going through the same thing I am. I was grateful to experience this event as it brought me joy." —*Shakira Bullock*

"It's so special to be included in this community. We're so appreciative of all that you do. Zack doesn't often want to go places and do things, and while we always try, it is always a wonderful experience for his sister as well to get to do special things, and to see/interact with other siblings." —*Rebecca Austern*

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world-renowned neuropathologist whose previous research advanced the molecular classification of pediatric brain tumors, helping to improve diagnoses and pave the way for more precise and personalized treatment approaches.

The new testing method, called TAPS sequencing, is designed to work with extremely small amounts of DNA. That's important because CSF samples, especially in children, often contain very little tumor material. Tumors naturally shed small fragments of genetic material into the fluid around the brain and spinal cord. By studying those fragments, researchers hope to identify the exact type of tumor, track how it responds to treatment, and even detect changes earlier than current methods allow.

This potential new procedure will make a big difference for children with brain tumors who currently have very limited options. For these kids, this clinical assay/test will reduce (or potentially eliminate) invasive and dangerous procedures/biopsies, clarify difficult diagnoses, and guide real-time treatment decisions. Moreover, this research can enhance tumor monitoring and/or prognostic tools, providing relatively quick, real-life information that can be incorporated within any clinical setting. In addition to providing more accurate diagnoses, the procedure could provide doctors with detailed information about tumor recurrence beyond the current methods such as MRIs—which only show tumors when it may already be too late—or the dangerous surgery described above.

Another important goal of the researchers is to make this technology widely available. They are designing the test in a way that will eventually allow it to be used in hospitals and laboratories across the country, rather than at just one medical center. That means more children and families could benefit from cutting-edge molecular testing, no matter where they receive care.

This year, Making Headway has approved a grant that will fund staff, medical supplies, and technology to focus this research specifically on pediatric brain tumors. While more work and validation are still needed, this project represents a critical step forward in the diagnosis and treatment of this terrible disease.

The Future of Brain Tumor Research is RADIANT

The future for pediatric brain tumor research has never looked brighter, and the Children's Brain Tumor Network (CBTN) is boldly leading the way. Its progress over the past year is nothing short of remarkable and is a testament to what's possible when science, compassion, and collaboration come together.

CBTN datasets are already fueling studies on immune vulnerabilities, liquid biopsy monitoring, AI-driven tumor classification, and next-generation CAR-T immunotherapies. The tumor organoid program expanded by more than 40 new patient-derived "mini-tumors" this year, now representing nearly every major type of childhood brain tumor. Altogether, CBTN research now underpins more than 350 peer-reviewed publications, with new studies this year redefining how pediatric brain tumors are understood and treated.

RADIANT is an advanced data infrastructure built on CBTN's foundation. While CBTN brings together data and biospecimens from across its global network, RADIANT integrates and structures clinical records, imaging, and molecular information into a cohesive, longitudinal view of each child's journey. This integrated view supports both research and clinical decision-making, helping clinicians and researchers find parallels among patients and their treatments. By moving beyond fragmented data to a more complete and connected picture, RADIANT enables insights that were previously out of reach. Following a successful pilot, the Pediatric Care eXpansion (PCX) program is scaling RADIANT across US CBTN member sites and beyond, with the goal of connecting 200 institutions and ensuring that no critical elements of a child's clinical journey are lost.

This level of coordinated multi-institutional data integration in pediatric brain tumor research is unprecedented. CBTN is building a system designed to shorten the time between discovery and impact, helping insights that once took decades emerge in years. Every child's data and every partnership bring us closer to better treatments and, ultimately, a cure.

Since 2021, Making Headway has been a supporter and Executive Council member of the Children's Brain Tumor Network (CBTN).

Head to the Hill

By Aleyna Rao, a rising Junior at Weehawken High School and pediatric brain tumor survivor.

In May 2026, five Making Headway families, Making Headway staff, and over 350 individuals from around the country participated in Head to the Hill, the National Brain Tumor Society's annual advocacy event in Washington, D.C. This annual event brings together survivors, caregivers, families, researchers, and advocates from across the country to meet with members of Congress and fight for increased brain tumor research funding and better support for patients.

This year, Head to the Hill attendees spoke at over 350 meetings with members of Congress and urged lawmakers to support several key initiatives, such as the BRAIN Act (Advancing the Bolstering Research and Innovation Now Act), to accelerate research and innovation for brain tumors and rare, deadly cancers. They also requested a 9% increase in funding for the Institutes of Health (NIH) and the National Cancer Institute (NCI), alongside sustained medical research funding from the Department of Defense.

As a pediatric brain tumor survivor, one of the few teenage advocates, and a first-time participant attending Head to the Hill, I was initially nervous about sharing my personal story. However, hearing other people's stories and feeling the supportive environment, I was encouraged to promote positive change to help future pediatric patients and families.

At two of the four meetings with lawmakers from New Jersey, I shared my personal journey of being diagnosed with medulloblastoma at eight years of age and subsequent struggles with the long-term impact of treatments. By sharing my experience, I helped lawmakers better understand the physical and emotional challenges of pediatric brain cancer, and the urgent need for funding that can lead to improved treatments, cures for pediatric brain tumors, and a better quality of life for survivors.

Most of all, Head to the Hill also gave me the chance to connect with other survivors who understand the challenges and share a common mission. I am grateful for the opportunity and will continue to advocate for better outcomes for this community.

Making Headway's own Head to the Hill teams met with over 15 Congressional offices from NY, NJ, and CT. Several of those representatives were already cosponsors of the BRAIN Act, and as a direct result of our meetings, three additional Congressmembers signed on. You can also be an advocate by contacting your representatives. It's easy, just visit makingheadway.org/advocacy.

In 2026, Ava (above) was diagnosed with an ependymoma and treated at NYU Langone. The hospital social worker on the pediatric neurosurgery team referred her family to Making Headway for an array of comprehensive services. Ava's mom sent the following email after a recent check-in from Making Headway's Executive Director, Dan Lipka.

Real Family, Real Impact

By Melinda Sanchez (Ava's Mom)

Hi Dan,

Thank you so much for checking in. It truly means a lot to me. Over the past three months, I've reached out to so many people, and you are one of the only ones who has truly lightened the load for me. You've been more helpful than I can even express honestly, more than family or friends, and I don't take that lightly.

I've bottled up so many emotions over the last three months and have stayed numb, trying to be strong for my other children and now for Ava. Hearing that I may lose my child, and not be able to watch her grow, graduate, have her first dance, or help her pick out her wedding dress...it's something I don't even have words for. It makes me feel like everything I ever dreamed of having with a daughter could disappear in the blink of an eye.

I didn't have the best childhood, and all I ever wanted was to give my children something better. Right now, I just feel lost. At the same time, with supportive people like you, I feel strong enough to keep fighting, advocating, and exploring every possible option for her.

Since your help, I've been able to reach out to Boston Children's, St. Jude's, and Cleveland Clinic to pursue second opinions before the cancer spreads further. I'm holding onto hope that maybe we can find a way to give her more time.

I've been doing everything I can to keep Ava happy and comfortable. She's now in her second week of chemotherapy, along with taking her medications, and she's been getting more tired each day. The comfy blankets and beautiful dresses you sent have truly helped keep her warm and happy—thank you for that.

I also want to be honest: this past month has been extremely difficult financially. It's not as easy as people think being a single mother of three, especially with one child battling cancer, while managing medications, appointments, and everything in between.

Because of Making Headway, I've been able to provide formula and diapers, and keep a roof over our heads. Without your help, we would have been facing a women's shelter. I am truly, deeply grateful. Thank you again for everything: for your kindness, your support, and for helping me stay strong through this.

Best,
Melinda (Ava's Mom)

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

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 tristate 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) nonprofit organization. EIN# 13-3906297.