making headway foundation

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

makingnews

Winter 2024

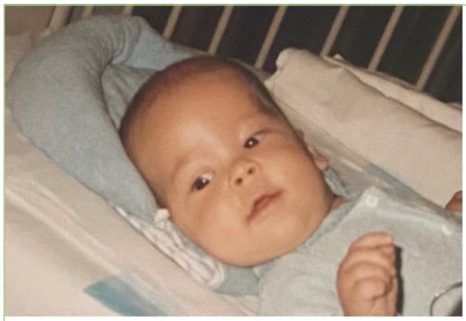
HIGHLIGHTS

MAKING HEADWAY PROGRAMS • FAMILY CARE AWARD • RAISING AWARENESS • FAMILY STORIES • LETTERS FROM MAKING HEADWAY • MAGIC CITY ON BROADWAY • PEDIATRIC NEURO-ONCOLOGY FELLOW • PARENTS' PERSPECTIVE • SCHOLARSHIP WINNERS • REAL FAMILIES REAL IMPACT

The Bonet Family

Photo credit: Justine Cooper Photography

www.makingheadway.org



Baby Jake in the hospital crib at NYU Hospital in 1990.

LETTER FROM OUR **CHAIR**

It Takes a Family, Literally!

When a child is diagnosed with a brain or spinal cord tumor, the consequences for the family go beyond what an outsider can imagine. It starts with the diagnosis. In our case, Jake's diagnosis was at his 3-month-old well-baby visit with his pediatrician in 1990. Imagine our shock and horror when we were told that our perfect baby had the deadliest form of pediatric cancer.

From that moment on, the ripple (really tsunami) effects on us were monumental. But as bad as it was, Clint and I were lucky. With no other children at the time, the two of us could take turns sleeping in Jake's hospital room during his extended stays for his brain surgery and his almost two years of chemotherapy. My wonderful employer (Citibank) allowed me to work from home (remember this was 1990) which enabled us to keep our insurance. Clint soon quit his Wall Street analyst position to work for himself, so that he could attend Jake's exhaustive twice daily therapies (physical and occupational) when he was not in the hospital. Both of us learned how to daily clean Jake's medical port that was embedded into his chest so that his chemotherapy could be delivered more easily into his body. This is besides all the times that Jake had to be poked and prodded with needles for blood draws and IVs for many varied reasons, or the times we had to rush Jake to the hospital because he ran a fever after chemotherapy when his white blood cell counts were low. The career paths for Clint and me became totally secondary to Jake's survival and recovery. Jake was incredible throughout. He was so tough that one of his nicknames was "Nails." One of his doctors correctly told us that Jake would not remember any of this, but that we were scarred for life. How right he was!

Even while we were going through this experience, we knew we had to do everything in our power to help other kids like Jake and their families. (Or was it just that Maya Manley roped Clint into attending a meeting at NYU when he was taking a shift with Jake in the hospital? lol).

I am enormously proud of what Making Headway does to help. Take a look at the full page list on our website of services that Making Headway provides to the children who are fighting brain and spinal cord tumors, as well as to their family members, and you'll see why. (makingheadway.org/annualreport).

Reading this newsletter, you will see that most of the articles are about children with brain and spinal cord tumors and their families. You will see pictures of groups of these children and families together, enjoying each other's company. We are all part of a shared experience that we would not wish on anyone else. We understand each other.

It is for this reason that most of our funds come from the extended families and friends of children with brain and spinal cord tumors. Even if you are not part of a family of a child with a brain tumor, please, please help us. Not only does it take a family—in the words of one of our benefactors, Hillary Clinton, "it takes a village!"

Stay well,
Elisa Greenbaum

Elisa Greenbaum

FROM THE **FOUNDERS**

Edward P. Manley Maya ♡

We are always pleased that our family outings are so popular. At our recent yacht cruise, it was wonderful for the two of us to see so many familiar faces of families that we have helped in the past and meet new families who are currently going through treatment. The outings give all families a day of fun and excitement without the stresses arising from their child's illness, and Dan, our Executive Director, will continue to find exciting, new events. We always like to hear from you at mayaed35@gmail, 914-238-4917, or the Making Headway office email (info@makingheadway.org).

WHAT MAKES MAKING HEADWAY **SPECIAL**

Making Headway Foundation provides unique customized programs, services, and grants that have a meaningful impact on the quality of life for children with brain and spinal cord tumors. We offer a holistic approach, blending medical treatment with emotional, educational, and social support. Everything offered by Making Headway is completely free for our families. Here are some key features that set the foundation apart:

Family-Centered Support

Making Headway offers psychological, social, and educational services to both patients and their families. This well-rounded approach addresses not only the illness but also its impact on the child's development and the family's well-being. This support may occur at the time of diagnosis, during and after treatment, or even years later. Whenever the family needs help, Making Headway is there.

Financial Assistance

The financial burden of having a child with a brain tumor is overwhelming. Significant expenses from medical treatments are even more challenging because one parent usually has to stop working to provide full-time caregiving for the sick child. For families that were already low-income, or headed by a single parent, it becomes almost impossible to make ends meet. Making Headway has three funds that provide families with emergency assistance to help cover bills or bereavement expenses. These funds are made possible through the generous support of the Manley, Taubin, and Justus families.

Educational Advocacy

Due to the toxic impact of brain surgery, chemotherapy, and radiation, children recovering from brain or spinal cord tumors may struggle when they return to school. At NYU Hassenfeld, Making Headway funds an educational coordinator who provides education support services and is a liaison between patients and families, school personnel, and hospital staff. Once a patient is discharged, expert advocates on Making Headway's Ongoing Care Team help families navigate the services and systems put in place by the Department of Education. This includes assisting families in requesting and accessing learning devices, linking families to free academic resources, and providing help and technology support.

Psychological Care

Challenges for children and their families do not end after medical treatment. Our support extends to patients, parents, and siblings who need assistance with long-term effects, including mental health concerns. Making Headway's Family Liaison, Maureen Isaia, works with each family to best understand their needs and, when appropriate, connects the family directly to an expert psychologist on our Ongoing Care Team.

Advocacy

Over the past several years, Making Headway has increased our advocacy at both the state and national levels. Examples of such efforts can be found on pages 4 and 5. Although we recognize the massive impact of childhood cancer on our communities, the problem is frequently neglected by elected officials and governmental agencies. Making Headway, along with advocate families and partner agencies, has made a concerted effort to ensure that our government understands the needs of children with cancer, and allocates appropriate resources for research, programs, and support services.

Other Programs, Services, and Grants

In addition to everything mentioned above, Making Headway also funds or administers: college scholarships (pages 10–11), fun events for families (page 7), pediatric neuro-oncology fellowships (page 8), a Care Coordinator, a Clinical Trials Manager, a Family Liaison, the Justus Joyful Moments Fund, tissue biorepositories at NYU and the Children's Brain Tumor Network, brain tumor research at Memorial Sloan-Kettering, medical transportation, and much more.


Lily Langbein with Looney Lenny

To support our programs, visit MakingHeadway.org/donate

HONORING **CHILDHOOD CANCER AWARENESS MONTH**

To further raise awareness of childhood cancer, NYS Senator Shelley Mayer arranged for the Mario Cuomo Bridge to be lit up with gold on the night of September 14.

September was Childhood Cancer Awareness Month and Making Headway Foundation, the Pediatric Cancer Foundation, and the Pediatric Brain Tumor Foundation took this opportunity to present New York State Senator Shelley Mayer with an Award of Excellence. For years, Sen. Mayer has been a champion for kids with cancer and recently proposed a bill that would require insurance companies to cover the cost of the neuropsychological evaluation that so many of these children need. These tests can cost thousands of dollars for families already overwhelmed with medical bills. In 2024, the bill unanimously passed the state Senate, but it failed in the Assembly. Undeterred, Sen. Mayer plans to reintroduce it in early 2025 and is optimistic about its passage this time around.

Attending the event was Naomi Wood, a 9-year-old brain tumor survivor. Her mother, Astrid, spoke for the TV cameras: "Two years ago this month, our world fell apart. Naomi was diagnosed with medulloblastoma at what we thought was an overly cautious visit to the Emergency Room for headaches she'd been having. It's still hard to put into words the devastation of those first weeks and months—and the extent to which her life (and ours as a family) have changed, dramatically ... There is a firehose of information that comes at you in that first year. Doctors and tests you never knew existed are coming at you—if you're lucky ... We didn't even know to ask for a neuropsychological assessment, which ended up being a critical piece of her ability to live a normal life as a brain cancer survivor."

The Wood family

2024 **FAMILY CARE AWARD**

When Jake Harary was diagnosed with medulloblastoma as a child, Making Headway was there for him, his sister, and his parents. Since that time, the entire Harary family has gone above and beyond to be there for Making Headway. On behalf of the Making Headway Board of Directors, we are proud to award the Harary family our 2024 Family Care Award. Their dedication to our mission and efforts to raise money to support other families, are deeply appreciated and truly respected.

Although we feel very unworthy of this beautiful honor, we are greatly humbled. I must say our lives would not have been the same without the Making Headway family. Dating back to before most of you reading this letter would know, there was Maya, doing arts and crafts non-stop, Adam the clown, Jose in the playroom, video games galore, delicious snacks (many of which Maya brought herself), videotapes to watch movies in the MRI machines, and the list goes on. It was a different era, and although much has changed, and our dear Dr. Allen is no longer walking the hallways checking in on patients, Maya and Edward's selfless dedication remains a pillar of solidarity: two wonderful humans who have devoted their lives to Making Headway and the betterment of so many sick children. We are forever grateful not only for the love and support Making Headway has shown us and our son but also for their attention to my younger daughter, who endured many trips to the hospital at a very young age just so she could be close to us while her brother received treatment. Maya's impact and kind ways were such that my daughter learned to see hospitals as places where people got better, not where the sick went. Such an influence has led her to pursue a career in the medical field. I highlight this as the less obvious (rather than the predictable stories) because Making Headway is not only for the sick children but it's so much more. Words fall short in trying to find the right praise for this wonderful organization. Thank you for so much, Making Headway.

All our love and admiration,
Jacqueline and Max Harary

The Harary family

LIFE'S TOO SHORT TO HAVE REGRETS

My daughter Layla So's battle with DMG ended when she was only 15 on Wednesday, August 7, 2024, at 5:40 p.m.

The battle began on Tuesday, October 11th, 2022. Despite getting the devastating news that she had a brain tumor, she tried to comfort her mother by saying, "It's OK, we can be chemo buddies!" (My wife was undergoing monthly immunotherapy infusions for skin cancer.) Once she had recuperated from the surgery, she spent her time devouring any information she could on her diagnosis and possible treatments. Eventually, she accepted the fact that her chances of survival were almost none. She didn't give up hope; she diligently looked into what research was being done for DMG. Upon learning that there weren't enough tissue samples for use in research, she asked us to donate the tumor as well as her brain after her death.

From diagnosis on, Layla became a different person, maturing very quickly. She didn't see her disease as a disability but as a unique gift—knowing she had limited time left, she decided to live without regrets. She started asking for more family gatherings, got closer to her friends and made up with ones she'd lost. She didn't want people to feel sorry for her, and even complained that she didn't need the accommodations her school gave her! When a girl at school made fun of her hair and called her "the cancer girl," she said she was glad the girl was acting her usual self instead of "being politically correct". Layla willed her motor skills back by returning to painting, sketching, scouting and karate. When radiation treatments weakened her, her karate instructor offered her a black belt, but Layla replied that she hadn't finished the 5k run and thus didn't deserve it. Against all odds, she worked to complete the requirements for Eagle Scout until her very last weeks.

In the last two months of her life, when she realized she didn't have much more time, she made it a point to bring family and friends together. She insisted on visiting family. She visited her grandparents' grave, and, seeing the condition of the headstone, wanted the family to gather to clean it up. (Unfortunately, we couldn't do it before she passed away.) She told us to continue taking care of each other. She didn't neglect her friends either, texting them from her hospital bed that she was sorry for being "a pain in the butt" sometimes, and listing the traits she admired about all her friends and family.

Layla went out of her way to hide any pain and sadness from her family and friends, even cracking jokes with a dark humor. She would apologize profusely for being a burden. Whenever we thought she was in pain or sad, she would smile, shrug her shoulders and say everything was good. When doctors and nurses asked her if something hurt, she would either respond "I don't know," or give a thumbs up and say "everything is OK."

Layla had no regrets; the regrets are ours. At 15 years old, she showed more grace and fortitude than many people five times her age. We are grief stricken by her passing because we will always think about what kind of person she would have been if given the chance. I used to tease Layla, our only daughter, that she was the best daughter I ever had—but she truly was the best daughter any parent could have asked for.

Solomon So
Proud father

ANOTHER SHOT AT THE MOON

On September 20, Making Headway Foundation Executive Director Daniel Lipka was invited to the White House for a roundtable on state advocacy for childhood cancer, part of the Biden-Harris Administration's Cancer Moonshot initiative. The goal of this event was to bring together a diverse set of federal and state policymakers, healthcare experts, and childhood cancer advocates from across the country to: (1) develop strategies and share best practices to maximize state programs, including cancer action plans and Medicaid, that address childhood cancer; and (2) gather commitments from participants to implement these strategies in order to improve childhood cancer outcomes.

The first discussion focused on ways to incorporate pediatric cancer into Medicaid policies and other state-level legislation. Experts discussed how state-level advocacy can help optimize the ability of state-led programs to support children and families impacted by cancer. The discussion covered policy recommendations, potential funding mechanisms, and the role of advocacy in shaping legislation that supports comprehensive care and equitable access to treatment for pediatric cancer patients and families.

The second discussion focused specifically on state cancer plans. As of 2021, 29 state cancer plans made

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A LETTER FROM OUR **EXECUTIVE DIRECTOR**

Imagine an ideal childhood, when life is filled with laughter, playgrounds, and endless dreams. Now imagine instead being one of the 4,500 children each year who find themselves in hospital rooms, surrounded by machines that beep and hum, with doctors and nurses bustling in and out. The innocence of childhood is disrupted by words like "brain tumor," "surgery," and "chemotherapy." Yet, somehow, amidst the uncertainty and fear, many of these children find a way to smile, to laugh, and to live.

For their families, the journey is a rollercoaster of emotions—fear, hope, despair, and determination, all swirling together. Parents who once worried about school projects and playdates now find themselves researching the latest treatments, consulting with specialists, and praying for a miracle. Siblings, too, are affected, often feeling a mix of confusion and sadness as they watch their brother or sister endure something so unfair and unimaginable.

The truth is, no child should have to battle a brain tumor. The treatments are harsh, the side effects daunting, and the emotional toll immense. In my time as Executive Director of Making Headway, what I have found remarkable is the way these children and their families face each day with bravery and grace. They become warriors in their own right, fighting not just for survival, but for the chance to live a life filled with joy, love, and dreams.

I try to focus on the days of triumph—when a scan shows the tumor has shrunk, or when a child is able to go home after weeks in the hospital, but there are also days of heartbreak—when the treatment isn't working, a side effect becomes a disability, or a child passes away. This is the reality that I work in every day.

To the children battling brain tumors and to their families: your bravery humbles me, your strength inspires me, and your love touches my heart in ways I could never fully express. You are not alone in this fight. Everyone at Making Headway stands with you, we support you, and we believe in you.

And to those reading this, if you find yourself moved by the stories and families in this newsletter, consider how you can help. I'm not shy about asking for help, and the best way to do so is by donating to support the programs at Making Headway. If you are reading this in print, a remittance envelope is enclosed, or you can always visit MakingHeadway.org/donate. Together, we can make a difference in the lives of these incredible children, and together we can work toward a future where no child has to endure this fight.

Daniel Lipka, Executive Director

"Another Shot at the Moon"
Continued from page 5

no mention of childhood cancer. Since that time, some states, including Ohio, Kentucky, and California, have successfully incorporated meaningful language about childhood cancers into their plans. In 2023, Making Headway and our partner agencies submitted a significant number of pediatric cancer recommendations to the New York State Cancer Consortium for consideration in their new 5-year plan. Although the plan was scheduled to be completed months ago, it is still being developed, and learnings from the recent roundtable will help us to continue advocating for our recommendations to be included.

National leaders gather at the White House to discuss pediatric cancer.
Making Headway Executive Director pictured on the far left.

Making Headway was pleased to be invited to participate in this important roundtable. It provided an excellent opportunity for learning as well as networking with other experts and advocates in the fight to get attention and resources focused on pediatric cancers.

SAVE THE DATE:
THE MAGIC CITY COMES ALIVE ON BROADWAY

Join Making Headway at the New Victory Theater on Sunday, April 6, 2025, at 3:00 p.m. to see the award-winning Broadway show, The Magic City. We're inviting Making Headway families to enjoy this special event free of charge. For everyone else, your ticket purchase or donation will directly support Making Headway's vital programs and services.

The Magic City tells the story of nine-year-old Philomena, who must learn to build a new life when her sister—and companion in play—gets engaged. Struggling to adjust to her changed world and the new stepbrother in her life, Philomena retreats into a magical realm of her own creation. Assembling books, toys, and everyday objects, she builds a miniature city that comes to life! Using overhead projection, paper shadow puppets, actors on camera, and live music, this new adaptation of The Magic City is a modern retelling that explores the complexities and joys of building a family. As cinematic as the world of The Magic City is, everything on stage is performed live—including the music. And while this show is wholly geared towards the tiniest of theatergoers, audiences of all ages will be charmed by this deeply moving and thoroughly funny production.

Don't miss this chance to be part of our biggest fundraiser of the year! For more information or to donate, visit makingheadway.org/MagicCity.

A **PERFECT** DAY

This fall, 206 family members, each impacted by a childhood brain or spinal cord tumor, boarded the Skyline Princess for a breathtaking, free, four-hour yacht cruise to the Statue of Liberty. Our annual Yacht Cruise is a very special event, as it gives both Making Headway parents and children a chance to bond with others who have gone through a similar experience. There is nothing like seeing dozens of children with cancer playing with each other without a care in the world, at least for one day. This year, the weather fully cooperated; it was a perfect afternoon, with clear skies and a cool breeze.

On behalf of all the families that attended, we extend our deepest gratitude to the Stadtmauer family, whose generous sponsorship made this special day possible. This was Making Headway's 19th Yacht Cruise and it might have been our finest to date.





Photo credit: Todd Shapera Photography, September 15, 2024

MAKING HEADWAY'S 2024
PEDIATRIC NEURO-ONCOLOGY FELLOW

Dr. Dardan Demaliaj has just completed his year as the 12th Making Headway Pediatric Neuro-Oncology Fellow. This fellowship was funded by the Making Headway Otto and Marguerite Manley Endowment at NYU Langone.

Pediatric neuro-oncology fellows play an essential role. They specialize in treating brain tumors in children, contribute to research for better therapies, and provide comprehensive care. At the same time, they receive the specialized training they need to continue working in this vital and under-staffed field.

"I have dedicated my career to curing children with all types of cancers, especially brain tumors. In my journey as a pediatric oncologist, I first trained at NYU and then moved to Los Angeles before returning to New York City. I have thoroughly enjoyed my time here, learning from Dr. Segal, Dr. Gardner, and Dr. Clymer, with their vast combined expertise. Former Chief of Pediatric Oncology at NYU, and current Making Headway Board Member, Dr. Jeffrey Allen's legacy is felt throughout NYU Langone. Among his triumphs was the creation of one of the first neuro-oncology training programs as well as the largest neurofibromatosis center. Although the field of pediatric neuro-oncology continues to advance, there is still a lot of work ahead of us. Much progress has been made, including identifying cures for what was once incurable. Unfortunately, this does not extend to every situation, and much work still lies ahead.

NYU has created an environment in which we are able to give these children the services they really need. They can see a physical therapist, nutritionist, neuropsychologist, schoolteachers, and child-life specialists. Without this backbone of a team, it would be very difficult to treat the patient. This is ultimately a very different culture and mindset from the adult neuro-oncology world, and we should be proud of the work both as an institution and as a field.

As I continue to the next phase of my career, I will always cherish the patients I met and the people I worked with, even though this fellowship was only one year long. And I am grateful to my colleagues and mentors, people to whom I can turn to for help, and who have taught me how to be a pediatric neuro-oncologist."

All the best,
Dardan Demaliaj MD MPH

Making Headway has committed to funding 100% of another Pediatric Neuro-Oncology Fellow at NYU in 2025. We remain dedicated to ensuring that children with a brain or spinal cord tumor receive the very best medical care when they are diagnosed and for years to come.

MEET NEW STAFF AT NYU

At the Stephen D. Hassenfeld (SDH) Children's Center for Cancer and Blood Disorders at NYU Langone, children with brain and spinal cord tumors are fortunate to have access to a full-time psychologist and neuropsychologist. These providers are available for all SDH patients and their families who are struggling to manage their medical diagnosis or are experiencing educational or emotional challenges related to their medical treatment. Patients not in active care (who are younger than 25) may also be eligible for these services through the SDH survivorship program.

Madeline Bono, Psy.D., is a pediatric psychologist who joined the team at the Hassenfeld Center this past October. As a pediatric psychologist, Dr. Bono's role is to help children and families impacted by complex health issues. She uses evidence-based interventions that support adjustment to illness and emotional coping, and she seeks to help patients and families feel empowered to navigate illness and treatment. Dr. Bono is committed to leveraging her role as a clinician, researcher, and advocate to center on patient needs and lived experiences.

Helen Tam, Ph.D. is a clinical psychologist who specializes in neuropsychological evaluations for children/young adults. She also joined the Integrated Behavioral Health Team at the Hassenfeld Center in October. Children with complex health issues are at increased risk for challenges with academic and adaptive skills development. Dr. Tam strives to help these kids and their families achieve the best possible outcomes for themselves outside of the hospital setting by describing their cognitive strengths and identifying appropriate, evidence-based interventions to help overcome their weaknesses.

Both authors have donated copies of their book to our local children's hospitals.

NEXT TO ME **FOREVER**

By Nubia Marquez

In the midst of the tumultuous COVID-19 pandemic, my beloved and only child, Matias, was diagnosed with a brain tumor. Following a more than six-hour surgery to remove the mass, he was diagnosed with Medulloblastoma types 3 and 4. I can still vividly recall the doctor's somber words: "I'm sorry, there's nothing more we can do." My brave little warrior was merely two years old at the time.

Yet, despite the grim prognosis, Matias's indomitable spirit led us all on a journey of Love, Faith, and Hope for three and a half years. He defied every prediction, demonstrating the resilience of the human spirit. Just over a month after his sixth birthday, on August 30, 2023, Matias bid farewell to this life and returned home. Now we have an angel in the heavens, who communicates with us and countless others on a daily basis.

Matias has shown us that we are eternal souls and that only the physical body passes away. He remains closer than ever to me now, albeit in a different and everlasting manner. Through his courage and unwavering love, Matias continues to illuminate our lives, reminding us of the boundless power of love and the eternal nature of the human spirit. Thank you, Making Headway, for your constant support during these challenging times. We remain a family of three.

Earlier this year, the Lopez family published "Next To Me Forever." From Amazon.com, "In this narrative, Nubia Marquez immerses us in Matias' touching, brief, yet profound journey in this life, where the battle against cancer intertwines with the uniqueness of autism and the brilliance of genius. At the same time, we witness how love, an endless source of strength, and hope, a beacon in the darkness, intertwine throughout his path and that of his dearest loved ones."

PAPER **MENSCHIES**

By Mindy Blumenfeld

My son, Hillel, was six years old when he was diagnosed with a brain tumor and needed 33 rounds of radiation treatment following surgery. My story is a familiar one, I am sure; but here is where something different happened. In order to keep him lying flat and still during the interminably long treatment where he lay masked and strapped to the bed alone in the great big room, I squeezed myself into a tight spot at the technicians' desk. Using their microphone, I too saved my son as I created adventurous tales about a fantastic set of quadruplets, Hilly, Pilly, Shimmy, and Shmaya.

Fascinated by these stories, my six-year-old son endured radiation treatment without any anesthesia, and the "quad squad" became his best friends throughout the years of rehab and multiple treatments.

Despite his initial remission, Hillel didn't make it. Ten years later, he died peacefully in our arms. But Hilly, Pilly, Shimmy, and Shmaya found a new life as the Paper Menschies in the children's picture book I co-wrote with talented illustrator Marc Lumer, who is also the producer of a popular Netflix children's series called Mighty Little Bheem.

Hillel and the Paper Menschies is a hybrid picture/comic book about a kid—just like yours—who learns he has a brain tumor, and needs the help of the Paper Menschies—Hilly, Pilly, Shimmy, and Shmaya, to fight Mad, Sad, and Scared who appear just as he is undergoing his first MRI.

The book takes the reader on a journey through nurses and needles, surgery, radiation, and rehab, and finally Hillel's triumphant return to school: a scar on his head, a little wobbly on his feet, still facing some deficits, but overcoming his feelings of sadness, anger, and fear, learning with mindfulness, humor, and faith to find courage, laughter, and hope.

When I wrote this book, I had all of our kids in mind—those with brain tumors and those facing any challenges that make them scared, mad, and sad. I hope my book (aimed at kids ages 5–11) brings new light to darker times.

MAKING HEADWAY COLLEGE SCHOLARSHIP WINNERS

The Making Headway College Scholarship Class of 2024 was our biggest ever. The recipients are 25 inspiring survivors of a brain or spinal cord tumor. Each winner has been awarded between $1,000 and $15,000 to help fund their dream of obtaining a college degree. Two $5,000 awards were funded by the Scott J. Reisser Memorial Scholarship Fund, established by the Reisser family in memory of their 22-year-old son, who succumbed to a brain tumor just short of realizing his dream of graduating from college. In addition, Dillon Berenty was the eighth winner of the annual Michael Schwartz Making Headway College Scholarship. This $10,000 scholarship was funded through donations raised by the Schwartz family and named in honor of their son, Michael, a 27-year-old brain cancer survivor. The remainder of the scholarships were funded through the generosity of Making Headway's donors. Since 2008 Making Headway has given out 176 college scholarships.

"I have always hoped that my story could help others find hope in times when there may be little. Being chosen [for this scholarship] means that what I had to share could help inspire others in similar circumstances to never give up." *—Dillon Berenty, DNET at age 17.*

"A scholarship from Making Headway means so much to me because I know it is coming from an organization that truly understands the challenges I have faced as a young brain cancer survivor. The fact that my academic achievements and commitment to the community are recognized in a manner that allows me to contribute to my education makes me feel so proud. I am so grateful for your support." *—Carly DeMartino, brain tumor at age 10.*

"Receiving this scholarship has reminded me of my strength, and leads me one step closer to helping create a difference in my life and in the lives of those around me." *—Abigail Memmesheimer, germinoma at age 14.*

"It's almost beyond words to describe what receiving a Scott J. Reisser Memorial Scholarship means to me. I was diagnosed with a brain tumor in 2013 and the past eleven plus years have been filled with challenges and rewards. I can never express enough thanks to Making Headway Foundation for their part in making my college dreams a reality." *—Matt Yautz, juvenile pilocytic astrocytoma at age 9.*

"This scholarship means a great deal to me as it not only eases the financial burden of my education but also motivates me to continue working hard towards my goals. It is an acknowledgment of my efforts and resilience, and I am deeply appreciative of the support from Making Headway Foundation." *—Rodina Elsayed, glaucoma (brain tumor) at age 16.*

"The college that I go to is expensive, and one of the reasons why I chose it is because of the learning resources they provide to students who have learning differences. This scholarship award will help us pay the tuition and for the extra tutoring."*—Cairo Gordon-Somers-Archer, neurofibromatosis Type 1 at 6 months.*

"Thank you so much for selecting me for this award! I am filled with pride to receive this; it makes my education a little more affordable." *—Adrianna Oliva, brain tumor at age 12.*

"When I was first diagnosed with cancer, I knew right away that I wanted to become a pediatrician to help other kids like me. This scholarship helps diminish the burden of financing an undergraduate degree and makes medical school more of a possibility financially." *—Rachel Coffey, pilomyxoid astrocytoma at age 10.*

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“The scholarship support from Making Headway has given me access to many opportunities at Syracuse University. My aim is to make a difference in the lives of others.“ —*Elaina Dub, fibrillary astrocytoma at age 3.*

“Representing the Scott J. Reisser Memorial Scholarship is both an honor and a blessing. The monies received will allow me to successfully graduate from Auburn University, and the acknowledgment that my bumpy road to get there will encourage me to pursue my dream career as an architect. While architecture can be grueling and scary, the lifelong lessons I've learned from my brain tumor experience—inner strength, compassion for others, pursuit of excellence and appreciation for life—will assist me in achieving my dreams.” *—Emily Calabro, suprasellar germinoma at age 10.*

“These scholarships are given in honor of those who've passed before they were able to reach their dreams. Being part of this scholarship program is additional motivation for me to reach my goals and become the best version of myself.” *—John Criscuoli, neuroblastoma at 8 months.*

“This scholarship will help alleviate the financial stresses brought upon my family by my treatments and help me pursue my dream of helping children in similar situations as a physician. So far, my education has offered me opportunities to grow as a leader and connect my peers both in New York and Atlanta to opportunities to serve childhood cancer patients, a cause that is deeply important to me. This scholarship will help me pursue an education that will lay the foundation for me to become a physician and leader who can leverage my unique insights to make the lives of childhood cancer patients easier in a clinical setting.” *—Giancarlo Cusimano, medulloblastoma at age 14.*

“After my diagnosis and surgery in the middle of my first year at Marist College, I thought my time pursuing a higher education was over. As a brain tumor survivor, I feel like so much has been taken from me. The support I've received from my family and friends has kept me alive. My gratitude continues to motivate me in furthering my education and bettering myself and my health.” *—Giovanna Cappetti, pilocytic astrocytoma at age 18.*

“This scholarship means the world to me as it supports my journey in higher education and allows me to continue my mission with JZips (t-shirts made for mediport access) - helping children and young adults with cancer feel more comfortable during treatment. It's an incredible honor to be recognized by Making Headway and I'm committed to making a positive impact through my studies and future career.” *—Jordan Harouche, Non-germinoma germ cell tumor at age 15.*

“I am very grateful to Making Headway for being selected for this scholarship. This award will lower the cost of tuition for me and my family, relieving a portion of the financial burden for this school year.” *—Kyla Coughlin, anaplastic ependymoma brain tumor at age 2.*

“This scholarship means so much to me because I am a girl who went through something unimaginable and I am attending my dream college. I am so grateful for this opportunity and that I am recognized for overcoming the traumatic experience I went through at age 4.” *—Kylie Kupperman, medulloblastoma at age 4.*

“The Making Headway scholarship means that I can continue my education and hopefully make a difference in the world. I am majoring in special education and really want to teach kids that it is okay to be different. I'd love to help kids learn how they can make changes in the world. I am so honored to be selected. Thank you.” *—Lily Adkins, ependymoma at age 1.*

Not pictured: 2024 winners Josiah Phillips, Dirimichi Emeanaa, Xingyu Liu, Anny Safier, Arden Segaloff, Nadine Whalen, Jackson Lamb.

CONNECTIONS

Dallas and his sister Aubrey on board the Making Headway Yacht Cruise.

Dallas was only three when he suffered an unexpected seizure and was rushed to the hospital in 2023. A full medical work-up resulted in the devastating diagnosis of a brain tumor called ependymoma. He swiftly underwent brain surgery, followed by six months of radiation. Thankfully, Dallas went into remission, but there was collateral damage. Dr. Stephen Sands, a neuropsychologist at Memorial Sloan Kettering Kids, evaluated Dallas's condition and recommended that he receive individualized services and accommodations as he entered kindergarten. This past spring, Dr. Sands referred Dallas and his family to Making Headway for help. Making Headway's Family Liaison, Maureen Isaia, immediately started her assessment by reaching out directly to the family. She spoke with Dallas' mom, Johneatha, offering her support and counseling.

Maureen contacted Making Headway's Ongoing Care Team member Marlene Chomsky, an educational advocate with Susan Lugar Associates. After meeting with Johneatha several times, Marlene started the advocacy process in the school district, even attending Dallas's Committee for Special Education Meeting. Throughout the process, Maureen stayed in contact with Johneatha, who opened up to her, saying she had overwhelming anxiety whenever Dallas was scheduled for follow-up MRIs. She feared that her little boy's tumor would recur. Maureen explained the psychotherapy services Making Headway makes available, and connected Johneatha to another member of Making Headway's Ongoing Care Team, clinical psychologist Dr. Robin Shaw. Soon after, Johneatha began receiving support from Dr. Shaw through weekly remote individual counseling sessions. She has found her work with Dr. Shaw to be immensely helpful in addressing her anxiety.

Of course, Maureen has also made sure Dallas's family was invited to the many fun events and programs that Making Headway offers. The family is touched and amazed by the community Making Headway has created, and Johneatha shed happy tears several times at last June's annual Family Fun Day, knowing that she and her family were not alone.

Maureen will continue to stay in touch with Johneatha, not only to coordinate the family's assorted services but to provide a personal connection and assure this family that Making Headway has their back—all at no cost to them.

When a child with a brain or spinal cord tumor needs help outside of the hospital, their doctor or social worker is encouraged to refer the child and their family to Making Headway. Making Headway's Family Liaison, Maureen Isaia, receives these referrals and immediately starts to provide care. Maureen is a New York State Licensed Clinical Social Worker with two decades of experience working with families in hospital settings. It is her job to conduct a detailed analysis of the situation and help each individual family by providing direct support or referrals to community or Making Headway services.

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 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

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