
Prince Family

2024–25
annual report

making headway foundation

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

Making Headway Foundation, Inc.
115 King Street
Chappaqua, NY 10514-3460

Telephone: (914) 238-8384
Fax: (914) 238-1693

makingheadway.org
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.

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.

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 care 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.

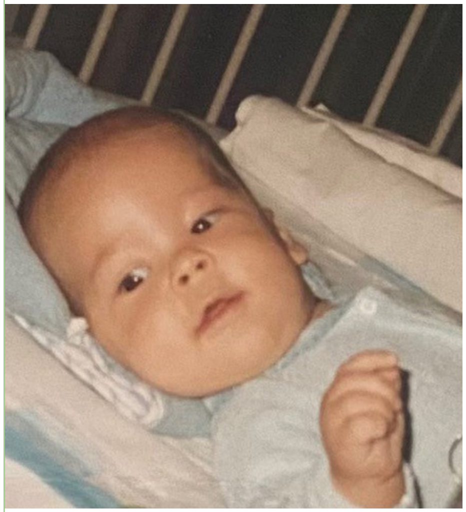
Other Programs, Services, and Grants

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.


The Zayas Family

To support our programs, visit MakingHeadway.org/donate

LETTER FROM OUR **CHAIR**



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

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, our son 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 Jake 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. Also, Jake had to be poked and prodded with needles for blood draws and IVs for many varied reasons. Sometimes 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. And when we lost Jake (to a different form of cancer), we doubled our efforts. Why am I telling you this, and why is it important? Because for the children going through the horrific experience of having a brain tumor, and for their families, the services Making Headway provides are vital.

I am enormously proud of what Making Headway does to help. Please take a look at this 2024-2025 annual report to see everything that Making Headway provides to children who are fighting brain and spinal cord tumors, as well as to their family members, and you'll see why. Thank you.

Stay well,
Elisa Greenbaum

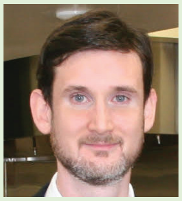
Elisa Greenbaum

FROM THE **FOUNDERS**

Edward P. Manley Maya

We are always pleased that our family outings are so popular. In 2024, Making Headway's annual Family Fun Day, Broadway Show, and Yacht Cruise were fantastic and it was wonderful for the two of us to see so many familiar faces of families that we have helped in the past as well as 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).

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, so 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 the unfair and unimaginable realities of treatment.

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

MAKING HEADWAY: **WHAT WE DO**

CARE
(IN-HOSPITAL)

- Care Coordinator/ RN to Help Families
- School/Education Coordinator
- Bereavement Support
- Connect Families to Needed Services
- Looney Lenny the Clown
- Welcome Program / Kits

COMFORT
(OUTSIDE THE HOSPITAL)

- Making Headway Family Liaison
- Individual & Family Counseling
- Educational Advocacy for Families
- Justus Joyful Moments Fund
- Family Events & Activities
- College Scholarship Fund
- Housing & Emergency Assistance
- Family Photo Project

CURE

- Clinical Trials Research Manager at NYU
- Tissue Biorepository Center at NYU
- Children’s Brain Tumor Network at CHOP
- Neuro-oncology Fellowship Program at NYU
- Brain Tumor Recovery Research at MSK
- Local, State, & Federal Advocacy

FAMILY **FUN** DAY

June 9, 2024, Making Headway hosted our 29th Annual Family Fun Day at the world-famous Rye Playland. It was a beautiful day, as over 450 survivors, siblings, parents, and volunteers joined the fun. Families enjoyed a BBQ lunch, clowns, face-painters, a kids' spa, caricature artists, a bubble show, VR games, our first-ever butterfly release, and all-day VIP passes to Playland. The Family Fun Day is just one of the many ways for our families to share a memorable, trauma-free day as a community.

Gina and Deanna Dimartino

Photo Credit: Nik Bucci

A MAGICAL AFTERNOON **ON BROADWAY**

March 3, 2024, Making Headway Foundation welcomed over 500 guests to Broadway's Lyric Theater to see "Harry Potter and the Cursed Child." Children and adults alike reveled in the magic of one of the world's most wondrous shows. While many of our guests were donors who graciously purchased tickets, the vast majority were families who have a child with a brain or spinal cord tumor; each of these families received free tickets courtesy of Making Headway. Our annual theatrical event is just one of many activities and events we host for families each year. This event was also our largest annual fundraiser, raising over $600,000 to support Making Headway's programs and services. As with all our programs and services, Making Headway's ability to provide free tickets to a show like this is possible only thanks to the generous donations of people like you.

A **PERFECT** DAY

This fall, over 200 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. This was Making Headway's 19th Yacht Cruise and it might have been our finest to date.

MAKING HEADWAY ACCOMPLISHMENTS: BY THE NUMBERS

Over the past 29 years, Making Headway has had an impact on thousands of families. We try to measure this impact through surveys, but it is not always easy to quantify. However, there are some things we can measure in data and numbers. Here are just some of the quantitative accomplishments.

Direct or indirect support to over
2,200
families

8,350+
hours of educational advocacy services

15,250+
hours of individual and family counseling

176
college scholarships

More than
75
events for families

Invested over
$29m
in grants, services, programs, and events for families impacted by a childhood brain or spinal cord tumor

Over
68
published research papers as a direct result of our grants

85,000+
donations, from more than
26,100
unique households

10
pediatric Neuro-Oncology fellowships fully funded

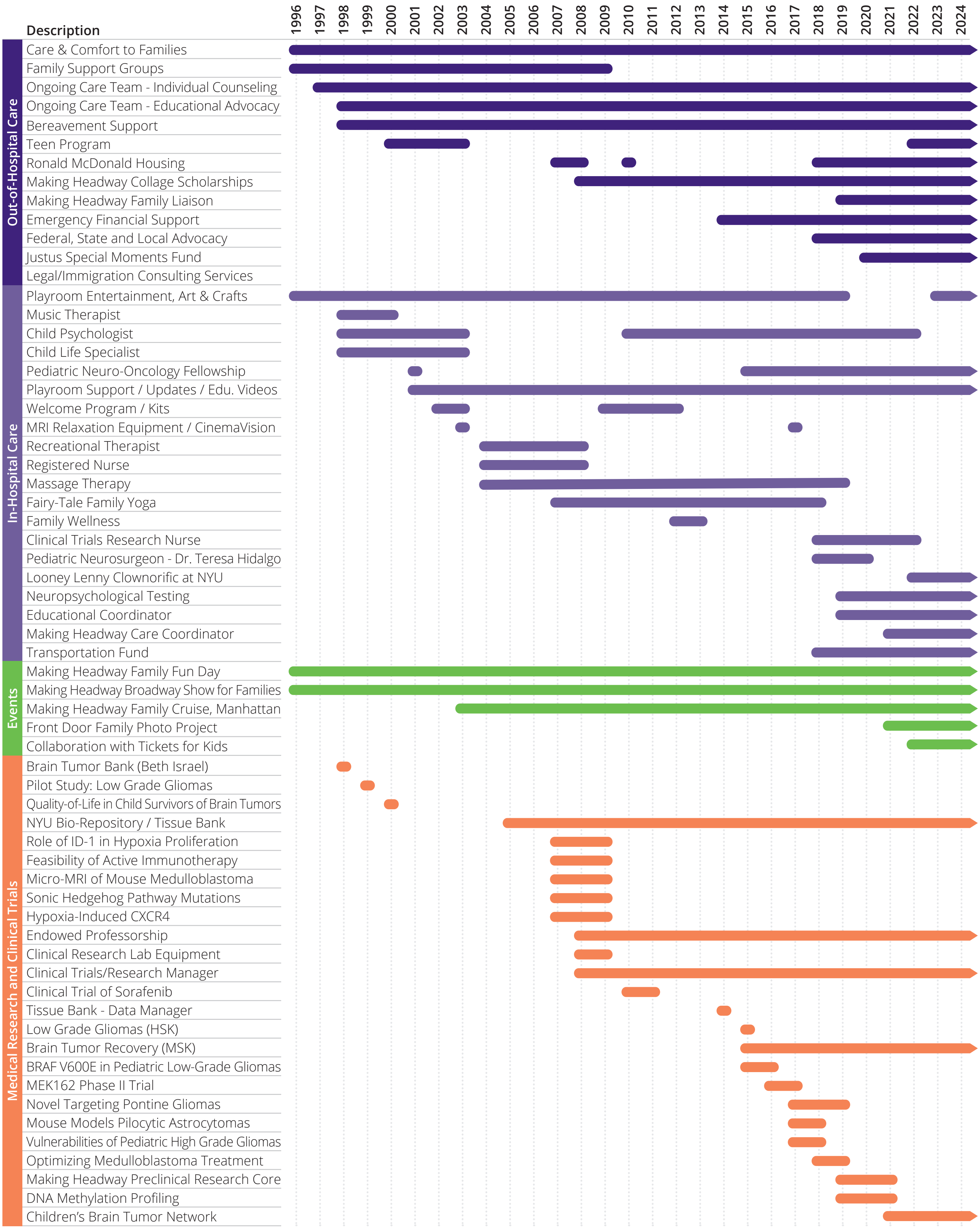
Funded over
172
research and quality-of-life programs at local hospitals

Assisted families from
10
major children's hospitals

Financial support for over
190
funerals

85%
of all donations have gone directly to programs and services

29 YEAR TIMELINE OF MAKING HEADWAY



MAKING HEADWAY WELCOMES NEW FAMILY LIAISON

Making Headway's new Family Liaison, Maureen Isaia, and her family.

I am thrilled and grateful to have joined the Making Headway Foundation Team!

It is an honor and privilege to work alongside the legacy of this foundation, and most importantly to work closely with the families that Making Headway serves. Healthcare systems are complex, and families need support and connection. I have spent my social work career in the high-pressure environment of inpatient hospital settings, working with families and children. I have seen firsthand what a devastating diagnosis and medical crisis does to a family. I am honored to take on the role of Family Support Liaison at the Making Headway Foundation.

Within my first weeks at Making Headway, I have begun meeting with pediatric social workers, doctors, and staff at multiple children's hospitals. These people are often the first point of referral to Making Headway. I am grateful for their assessment skills and knowledge, which enable them to connect many families that can benefit from Making Headway's programs and services. I look forward to strengthening our professional relationships and making sure that the children they serve are in good hands.

But the biggest reward this role has offered me is meeting and talking with the children and families impacted by a brain or spinal cord tumor. I have been touched and moved by many of their personal stories and journeys. I have spoken with some who are dealing with the initial shock of diagnosis and others who are conquering survivorship years later. I am amazed by their strength and perseverance.

My hope is to bring to parents and children my knowledge and experience as a medical social worker, and to offer care and comfort, as a mother of two young children myself. I am here to provide support, guidance, and connection. I want the Making Headway families to know that they can always reach out to me.

Maureen Isaia, LCSW, Family Support Liaison
Email: Family@makingheadway.org
Cell: (914) 354-0264

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' 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' 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' 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.

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

CARE AWARD

Making Headway is delighted to announce Dr. Sharon Gardner as the recipient of our fourth 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.

Tribute by Jeffrey Allen, MD,
Emeritus Director of Pediatric Neuro-oncology at NYU Langone Medical Center

Dr. Sharon Gardner retired in May, 2024 and I am honored to compose this tribute to her in honor of this special award. Dr. Gardner and I have been friends and collaborators for over 30 years, sharing various aspects of the care of children with brain and spinal cord tumors. Dr. Gardner has earned the admiration and respect of her patients, their families, and her colleagues. She is a woman of extraordinary modesty, dedication, and kindness and she has had the courage to take on some of the most difficult challenges in pediatric neuro-oncology, such as the management of infants with brain tumors and children with diffuse intrinsic pontine gliomas (DIPG).

Over the years, in addition to caring for infants with brain tumors, Dr. Gardner has assumed many other responsibilities in the Division of Pediatric Oncology at NYUMC, including supervising the care of children with cancer at Hassenfeld Children's Hospital, supervising pediatric residents and oncology fellows, serving on the Institutional Review Board at NYUMC, and overseeing the clinical research activities and protocols of the Pediatric Oncology Clinical Trials Office. She also conducted several innovative clinical trials with new drugs such as ONC201 for DIPG and new high dose drug combinations followed by autologous transplants in children with medically refractory cancer.

Dr. Gardner was very devoted to her patients and they relied on her guidance and were grateful for her accessibility. She would frequently spend nights and weekends in the ER and hospital ensuring that her patients received optimum care. She often shared her extensive experience and wisdom with us at our weekly pediatric neuro-oncology tumor board meetings and was eager to help other colleagues provide optimum care of their patients.

We all hope that in her retirement Dr. Gardner will have many more opportunities to pursue her aspirations outside of medicine, but knowing her I suspect she will stay involved in our profession for many more years. On behalf of her many grateful patients and colleagues and the Making Headway Foundation Board, we wish Dr. Gardner good health and a well-deserved long rest.

IN MEMORY OF THOSE WHO PASSED

Each year, more than 500 children in the U.S. lose their lives to brain or spinal cord tumors. In 2024, we remember and honor the children who were part of the Making Headway Foundation family—loved, supported, and never forgotten.

Amelia
Caleb
Daniela
Danny
Don
Edilin
Genesis
Jasmina
Jesselyn
Keanu
Kenzie
Layla
Lea
Melonie
Peter B.
Peter R.
Satya
Siya
Yusra
Zaniya

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.

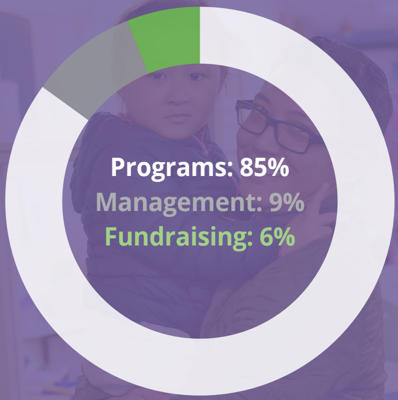
Solomon So
Proud father

FINANCIAL SUMMARY 2024

Revenue	$1,278,100
Winter Show	$653,593
General Contributions	$405,415
Grants Received	$72,246
Other Events	$34,635
Interest/Unrealized Gains/Other	$112,212

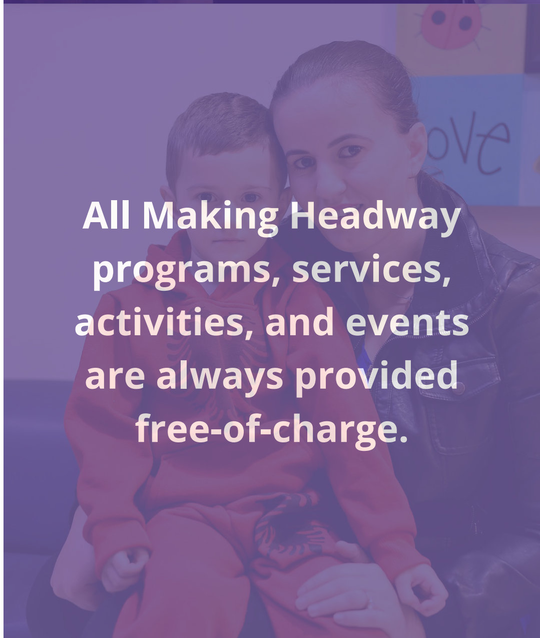
Expenses	$1,321,183
Making Headway Program and Support Staff	$353,778
Research Grants	
Research Labs	$75,024
CBTN & NYU Biorepository	$61,553
Patient Support Programs	
Individual Counseling/Therapy	$329,349
Educational Coordinator/ School Advocacy	$112,355
Direct Patient Suppot	$32,126
Playroom / Entertainment	$20,500
Events and Other Programs	
College Scholarships	$71,223
Family Events	$57,540
Funeral Expenses	$48,306
Other Expenses	
Supplies / Printing / Copying / Postage	$44,234
Outside Services / Technology / Outreach	$25,994
Office Rent / Insurance / Professional Fees	$72,643
Fundraising Events & Expenses	$16,557

Notes: Unaudited financial data as of March 1, 2025 (accrued basis).
Making Headway uses a fund balance savings account to cover any yearly deficits.



85%
of our total budget goes directly to programs, services, or research.

In 2024, Making Headway increased our capacity to directly assist families outside of the hospital.



All Making Headway programs, services, activities, and events are always provided free-of-charge.


Jillanena Diptee


The Bonet Family

Dallas D'Antonio

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.

Board of Directors

Staff

Daniel Lipka, Executive Director
Jennifer Samuels, Office Manager
Maureen Isaia, Family Liaison

Medical Advisory Board

Jeffrey Allen, MD, Emeritus Professor of Pediatrics and Neurology, NYU Langone Medical Center
Oren Becher, MD, Division Chief Pediatric Hematology Oncology, Mount Sinai Health System
James Garvin, MD, Pediatric Hematologist Oncologist, NY-Presbyterian Morgan Stanley Children's Hospital

Contact

Making Headway Foundation
115 King Street, Chappaqua, NY 10514
(914) 238-8384
info@makingheadway.org
www.makingheadway.org

MakingHeadwayFoundation
@makingheadwayfd
@makingheadwayfd

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

This report 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.