Nora Osterman-Davis, age 10

2023–24

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

Over the past 28 years, Making Headway has consistently improved, diversified, and expanded our services to best meet our mission to help children with a brain or spinal cord tumor and their families. Our motto of Care, Comfort, and Cure guides our programs to ensure that we address the complex needs of families throughout the entire process. This includes ***Caring*** for the family on their long journey that begins at the time of diagnosis of a child's brain or spinal cord tumor. We strive to create a sense of family and ***Comfort*** at the hospital or outpatient clinics where families may spend countless days or months. Finally, it includes our unrelenting passion to learn more about pediatric brain and spinal cord tumors, develop better treatments, and find a ***Cure***.

MAKING HEADWAY: **WHAT WE DO**

Our Mission: 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.

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

CARE

Fully Funded RN/Care Coordinator to Help Families at the Hospital

Individual & Family Counseling

Educational Assistance

College Scholarship Fund

Bereavement Support

Housing & Emergency Assistance

Connect Families to Needed Services

COMFORT

Expert Psychological Support and Educational Advocacy for Families

Making Headway Family Liaison

Justus Joyful Moments Fund

Family Events and Activities

Looney Lenny the Clown and Entertainment at Hassenfeld

CURE

Clinical Trials Research Manager

Tissue Biorepository Center

Children's Brain Tumor Network

Neuro-oncology Fellowship Program

Local and Federal Advocacy

Brain Tumor Recovery Research at MSK


Elisa, Clint, and Augusta Greenbaum at the funeral of Jake Greenbaum.

LETTER FROM **OUR CHAIR**

For each of Making Headway's two newsletters in 2023, I wrote a "Letter From Our Chair" column. For this annual report, I have combined parts from those columns into one:

It is important to acknowledge the elephant in the room: more children die from pediatric brain tumors than from any other type of pediatric cancer. Why is that? Because, as everyone knows, anything involving the brain is exceedingly complicated. After all, "it's not brain surgery" means that, in comparison, everything else is easier. Making Headway Foundation spends a significant amount on brain tumor research. Researchers around the world have had some success over the years, and progress has been made, but not as much as for other types of pediatric cancers such as leukemia. An unsuccessful treatment for a child with a brain tumor leads to one incredibly sad outcome—the child dies. Making Headway has never denied a request by one of our trusted social workers for funeral aid for a child with a brain or spinal cord tumor. Over the past ten years, we have provided 185 families in need with some level of support for a funeral or burial, totaling half a million dollars. The families Making Headway has supported through this program reside everywhere throughout the New York City area, with the greatest number in Brooklyn and Queens, reflecting the overall distribution of where our families live. Those who passed ranged from newborns to adults (the latter were diagnosed as children and continued to work with Making Headway).

Every year, many donations are made in memory of a child who has passed. These donors are especially big-hearted; they have found a way to turn a tragedy into hope for others. On a very personal note, friends and relatives of the Greenbaum family have been remarkable in keeping the memory of our Jake alive with their very generous donations since Jake's death in 2020.

Since our founding in 1996, Making Headway has lost over three hundred children to this terrible disease. We must always remember them. It is our wish that someday, the battle will be won to cure those with pediatric brain and spinal cord tumors. In the meantime, we will continue to do all we can to provide Care and Comfort to the children and their families, and work to bring about a Cure. That is why we desperately need your continued generous support.

One last thing: in this age of polarization, it is good to note that all of Making Headway's services are provided free to children with brain or spinal cord tumors and their families. We do not care about their sex or gender, color, religion, nationality, or income level. You can truly feel good about your donation, especially since it helps those fighting the deadliest form of childhood cancer.

Stay well,
Elisa Greenbaum

Elisa Greenbaum

FROM THE **FOUNDERS**

Dear Friends and Families,

Three years ago, we both stepped down as Officers of the Foundation and were honored with the "emeritus" title. But we are still active, working with the new leadership to continue down the path we started walking 28 years ago, helping families and their children in difficult times. In the last newsletter, we included our phone number and email. Since then, many families we have worked with in the past have gotten in touch to let us know how they and their children are doing, or share any problems they are facing. Please continue reaching out to us; we love hearing from you. We welcome letters as well:

Edward and Maya Manley
35 Alpine Lane, Chappaqua, NY 10514
914-238-4917
mayaed35@gmail.com

Maya and Edward

Maya ♡ Edward P. Manley

A LETTER FROM OUR **EXECUTIVE DIRECTOR**

Brain and spinal cord tumors in children are a harsh reality that affects thousands of families every year. No child of any age is immune. Whether they are infants, toddlers, school-age kids, or adolescents, these young warriors face a daunting journey filled with pain, uncertainty, and tremendous challenges.

The strength and courage displayed by the children and their families testify to the indomitable human spirit. As the personal stories featured in this report demonstrate, families' tenacity and ability to embrace life's challenges with unwavering determination are nothing short of awe-inspiring. These experiences paradoxically underscore life's fragility and the importance of cherishing every moment.

Children with brain tumors require specialized care that extends beyond medical treatments. In the upcoming year, Making Headway will continue to support educational advocates, psychologists, a pediatric neuro-oncology fellow, an in-hospital care coordinator, a clinical trials manager, medication management experts, college scholarships, family events, national and local advocacy efforts, a dedicated family liaison, financial support, tumor banks, and so much more. Research also serves as a beacon of hope for children with brain tumors. Your donations fund essential studies and clinical trials to uncover the mysteries of these tumors, find improved treatment options, and ultimately discover a cure. Progress has been made, and with your help, we can accelerate the momentum and save more young lives.

These children deserve a fighting chance at a brighter future. Your donations to Making Headway can have a profound impact by funding research, providing crucial support, and offering hope to them and their families. As part of the Making Headway family, you help surround them with an outpouring of love and support. By donating, you are contributing to the well-being of these courageous children, making care possible for those most in need, and advancing the quest for a cure and better treatments. Your generosity today can transform the trajectory of these young lives, giving them a chance to overcome adversity and thrive. Join us in this critical mission to make a difference in the lives of thousands of children.

Daniel Lipka, Executive Director

A LOVELY **TRADITION RETURNS**

On September 10, 175 people, each directly impacted by a childhood brain or spinal cord tumor, boarded the majestic Skyline Princess for a four-hour yacht cruise around the Statue of Liberty. The families braved torrential rain as they boarded, but we were rewarded half an hour later when the sky cleared and the sun streamed down upon the East River. This was our first cruise since the start of the pandemic and our 18th since 2003. It was a wonderful opportunity for families to connect with one another and enjoy a rare, carefree day. And, like all Making Headway events, it was completely free for all our guests. We'd like to thank the Stadtmauer family, who once again sponsored us with an extremely generous gift. The Making Headway Family Yacht Cruise was yet another enjoyable opportunity to connect with other families and just have a day without stress.

Credit: Todd Shapera Photography

Maya Manley with sweet treats

Amayrah Baptiste and Looney Lenny

Bartla Family

Carrabs Family

HEAD TO THE **HILL**

By Rhea Kochhar

Thanks to the Making Headway Foundation, I had the chance to join the National Brain Tumor Society's "Head to the Hill" advocacy event in Washington, DC. This event was important to me because of my personal experience of being diagnosed with a brain tumor twice. Meeting people who know and understand what this devastating disease entails, sharing my story with them, and learning about theirs really moved me.

Coming together as a brain tumor community to speak up and ask Congress for additional funding for this cause was a no-brainer for me. I know personally what young patients face: that there is no treatment specifically approved for pediatric brain tumors. Various drugs are thrown at kids like me, including chemotherapy for breast cancer—which I got—in the hope something will work.

It was important for me to speak up for myself and for those who cannot. So many don't make it, and for those who do survive, it is a long and harsh journey. But there was a reason to be there beyond sharing our stories. We were there to raise awareness about brain tumors so that Congress can fully understand the needs of the community and address those needs. We requested that they do more so that brain tumor survivors can get the support they need, more research can be done, new treatments can become available, and a cure can be found!

Nobody needs to go through the pain and suffering that a brain tumor diagnosis brings. Just as every drop helps fill a bucket, every story, every experience, and every voice matters. Joining the Head to the Hill event has motivated me to share my passion and involvement further by raising funds and awareness. When we stand up for ourselves and what we believe in, and when more voices join us, we become stronger and more powerful. Our voices become one, touching people and making them reflect on what needs to be done. Head to the Hill gave us a platform, gave us a voice, gave us hope and optimism, and gave us the opportunity to help make a difference! The energy was contagious, and I hope to be there again next year.

Left, Rhea Kochhar. Center, Baljeet Kochhar. Right, Dr. Catherine Young, White House Assistant Director of Cancer Moonshot Engagement.

> "Participation in public policy-focused advocacy, including in the National Brain Tumor Society's "Head to the Hill" annual mobilization on Capitol Hill, is an important way that parents, childhood brain tumor survivors, and caring individuals can make a huge difference. The 2023 "Head to the Hill" event, including Making Headway Foundation and NBTS volunteers, brought power and passion to this year's effort to further increase federal investment in brain cancer research and improve access to health benefits. —David Arons, CEO, National Brain Tumor Society."

NYS **CANCER CONSORTIUM**

Survivors of pediatric brain tumors, parents, social workers, doctors, nonprofit leaders, and others came together to ensure that the next five-year New York State (NYS) Comprehensive Cancer Control Plan specifically includes issues related to childhood cancer. In the previous version of the plan, pediatric cancer was woefully underrepresented, mentioned only a few times throughout the 78-page document. Our goal was to remedy this situation by bringing together those closest to the issue of pediatric cancer to develop a list of critical goals, objectives, and strategies for inclusion in the 2024–2029 plan.

Making Headway and other leaders of this project are currently working with the NYS Comprehensive Cancer Control Plan Steering Committee to integrate our recommendations into the new plan. A full list of these recommendations can be found at: **www.MakingHeadway.org/CancerPlan.**

Making Headway Foundation gratefully acknowledges everyone who contributed to this process: Whitney Bagliebter, John Barrasso, Candida Batista, Steven Brody, Cindy Cambell, Nina Connors, Aaron Czik, Georgie D'Avanzo, Dr. Ira Dunkel, Jacob Ellen, Kim Gilman, Mike Henry, Scott Kennedy, Greg Licciardi, Daniel Lipka, Steve Marder, Mary McCabe, Dr. Shakeel Modak, Dr. Morgan Pines, Dr. Chrissie Salley, Beth Silber, Eileen Stark, Dr. Maria Luisa Sulis, and Steve Wosahla.

MAKING HEADWAY ACCOMPLISHMENTS: BY THE NUMBERS

Over the past 28 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. There are some things we can measure in data and numbers, however. Here are just some of the quantitative accomplishments of our work.

Direct or indirect support to over
2,175
families

8,250+
hours of educational advocacy services

13,750+
hours of individual and family counseling

152
college scholarships

More than
70
events for families

Invested over
$28m
in grants, services, programs, and events for families impacted by a childhood brain or spinal cord tumor

Over
66
published research papers as a direct result of our grants

83,000+
donations, from more than
25,900
unique households

10
pediatric Neuro-Oncology fellowships fully funded

Funded over
170
supporting research and quality-of-life programs at local hospitals

Assisted families from
10
major children's hospitals

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

Financial support for over
185
funerals

28 YEAR TIMELINE OF MAKING HEADWAY

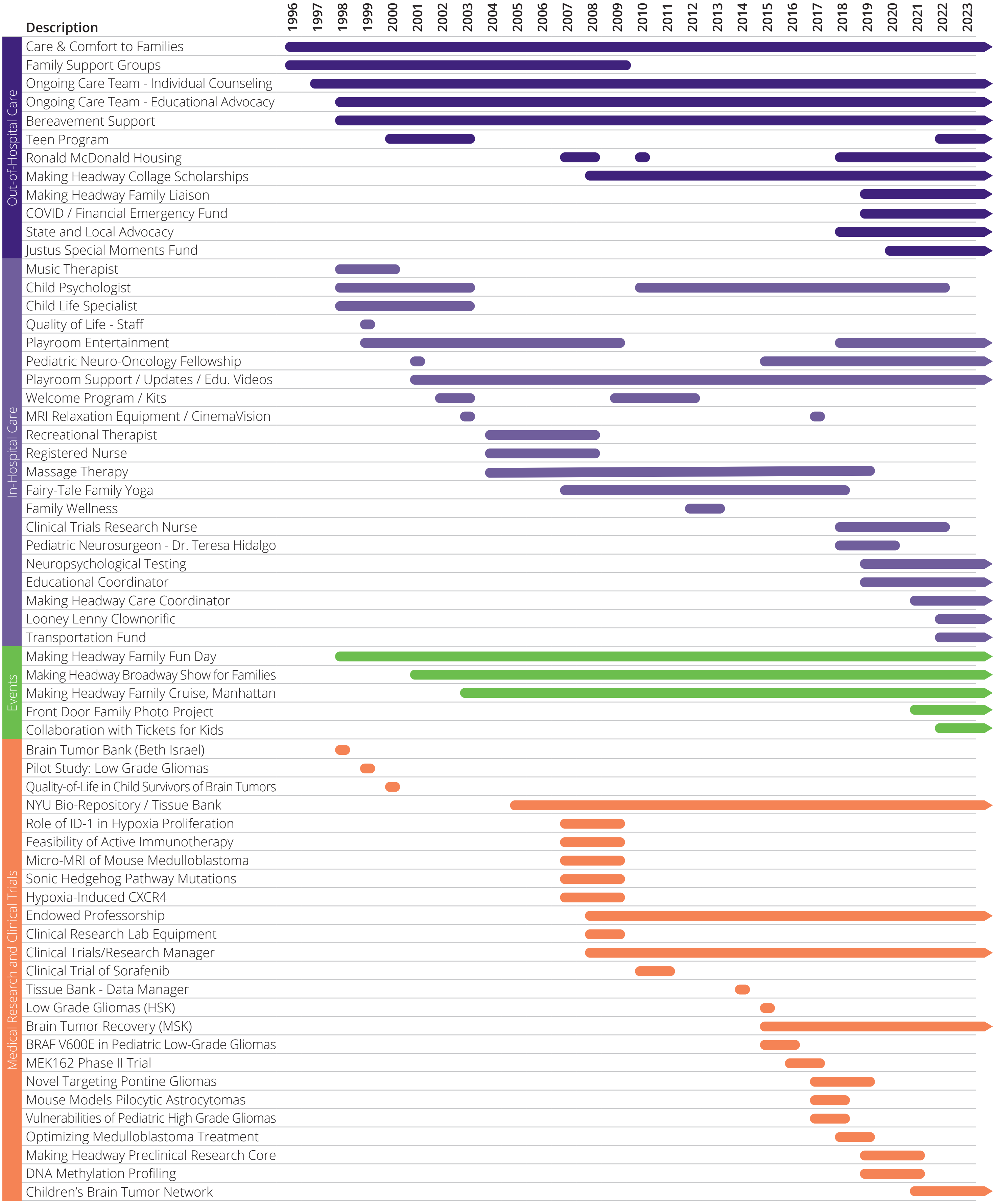


Photo by Todd Shapera Photography

SILLINESS
WITH PURPOSE

By Looney Lenny

I had been working with hospitalized children as Looney Lenny the Clown for over a decade when I met Maya Manley. After watching one of my playroom performances, Maya pulled me aside and introduced me to Making Headway's mission. Flash forward 18 years: Looney Lenny has become an integral component of the Making Headway family and beyond.

Being Looney Lenny has evolved into my life's greatest accomplishment. I have entertained children for more than half my life, and it is not an occupation I take lightly, despite the job title. My job is to make children and parents laugh at a stressful, often frightening time. My goal is to use magic and laughter as a distraction from pain and hopefully prevent traumatic, long-lasting memories. I attempt to cast a magical net over illness and transport the patient and their family to a stress-free moment where my red nose and blue eyebrows provide momentary relief from needles and IVs. Once, a nurse described how the 8-year-old boy I had just entertained couldn't stop talking about me:

"He was so excited telling us about your tricks that he didn't even notice I was hooking him up to an IV! That was a first."

What ultimately makes ongoing hospital visits so valuable is the impact of creating consistent, long-term relationships with the children. These relationships ensure that, together with Making Headway, I am a safe and trusted member of a child's care team and an ally in their treatment.

During the pandemic, when in-person hospital visits were prohibited, Making Headway recognized hospitalized children's loneliness and funded my Zoom visits, which turned out to be just as successful as in-person ones. With a little adaptation, I was able to continue to entertain and distract, maintaining my connections with the children—especially important during the most isolating years of most of our lives.

Making Headway isn't merely an organization; it is a family whose allegiance is unwaveringly devoted to sick children and their caregivers. Not only do they fund doctors and researchers to enable medical advancements, but they also understand the journey to well-being is layered; it needs a sympathetic support system and lots of clowns along the way. It is amazing to see what has been created in only 28 years. I am incredibly excited to be a part of the team as we move into the next magical chapter.

> *"Clowns in hospitals might seem like just a bit of fun entertainment for kids, but if having a clown around can make children less scared or even feel slightly less pain, it's entertainment that makes a hospital stay more bearable for young patients — and there's nothing silly about that." —Forbes Magazine*

FAMILY **FUN** DAY

On June 18th, Making Headway hosted our 28th Annual Family Fun Day. The 2023 event took place at the world-famous New York Hall of Science in Queens, NY. Over 300 survivors, siblings, parents, and volunteers attended. This event is just one of the special ways that Making Headway gives back to families who have been impacted by a childhood brain or spinal cord tumor.


Balkis Leal (brain tumor survivor) and Maya Manley


Avery Berthold and Making Headway volunteer Destiny Lipka


Valentina Carrabs (Medulloblastoma survivor) with her family

Photos by Todd Shapera Photography

CARE AWARD

Making Headway is delighted to announce Patricia Ryan-Johnson as the recipient of our third annual Care Award. Patricia, a social worker at Hassenfeld Children's Center, has collaborated with Making Headway for more than 15 years, going above and beyond to ensure families receive the help they require. She has worked tirelessly to connect us with families, recommended professionals to expand our breadth of therapeutic services, organized reduced-rate housing (paid for by Making Headway) for out-of-state clinical trial patients, and much, much more. We asked Patricia to tell us her story:

My father was my hero, and he was a hero to many other people, too. Dad was a sandhog, meaning he worked building New York City's tunnels. One day, there was a fire in a tunnel, but firefighters refused to go down to rescue the men trapped deep within. So my father went down instead, carrying men out on his back and saving many lives. He was injured in the process, but Mom, the strength behind Dad's wings, held our family of four children together during his hospitalization. Another time, my best friend's father came home very upset; he had just been fired. When I told Dad what had happened, he went straight to my friend's house and hired her father on the spot! No fanfare; just neighbor helping neighbor.

I have so many memories like this, but these are two that mean the most to me. Both my mother and father were very special people. I learned from them to be there for—and help—other people as much as I can. My career was in their honor.

My father was always a union man, so when I became a social worker, I made sure I was part of a union, too. And when he died of cancer, I decided to dedicate my work to him by working with cancer patients. Emulating my parents, I sought out people with like minds and similar worldviews to help me do the best possible job and ensure the best outcomes for each child and family I came to know.

My happiest day at work was when I met Maya Manley. Maya was someone I could look up to and admire. She worked tirelessly every day to ensure each family had all they needed, and she became my confidant and dear friend, enabling me to help families in critical ways. For example, during one especially hot July 4th weekend, a family whose child had a serious illness had no air conditioner. Maya sprang into action and before anyone knew it, there was money for this life-saving device! Another time, when there was a new clinical trial and children were flying in from around the world to participate, I went to Maya and the Making Headway Foundation to cover the costs of lodging in NYC. Thanks to Maya, Making Headway found a way to cover the lodging costs for every family in the trial, ensuring care would be available to everyone, regardless of their ability to pay. I have a million such examples; Maya has blessed the lives of innumerable children and their families, and she has certainly blessed me!

While I appreciate this honor and this award, I must share the blessing with my Mom and Dad, with Maya, and with my family: Bob, Lindsey, and Ryan, who have always been my biggest supporters. My greatest honor is to do this work and get to know and love each child and family.

FAMILY **CARE** AWARD

For their 25 years of compassion, commitment, and hard work to help children who have been diagnosed with a brain or spinal cord tumor, the 2023 Making Headway Family Care Award was presented to the Casale family. Through their efforts and leadership, Making Headway has received over $400,000 from 1,700 donations. This includes proceeds from the Fore A Difference Golf Tournament, which the Casale family have hosted for nine consecutive years. Due to their efforts and personal generosity, children with brain tumors, and their families, have been able to receive the high-quality, critical services they need and deserve. The Casales represent the very best of Making Headway's philosophy and mission.

Steven and Tracey Casale's daughter, Sophia, was diagnosed with optic chiasmic glioma as a baby. In the 25 years since that time, she has blossomed into a caring and successful woman. She recently graduated from UMass-Boston's Gerontology and Management of Aging Services Master's Degree program; she strives to understand older adulthood and one day contribute to the field of aging in some way. She once wrote about her upcoming career, "I'll always remember how powerful a meaningful hug, big smile, and generous heart can truly be. I have Making Headway to thank for that." Sophia's commitmen to helping others honors Making Headway's mission and reflects her parents' loving dedication.

Making Headway Foundation is sincerely grateful for the efforts of the Casale family. We will continue our work to make them proud.

IN MEMORY OF THOSE WHO PASSED

Every year, over 500 children in the U.S. will die from a brain or spinal cord tumor. Some of these children were loved and cared for by Making Headway Foundation. We honor and remember those we lost in 2023.

ALEXANDER
ANGEL
ANTHONY
ASHLEY
AUGUST
AZIZA
BILLY
BRANDON
CHARLOTTE
DANIEL
FLORENTINA
JAMES
JASMINA
JEFFREY
JOHNNY
JONATHAN
JOSEPH
JURNEE
KAIDEN
KYLE
LITZY
LUIS
MALACHI
MANPREET
MARCELLA
MATIAS
MERRY
NATHALIE
PENELOPE
RICHARD
SUSAN
WILLIAM

HER BRIGHT LIGHT SHINES IN MY HEART ALWAYS

On June 30th, 2023, we lost a beautiful child who was a loving part of our Making Headway family. We were deeply saddened by the passing of Charlotte Bishop-Ortega at the age of 5. She was diagnosed with a very rare brain tumor when she was only 2 1/2 years old.

By Patty Bishop,
Charlotte's grandmother

Charlotte was a smart, affectionate, sassy little girl. She loved to have tea parties and fashion shows with her Barbie and Anna & Elsa dolls. She loved books and was a whiz at finding Waldo. Charlotte was a delight to be with and was always cheerful despite the ongoing medical treatments and challenges she faced. Her bravery was remarkable for such a young child. She leaves us much too soon and will be so terribly missed. Her parents, foster parents, grandparents, aunts, and uncle will cherish the wonderful memories of Charlotte forever. She was a bright light in our lives and her light will remain in our hearts always. My sincere thank you for Making Headway's love and support, I will forever be grateful.

MY SUNSHINE ON A CLOUDY DAY

By Jannelly Larriu

At the age of 10, my nephew, Jonathan, was diagnosed with neurofibromatosis type 2, with tumors in both his brain and spinal cord. He sadly lost his battle on December 24, 2022, just six days shy of his 26th birthday.

I miss him so much it hurts. I miss his smile. Jon did not let his disease define him. Even after numerous surgeries, he always had a smile for my family and me. Jon had this smile that was infectious. A smile that did not go dull, no matter what. His smile was evidence that he was loved and valued. Jon's smile reminded me not to stress the small stuff because to go through what he went through and still wear that smile was a lesson for us all. Through our ups and downs, we can choose to smile and be the light that brings sunshine on a cloudy day. He was my sunshine!

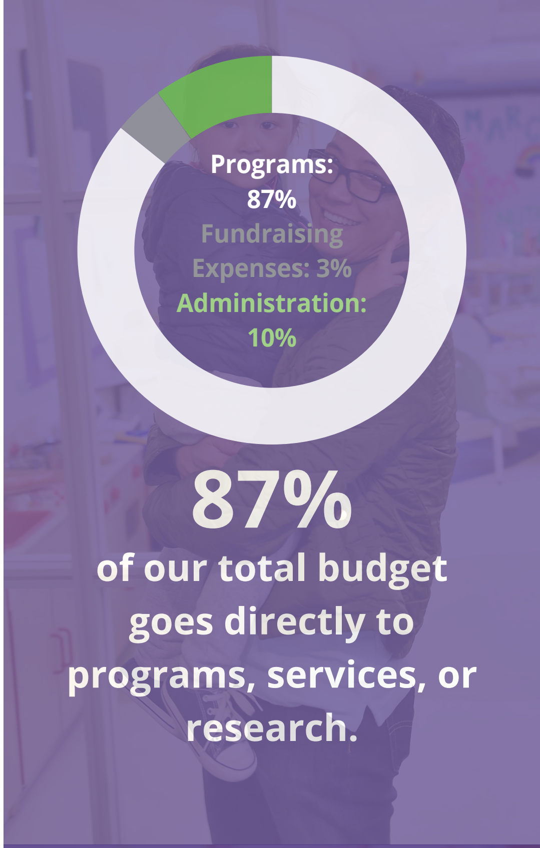
I want to thank Making Headway for helping with the bereavement costs and for continuing the work to find a cure for brain and spinal cord tumors. Jon did not live to see a cure, but I hope with the help of Making Headway, we will find one in this lifetime.

FINANCIAL
SUMMARY 2023

Revenue	**$1,294,199**
Winter Show	$630,127
General Contributions	$375,990
Grants Received	$45,000
Other Events	$64,281
Interest/Unrealized Gains/Other	$178,801

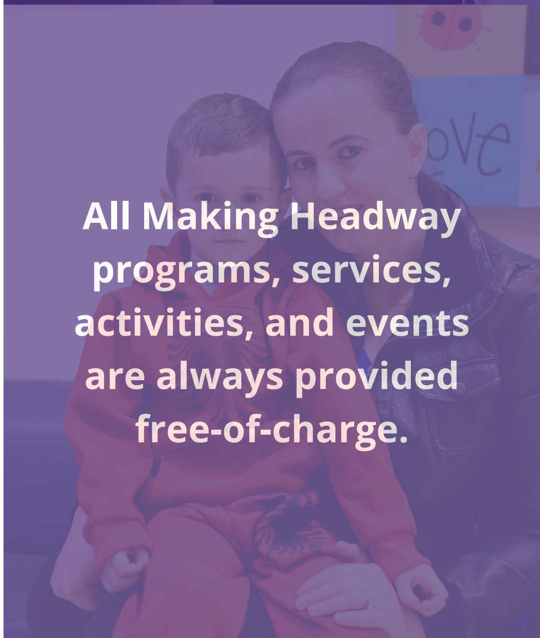
Expenses	**$1,278,482**
Making Headway Program and Support Staff	$291,986
Research Grants	
Clinical Trials Manager	$70,142
Research Labs, CBTN, & Biorepository	$31,605
Patient Support Programs	
Individual Counseling/Therapy	$243,419
Making Headway Care Coordinator	$145,168
Educational Coordinator/School Advocacy	$88,475
Playroom / Entertainment	$25,000
Housing / Advocacy / Joyful Moments Fund/ Other	$19,744
Events and Other Programs	
College Scholarships	$72,954
Family Events	$57,746
Funeral Expenses	$53,390
Other Expenses	
Supplies / Printing / Copying / Postage	$43,734
Outside Services / Technology / Outreach	$22,514
Office Rent / Insurance / Professional Fees	$71,704
Fundraising Events & Expenses	$40,902

Notes: Unaudited financial data as of February 1, 2024 (accrued basis).
Making Headway uses a fund balance savings account to cover any yearly deficits.



87%
of our total budget goes directly to programs, services, or research.

In 2023, Making Headway continued to expand programs and services while increasing financial efficiencies.



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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

Medical Advisory Board

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.