

2021-22 ANNUAL REPORT

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making headway
foundation

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





Over the past 25 years, Making Headway has consistently improved, diversified, and expanded our services to best meet our mission. 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



CARE

Making Headway Care Coordinator
Individual & Family Counseling
Educational Assistance
College Scholarship Fund
Bereavement
Housing & Emergency Assistance



COMFORT

Psychological & Education Services
Making Headway Family Liaison
Clinical Trials Nurse
Justus Joyful Moments Fund
Family Events and Activities
Hassenfeld Playroom
Entertainment



CURE

Preclinical Core Research Center
Clinical Trials Research Manager
Tissue Biorepository Center
Children's Brain Tumor Network
Neuro-oncology Fellowship Program
Local and Federal Advocacy



MESSAGE FROM MAKING HEADWAY'S NEW CHAIR, ELISA GREENBAUM

Why Would I Want to be the Chair of Making Headway? (And why I hope you will support me and the Foundation.)

At the beginning of its 25th anniversary year, Making Headway Foundation elected me as its new Chair. I take the reins from Edward Manley, who was our wonderful Chair from the inception of the foundation, and for the next quarter of a century. I have the responsibility of filling his big shoes.

But given all that has happened to me in the past year and a half, I've been asked, why would I take this job?

Since our first-born son Jake was diagnosed at three months old with a rare, malignant brain tumor in February of 1990, there was hardly a moment that pediatric brain tumors have not been a part of my life. For almost 32 years, I have been actively raising money to help children with brain and spinal cord tumors. It was

also our way of giving thanks for the gift of Jake's life. For the past 25 years, I have been an active board member of Making Headway. All this time, I was caring for our survivor—our special needs son, Jake (and later, also his sister, Augusta).

But tragically, at the end of August 2020, our delightful Jake died at age thirty from an aggressive (non-brain) cancer. Then, this past July, I badly broke my leg in a bike accident that required two complex surgeries and hospitalizations, kept me off my feet for three months, and will require extensive rehabilitation.

So wasn't it time, and fair, for me to step away from this stressful affliction, to live my own, unencumbered life?

I couldn't. My husband Clint couldn't either (Clint is a Making Headway Founder and board member). We learned this philosophy by example from Ed and Maya Manley. They couldn't walk away 35+ years ago,

after their daughter Cynthia survived a brain tumor. (Cynthia graduated college, got married, and lives upstate.)

Brain tumors are the #1 cancer killer of children. Brain surgery is acknowledged as the pinnacle of difficulty. For survivors, follow-up chemotherapy and radiation cause their own side effects and collateral damage. Currently, we can't prevent pediatric brain tumors from happening. But it is my pledge to lead Making Headway to live up to its name: To "make headway" in caring for children who have brain and spinal cord tumors (particularly in the hospital); to "make headway" in comforting these children, their parents and their families; to "make headway" in the fight to cure pediatric brain tumors.

To do all of this costs money. Since our inception, Making Headway has spent over \$26 million towards fulfilling our mission of Care, Comfort, and Cure. We have a current annual budget of \$1.5 million. We have three full-time employees, and pay for 28 outside specialists (Neuropsychologists, Educational Coordinator, Pediatric Neuro-Oncology Fellow, Clinical Trials Research Nurse, Care Coordinator, etc.). The point of this is, while the Making Headway Foundation has the warmth and passion of a family charity, we are highly professional, and an important presence in the world of pediatric brain tumors. Your donations will be well-spent, supporting our very important mission to help the most desperate of situations. Together, we can make headway!

Elisa Greenbaum

CURRENT PROGRAM HIGHLIGHTS



In 2021, Making Headway has continued to expand our Ongoing Care Team in response to the new reality of COVID-19 and its psychological impact on children, siblings, and parents. We've also increased direct support for NYU Hassenfeld families trying to navigate the complex and often overwhelming number of doctors and treatment visits they need. The situation is especially complex for families taking part in clinical trials, which may happen when their child's illness has not responded well enough to standard treatments. Overall, Making Headway has been moving resources from family events—postponed by the pandemic—to services that offer families immediate help.

ONGOING CARE TEAM

The Making Headway Ongoing Care Team was a revolutionary concept 25 years ago, and has proven to be one of the most impactful aspects of our work. A child's serious illness is an intensely personal experience for the whole family. The value of free-of-charge individual or family counseling sessions with licensed psychologists, specializing in dealing with the unique issues that these families face, can hardly be measured. Nor can the value of expert educational advocacy to ensure these children have the best school experience they can possibly have. What started as a team of four has grown to encompass 28 highly qualified professionals—many bilingual—including community-based specialists in areas such as neuropsychology and bereavement.

NEUROPSYCHOLOGY TEAM AT NYU HASENFELD

Although Making Headway provides psychological support to families through our Ongoing Care Team, we understand that comprehensive support starts in the hospital, immediately after a child is diagnosed with a brain tumor. Through one of our grants, Making Headway Foundation has enabled NYU Hassenfeld to maintain a full-time licensed clinical neuropsychologist, allowing for increased and enhanced neuropsychological interventions including screening, testing/assessment, and treatment. In addition, Making Headway's support of NYU's educational coordinator enables her to partner with the neuropsychologist, helping to advance children's educational and developmental progress throughout the course of treatment.

In 2021, the Making Headway-funded neuropsychologist significantly increased the number of assessments and testing hours for patients. This was vitally important, as pediatric brain tumor survivors may experience cognitive decline post-treatment, and neuropsychology assessments are critically important to assessing short and long-term needs. The combination of neuropsychological testing, specialized mental health services, and educational support, gives each child the best chance to overcome current and future challenges and achieve their individual potential.

MAKING HEADWAY CARE COORDINATOR

Sarah Coughlin, the Making Headway Care Coordinator, supports the NYU pediatric Neuro-Oncology program by organizing schedules and serving as the first point of contact for all patients and their families. Sarah addresses their questions, concerns, or care coordination needs, and places check-in calls after care to ensure everyone is doing well. Her work leads to safer, more efficient, more timely care for patients, and removes the burden of effective care coordination from families—especially valuable for patients who have complicated care and follow-up needs. This, in turn, improves long-term outcomes.

"Sarah has been an asset to the team, and a wonderful liaison between our patients and families and our multidisciplinary team of providers. Her attention to detail has been instrumental in ensuring a patient-centered approach to care, and she's worked diligently with the Making Headway Family Liaison to connect interested families to the foundation's available services."

—Dr. Theo Nicolaides, Program Supervisor

OTHER PROGRAMS

Beyond these highlighted programs, Making Headway has invested in and continued a number of other grants, including ones supporting: a clinical trials manager and clinical trials research nurse, the Center for Biospecimen Research and Development (tissue bank), the Making Headway Preclinical Core, bereavement support, pediatric Neuro-Oncology fellowships, Ronald McDonald housing, college scholarships, DNA methylation profiling, the Making Headway family liaison, COVID-19 emergency support, the Justus Special Moments Fund, various continuing medical research projects, and many other direct and indirect programs and services.

COMMEMORATING MAKING HEADWAY'S 25TH ANNIVERSARY

Making Headway's 25 years of serving children and families has been recognized beyond our own community of brain tumor survivors. This fall, Making Headway received official proclamations describing the needs of children with brain or spinal cord tumors, and distinguishing our mission to provide Care, Comfort, and a Cure.

Each proclamation commends Making Headway on our unceasing dedication to helping children and our tangible impact on families, medical research, hospital care, and much more. As one elected official said, "Organizations like Making Headway don't happen every day, and lasting for 25 years is an incredible achievement."

Additionally, Westchester County named October 17th "Making Headway Foundation Day" in honor of our silver anniversary. We would like to thank the following officials for their ongoing support and for ensuring the passage of proclamations that acknowledge the seriousness of pediatric brain tumors and Making Headway's role in helping those impacted by this terrible disease.

- US Congressman Mondaire Jones
- NYS Senator Pete Harckham
- NYS Assemblyman Chris Burdick
- Westchester Legislator Vedat Gashi



Over the past several months, in preparing for this annual report, I have had the opportunity to look back at the amazing

25-year history of Making Headway. Making Headway's long-lasting, steadfast dedication is demonstrated by our commitment to effective core programs and services. For 25 years, our Ongoing Care Team of psychologists, psychiatrists, and educational advocates has helped thousands of families. Our family events, investments in hospital playrooms, and medical research have been going strong for over 20 years. However, what makes us unique is our ability to create new programs and adjust to the changing needs of families and hospitals. Innovative programs like family wellness, college scholarships, massage therapy, and neuropsychological testing have come about as a direct result of learning the needs of families and reacting decisively to meet those needs.

On a personal note, it is almost overwhelming to look back at Making Headway's impact and imagine the awesome responsibility of continuing these efforts for the next 25 years. We are working with families who have a child with a brain or spinal cord tumor. I write that often, but I think about it all the time. I'm going to ask that you take a moment right now, close your eyes, and really try to put yourself in their shoes—really think about having to make life-altering medical choices for your child, and having to trust their mortality to the hands of strangers.

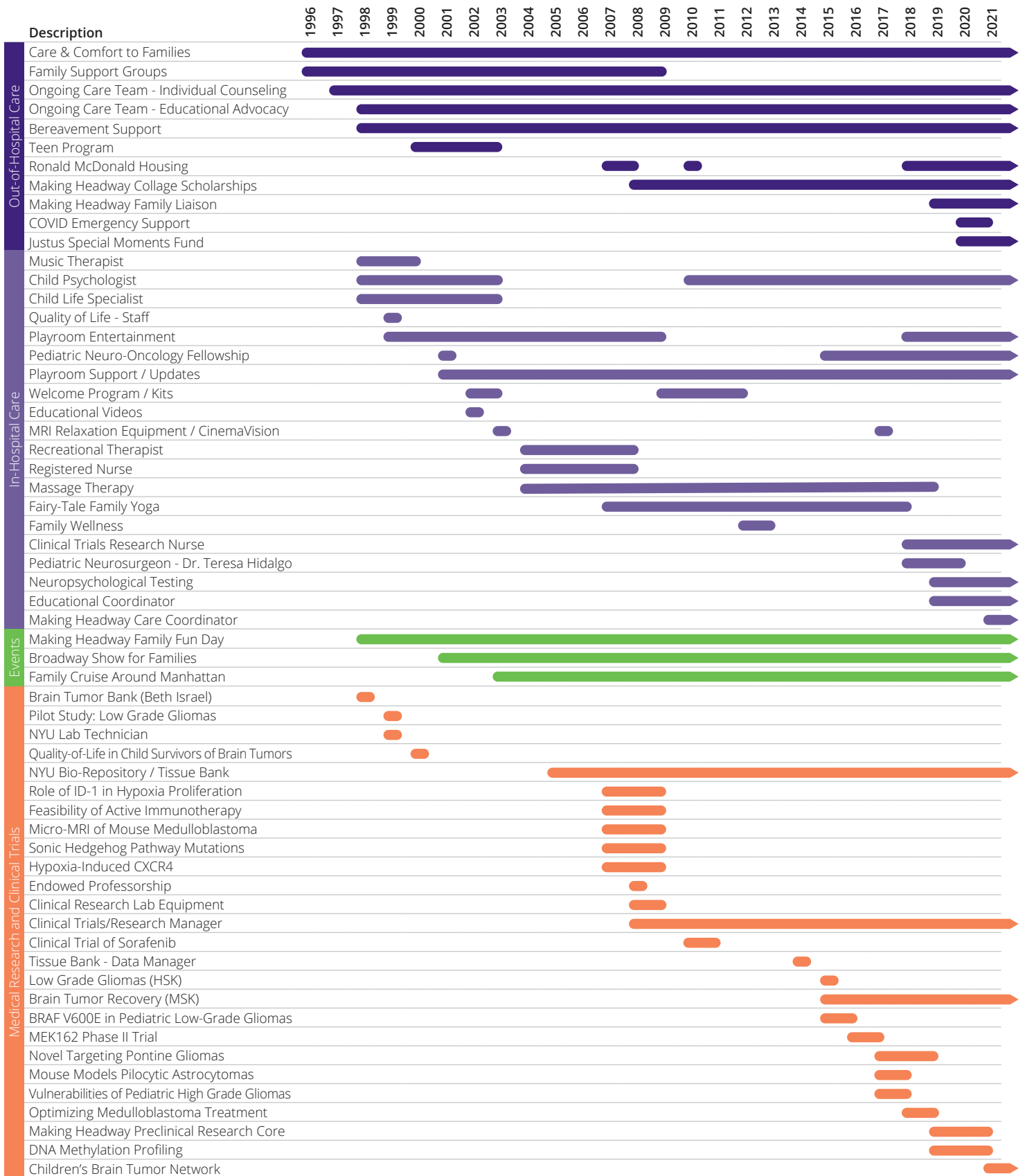
Imagine what it is like to have the lives of everyone in your family altered forever in a single moment, knowing there was nothing anyone could have done to prevent it.

If you couldn't image this scenario, or just didn't want to, you are not alone. Most people don't even want to think about or acknowledge that childhood cancer exists in this world. But it does, and these families need help—all of them, even the strongest ones out there. They need help from doctors, nurses, and child life specialists. They need help from their own families and their own communities. They need help from expert psychologists, therapists, and educators. No family should have to do this alone, and at Making Headway, it is our proud mission to make sure they never have to. Yet it is only through the support of our donors that we can continue our work.

Some of our supporters have been here since we started in 1996, and some may make their first donation today, but wherever you stand on this continuum, know that your contribution makes an important impact. Making Headway has the vision to have a real impact, the stability to make both short and long-term decisions in the best interest of families, and the track record to show it works. Over the next 25 years, we will continue to focus on our mission and always do what is right for children with brain and spinal cord tumors.

Daniel Lipka, Executive Director

25 YEAR TIMELINE OF MAKING HEADWAY



MAKING HEADWAY ACCOMPLISHMENTS: BY THE NUMBERS

Over the past 25 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
2,000
families

8,000+
hours of educational
advocacy services

12,000+
hours of individual
and family counseling

114
college scholarships

More than
65
events for families

Invested over
\$26m
in grants, services, programs,
and events for families impacted
by a childhood brain or spinal
cord tumor

Over
60
published research papers as a
direct result of our grants

75,000+
donations, from more than
25,000
unique households

8
pediatric Neuro-Oncology
fellowships fully funded

Funded over
150
supporting research and
quality-of-life programs
at local hospitals

Assisted families from
9
major children's
hospitals

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

Financial support for over
150
funerals



There are so many ways you can help a child with a brain or spinal cord tumor. You can volunteer at a local nonprofit, participate in fundraising events, or donate to Making Headway. But there is another thing you can do that you might not have thought of: advocate for important state and federal legislation that increases investments in research, directly helps families, or helps create a platform for future medical discoveries. Here are some examples:

THE CREDIT FOR CARING ACT (H.R. 3321 / S. 1670) would provide family caregivers with financial relief, and help offset some of the expenses they incur when taking care of a sick child or other family member. Caregivers play a critical role in helping brain tumor patients navigate their health care journey, but often incur significant financial costs as a result. Family caregivers spend, on

average, nearly 20% of their total income on caregiving activities. For families whose child is diagnosed with a brain tumor the costs are even more extreme, given that one parent usually has to quit their job to manage their child's constant doctor and hospital visits, as well as being a full-time caregiver. Through this legislation, families would receive a credit of up to \$5,000 to help cover all these costs.

THE GIVE KIDS A CHANCE ACT (H.R. 5416) will give children with cancer the opportunity to receive trials of two or more drugs at the same time. The legislation will authorize the FDA, at its discretion, to require companies undertaking regulatorily-directed pediatric cancer trials to plan combination trials instead of single drug trials, giving kids with relapsed cancer a better chance of success. The Give Kids a Chance Act will also require biotech

firms and pharmaceutical companies to pay for their pediatric cancer trials.

THE GABRIELLA MILLER KIDS FIRST RESEARCH ACT 2.0 (H.R. 623 / S.1523) redirects penalties collected from law-breaking pharmaceutical, cosmetic, supplement, and medical device companies to pediatric and childhood cancer research. The Kids First program supports critical research into pediatric cancer and structural birth defects, and has focused on building a pediatric data resource combining genetic sequencing data with clinical data from multiple pediatric cohorts.



To get involved or learn more about each of these acts and find quick links to support them, visit www.MakingHeadway.org/advocacy.

Making Headway Joined CBTN Executive Council

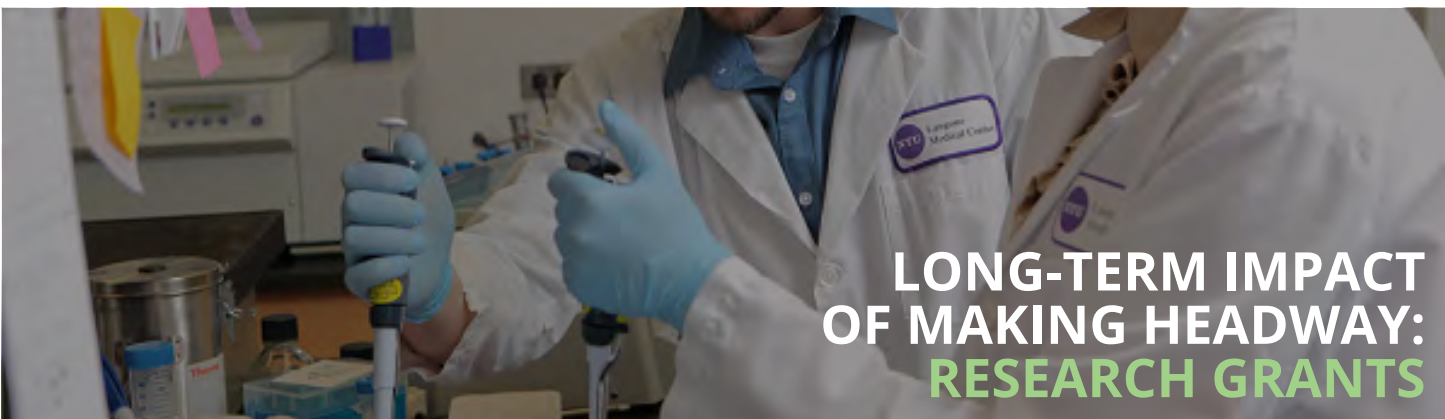


In 2021 Making Headway was pleased to join the Executive Council of the Children's Brain Tumor Network (CBTN). CBTN is dedicated to driving innovative discovery, pioneering new treatments, and accelerating open science to improve health for all children diagnosed with a brain tumor. "Innovation through collaboration" is made possible by CBTN's biorepository and shared data portals, as well as the expertise of leaders in the field of biomedicine. This collaborative research effort has 26 primary member institutions; and has enrolled more than 4,361 subjects and collected more than 50,000 specimens.

Through CBTN, researchers share expertise, specimens, and data to accelerate the finding of less toxic, more effective treatments and cures for children with brain tumors around the world. What sets CBTN apart from other biorepositories is the immediate and free availability of data for any researcher in the world, with the caveat that all information resulting from its use be shared back for everyone's use.

Just recently, CBTN received some extremely exciting news. The National Institutes of Health (NIH) has approved its request

for support in sequencing a considerable portion of the remaining CBTN bank. CBTN's entire cohort of 4,594 specimens will undergo whole genome sequencing, and 1,531 subjects will also get RNA sequencing. The sequencing will provide researchers with unprecedented access to extraordinary data, which will provide fundamental insights into the causes of pediatric brain tumors, how they grow, and how patients can be effectively treated. At a cost equivalent to about \$45 million, this is one of the largest projects of its type NIH has ever funded.



LONG-TERM IMPACT OF MAKING HEADWAY: RESEARCH GRANTS

Medical research into pediatric brain tumors is extraordinarily complex to conduct and often very difficult to evaluate. The image of an individual doctor experiencing some masterful insight that leads directly to a new treatment is the stuff of Hollywood, not real life. For something as complicated as childhood brain tumors, it takes teams of researchers, from many hospitals and companies, decades to make breakthroughs, with every small bit of understanding working together to gradually build new knowledge. And even with that knowledge, it may be another decade before actionable treatments can be developed, tested, and approved for safe use. Over the past 25 years, Making Headway has done our part in this process, because we know that if we don't try, there will never be any breakthroughs, new treatments, or a cure. As we celebrate our 25th anniversary, we look back at a few of our research grants to see their short and long-term impact.

DR. DANIEL TURNBULL, 2007 MICRO-MRI OF MOUSE MEDULLOBLASTOMA PROGRESSION AND RESPONSE TO THERAPY



The original goals of this grant were to use micro-MRIs to better understand medulloblastomas (a malignant central nervous system tumor) in mice, and to analyze the effects of cyclopamine, a naturally-occurring chemical, on the progression of these tumors.

Unfortunately, the researchers were not able to achieve their primary goals, but the techniques they used to image the medulloblastoma progression had a lasting impact, allowing the team to investigate a number of approaches to detecting early stage medulloblastomas using MRIs. This led them to form collaborations in which Manganese Enhanced MRI (MEMRI) was employed to study tumor progression; MEMRI turned out to be a very useful tool for studying medulloblastoma biology and for use in preclinical drug studies. Even today, this research has continued. In a fruitful collaboration with the Joyner lab at Memorial Sloan Kettering Cancer Center, researchers applied MEMRI to two mouse models of a common form of medulloblastoma, pinpointing mutations that lead to medulloblastomas forming in the cerebellum. At least four publications have come from this research, most recently just this year.

DR. MATTHIAS KARAJANNIS, 2010-11 CLINICAL TRIALS: THE MULTI- INSTITUTIONAL PHASE II STUDY OF SORAFENIB



As we know, most clinical trials fail, but even when that happens, scientists can glean valuable information from them. This was the case with Making Headway's Phase II research study into the drug sorafenib. We learned from the clinical trial and accompanying laboratory research that sorafenib is not effective in treating BRAF fusion

positive and NF1 related low-grade gliomas, and identified the underlying molecular mechanisms that explain why these treatments fail. Based on this knowledge, a different class of drugs, called MEK inhibitors were studied in subsequent trials and shown to be effective.

DR. RICHARD POSSEMATO, 2017-2018 VULNERABILITIES OF PEDIATRIC HIGH GRADE GLIOMAS



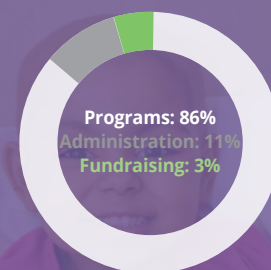
Funding provided by the Making Headway Foundation enabled this research team to generate metabolic profiles of a precious set of pediatric brain tumors, including diffuse intrinsic pontine gliomas (DIPG) and pilocytic astrocytomas. The team was then able to compare these profiles to metabolic profiles that had previously been generated from adult brain tumors. In addition, they used patient samples to generate additional DIPG cell line models for future testing. Specifically, the team was able to take the first look at how pediatric brain tumors make use of nutrients from the environment; this knowledge will help researchers explore how to target metabolic pathways and nutrient acquisition in future work, and may provide critical insights into future discoveries. The study's principal investigator is also collaborating with an investigator at another institution to consider the impact of metabolism on a novel anti-cancer agent on pediatric gliomas.

FINANCIAL SUMMARY 2021

Revenue	\$1,268,601
Winter Show	\$712,033
General Contributions	\$385,165
Trusts and Bequests	\$90,000
Grants Received	\$73,890
Other Events	\$5,556
Interest/Dividends/Other	\$1,957

Expenses	\$1,316,066
Making Headway Program and Support Staff	\$302,803
Research Grants	
Clinical Trials Manager and Nurse	\$113,614
Aspects to Recovery from a Brain Tumor	\$44,229
Research Labs, CBTN, and Biorepository	\$41,642
Patient Support Programs	
Individual Counseling/Therapy	\$186,511
Making Headway Care Coordinator	\$125,240
Neuro-Psychology Testing	\$77,098
Individual Educational/School Advocacy	\$75,922
Playroom / Entertainment	\$15,264
Housing / Advocacy / Joyful Moments Fund/ Other	\$13,441
Other Programs	
College Scholarships	\$102,213
Funeral Expenses	\$91,983
Other Expenses	
Supplies / Printing / Copying / Postage	\$50,711
Outside Services / Technology / Outreach	\$44,607
Office / Insurance / Professional Fees	\$29,368
Fundraising Events	\$1,420

Notes: Unaudited financial data as of February 1, 2022 (accrued basis).
Making Headway uses a fund balance savings account to cover any yearly deficits.



86%
of our total budget
goes directly to
programs, services,
or research.

**Making Headway
continues to adjust
our programs and
services to meeting
the ever-changing
needs of children
with CNS tumors.**

**The COVID-19
pandemic continues
to impact our
finances in many
ways, including
reductions in the
costs and revenue
from canceled
fundraising and
family events.**



The Future

If the past is any indicator, Making Headway's next 25 years may be very similar to our first quarter century. Too many children are still being diagnosed with brain and spinal cord tumors, leading to serious, lifelong challenges for them and their entire family. In fact, if, as we hope, technology leads to more children surviving, the need for ongoing care support will be greater than ever. Most of our programs are not standard at most local hospitals, and the need for Making Headway's services will continue to grow.

We still hope that treatment for children with a brain or spinal cord tumor will fundamentally change over the next 25 years. Through new technologies, like artificial intelligence and advanced DNA sequencing, combined with truly collaborative worldwide research efforts, scientists will be able to detect tumors earlier and treat them with non-toxic therapies. We dream of a

day when craniotomies, radiation, and chemotherapy have been replaced with new treatments that do not cause any long-term damage. Perhaps treatments will be custom-designed for each child and each tumor, maximizing their effectiveness while minimizing their side effects.

Reaching these goals will not be easy. It will take a massive investment from government agencies, pharmaceutical companies, hospitals, and philanthropic foundations. It will take new levels of advocacy, and long-lasting partnerships among those in this field. New treatments are likely to come only from new and extraordinary collaborations that will involve hundreds of researchers, dozens of institutions, terabytes of shared data, and a single, shared goal.

In the meantime, Making Headway will continue to be on the ground floor, helping every family we can. We will benefit from the lessons

learned over the past 25 years, while continuing valuable programs as well as developing new services that directly meet the needs of children and their families. We will continue our mission to provide Care, Comfort, and Cure through strategies that are effective and efficient and, with your support, provide new and deeper levels of individual and family care. We will keep an open mind, always with an eye to new solutions, moving forward hand-in-hand with the families we serve.

In our very first flyer, we wrote that our mission was to "Enhance medical care by providing humanistic and psychosocial services, research, education, and training." For 25 years we have been steadfast in our dedication to that cause, and will remain so for the foreseeable future. Together, we can directly help children with brain and spinal cord tumors. We are so grateful for your past support and know that you will be with us in the years ahead.



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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 **MakingHeadwayFoundation**
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Making Headway services are available to all pediatric brain and spinal cord tumor patients and their families throughout the NY/NJ/CT tri-state area.

Making Headway is a 501(c)(3) non-profit organization. EIN# 13-3906297.

