



2020-21

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



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the Care, Comfort, and Cure of
Children with Brain and Spinal
Cord Tumors**

About Making Headway

*"Making Headway was a lifeboat off
our lonely island of hopelessness."*

That's how one father described his family's experience with the Making Headway Foundation after his son was diagnosed with a brain tumor. It aptly depicts exactly why we were founded. Of course, children diagnosed with a brain or spinal cord tumor need medical attention, first and foremost. But such a devastating diagnosis creates many other needs as well, for both the child and the family. Few hospitals are equipped to address these other needs. That's where Making Headway comes in.

For over two decades, Making Headway has filled the gap between medical care and the myriad other supports children and their families need. Open to all local families, our programs provide support and resources from diagnosis through treatment and, often, many years beyond. From friendly faces and comforting activities in the hospital, to ongoing emotional and psychological support, and educational guidance and advocacy, Making Headway's trained professionals are there for as long as they are needed. Our funding also provides our partner hospitals with highly technical medical resources and neuro-psychological expertise, and supports cutting-edge research around the world—research that we hope will one day make our mission obsolete.



FROM OUR CHAIRMAN

Even in this difficult time of COVID-19, one thing remains constant. Every single day, 13 children in the United States are diagnosed with a brain or spinal cord tumor. For those in the tri-state area, as well as the many others who come to New York for treatment, our mission is to provide the resources needed to make their journey through a devastating disease less stressful. We do so by funding programs at the NYU Langone Hospital and providing a multitude of services for the family once the child leaves the hospital. We are so grateful to all our supporters who have allowed us to extend needed care and comfort

for children and families that need help today, as well as to fund research toward the cures of tomorrow. During 2020, we worked hard to continue our programs, expand them when necessary, and assure every family that we will continue to be there for them. There will always be challenges and obstacles to face; however, these will never deter Making Headway from continuing our mission of care, comfort, and cure.

Edward Manley, Chairman

FROM OUR EXECUTIVE DIRECTOR

2020 marked my fourth year as the Executive Director of the Making Headway Foundation. During this time, I have come to understand and truly appreciate the impact that Making Headway has had on families with a child diagnosed with a brain or spinal cord tumor. Over the years, I have gotten to know hundreds of families and, through their experiences, I have gained a deeper understanding of core life experiences such as perseverance, flexibility, love, and sorrow. Every day, Making Headway continues to be inspired by the families we encounter and it reminds me to

always be diligent in our work, think creatively, and focus on our mission. Each family, along with our Board of Directors, sets the tone for the organization and inspires our staff to take this work seriously and with steadfast fortitude. I am proud to be part of this team and I am fully devoted to pursuing Making Headway's mission with enthusiasm, resourcefulness, empathy, and hope.

Dan Lipka, Executive Director

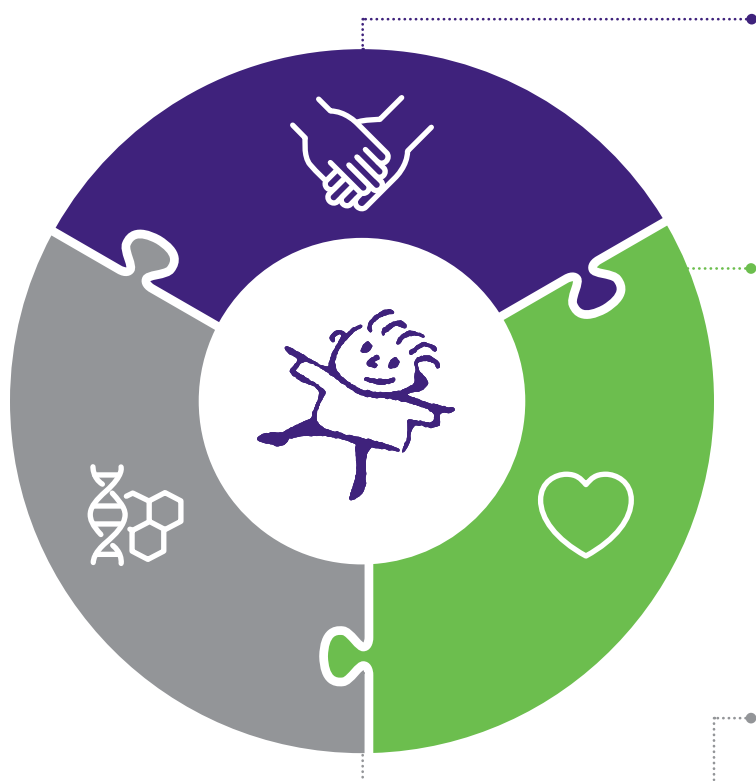


Over the past 20+ years, Making Headway has consistently improved, diversified, and expanded our services to best meet our mission. Our motto of Care, Comfort, and Cure guides our programs to ensure that we address the complex needs of

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. And 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 Entertainment
Hassenfeld Playroom Improvements

CURE

Preclinical Core Research Center
Clinical Trials Research Manager
Tissue Biorepository Center
Pediatric Neurosurgeon
Neuro-oncology Fellowship Program
Local and Federal Advocacy



COVID-19

In many ways, COVID-19 dominated every aspect of 2020. Health concerns, access to medical facilities and services, dramatic changes to work and school, and economic impacts affected nearly every single person in the world. Faced with a global pandemic, rising unemployment and political unrest, it is easy to forget about everything else. But it is during these times that we must be hypervigilant, remembering that the world continues to move forward and the needs that families had before this crisis haven't gone away. Every day children are still diagnosed with brain or spinal cord tumors; they still need expert medical care and a vast array of support services. Organizations such as Making Headway, which support those experts and services, also need

continued support.

Making Headway Foundation's programs, services, and fundraising have all been challenged in the face of COVID-19. Quality-of-life services, such as in-hospital therapeutic massage, advanced psychological evaluations, and playroom activities have been reduced or curtailed. Our researchers may be able to access their labs only a few times a week, or not at all. Making Headway events for families have been cancelled or suspended. Fundraising events, which also honor children who have passed, have all been postponed.

In 2020, Making Headway worked swiftly to modify or develop new programs to address the realities of today.

The Making Headway Family Liaison, Jenn Cabarcas, has called hundreds of families to provide emotional and practical support. For families in mental crisis, she may provide referrals to our Ongoing Care Team of psychologists (services are free to all the families we work with). When we don't have the needed resources or services in-house, our staff works to find other organizations or agencies that can help, and assists families in navigating often-complex bureaucracies to access those services. No matter what is happening in the world, Making Headway Foundation will always be focused on providing Care, Comfort, and a Cure for children with brain or spinal cord tumors.

“

Monday, July 22, 1:03 p.m. was the exact time I received the call from Dr. Forem. My daughter, Kadence, was diagnosed with multiple brain tumors. We discussed next steps as we had to move aggressively given that Kadence's right side and overall motor functions were beginning to be affected. My family and I had a hard time trying to cope and grasp it all. Kadence began chemo shortly thereafter; however, her body wasn't reacting well to her initial treatment plan and that saddened me a great deal. During my third visit to Hassenfeld, I met Maya. She simply touched my shoulder and said "Hello, how are you?" and I began to weep. We spoke at length and, without her knowing, she restored my faith that day. After our conversation, I had a different outlook and approach to our new normal and Maya continued to be a light with each visit. Kadence began to look forward to our trips to Hassenfeld because she knew Maya would have treats and Looney Lenny would give her a million dollars or a coin after performing one of his tricks. Our journey is far from over but Making Headway has definitely helped make things easier to deal with and my family and I are beyond appreciative. —Danielle Casimir

“

When my son Cairo was diagnosed with learning difficulties I was overwhelmed. Trying to navigate "the system" and receive help for my son left me confused and feeling helpless. I knew my son could receive services provided by the Department of Education, even though I chose to send him to a private school. But when services began I didn't know if he was receiving all that he needed in order to have a successful educational experience. I had no one to speak to or ask questions of. I felt like I was imposing on my son's school because they are not a school designed for special education. When I became connected with Making Headway's Education Advocate Patty Weiner, I felt a weight lift off my shoulders. Patty has been an invaluable resource. She has a tremendous amount of experience and connections and has helped me not only with the DOE (obtaining testing for my son and understanding the results) but also with my son's school. I now know that I have someone looking out for my son's best interests and who will make sure that he is receiving all the services he is entitled to. I can't thank Making Headway enough for providing this valuable resource to our family. —Kelley Archer



PROGRAM HIGHLIGHTS

CARE

Making Headway Care Coordinator

For 2020, we're pleased to announce that Making Headway agreed to fund the new position of Pediatric Neuro-Oncology Care Coordinator at NYU's Stephen D. Hassenfeld Children's Center for Cancer and Blood Disorders. Scientific discoveries and technological advancements have improved the survival rates and quality of life for patients with central nervous system (CNS) tumors. Yet these new diagnostic testing and treatments have made the logistics of caring for children increasingly complex. Families who are already over-stressed are told to schedule evaluations with a range of specialists, yet are on their own to keep track of all these activities. It can be overwhelming.

To address this concern, the new care coordinator, an experienced registered nurse, will coordinate with the neuro-oncology team to create and maintain treatment plans for families, ensuring children complete all their evaluations. They will also work with families to coordinate second opinion appointments, including ensuring that tissue, imaging, medical records, and pathology results are sent to the other providers. The care coordinator's other major role will be to coordinate processes for the Making Headway Pediatric Brain and Nervous System Tumor Tissue Bank, including coordinating all the outside testing of Hassenfeld patients' samples required

for accurate diagnosis and identification of therapeutic targets. Because the care coordinator, who will work for NYU Langone, will have access to many families that might benefit from Making Headway's programs and services, they will also meet regularly with our own Family Liaison, Jenn Cabarcas, and Making Headway Co-Founder Maya Manley. In this way, Making Headway can ensure we are reaching all the families we possibly can.

Individual and Family Counseling

In addition to our team of expert educational advocates, Making Headway's Ongoing Care Team includes professional psychologists and psychiatrists. Many children's hospitals provide very limited psychological support for patients and almost no such services for parents or siblings. Making Headway has helped fill this gap with our own team and in 2015 we began providing funding so that NYU Hassenfeld Center could maintain a dedicated neuropsychologist on its staff. With this professional helping so many families at the hospital, our own team was needed less on-site, and we began expanding our services deeper into the community.

In late 2018, Making Headway embarked on a robust and dedicated effort to bring access to free psychological services to any local family that has a child diagnosed with a brain or spinal cord tumor. Since that time, we have revitalized and

expanded our Ongoing Care Team through increased outreach partnerships with other children's hospitals. We still work with many families seen at NYU, but now we are also able to help families treated at the Morgan Stanley Children's Hospital (NY Presbyterian/Columbia), Cohen Children's Hospital (Northwell), Memorial Sloan Kettering, and Kravis Children's Hospital (Mt. Sinai). The result is that in 2020 Making Headway was able to provide critical support for three times as many families (totaling 835 hours of expert care).

Making Headway College Scholarship Fund

In 2020, Making Headway awarded \$5,000 college scholarships to each of 15 inspiring survivors of brain or spinal cord tumors. Two of these 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 achieving his dream of college graduation. 2020 also marks the first year of the Michael Schwartz Making Headway College Scholarship. This \$16,000 scholarship is funded from donations raised by the Schwartz family and is named in honor of their son, Michael, a 24-year-old brain cancer survivor. The 2020 Michael Schwartz Scholarship is dedicated to the memory of Jake Greenbaum, son of Making Headway's Co-Founders Elisa and Clint Greenbaum, who passed away in 2020.



PROGRAM HIGHLIGHTS

COMFORT

Psychological Testing and Educational Services

Ensuring children's continued developmental and educational progress is essential to help them adjust and maintain a normal lifestyle as they contend with medical illness. NYU Hassenfeld's pediatric team is one of the most comprehensive teams in the country, thanks to the expertise of Sarah Powell, a neuropsychologist whose position is funded by Making Headway. Throughout the evolving COVID-19 pandemic, Dr. Powell has used telemedicine to maintain services, allowing children and their families to continue accessing psychological support and neuropsychological testing from the safety of their homes.

In addition, as a result of their cancer diagnoses and associated treatments, young patients are often deprived of the consistent teaching, enrichment, and social experiences that school offers. To complicate matters, both tumors and their treatment can lead to common and lasting neuropsychological effects that can affect learning over time. Many young patients need an array of educational services, supports, and therapies to ensure their continued progress both during and after treatment. To meet this need, Making Headway is once again funding an exceptional educational coordinator at NYU Hassenfeld, Julia Gomez.

Making Headway Family Liaison

2020 was the first full year for the Making Headway family liaison, who

had an immediate and meaningful impact on hundreds of the families we work with. The role, originally designed for face-to-face interaction with families at hospitals and in their homes, was radically transformed by the COVID-19 pandemic. As we described earlier, in 2020 the family liaison, Jenn Cabarcas, made hundreds of calls to families providing emotional and practical support. She provided families in mental crisis with referrals to our Ongoing Care Team of psychologists. She provided those facing overwhelming financial challenges with support through the Making Headway Emergency Fund and the David Justus Fund. She researched and reached out to other community organizations to get the best available services for those families whose needs were beyond our expertise. During a year in which COVID-19 negatively impacted so many, Jenn focused on empowering our families, and inspiring them to succeed at their goals. She worked passionately to make lives better, creating smiles and moments of happiness wherever she could.

Clinical Trials Nurse

Due to the overwhelmingly positive response from families, Making Headway is continuing to fund Kara Donovan, NYU Hassenfeld Clinical Trials Research Nurse. First funded two years ago, Kara helps families manage the vast array of responsibilities they face during a clinical trial. Her role has become especially indispensable in 2020, with the pandemic: the clinical

trials nurse works with families to set up telehealth visits, oversees complex procedures for mailing out vital medications, and works with families to ensure their proper administration, monitoring, and documentation.

Justus Joyful Moments Fund

David Justus died at the age of 51 on March 26, 2020, after an almost two-year battle with glioblastoma. David believed that life should not be measured by time, but by joyful moments. He was blessed to have many, both before and after his brain cancer diagnosis. In collaboration with Making Headway, his wife, Rachel, and children, Emma and Oliver, established a fund to honor David and help deserving families create amazing moments of their own.

In 2020, when most of the traditional in-person Making Headway events had to be canceled, we searched for new ways to bring some joy to families and remind them we are here for them. We concluded that the Front Steps Project, a movement which sends a professional photographer to people's homes (or another public space) for a 30-minute outdoor photo shoot, might be the perfect thing. This past fall, we located and vetted talented professional photographers throughout the tri-state area to participate. There was no cost to the families; Making Headway and the David Justus Joyful Moments Fund picked up all costs. In all, 20 families participated, posing for fun, relaxed, and memorable portraits.



PROGRAM HIGHLIGHTS

CURE

Making Headway Pre-Clinical Core

Making Headway's Preclinical Core has revolutionized researchers' abilities to test new treatments for pediatric brain tumors. Led by Dr. Guisheng Zhao, the lab uses technology to create models of more than 30 distinct pediatric CNS tumor subtypes—previously extremely difficult to come by. The Core is providing the materials needed by regional, national, and international hospitals, as well as pharmaceutical companies and universities, to test potential new drugs and treatments. Making Headway has committed to funding this vital project for three years; at the end of 2021 it will become financially self-sustainable.

Clinical Trials Research Manager

Clinical Trials are the most effective way to bring new treatments to children with brain or spinal cord tumors. They can also be a last resort for children who do not respond to traditional treatments. In order for the NYU Hassenfeld Center to be part of as many clinical trials as possible, Making Headway has funded Anna Yaffe, Clinical Trials Manager, for over a decade. In 2020, hundreds of clinical trials have been conducted, with thousands of children receiving critically important and novel treatments.

NYU Pediatric Neurosurgeon

Two years ago, Making Headway contributed funding to NYU Medical Center for an exceptional young neurosurgeon, Dr. Teresa Hidalgo. Dr. Hidalgo, who is emerging as a leader in her field, has become a vital part of the Pediatric Neurosurgery Division's clinical and research efforts. In 2020, she has performed hundreds of pediatric brain surgeries, including extremely complicated, lifesaving procedures, while she is also conducting research into molecular subgroups in low-grade pediatric brain tumors and the molecular pathology of optic pathway gliomas. Dr. Hidalgo is a compassionate, caring person who relishes mentoring medical students—especially women and underrepresented minorities—and treats every family as if they were her own.

Bio Repository Center/ Brain Tumor Bank

For the past 13 years, Making Headway has funded the NYU Bio Repository Center/Brain Tumor Bank, enabling NYU to collect rare and valuable specimens and clinical data for distribution to leading researchers around the world. In the past year,

NYU has begun using expanded molecular pathology capabilities to analyze collected tissues, such as performing DNA sequencing and methylation profiling on most pediatric brain tumors. In 2020, the Tumor Bank, led by Dr. Theo Nicolaides, will join the Children's Brain Tissue Network, exponentially increasing the Bio Repository Center's ability to share rare tissues and data with leading researchers.

Neuroanatomical, Cognitive, & Family Aspects to Recovery

Today, when two-thirds of children with brain tumors survive, it is critical to understand how their quality of life might be affected going forward. This grant supports a longitudinal research project led by Memorial Sloan Kettering neuropsychologist, Dr. Stephen Sands. The project has partnered with over 50 children's hospitals around the country to evaluate the impact of socioeconomic status, home environment, parenting, and parental distress on pediatric brain and spinal cord tumor patients. It is possible the study will lead to the ability to identify which children might be at increased risk for neuropsychological decline, so they can receive early interventions and support.

IN THEIR OWN WORDS



This was our first-time taking family photos together and it was especially nice to photograph mostly in our backyard and color coordinate our family's outfits. We met Maya many years ago after taking our son to NYU for yearly visits with Dr Allen for NF1. We feel very fortunate to be a part of this organization and to be granted such lovely experiences like the family portrait series.

—Steiner Family

Words cannot express how grateful we are for the support that Making Headway Foundation is providing to our family during this challenging time. As a medical social worker, I have seen firsthand how a family member's illness can impact an entire family system. Making Headway is helping my children and our entire family access the highest quality support and expertise to guide us through the brain cancer diagnosis and treatment. We feel incredibly lucky to be connected to such a special organization that goes above and beyond for the families they serve.

—Rachel J.

Making Headway Foundation had made so much possible for our family. I first met Maya when we had our long, four-month stay at NYU. She would often be our only visitor and I began to look forward to the days she would visit. Financially, Making Headway also has paid for our stay at the Ronald McDonald House and provided other support to help keep me on my feet when I felt I was just about to crash. This is a foundation that offers more than I could have imagined, they offer love and support.

—Lene Grey

We have personally seen the positive impact Making Headway has had on so many families including our own. It's been over 13 years since Ryan's diagnosis and we are so grateful to have had the amazing support of this organization helping us navigate diagnosis, treatment and now thankfully survivorship...Smaller foundations like Making Headway don't get the kind of publicity that larger charities do, but the work they do is invaluable to the families impacted by brain and spinal cord tumors.

—Caren Carder Tucker

So many of us have been living in the shadow of a brain tumor diagnosis for such a long time. Pursuing a college education lets us emerge out of that darkness. This scholarship is such a meaningful gesture that honors everything survivors have accomplished and encourages everything we still want to accomplish. Thank you for lighting the way and helping us shine.

—Michael Holtz, Making Headway Scholarship winner



After struggling with the Department of Education for nearly five years on Eve's behalf, we felt defeated and nearly gave up hope. When Eve learned that she would not have to

continue at her school, however, and will attend a place that will support her in the future, a heavy weight was visibly lifted from her. Eve has been elated ever since and resembles much more the carefree and happy child I used to see. I struggle to fully express how grateful I am to you and the Making Headway Foundation, who have continually offered such beautiful programs and support to children that have suffered so much. Eve feels like she has been given a second chance at a future, and beams when I tell her that she is supported by a team of people that revere her and all the children who have likewise battled brain and spinal tumors.

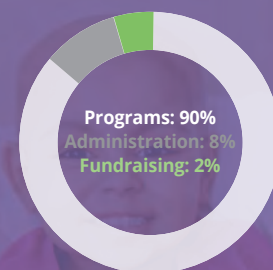
—Susan Kenny

FINANCIAL SUMMARY

Revenue	\$1,318,541
Winter Show	\$581,085
General Contributions	\$335,880
Trusts and Bequests	\$165,081
Other Events	\$134,417
Grants Received	\$61,775
Race for Ace	\$35,746
Interest/Dividends/Other	\$4,558

Expenses	\$1,589,924
Staff and Taxes	\$293,321
Research Grants	
Pediatric Neurosurgeon	\$218,400
Research Labs and Biorepository	\$170,320
Clinical Trials Manager and Nurse	\$118,298
Aspects to Recovery from a Brain Tumor	\$47,250
Patient Support	
Neuro-Psychology Testing and Educational Support	\$144,209
Making Headway Care Coordinator	\$114,490
Housing / Advocacy / Joyful Moments Fund / Other	\$32,998
Massage Therapy / Playroom / Entertainment	\$8,360
Out-of-Hospital Programs	
Individual Counseling / Therapy	\$160,971
Individual Educational / School Advocacy	\$24,771
Events and Other Programs	
College Scholarships	\$86,751
Funeral Expenses	\$66,086
Family Events	\$407
Other Expenses	
Rent / Insurance / Professional Fees	\$46,908
Supplies / Printing / Copying / Postage	\$32,580
Outside Services / Technology / Outreach	\$14,665
Fundraising Events	\$9,139

Notes: Unaudited financial data as of February 1, 2021 (accrued basis).
Making Headway uses a fund balance savings account to cover any yearly deficits.



90%
of our total budget
goes directly to
programs, services,
or research.

Newly funded
programs/staff
positions, like the
Making Headway
Care Coordinator,
and the Making
Headway Family
Liaison, resulted in
90% of our budget
being dedicated to
direct services and
programs.

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



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

Edward Manley, Founder & Chairman
Clint Greenbaum, Founder & Treasurer
Sam Schwartz, Vice President, Research
Elisa Greenbaum, Vice Chair
Audrey Manley, Secretary
Maya Manley, Founder
Jeffrey Allen, MD
David Almeida
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Daniel Lipka, Executive Director
Jenn Cabarcas, Family Liaison
Jennifer Samuels, Office Manager



Medical Advisory Board

Dr. Jeffrey Allen, Director of Clinical Neuro-Oncology, NYU School of Medicine, New York
Dr. Karl Kothbauer, Chief of Neurosurgery, Luzerner Kantonsspital, Switzerland
Dr. Oren Becher, Attending Physician, Hematology/Oncology, Ann & Robert H. Lurie Children's Hospital of Chicago

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 **MakingHeadwayFoundation**
 **@makingheadwayfd**

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.

