For almost 25 years, Making Headway Foundation has passionately endeavored to fulfill our mission to help families impacted by childhood brain or spinal cord tumors. In 2019, we continued to improve and expand our services, while investing further in medical research. In 2020, Making Headway will pursue our commitment to providing critical services to families in need.

I want to thank all our donors for their gifts during the past 12 months. Your generosity has propelled our forward progress. For example:

- To enable many more families to avail themselves of our free-of-charge psychological and educational consulting services, we have expanded our outreach to eight other hospitals in the tri-state area.

- We added numerous consultants, throughout the tri-state area, in order to provide the one-on-one assistance that is so effective in helping the children and their families deal with the issues they face.

- Our research efforts remain focused at the NYU Langone Medical Center in New York, where we approved grants totaling $1 million for clinical trials, storage of tissue samples, a translational research laboratory for pediatric neuro-oncology, and a new technology to more accurately diagnose and classify pediatric brain tumors on a molecular basis, called methylation profiling. Your ongoing support will enable our dedicated Board and office staff to widen our array of services, reach out to many more families, and fund exciting new research projects.
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*.
About Pediatric Brain Tumors

This year, more than 5,000 children across the U.S. are likely to be diagnosed with a brain, spinal cord, or other central nervous system (CNS) tumor by age 20. In fact, CNS tumors are the second most common childhood cancer, accounting for about 26% of cancer in children under 15. Unfortunately, overall mortality rates for these children have not decreased in over 20 years. Pediatric CNS tumors lead to more deaths than any other disease or medical condition.

The needs of children with brain and spinal cord tumors differ from those of other children with cancer. Symptoms that lead children to be diagnosed in the first place—such as seizures, changes in vision or behavior, weakness or symptoms of raised intracranial pressure require the attention of highly trained specialists. In addition, as a consequence of both the tumor and its treatment, many children who survive a brain tumor may acquire physical and behavioral impairments, ranging from learning deficits, impaired coordination and balance, weakness, and visual and hearing alterations. Their ability to cope and accommodate requires a range of rehabilitative, psychological and educational services.

### Treatments

How CNS tumors are treated depends on a range of factors, including the tumor type and location.

**Surgery:** When tumors remain localized, slow growing, and arise in accessible parts of the central nervous system, complete surgical removal may be possible with acceptable post-operative morbidity. Otherwise, some form of tissue sampling may prove very useful, such as a stereotactic biopsy, in guiding treatment planning.

**Radiation:** Radiation therapy uses high-energy beams, such as X-rays (photons) or protons, to kill tumor cells. A radiation oncologist will guide the patient and their families in selecting the best type of radiation treatment plan to include either photons, protons, or stereotactic radiation therapy such as gamma knife. Factors such as the amount, extent, and type of radiation have variable consequences to normal brain tissue and younger patients are most vulnerable to treatment-related long term side effects.

**Chemotherapy:** Chemotherapy uses drugs to kill tumor cells. Traditional chemotherapy is usually universally toxic to all rapidly growing tissues including the brain tumor and other normal rapidly multiplying tissues such as the bone marrow and lining of the digestive system. These drugs may be given by mouth, IV, or on occasion administered directly into a cerebrospinal fluid. A major challenge in the use of chemotherapy is to insure adequate delivery to the brain, which is normally protected by the blood-brain barrier.

**Targeted Drugs:** Researchers are learning more about changes in the DNA of tumor-related genes that increases their ability to multiply and spread. A molecular analysis of a tumor tissue sample is required to select the best targeted therapy. New drugs developed through this method have different, and often less serious side effects, and have enabled miraculous outcomes in other types of tumors. Targeted therapies, such as oral MEK inhibitors, angiogenesis inhibitors, immunotherapy, and tumor derived vaccines, all have the potential to increase quality of life for children and even lead to a cure. Making Headway invests in a range of research projects like these as a critical part of our mission.
Care
Support for All the Other Challenges
When a child is diagnosed with a brain or spinal cord tumor, parents are naturally focused on finding the best possible medical care. But once that care is in place, a whole new world of challenges emerges. Traditionally, limited hospital and community based resources existed for families undergoing this ordeal. Making Headway has worked hard to change that, funding caring professionals who provide free-of-charge support for families every step of the way, even when medical treatments are long over.

Educational Assistance
Surgery, chemotherapy, and radiation therapy are often part of a curative treatment plan, but all have potential serious short term and long term unintended side effects. Many of these children develop learning and other disabilities. Academic as well as social adjustments can be extremely difficult as children transition back, and educational challenges can continue indefinitely.

To further complicate matters, many teachers and school administrators are unprepared or ill-equipped to address the child's specific educational and physical needs. Parents may not be fully aware of their child's legal rights, or know how best to advocate for them. Making Headway provides families with access to educational specialists who are trained and experienced in the special needs of these children. The specialists work right alongside families:
• Advocating for the child
• Assisting the family and school officials as they identify appropriate support and accommodations
• Ensuring the school provides these services, as required by law
• Continuing to provide support and resources, year after year

Since our inception, Making Headway education specialists have provided thousands of hours of educational counseling and advocacy for hundreds of children—often throughout their entire educational career—to help them succeed.

Individual Counseling
When a child becomes seriously ill, every member of the family may face intense, painful, and frequently overwhelming feelings. Differences in the way individual family members react often lead to further tensions and emotional trauma. Under these circumstances, the help and support of experienced behavioral health experts such as psychologists, psychiatrists and social workers can be critical. Making Headway Foundation offers free-of-charge individual counseling sessions—in person or by phone. The sessions are available to anyone in need, including the sick child and his or her parents and siblings.

College Scholarship Program
Every year, we help ambitious young brain tumor survivors get closer to their career and life goals. Making Headway Foundation provides funding for the Scott J. Reiser Memorial Scholarship Fund—named for a young man who passed away just short of achieving his dream of college graduation. Winners of the 14 scholarships distributed in 2019 are pursuing fields as wide ranging as computer science, environmental studies, and journalism. Not surprisingly, every year a great number of winners pursue healthcare-related fields, from neuroscience to nursing.

Temporary Housing Assistance
Families will travel from around the world to find the best treatment for their children. This was the case when Dr. Sharon Gardner, pediatric neuro-oncologist at NYU Langone Medical Center, began a new clinical trial, with a drug called ONC-201, to treat a fatal type of childhood brain tumor called diffuse intrinsic pontine glioma (DIPG). To participate, families needed to travel to NYC for several days each month. During their stay, Making Headway Foundation arranged and paid for housing at the nearby, recently renovated Ronald McDonald House.

“This college scholarship has brought tears to my eyes because in the last 7 months as I struggled with recovering from surgery, I didn’t know how I was going to pay for school again. I’m very grateful for this. I truly thank this foundation for awarding me with this opportunity. I’m happy, I’m blessed, and I’m motivated. Thank you!”
— Rashell Burrus

Rashell was diagnosed with Giant Cell Astrocytoma at age 15. She is currently attending the NYC College of Technology and hopes to be a Child Life Specialist.
Comfort

Reducing the Anxiety of Hospital Visits
Most children treated for brain and spinal cord tumors have an initial stay at the hospital, then must return dozens of times for evaluations, treatments, procedures, and therapy. Yet hospitals can be scary and stressful places, for children and adults alike. Fortunately, Making Headway's longstanding partnership with the Hassenfeld Children's Center at NYU Langone Medical Center provides us with the perfect opportunity to infuse some calm and even playfulness into hospital stays and treatment visits.

With the help of Making Headway's funding for enhanced staffing, supplies, and special services, the Playroom at Hassenfeld Children's Center goes a long way toward making children, their parents, and siblings feel safe and comfortable. On any given day, children of all ages and backgrounds can be found there, happily absorbed in arts and crafts activities or play, or munching on delicious, healthy snacks. Professional entertainers and child therapists are on hand, working with children one-on-one or leading group activities. A licensed masseuse brings the proven physiological and psychological healing benefits of massage therapy to children and family members, alike. Many children who have been treated at Hassenfeld cite time in the Making Headway-staffed playroom as one of their fondest memories.

Annual Family Events
When we ask the families we've worked with what they like best about Making Headway, they nearly always mention one or more of our beloved annual events. Each year, Making Headway hosts a summer party called Family Fun Day, a fall Yacht Cruise around the New York City harbor, and a winter theatrical event on Broadway. Each of these activities provide children and their families a brief moment in time to forget the trauma and pain of their illness and just have fun. The events are also a great way to meet others who share and understand their experience in a way that those who haven't lived through it can't always do.

In 2019, Family Fun Day was held at the New York Aquarium, on Coney Island, and our Broadway outing to the New Victory Theater featured seven masters of illusion and magic from Korea in their mind-bending show, SNAP! Our fall Yacht Cruise once again featured a breathtaking water cannon show, courtesy of the New York Fire Department.
Cure
It Can Happen To Anyone
Each year, over 5,000 children are diagnosed with a brain or spinal cord tumor. Brain cancer is now the leading cause of cancer deaths among children, and all tumors, whether cancerous or not, can have devastating effects on a child's physical, psychological, emotional, and cognitive health. Meanwhile, the side effects of even the best current treatments can be equally devastating.

Primary pediatric CNS tumors are fundamentally different from those found in adults both in their molecular classification and response to treatment. Funding for research continues to be woefully inadequate.

Making Headway Foundation is dedicated to making a difference in this area, coming at it from a wide range of angles. We:

- support world-class research by leading doctors and scientists
- fund facilities that conduct state-of-the-art research
- provide staffing to expand clinical trials
- maintain a brain tumor tissue biorepository used by researchers around the world
- sponsor pediatric neuro-oncology fellowships to develop the next generation of talent in this vital area

Here are comments from some of the researchers at NYU Langone Medical Center who have benefited from Making Headway funding...

The Making Headway Foundation Preclinical Core grant has been invaluable in our quest to study a major type of childhood brain tumor called Pilocytic Astrocytoma. The funding allowed us to develop new techniques and methods that enable us to understand how this tumor arises genetically in children. Our work has led to the development of new models that can be used to test new therapies to target these brain tumors. —Dr. Thales Papagiannakopoulos

Funding from the Making Headway Foundation has been instrumental for our goal of capitalizing on our discovery that Diffuse Intrinsic Pontine Gliomas (DIPGs) have an over-represented epigenetic signature. We are now collaborating with chemists to develop drugs that can similarly disrupt this recognition and, thus, specifically target DIPG tumors. —Dr. Danny Reinberg

The Making Headway grant gives us the opportunity to study the long-term effects of treatment for brain tumors in children. We were able to investigate the significance of the molecular subgroups of malignant pediatric brain tumors. This information contributes to direct new surgical and medical interventions allowing us to avoid unnecessary irradiation and its potential long-term effects in vulnerable children. —Dr. Teresa Hidalgo
Making Headway is always looking for ways to extend and expand our reach. We are proud of some of our newer accomplishments in 2019.

Expanding Our Services
During 2019, Making Headway began working with several new hospitals to identify and provide services to children with a brain or spinal cord tumor. Our partnerships now include four hospitals in New York City (NYU Langone Medical Center, Mount Sinai Kravis Children’s Hospital, NY Presbyterian’s Morgan Stanley Children’s Hospital, and Memorial Sloan Kettering) and one each on Long Island (Cohen Children’s Center); Westchester (Maria Fareri Children’s Hospital); and Connecticut (Yale New Haven Children’s Hospital).

To serve this growing population of families, we have expanded our Ongoing Care Team. We searched for highly trained and experienced psychologists, psychiatrists, and educational advocates that can support families in each location, and ultimately contracted with more than a dozen new doctors and experts. Families served through our partner hospitals now have free access to these professionals, who work with and advocate for their families as they navigate life during and following treatment.

Expanding Therapy Program
Making Headway has been providing free access to psychologists and psychiatrists for over a decade, but in 2019 we dramatically increased this program. Our budget for these services almost tripled as Making Headway worked with new families throughout the area. These services are available to the sick children, as well as their parents and siblings. The program is critical not only because it meets the real life needs of families, but because most experienced psychologists and psychiatrists do not accept insurance and the costs are substantial.

New Family Liaison
We recently welcomed our new Family Liaison, Jenn Cabarcas. Jenn did her graduate work in psychology, with a concentration in youth and adolescent development, and has significant experience working with children who face emotional challenges, have developmental disabilities, or are medically fragile, as well as their families.

Jenn has only just begun her work with Making Headway families, and she has already begun to make a name for herself as she warmly connects with families, making them comfortable and helping them find the support and services they need.

Spreading the Word
“Did you know that brain and spinal cord tumors are the deadliest form of pediatric cancer?” These words, spoken in voice-over by Vanessa Williams, are the start of Making Headway’s first-ever outreach video, It Could Happen to Anyone. The culmination of months of work by a host of supportive and talented individuals, many of whom volunteered their time, the video was produced last spring by acclaimed documentarian, Dan Wilson.

It Could Happen to Anyone takes viewers through a year in the life of a family—from the eyes of the Dad—in just 90 seconds. Shot with professional actors over two long days, it went through weeks of editing and review before being released in three versions: the full 90 seconds as well as Facebook- and Instagram-friendly lengths of 60 and 30 seconds, respectively.

The new video has been released on social media, where it has attracted many thousands of views, and was distributed to numerous local television stations. It can be seen at https://makingheadway.org/video

“For the last 13 years, I have been working with families and children that have been diagnosed with developmental disabilities, connecting them with services and assisting them in their areas of need. I am excited to have begun my next journey at Making Headway! I am looking forward to cultivating successful as well as meaningful relationships with our families as well as other agencies in order to provide the best services. My focus is on empowering the families and inspiring them to succeed at their goals. ‘Life is not about waiting for the storm to pass, but learning and perhaps teaching others how to dance in the rain.’ (Vivian Greene) And that is what I plan to do.”

— Jenn Cabarcas
Making Headway 2019–20 Annual Report

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

In response to a surge in need, Making Headway increased spending for individual counseling and bereavement services. Spending also decreased for several grants due to underspending by the grant recipients.

Making Headway received the highest level awards, from both Guidestar.org and GreatNonProfits.org, for six consecutive years.

Financial Summary

Revenue $1,762,210
- Realized Gains from Stock Sales $727,894
- Winter Show $533,403
- General Contributions $239,629
- Other Events $117,390
- Race for Ace $74,430
- Interest / Dividends / Other $30,807
- Grants Received $25,000
- Trusts and Bequests $13,657

Expenses $1,484,980
- Staff and Taxes $205,449
- Research Grants
  - Pediatric Neurosurgeon $163,798
  - Clinical Trials Manager and Nurse $115,927
  - Pediatric Neuro-oncology Fellowship $111,238
  - Research Labs and Biorepository $72,093
  - Other Research Grants $72,000
- Patient Support
  - Neuro-Psychological Testing $125,475
  - Massage Therapy / Playroom $66,088
  - Housing / Advocacy / Other $15,917
- Out-of-Hospital Programs
  - Individual Counseling / Therapy $143,424
  - Educational Counseling / Advocacy $34,902
- Events and Other Programs
  - Family Events $88,857
  - College Scholarships $70,000
  - Funeral Expenses $68,880
- Other Expenses
  - Rent / Insurance / Professional Fees $56,676
  - Supplies / Printing / Copying / Postage $29,483
  - Outside Services / Technology / Outreach $26,388
  - Fundraising Events $18,383

Notes: Unaudited financial data as of February 1, 2020 (accrued basis).
Making Headway uses a fund balance savings account to cover any yearly deficits.
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  
David Almeida  
Charles McMahon  
Susan Rubin  
Greg Taubin

**Staff**
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

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