



making headway
foundation

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

makingnews

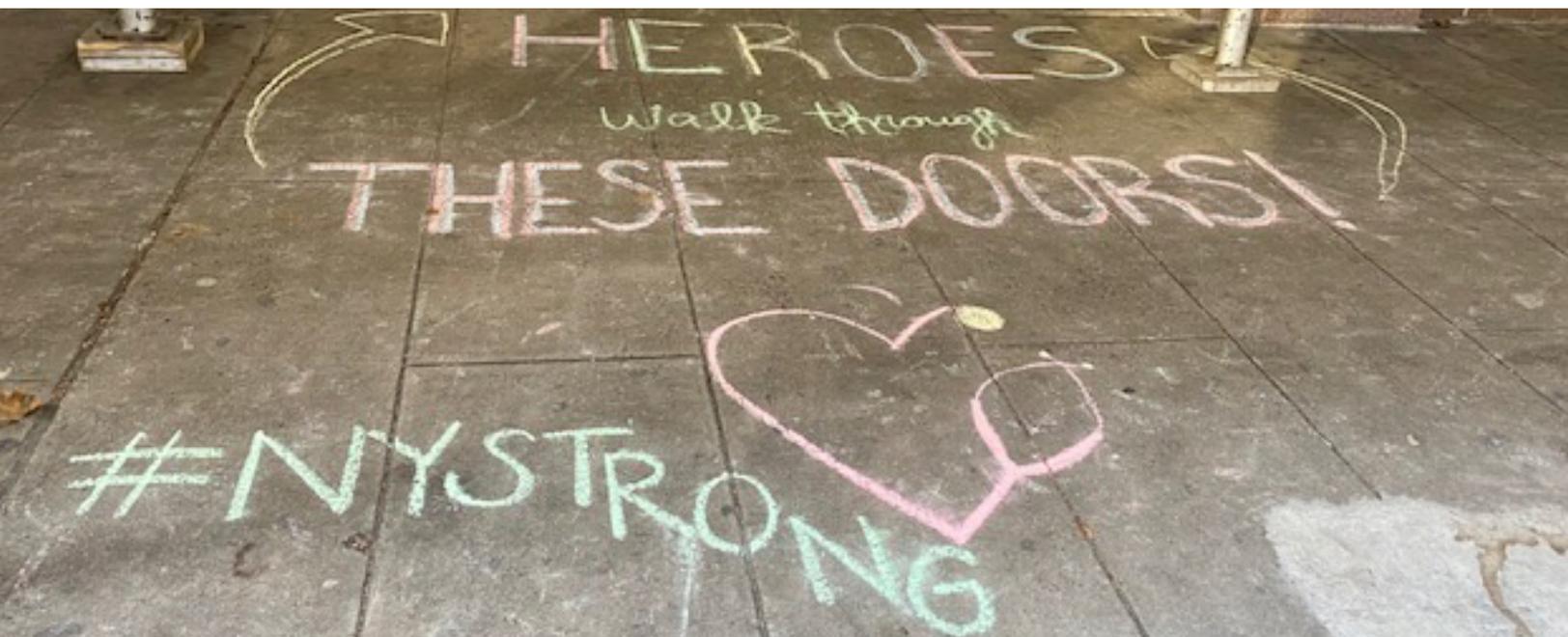
Summer 2020

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LETTER FROM OUR CHAIRMAN & FOUNDER

It is indeed a difficult time for all of us. COVID-19 has thrown our lives into disarray. During these uncertain times, we want to reassure you that we are here for you, that we continue to support our care teams and patient families, and that the current situation will not deter Making Headway from continuing its mission of care, comfort, and cure.

The frustrating news: our April 2020 Winter Show, *Magic Shadows*, had to be cancelled—as did many of our upcoming fundraising events, such as *Gains for Brains* and the *McCabe Drive for a Cure* golf tournament. We know how many of our supporters and patient families have enjoyed attending these events in the past.

The good news: the bulk of our fundraising efforts occurred earlier in the year, so we were able to achieve some much-needed funding for our programs. We are also fortunate to have sufficient reserves to continue offering our care programs at Hassenfeld and NYU, and our free-of-charge consulting services, in each case adhering to the recommended protocols for a safe environment for children and families. Furthermore,

we are hopeful that some fundraising events could take place later this year.

I hope that all of you—children, families, donors, and readers—have been able to stay safe and healthy. We all look forward to when life will begin to return to a somewhat “normal” status. In the meantime, think about and use your stored good memories to help calm anxiety. It has certainly helped me, and can do us all good.

As always, your support of Making Headway allows us to extend needed care and comfort for children and families today, and to fund research toward the cures of tomorrow. We thank you.

Edward P. Manley

Congratulations to Making Headway’s first Care Award winner, Patty Weiner!

Children who survive a brain or spinal cord tumor often develop physical or learning disabilities as a result of their treatment, and may need special services to achieve their best in school. But accessing these services can be a steep challenge. That’s where Making Headway’s Ongoing Care Team comes in.

For the past 20 years, Patty Weiner has been one of the most knowledgeable, hard-working, and dedicated members of this vital team. As Senior Educational Advocate, she has provided over 3,000 hours of expert support to ensure children receive all the educational services they need. Patty’s knowledge and passionate advocacy on behalf of families has earned her the respect of school administrators and special educators throughout the region.

Throughout her career, Patty has earned multiple awards. She has authored textbook chapters and journal articles, founded a parents’ advocacy

group, and initiated a taskforce of school administrators, parents, and healthcare professionals. As founding director of the graduate program in Child Life at Bank Street College of Education, she co-created numerous courses—including one on neonatal intensive care, which is especially dear to her heart. In short, Patty Weiner exemplifies Making Headway’s vision of helping families through compassionate and comprehensive service.

After thirty-five years as a child life specialist, educator, and education/healthcare consultant, Patty is retiring. She has been inexpressibly important



I have enjoyed every minute of working for Making Headway Foundation, helping, caring, and consulting for the children and their families in the schools.

—Patty Weiner

to hundreds of families and to Making Headway Foundation. For all of her work, we are proud to present Patty Weiner with the first ever Making Headway Care Award. On behalf of everyone at Making Headway, thank you, Patty: we hope you enjoy your well-deserved retirement!

COVID-19 AND PEDIATRIC BRAIN TUMORS

Since the outbreak of COVID-19, Making Headway Foundation staff have been asked the same question many times: “Are children with brain or spinal cord tumors at increased risk for coronavirus infection?”

Until recently, public health professionals agreed that healthy children had a low risk of serious illness due to COVID-19. And while it now appears that some children have become gravely ill from a coronavirus-related inflammatory disease, the vast majority of people becoming seriously ill from COVID-19 seem to be adults. Nonetheless, evidence does clearly point to the fact that people with underlying health conditions—or a weakened immune system—are at greater risk of serious illness. And unfortunately, many cancer treatments can weaken a child’s immune system. Children who may be at greater risk include those who:

- Are currently undergoing chemotherapy or have undergone chemotherapy within the last three months
- Are being treated with immunotherapy or other ongoing cancer antibody treatments

- Are receiving other targeted cancer treatments that can affect the immune system, such as protein kinase inhibitors, or who are taking immunosuppression drugs
- Have had stem cell or bone marrow transplants within the last six months

In addition, radiation treatments and certain medicines may weaken the skin or membranes lining the mouth and digestive tract, making it easier for certain kinds of germs to enter.

If you believe your child may be at risk for one of the above reasons, speak to a member of your medical team. Because we all still have much to learn about COVID-19, doctors may not be able to provide much in the way of specific information, but they will have information regarding the risk of infections in general for children being treated for cancer. You can also stay up-to-date by checking the CDC website regularly: www.cdc.gov. Finally, during this public health crisis, Making Headway will continue to be a resource to families: helping to solve problems, sharing information, connecting you with community resources, and comforting families in need.



Some people who believe they are not at high risk for serious infection may forget that even people without any symptoms can spread COVID-19. Please remember all the people—including children—who are at a higher risk for becoming very ill or even dying from this terrible disease. By exposing yourself to the virus, you could be exposing them, too. The best way to protect vulnerable people is for all of us to wear masks, wash hands frequently, follow social distancing guidelines, and protect ourselves.



Making Headway Foundation can only exist with the help of generous and recurring donations from friends and supporters

like you. Unlike the case with many charities, many of Making Headway’s donors have been directly affected by a pediatric brain or spinal cord tumor,

or have a close relationship with a child diagnosed with one. Each year, we receive over 2,500 donations, and each comes with a story. Every one of these stories is precious, and since every donation has a special meaning, Making Headway works hard to ensure every dollar we get goes to achieving our mission.

Among the 20,000 donors who have contributed since our founding, there are those who have gone above

and beyond. This is the first time Making Headway is formally honoring members of our 20-50 Cure Club (donations for 20+ years or 50+ total donations) who make it possible for Making Headway to structure our budget, plan for the future, and invest in long-term programs and research projects. We are so grateful to all our donors, but want to give special recognition to active 20-50 Cure Club members (see the enclosed donor insert to identify those in this Club).

MAKING HEADWAY MEDICAL TREATMENT GRANTS

Every year, Making Headway awards grants to support a variety of interventions that impact children with brain or spinal cord tumors. Over the years, we have focused on everything from ensuring that children have access to the best neurosurgeons, to funding unique laboratories that enable new drugs to be tested on any type of pediatric brain tumor. As we look to the future and fund the development of state-of-the-art technologies, we also remember to care for each family as if it is our own.



NYU Pediatric Neurosurgeon, Dr. Eveline Teresa Hidalgo

Removing a tumor is often the first step on a child's long recovery from a life-threatening diagnosis. Yet performing neurosurgery on a child is perhaps the most challenging of medical disciplines, which explains why doctors specializing in this area are so rare and so important. These doctors need not only extraordinary expertise to deal with the tumor, but also exceptional interpersonal skills to work compassionately with parents and children. Making Headway

is proud to support Dr. Eveline Teresa Hidalgo, one of the finest young pediatric neurosurgeons in our region. Dr. Hidalgo speaks five languages, was trained at world-class hospitals around the globe, and is clearly a future leader in the field. She joins a team at NYU that includes two of the most experienced and talented pediatric neurosurgeons in the world: Dr. Jeffrey Wisoff and Dr. David Harter. Every year, this team performs hundreds of pediatric brain surgeries, saving lives and giving hope to every family.

Center for Biospecimen Research and Development

Five years ago, Making Headway helped start the Center for Biospecimen Research and Development (BioRepository) at NYU Langone Health. We have continued to invest in staff to manage this facility, which has collected over 100 rare pediatric brain tumor tissue samples. These samples provide germline DNA information that increases understanding of the pathogenesis of specific diseases, and aids in the development of therapeutic agents to address them. Now, the NYU BioRepository has enough tissue and infrastructure to start contributing to national and international research projects. In 2020, NYU has been invited to be a participating member of The Children's Brain Tumor Tissue Consortium (CBTTC). CBTTC was formed to centralize storage of tumor samples in order to accelerate pediatric brain tumor research across the country. By working together, researchers dramatically increase opportunities to find better treatments and a cure.

DNA Methylation

This grant provides the funds needed to utilize a cutting-edge technology, DNA methylation, to accurately diagnose every child with a brain tumor at NYU. Recently, this test prevented a serious misdiagnosis: what appeared to be a medulloblastoma turned out to be a glioblastoma, and treatments for these two kinds of tumors are significantly different. Correct diagnoses not only increase treatment effectiveness but also reduce negative side effects, and knowing the exact genetic diagnosis can literally make the difference between life and death. Dozens of children will receive this advanced diagnostic analysis at NYU this year, but Making Headway is working to expand access and is currently looking for donors or partners to take this program nationwide.

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Making Headway Preclinical Core

Researchers who are developing drugs to destroy tumor cells need access to specific cell lines to test the efficacy of their ideas. But finding cells for rare tumors, such as the many sub-types of pediatric brain tumors, is hard to do, and almost impossible to do on one's own. That's where the Making Headway Preclinical Core comes in. Researchers and technicians, led by *Dr. Theodore Nicolaides*, are creating test-ready cells for every type of pediatric brain or spinal cord tumor. Over the past 18 months, our team has built the lab, created all of the infrastructure, developed new methodologies, and successfully stabilized cell lines for 13 tumor types including medullablastoma, pilocytic astrocytoma, and difuse midline glioma. During the next 18 months, the laboratory hopes to make an additional 15 subtypes of tumors available to researchers around the world.

Beyond these grants, Making Headway supports a variety of other quality-of-life programs and research projects including Massage Therapy (NYU), a Pediatric Neuro-oncology Fellowship (NYU), Advanced Psychological Intakes and Assessments (NYU), Neuroanatomical, Cognitive & Family Aspects to Recovery from a Brain Tumor (Memorial Sloan Kettering),

Novel Targeting of an Epigenetic Signature in Diffuse Intrinsic Gliomas (NYU in partnership with St. Baldrick's), Phase I/II study of MEK162 (Dana-Farber Cancer Institute in partnership with the Pediatric Brain Tumor Foundation), and Optimizing Medulloblastoma Treatment (Harvard School of Health in partnership with St. Baldrick's).

Clinical Trials

The Hassenfeld Children's Center's Clinical Trials Office (CTO) manages 87 active research projects, approximately 50 percent of which are devoted to the study of pediatric central nervous system cancers. The CTO also maintains and oversees data management of an additional 50 Children's Oncology Group studies. Clinical trials, which seek to establish how effective new

treatments may be, are often the only option—and hope—for children with a disease that has no other treatment. For many years, Making Headway has been providing funding to support CTO senior staff. In addition, starting in 2019, Making Headway also began funding a clinical trials research nurse to help families manage the overwhelming complexities of participating in some of these trials.

HEAD TO THE HILL

For the past several years, Making Headway has played a significant part in Head to the Hill. This event, organized by the National Brain Tumor Society, usually brings over a hundred families to Washington, D.C. to advocate for issues relating to brain cancer research and patient care. In 2020, the in-person event was cancelled due to COVID-19, but that didn't stop us from doing everything we could to connect with our Congressional representatives. Making Headway families, and families from every state in the union, wrote letters, sent emails, created videos, and had virtual meetings with our elected leaders. Our main objectives were to:

- Support medical research by appropriating a \$3 billion increase

for the National Institutes of Health, and a \$500 million increase for the National Cancer Institute.

- Fund the Childhood Cancer STAR Act, which is sweeping childhood cancer legislation that will help children with cancer live longer, healthier lives.
- Provide funding to continue the White House's Childhood Cancer Data Initiative, which will establish more efficient ways to share and use childhood cancer data.
- Enact the Cancer Drug Coverage Parity Act (H.R. 1730, S. 741) so brain tumor patients who must access patient-administered anti-cancer medicines can do so affordably.
- Improve quality-of-life, personal well-being, and pain management for brain tumor patients by enacting the Palliative Care and Hospice Education and Training Act (PCHETA, H.R. 647/S. 2080).

If your child has a brain or spinal cord tumor and you need help or advice, please feel free to contact Making Headway Foundation at 914-238-8384 or info@makingheadway.org.



A LETTER FROM OUR EXECUTIVE DIRECTOR



The truth is that COVID-19 will likely dominate everything about 2020. The health and economic impacts will affect

every single person in the world. When there is a global pandemic and depression-level unemployment rates, it is easy to forget about everything else. But it is during these times that we have to be hypervigilant, remembering that the world continues to move forward and the needs 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 canceled completely. Our researchers may only be able to access their labs a few times a week, or not at all. Making Headway events for families have been cancelled or indefinitely suspended. Fundraising events, which also honor children who have passed, have all been postponed.

It is during these difficult times that we must stand together and refuse to give up. As individuals, organizations, and communities, it is our obligation to work harder, be more flexible, and solve problems to help those in need. At Making Headway, we are modifying or developing new programs to address the realities of today. The Making Headway Family Liaison, Jenn Cabarcas, is calling 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. With your support, we can overcome all challenges and continue to make the world a better place.

Daniel Lipka, Executive Director



MAKING HEADWAY FAMILY EVENTS

For a child with a brain or spinal cord tumor, life can be painful, stressful, and scary. Each year, Making Headway hosts a round of special events just so these children and their families can have fun and meet other families who share their experience. Most years, our three biggest annual events include a spring Broadway show, a summer Family Fun Day, and a fall Yacht Cruise around Manhattan.

However, with the advent of COVID-19 we've had to adjust. Our spring Broadway event was canceled when Broadway was shut down. Hoping for the best, we originally rescheduled our Family Fun Day from June 21 to August 22. However, we have been advised by NYU doctors that it will probably not be safe to hold this event even in August, and therefore we have no choice but to cancel the event. Moving forward, we will continue to consult with experts to ensure that any event we host is safe for everyone.



MISSED FUNDRAISING OPPORTUNITIES

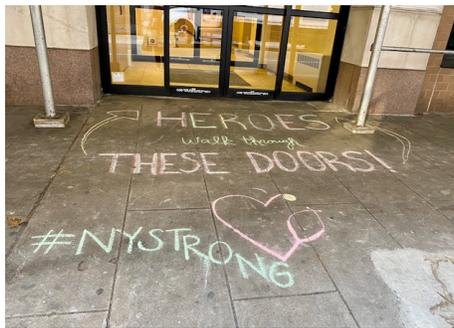
Normally our summer newsletter would feature descriptions of the wonderful events that have been held to raise money in support of our mission. This year, the *Brian McCabe Drive for a Cure*, *Gains for Brains Lacrosse Showcase*, *Kicks for Cancer*, *Fitzgerald Mardi Gras Bash*, *Nicky Docu Memorial Golf Tournament*, and many others have all been canceled or indefinitely delayed due to COVID-19. These events honored children who have passed away and also helped support our investments in new research projects. If you were part of one of these events in the past, or just want to help us make up for this loss of critical revenue, **please consider contributing directly today, at [MakingHeadway.org/donate](https://www.makingheadway.org/donate).**

UPDATE FROM THE STEPHEN D. HASSENFELD CHILDREN'S CENTER FOR CANCER & BLOOD DISORDERS

By Dr. Theodore Nicolaidis, Director, Pediatric Neuro-Oncology and Dr. Elizabeth Raetz, Medical Director, Stephen D. Hassenfeld Children's Center for Cancer and Blood Disorders

The COVID-19 pandemic has devastated countries and cities throughout the world. In the past few months, New York City has been among the hardest hit and continues to be an area of constant vigilance. Across the NYU Langone Health system, we followed the "PAUSE" directives of Governor Cuomo by initially delaying all non-urgent surgeries and procedures and devoting much of our resources to caring for adults and children with COVID-19.

However, children with cancer and other life-threatening conditions cannot simply pause their treatments without risking devastating consequences. At the Stephen D. Hassenfeld Center, our top priority has been to ensure that their care can continue safely and without interruption. We are happy to report that our center has remained open every day throughout this crisis, providing excellent care and comprehensive support services. In fact, we did not delay any



critical treatments for patients—in the hospital or clinic—during this time.

Our dedicated team of medical and psychosocial providers, pharmacists, administrative staff, and research coordinators has adjusted its workflows and developed innovative procedures to keep children, families, and staff as safe as possible, while continuing to provide all the care that simply cannot wait.

Some notable changes we made include:

- We converted some clinical visits to "video visits" so patients can remain at home. These visits allow medical providers to speak directly to families, while everyone stays safe.
- We are also practicing social distancing in our clinic, thanks to recently completed renovations. We now have

13 private infusion or examination rooms, to which staff escort children immediately upon check-in. Additionally, all patients and staff are screened for fever and symptoms of illness when they arrive each day.

- Our education coordinator is working with families who require support and guidance while navigating the Department of Education. Our social workers and psychologists have been regularly communicating with families to provide support and resources during this unsettling time.
- Finally, all clinical research has continued, with team members rotating on site to be available for every study visit, including all neuro-oncology patient visits.

While we certainly hope this crisis ends as soon as possible, rest assured children with cancer and blood disorders continue to receive the very best care and support at the Stephen D. Hassenfeld Center. As always, we are incredibly grateful for the longstanding support of the Making Headway Foundation, which provides us with critical resources to help children and families in their time of greatest need.

DAVID 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. His wife, Rachel, and children, Emma and Oliver, were

known as The Justus League. They have established a fund to honor David and help deserving families create amazing moments of their own. Please help celebrate David's legacy and learn more about the David Justus Joyful Moments Fund.

 makingheadway.org/davidjustus

The David Justus Joyful Moments Fund is administered by Making Headway Foundation and will directly help families who have a child diagnosed with a brain or spinal cord tumor.



FORTUNATE FOR EVERY DAY

By Ben Schade

Around the time when I was five years old, headaches and migraines were a big part of my day. You could say they were like an additional sibling to my sister, Laura, that I got to hang out with—but not as much fun. After many, many visits to various doctors to figure out what in the world was going on, my parents made the great decision to visit a neurologist in New York City. Little did any of us know that trip would result in being admitted to the hospital, after learning the cause of headaches was a tumor that had decided to become friends with the cerebellum of my brain.

My memories of being in the hospital are spotty, but I remember a few pieces. At the time I had fairly long hair and I remember the fear I had that I may need to get it shaved off for my upcoming operation to remove the tumor. Fortunately, that fear ended up being a non-issue. I was able to retain my hair, but the operation did result in me having a scar on the back of my head to be self-conscious about. I remember the tremendous staff at NYU, the great care I was given, and how they always tried to make me laugh (especially Adam the clown). Most

important, I remember, and always will remember, meeting Maya and Edward Manley, who supported my family and me during this time and long after. And how could I forget the awesome Beanie Babies that were given to me after being purchased in the hospital gift shop?

After successful surgery (thank you Dr. Jeffrey Wisoff) and treatment (thank you Dr. Jeffrey Allen), I was released from the hospital. With the location of my tumor being the cerebellum, physical therapy was required to relearn some everyday skills—to name a few: balancing, walking, and picking up and holding an object.

Fast forward a handful of years to age 31: I have a full-time career in golf administration, where I get to follow my passion every day, and my wife Jenna and I are awaiting the arrival of our first child.

Most people would never know what I went through when I was younger, but I'll never forget it, and am fortunate for every day. I have so much to be thankful of and so many to be thankful for, but I'd be remiss if I didn't say thank you to Maya, Edward and the Making Headway Foundation for all that you've done for me and everyone else in need. That scar that I was once self-conscious about is now something I'm proud of, as it shows where I was and how far I've come.



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

This newsletter is dedicated to our donors and supporters, whom we celebrate every day.

Managing Editor
Robin Hardman

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

