



**making headway
foundation**

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

makingnews

Fall/Winter 2018

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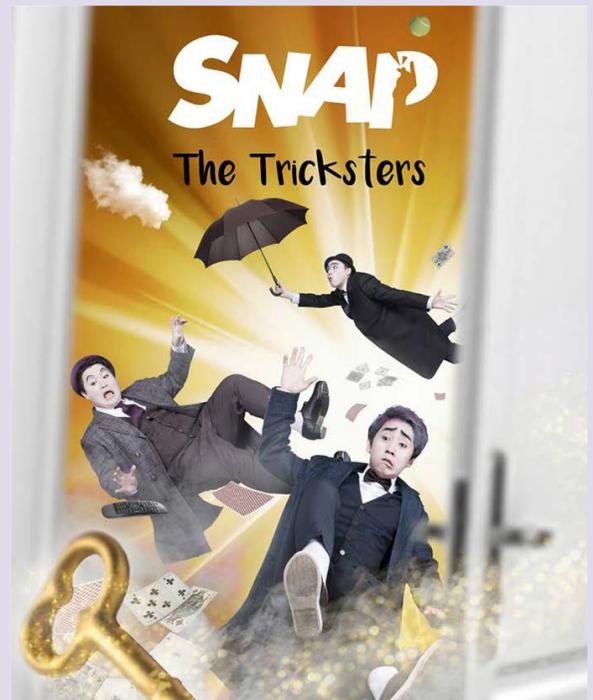
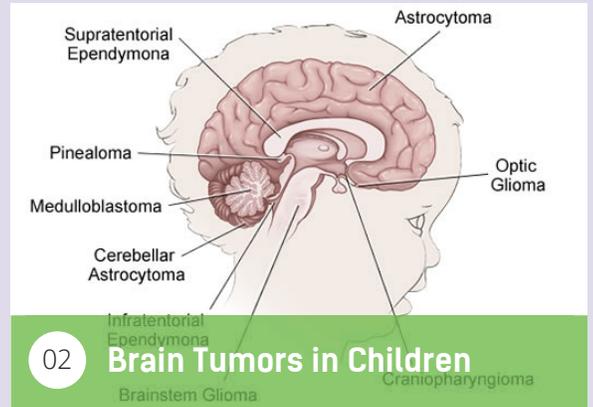
Grace Strum's battle to survive and thrive



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Letter from our Chairman & Founder

The past year has been an excellent one for the Foundation. Our winter show, Airplay, was the second most profitable event in the Foundation's history, raising over half our budget for the year. Smaller events, contributions, and grants covered the rest, enabling us to expand our programs of comfort and care and fund additional research.

We are serious about our commitment to improve the lives of the children and their families that we serve. At our recent Board meeting, we approved close to \$1 million of new grants. They range from new research initiatives that identify new treatments, to expanding our support services to new hospitals in the area.

During the past year, Maya and I have been able to do less work for the Foundation, as the day-to-day tasks are well taken care of by Dan, our Executive Director, and Jennifer, our Office Administrator. Dan has a keen sense of being able to anticipate upcoming needs and develop strategies to fulfill them. Jennifer makes sure that all data is accurately recorded, bills are paid promptly, and thank you letters and cards are prepared and mailed in a timely manner. With the office functioning smoothly and an active Board to guide the Foundation we are confident that it will continue to thrive when it is time for us to step back completely.

Edward P. Manley

FAST FACTS

MORE THAN 28,000 U.S. CHILDREN ARE LIVING WITH A BRAIN TUMOR

Brain and spinal cord tumors—known as central nervous system tumors (CNS)—are the most common type of solid tumor in children.

CNS tumors cause more childhood deaths than any other disease.

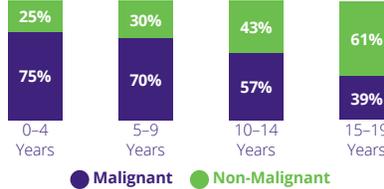
There have only been three FDA approved drugs to treat brain tumors in the past 30 years.

MOST COMMON PEDIATRIC CNS TUMORS



- Pilocytic astrocytoma: 24%**
5-year survival rate: 97%
- Embryonal tumors: 20%**
5-year survival rate: 63%
- Glioma malignant, NOS: 17%**
5-year survival rate: 63%
- Medulloblastoma: 11%**
5-year survival rate: 73%
- Diffuse astrocytoma: 7%**
5-year survival rate: 83%
- Ependymal tumors: 7%**
5-year survival rate: 75%
- PNET: 4%**
5-year survival rate: 55%
- Glioblastoma: 3%**
5-year survival rate: 19%
- Other: 7%**

PEDIATRIC CNS TUMORS



Brain Tumors in Children

More than 28,000 U.S. children are living with a brain tumor, and 13 new diagnoses are made each day. Brain and central nervous system (CNS) tumors are the most prevalent form of pediatric cancer in kids under age 19, and are the leading cause of cancer-related death—higher than leukemia.

Brain tumors may be low grade (less aggressive) or high grade (very aggressive). Among children, there are over 100 different subtypes of CNS tumors. The diversity of the tumors, often based on different genetic markers, makes treating this disease especially difficult. Fortunately, the majority of children diagnosed with either malignant or benign brain tumors survive (although survival rates range greatly, from 1% for children with DIPG to 95% for those diagnosed with Pilocytic Astrocytoma). Yet more than any other cancer, brain tumor survivors usually experience lasting and life-altering physical, cognitive, and psychological effects.

What Causes Tumors and What Do We Know About Treatment?

Brain tumors are the result of a genetic alteration in the normal cells of the brain, causing a mass of

abnormal cells to grow. How and why these alterations occur is still not well understood; while some are hereditary, the majority are not, and their origins are unknown.

Far too little research funding is currently devoted to addressing pediatric brain tumors, and what research there is moves forward only incrementally. 78 investigational brain tumor drugs entered the clinical trial evaluation process between 1998 and 2014, and of these, 75 failed. In fact, only three drugs and one device have been approved by the FDA to treat brain tumors in the last 30 years. As a result, surgery and radiation remain the standard of care in most cases, and mortality rates have remained little changed in the last three decades.

Making Headway is Making a Difference

At Making Headway, we're funding cutting-edge research specific to pediatric brain and spinal cord tumors, as well as supporting staff positions, clinical trials, tissue banks, DNA sequencing, and programs that make collaborative research possible. We are dedicated to finding better treatments and a cure.

Making Headway is Honored With a CAPTRUST National Grant

Making Headway is delighted to have received the CAPTRUST Community Foundation's 2018 National Grant. CAPTRUST Foundation's mission is to enrich the lives of children in the communities it serves, and each year it takes applications from charitable organizations throughout the country that support this goal. This year, after a strenuous vetting process, Making Headway was one of just three organizations selected to receive the prestigious award.

One hundred percent of the new grant will go directly to serving children diagnosed with a brain or spinal cord

tumor. Specifically, the funds will be applied to programs that ensure each child receives the special education services they require at school, that expert psychological care will be provided at no cost to children who need it, and that the playrooms at local children's hospitals will receive much-needed improvements.

We are grateful to CAPTRUST employee Maria Barbieri for bringing this grant opportunity to our attention. Maria's son, Peter, survived a brain tumor, and their family has received numerous services from Making Headway, including educational advocacy and

psychological counseling. They have also enjoyed attending the annual winter show and fall cruise, and Maria participated with Making Headway in the Head to the Hill event earlier this year. Thank you, Maria!



Making Headway's co-founders, Edward and Maya Manley, were joined by our executive director and CAPTRUST staff for an awards presentation at the organization's Greenwich branch.

A Letter from our Executive Director



Throughout our lives, we experience and understand how complicated the world can become. However, there

are circumstances that we should see with perfect precision, passion, and perspective. For the staff and supporters of the Making Headway Foundation, our mission provides this clarity and inspires us to make a difference. Childhood brain and spinal cord cancer is one of the most common and deadliest forms of cancer in children. Those diagnosed with this disease will need help for the rest of their lives—as will their siblings, parents, and other family members. Making Headway is dedicated to providing the services and assistance that these individuals need, for as long as it takes.

Research to develop better treatments and a cure for childhood brain and spinal cord tumors is considerably

underfunded. The reality is that diseases that do not generally impact adults do not get the attention of pharmaceutical companies, medical institutions, or government research laboratories. Furthermore, while investments in general science may yield helpful results for addressing some diseases, the technical uniqueness and complexity of childhood brain tumors make it unlikely our patients will ever benefit from those. Making Headway is dedicated to filling this gap by investing in cutting-edge, translational research projects for as long as it takes.

Over the past few years, Making Headway has been fortunate to receive enough financial support to expand both our programs for families as well as our research efforts. New grant awards allow us to expand our programs to new hospitals in the region. New partnerships provide us with the opportunity to fund much-

needed, world-class research initiatives, and generous donations allow us to create meaningful programs. However, there is so much more that we can do to help families. The more financial resources we have, the more families we can help and the more ways we can help them—it is as simple as that.

Helping families who have a child diagnosed with a brain or spinal cord tumor is not a complicated or controversial idea. In a complex world, it is a mission that we can all be proud to support. At Making Headway, we have seen entire communities join to help a family or honor a lost child. We are asking all of you to come together with us to help all of the families there, with all the services they need, for as long as it takes. Thank you.

Daniel Lipka
Executive Director

A Lovely Day for a Sail



On Sunday, September 16, Making Headway welcomed hundreds of family members to our annual **Family Yacht Cruise** around Manhattan. Each fall, the much-anticipated event brings together families who have had a child diagnosed with a brain or spinal cord tumor for an afternoon of fun activities, delicious

food, and breathtaking views aboard the majestic Skyline Princess. As always, the event was capped off with a stunning New York Fire Department water cannon show. We're delighted to point out that this event has been held for so many years that guests who first came as children are now bringing their own

children. All in all, it was a beautiful day of community, well-being, and joy. We are also extremely grateful to Richard and Marisa Stadtmauer for sponsoring the cruise each year.

View all the pictures at makingheadway.org/cruise



A Hole in One for Making Headway

The day started early for the participants in the 7th annual **Brian McCabe Drive for a Cure Golf Outing** on September 24. Breakfast was served at 7am, and by 8am the eager players had hit the tees for a shotgun start. As always, the

tournament was followed by a convivial lunch, silent auction, and prizes. Eileen and Mike McCabe organize this fundraiser each year in honor of their son Brian, and this year they raised \$44,000—bringing the total support for Making Headway's programs to \$340,000 since the event was first launched.



"Say It, Fight It, Cure It!"

On October 2, fans of all ages turned out to root for the home girls' and boys' soccer teams at Long Island's Hauppauge High School. But this time they were supporting more than a few good field goals. It was the 10th annual **Kicks for Cancer**, held in memory of former

student and team member, Courtney Tomkin, who succumbed to DIPG—a lethal brain tumor—in 2008. Courtney's coach, friends, and family organize the enthusiastic fundraising event each year, generously donating proceeds to support the work of several organizations, including Making Headway Foundation.



Walking Or Running, this Race Was From the Heart

Over 250 people—runners and walkers alike—came together in Yonkers on September 15 for the 12th annual **Woodlawn Run for a Cause**. Making Headway was delighted to have been chosen as

one of two beneficiaries of the 3.1 mile race this year. We look forward to using our share of the more than \$18,000 raised for research, as well as to benefit the many families that depend on us to provide care and comfort during one of life's most heart-wrenching experiences.



Upcoming: Annual Winter/Spring Theatrical Event, SNAP!

**Sunday, April 14, 12:00pm
New Victory Theater
209 West 42nd Street
New York, NY**

Don't miss the fun this spring—save the date for our biggest fundraiser and family event of the year! Billed as a "contemporary mystery performance," **SNAP** is a magic show like none other. This beguiling tour-de-force boasts a

cast of Korea's seven greatest illusion artists in an enchanting, engaging, and hilarious performance which has won awards and accolades all over the world. We'll be inviting Making Headway families to take a day off from their cares and enjoy this event for free; for everyone else, your ticket purchase or donation makes Making Headway's programs and services possible. Visit makingheadway.org/snap for more information or to donate.

Funding Key Staff to Assist Patients and Families

For over a decade, Making Headway has worked with the NYU Stephen D. Hassenfeld Children's Center for Cancer and Blood Disorders to develop a world-class level of care for pediatric cancer patients. This includes the funding of several key staff positions that substantially and directly support patient care and research:

- For the first time, Making Headway has awarded a grant to fund an exceptionally qualified pediatric neurosurgeon at the NYU Langone Medical Center. Dr. Eveline Teresa Hidalgo received an MD from Bern University in Switzerland and completed her residency in neurosurgery at the University of Bern and Kantonsspital Aarau. She achieved Swiss board certification in neurosurgery in 2013 and in 2016 was appointed to the position of clinical instructor in the Division of Pediatric Neurosurgery at NYU Langone Medical Center. Dr. Hidalgo, who speaks fluent English, Spanish, French, and German, has distinguished herself as an exceptionally talented neurosurgeon, teacher, and investigator. She will become the fourth full-time pediatric neurosurgeon at NYU, reflecting a significant increase in the number of childhood brain tumor surgeries each year.
- Through a Making Headway grant, the Hassenfeld Center is able to retain a full-time licensed clinical psychologist, Dr. Katelyn McGee. Dr. McGee provides enhanced neuropsychological interventions for patients, including screening, testing/assessment, and treatment. Her position completes a team of three pediatric neuropsychologists who provide treatment to all patients at Hassenfeld, setting an example for other medical institutions.
- The Hassenfeld Children's Center's clinical trials office currently manages 84 active research projects, all devoted to the study of pediatric cancers. Managing so many clinical trials is a complex and difficult process. With Making Headway funding, NYU is able to staff a full-time Clinical Trials Manager, Anna Yaffe, to oversee collaborations; work with researchers, doctors, and families; and lead the institution's efforts to complete credible, organized, and efficient clinical research trials.



Dr. Eveline Teresa Hidalgo

Forging Ahead with Research



Two critical research projects are seeing significant progress toward their goals, supported by a second year of funding from Making Headway. The first, led by Dr. Danny Reinberg, aims to devise a therapy for blocking the development of DIPGs, one of the most deadly forms of pediatric brain cancer. The project has identified a novel epigenetic signature in DIPGs and has already reached a substantial number of its goals, including an initial demonstration that it is feasible to use cell penetration to target LEDGF and HDGF2 (growth-enabling proteins in DIPG cells). The second grant, led by Drs. Thales Papagiannakopoulos, Matija Snuderl and Iannis Aifantis, addresses pilocytic astrocytoma (PA), one of the most common types of brain tumors in children. The project is seeking to identify precision medicine-based therapeutic strategies for the treatment of PA.

A Critical Partnership



Currently, the side effects of radiation therapy lead to lifelong, devastating cognitive impairment. But researchers at the Sarosiek Laboratory at the Harvard School of Public Health recently discovered that by using a targeted drug to decrease the expression of a key protein in the brain, tumors can become more sensitive to radiation therapy while healthy brain cells become less sensitive. Making Headway is partnering with the St. Baldrick's Foundation to co-sponsor the lab's further research into this phenomenon, which promises to increase cure rates while decreasing the negative effects of treatment. The project is titled Optimizing Medulloblastoma Treatment Outcomes by Modulating Myc.

Making Headway offers numerous ongoing care programs to support families outside of the hospital, both during and after treatment. Here are a few:



Individual and Family Counseling

A child's serious illness is an intensely personal experience for the entire family. Some people need help understanding or working through painful emotions. Others have a hard time finding the language to articulate their feelings or concerns. Relationships among family members may become strained. As a result, experienced, expert psychological care is often just as important as medical care.

Making Headway offers free-of-charge counseling sessions with licensed psychologists who are specialists in dealing with the unique issues local families in this situation face. Short-term counseling is available for the sick child, parents, and siblings. Thus far, over 400 families have taken advantage of this

service, receiving nearly 9,000 hours of counseling to assist them in developing coping skills.

Education Advocacy

One of the most serious challenges facing young survivors of a brain or spinal cord tumor is returning to school. As a result of surgery, chemotherapy, and radiation treatments, most children experience learning disabilities, and many have difficulty adjusting socially. Children may be unable to keep up with their peers; they fall behind academically and may experience rejection and social isolation.

Making Headway's trained, experienced educational specialists provide free-of-charge, long-term education assistance, and advocacy. Over 200 families have

benefited from these services, which include: advocating for the child; assisting the family and school in identifying appropriate support and accommodations; and ensuring the school provides these services.

Introducing Making Headway's Respite Care Program

When a child is diagnosed with a brain or spinal cord tumor, the entire family faces an overwhelming level of stress. Consumed with caring for their child, parents are often left with little or no time to care for themselves. For the long-term well-being of a family, parents need to be able to relax and spend time with each other.

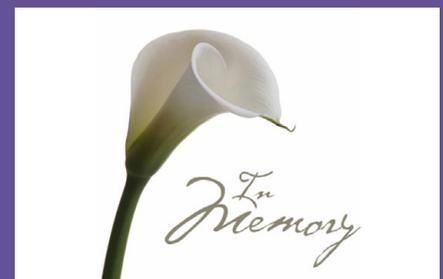
In response to this, Making Headway is piloting a unique Respite Care Program for our families. The program will coordinate and pay for highly trained and vetted nurses, home health aides, or babysitters to provide in-home care for children. Parents can use the care several times a year, giving them the opportunity to spend time together, knowing their children have safe, medically-appropriate care. The one-of-a-kind respite program is a natural extension of our mission to provide a wide scope of meaningful assistance to support the psychological well-being of the entire family.

35 years ago, Cynthia Manley returned to school after undergoing surgery, radiation, and chemotherapy to treat her childhood brain tumor. Like so many children who survive a brain tumor, Cynthia would require special care and services to continue her education. At the Robert E. Bell School, the Manleys found a kindred spirit in the Principal, Ms. Josephine Campbell. Maya Manley remembers how "Ms. Campbell took Cynthia under her wing and looked after her like a mother." Josephine Campbell would always personally ensure Cynthia's needs were met, including the creation

of specialized spaces and services. Josephine Campbell was one of Making Headway's first supporters and also inspired other teachers and community members to value our mission. After her service at the Bell School was over, she retired to Florida.

It is with our deepest sorrow that we share the news that Josephine Campbell passed away on May 30th, 2018. She was a true friend of Making Headway and a sincere advocate for children. Her dedication helped to inspire our educational advocacy program, which continues to this day.

Josephine Campbell will always be in our hearts, as we were in hers. Upon her passing, she left a sizeable and very generous bequest to Making Headway. Planned giving is vital to our sustainability and we are eternally grateful for her life and her support.



Real Families, Real Impact



Cindy Sturm's first encounter with Maya Manley came when she was sitting in the ICU, where her eight-year-old daughter Grace lay in a coma. She got a phone call from a woman who seemed obviously concerned and compassionate—but Cindy had no idea who she was. Confused and overwhelmed, she handed the phone to her husband, Andy. "Oh, yes," he said, "Someone told me about her!" Someone from the Chappaqua school where he taught had connected them to Making Headway.

Grace was diagnosed with a benign brain tumor in July 2009. The prognosis looked good. After a successful surgery, doctors said she'd be in intensive care for a week, followed by four weeks in rehab. She'd be ready to enter third grade in September, right on schedule. But Grace didn't make it out of the ICU as planned. Instead, she suffered a grand mal seizure, and slipped into a coma. She didn't regain consciousness for five long weeks. It was during this terrible time that Maya Manley started working with the family on a regular basis.

She invited the Sturms, who also have a younger daughter, Lauren, to the annual yacht cruise, where they were buoyed

by meeting so many other families who had gone through similar experiences. Soon they were regularly attending Making Headway-sponsored events: the fall cruise, the winter/spring show, and Family Fun Day.

While both their home community of New Fairfield, Connecticut and Andy's work community came out in force to support them during this acute phase of Grace's illness and recovery, as time went on the connection with Making Headway grew.

During one of their early encounters, Maya told the Sturms about the foundation's educational assistance and advocacy program. Grace had finally returned to school in May of her third grade year. Although the trauma to her brain had impacted her greatly, she thrived in a school environment. The family wanted her to be able to stay in the school she'd always gone to, with the kids she knew. But the educators there didn't really know what to do with a child with her disabilities. Making Headway's Dr. Susan Leslie came to the rescue.

"Susan was able to advocate for Grace, and help build a program that allowed her to stay in the school system that she was accustomed to. She has been such a wonderful advocate for us; she's made it possible for Grace to be the best that she can be," says Cindy.

Grace is now a high school senior, and Dr. Leslie has remained by the family's side, helping to negotiate and advocate throughout her schooling. And that's one of the things the Sturms appreciate most about Making Headway—we're in it for the long haul.

"When we were on the cruise this fall, I ran into a 22-year-old who's been with Making Headway for a long time...it's wonderful that you don't age out. When you suffer a major medical issue, it doesn't just resolve itself, and it's great to talk to people at different stages of the recovery. I am just so grateful to Making Headway for not closing the doors—they're always there for us." —Cindy Sturm



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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.