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Letter from our Chairman & Founder

After 21 years of being involved in the daily operations of the Making Headway Foundation, it is nice to finally loosen my grip on the reins. We have a new team at the office, Executive Director Dan Lipka and Office Administrator Jennifer Samuels. They have already taken over a great deal of the day-to-day work, and I am confident that they will continue to expand their roles to take on added assignments, leaving me more time to focus on issues and opportunities facing the Foundation, plus a bonus: more time for my grandchildren!

It is so encouraging to witness our donors' confidence in the work we do. We have recently concluded our Winter Show fundraiser, which successfully generated enough contributions to fund half of our budget for this year. Additionally, we are seeing greater interest on the part of our families in establishing new fundraising events. These activities will ensure we can continue to grow and expand the supportive services we provide to our families and fund additional research programs to improve the outlook for our patients.

Maya and I are most grateful to all of our donors, and thank our Board of Directors for their support and guidance.

Edward P. Manley

Three New Cutting Edge Research Projects Funded by Making Headway

Making Headway is delighted to announce grants for three important new research projects. Each is designed to help scientists better understand specific aspects of pediatric brain tumors, in order to find better treatments. As is often the case with Making Headway grants, these projects focus simultaneously on specific research goals and on creating resources that improve efficiency for other researchers. To learn more, visit our website, makingheadway.org/research.

Novel Targeting of an Epigenetic Signature in DIPG

DIPGs are one of the most lethal kinds of cancer, often with a poor prognosis. Resistant to chemotherapy and radiation, they are situated in parts of the brain that make surgical removal nearly impossible. Now, thanks to genetic profiling, researchers have begun to understand more about the mutations that cause DIPGs. In a new study led by Dr. Danny Reinberg, researchers will use CRISPR/Cas9 techniques to test new methods for blocking the development of these deadly tumors.

Identifying Vulnerabilities of Pediatric Gliomas

An important tool in understanding how to combat brain tumors is understanding how tumors acquire the nutrients that keep them alive and growing. Researchers have discovered that tumor metabolism in children is different from that of adults. This project, led by Dr. Richard Possemato, develops models of pediatric tumors in animals in order to better understand how they grow, and how gene manipulation might slow or even stop that growth.

Developing Novel Mouse Models of Pilocytic Astrocytoma

Pilocytic Astrocytoma (PA) is the most common type of pediatric brain tumor. It can lead to serious outcomes, including failure to thrive, growth impairment, vision loss, neurological deficits, and sometimes death. Now a team of scientists led by Dr. Thales Papagiannakopoulos is working to genetically engineer laboratory mice that exhibit the same genetic alterations found in PA. These models will enable researchers to test targeted therapies and identify new treatment strategies.

Leveraging Our Resources: Announcing an Exciting New Partnership

Recently-released data from the National Center for Health Statistics revealed that pediatric brain cancer is now the leading cause of cancer deaths in children. Yet research grants for childhood brain or spinal cord tumors continue to be underfunded, even among large pediatric cancer organizations. That's why Making Headway is excited to announce a partnership with St. Baldrick's Foundation to support a grant



targeting pediatric brain tumor research. St. Baldrick's is a non-profit organization devoted to finding cures for childhood cancer. It funds more relevant studies than any group outside the federal government. This renowned organization has agreed to match a \$50,000 grant from Making Headway, doubling our ability to support vital research. We're currently working on identifying one or more research projects that will make the best use of this opportunity.



Exercising the Heart

More than 100 fitness enthusiasts showed up to cycle—or cheer on their spinning friends—while raising money for a great cause at the second annual **Race for ACE** spin-a-thon. Organized by Susan Rubin in memory of her son, Andrew

Cooperman Ecker (“ACE”), the early June event was a rousing success once more, with everyone heading out for a friendly drink after the hard work was done. Proceeds went to Making Headway, which provided support for Andy and his family during a terrible time.



In this Tournament, Every Team Won

In April, it was time for the third annual **Gains for Brains** invitational lacrosse fundraising tournament. Eighteen of the country's top-ranked girls lacrosse teams competed in this series of exciting matches held at Cold Spring Harbor High. Interestingly, Courtney Tomkin, whose memory is honored each year in *Kicks for Cancer*, was also the inspiration for this event:

Back in 2008, journalist Andrew Rappaport was so moved by an interview he conducted with the bright young woman, just months before she died, that he vowed to do something in her memory. The result, a few years later, was the first **Gains for Brains**, and its resounding success has led him to hold it again each year since. As always, 100% of the proceeds went toward the programs and services provided by Making Headway.



Something Magic

Gravity means nothing to the members of Liberi Di, the Italian “physical theater” group that brought its wondrous show, **Something**, to hundreds of Making Headway families this past April. The annual winter/spring event, held at Manhattan's New

Victory Theater, was an opportunity for children and their parents to take a break from doctors and therapists and enjoy an afternoon of magic. By turns breathtaking, whimsical and funny, the show combined acrobatics, theater, music and dance for a truly awe-inspiring afternoon.

For over 20 years, Making Headway has invited families to an annual Broadway event such as this one. We are unique among organizations addressing pediatric tumors, in that our mission is to provide not just medical but emotional and social support to the whole family, both in and out of the hospital. We are delighted that so many families could join us for this entertaining afternoon.

The Opposite of Spinning Their Wheels

Teens were also the driving force behind **Fly for a Cause**, a fundraising spin-a-thon organized by student Faye Merchand and members of the One Life Club at Scarsdale High School this past March. The lively event carried on a tradition that began four years ago, when Fazi Shaikh founded the club in memory of his friend, Jack

Reyna, who had passed away from brain cancer. Searching for a way to raise funds for Making Headway, the foundation that had done so much for his friend, Fazi was connected with fellow student, Alexis Zachem (see page 8), who was planning a spin-a-thon. This year, though both Fazi and Alexis have moved on to college, the generous tradition continued with another fun and meaningful afternoon spin.



Why I'm Doing My Part By Victoria Murphy

I am excited and honored to be hosting a charity fundraiser for the Making Headway Foundation on June 17. Making Headway is especially dear to me since it was there for my son, George, and our whole family 25 years ago.

As a preemie twin, George suffered a Grade IV intracranial hemorrhage, meaning he had severe bleeding in his brain. We were blessed to find Dr. Fred Epstein at NYU Langone Medical Center. I will never forget the day I was sitting in the waiting room with George, thinking, "How will we get through this?" Suddenly, a woman with a warm, caring smile peered into the room; she invited me to bring George to where she and a group of children were frosting cupcakes. Our day—and our lives—changed forever!

The woman was Maya Manley, and it brought me comfort to speak to her, a mom who had been through illness and surgeries with her daughter, Cynthia. Many of our friends and family had no idea what we were going through, and until then we felt isolated and alone.

In the years that followed, we enjoyed the boat trips, shows, and summer picnics hosted by Making Headway. They were a wonderful respite not just for George but for me, my husband and George's sister, Katelyn—a brief distraction from surgeries, medications, and the daily heartache and struggles of parenting a child who is ill. Katelyn also loved a monthly siblings' group they offered at the time. Many times, the well child is left feeling less important than the child struggling with an illness, and Making Headway's sibling meetings allowed Katelyn to feel special for a day—as well as to vent!

Today George is a contented 26-year-old boat captain, volunteer fireman, first responder and student. The happy memories left by Making Headway far outnumber George's recollection of doctor's appointments, CT scans, and surgeries.

Words cannot express our gratitude for the kindness, support and generosity we received from Making Headway. So,

as Director of Events at the Lilly Pulitzer store in Manhattan, I decided to host a charity fundraising event at our store. The event took place at 1020 Madison Avenue on June 17th and 10% of purchases went to the best cause I can ever imagine!

Want to Host a Fundraising Event? We're Here to Help!

Much of the funding Making Headway needs to support our vital work comes from fundraisers dreamed up and planned by people like you. Events can be big or small, and have ranged from shopping-for-a-cause activities, like Victoria organized, to sports tournaments, parties, and walk-a-thons. If you've been touched or inspired by our work, and would like to do your part to make a difference, contact our office at (914) 238-8384 or email dan@makingheadway.org. We can make a suggestion or talk through your idea, and will be happy to help you make your idea a reality.



Another Sort of Goal

Each year, the generous student-athletes at Long Island's Hauppauge High School host a week-long soccer tournament, **Kicks for Cancer**, in memory of former student, Courtney Tomkin. After Courtney passed away from DIPG (a lethal brain tumor) in 2008, her classmates, friends, and family launched this event to

honor her memory and raise funds for Making Headway. Last fall, in addition to participating in the tournament, current members of the Hauppauge Lady Eagles varsity team visited the NYU Hassenfeld Children's Center. The visit provided them with an opportunity to see first-hand what their fundraising efforts mean to so many families.

Hitting the Links for a Cause

On a recent beautiful June afternoon, an enthusiastic group gathered for some friendly competition on the greens, a buffet dinner, and special silent auction at the annual **Nicky and Thomas Docu Memorial Golf Outing**. This event, now in its 15th year, was started by Tom Docu in memory of his son Nicky, who died from a brain tumor. Tom passed away a few years ago, but



the event continues, led by Jim O'Reilly and a team of family and friends, who now honor the lives of both father and son. All proceeds from this charity event went directly to programs and services at Making Headway.

Making Headway Family Yacht Cruise

**Sunday, September 10
11:30am-3:00pm
Chelsea Piers (Pier 60)
New York, NY**

The Yacht Cruise is another opportunity for "our families" to spend a day with no goal other

than fun and relaxation. Sail the waters around Manhattan, enjoying the sights as well as on-board food and entertainment. Best of all is the traditional water cannon show by the NYFD, arranged each year by Tom Ryan, whose son had been diagnosed with a brain tumor.



Making Headway's Annual Family Fun Day

**Sunday, June 18
Life the Place to Be
2 Lawrence St
Ardsley, NY**

There are usually no "days off" for families impacted by a childhood brain tumor. At Making Headway, we make it our business to give the

families we work with a few special days each year to really enjoy. Now in its 23rd year, the Making Headway "Family Fun Day" brings together hundreds of children and families for a day of music, adventures, games, and comradery. If you're a child or family member that's been touched by the work of Making Headway, this day is for you!



Brian McCabe Drive For A Cure Golf Outing

**Monday, September 25
7:00am-3:00pm**

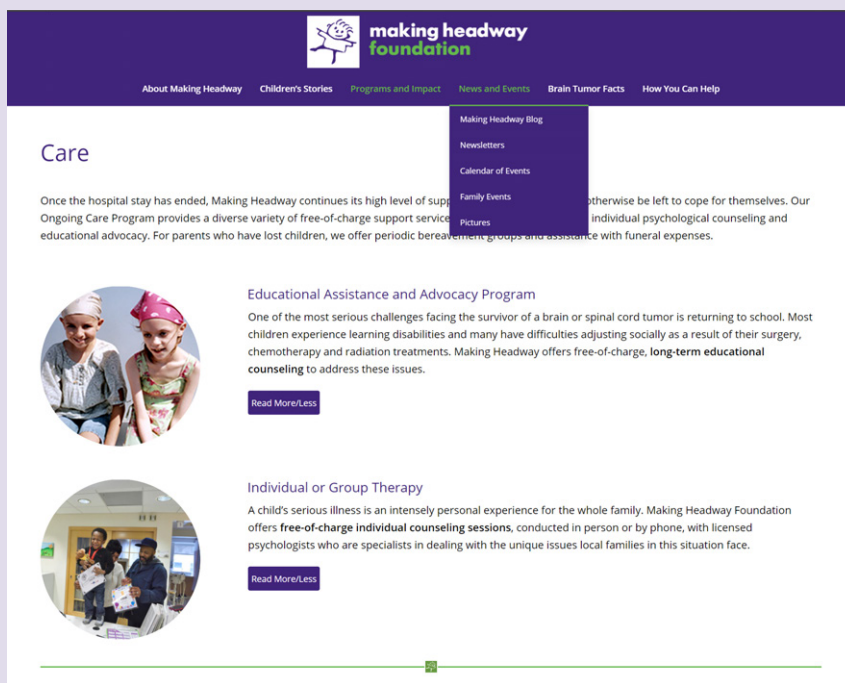
**Pelham Bay and Split Rock Golf Course
870 Shore Road
Bronx, NY**

Great golfing, delicious food, and a bountiful silent auction—all for the best of causes. What more could anyone ask for? This event is organized by Eileen and Mike McCabe in honor of their son Brian.

Visit Our New Website!

Have you checked out the Making Headway website lately? If not, you'll want to drop by, because it's undergone a makeover and there's plenty to see! The "new and improved" site contains information about our programs, stories about children and families that we've helped, facts about brain and spinal cord tumors, and the research we fund. You'll also find information about past and upcoming events, up-to-the-minute news and stories on our blog, and archives of past newsletters. Most important, you'll find information about how you can help—from easy on-line donating to organizing a fundraising event—with a wealth of options in between.

So stop by for a visit now, at www.makingheadway.org!



A Letter from our Executive Director



Last fall, I was honored and excited to join the Making Headway family as their new Executive Director.

For almost 20 years, I have worked in the non-profit sector, championing the causes of refugees, children, and local communities. At Making Headway, I found something special: an organization that is passionately dedicated to helping children diagnosed with pediatric brain or spinal cord tumors. It was when I first met the Board of Directors that I realized how unique this organization was. It is one thing to know a child who is sick, but

it is quite another when it is your own child. Almost all of the board members have had a child diagnosed with this disease, so they truly understand the impact that it has on the child, the family, and the community. Their insights helped to develop Making Headway into the rare type of non-profit organization that tries to meet all the diverse and changing needs of families. Over the past eight months, I have met many parents and children who are served by the programs and grants of Making Headway. I understand that their fight is our fight, their victories are our victories, and their grief is our grief. I am inspired and motivated by the families we serve,

and will work to provide them with the resources they deserve.

Making Headway is an extended family and we are all part of it. I am proud to serve as Executive Director and do my part to help us meet our mission. You can also contribute to the cause. If you have ideas for programs, services, or fundraising activities please give me a call at (914) 238-8384. I'm looking forward to a long career at Making Headway, and to working with you to ensure it continues to be an effective, efficient organization. Thank you.

Making Headway Program Highlight: Helping Researchers World-Wide

One of the most exciting projects supported by Making Headway is the NYU Pediatric Brain and Nervous System Tumor Research Registry and Tissue Bank. Thanks to this

biorepository center, which catalogs and stores sample tissue from thousands of children with brain or spinal cord tumors, researchers from around the world have access to an invaluable scientific resource. The registry is even more vital at a time when molecular pathology, or the study of how diseases function at the molecular level, has increasingly become a research focus.

We are proud to help fund the position of Data Manager at this

center, as well as cover the cost of sharing samples. While this is an important piece of the “cure” part of our mission, it is also more than that. When the worst happens, and a child dies, parents often seek some meaning in this unfathomable event. Our many years of working with families have taught us that it can sometimes be helpful to know that some small good comes of this pain. By donating their child’s tissue to the tissue bank, some parents find a bit of comfort during a time of terrible loss.



Head to the Hill

Brain tumor survivors who participated in 2017

On Tuesday, April 9th, Making Headway participated in Head to the Hill, a day of advocacy in Washington, D.C. to support funding for brain tumor research. Organized by the National Brain Tumor Society, the event brought together over 300 people, from nearly every state, to educate and lobby their own congressional representatives. Almost everyone had a direct, personal connection to somebody with a brain tumor, and they shared intimate stories of grief, struggle, courage, and hope. The goals of the day were straightforward. Participants advocated for two specific legislative actions: a \$2 billion increase in the overall budget

of the National Institutes of Health (NIH) and the passage of the Childhood Cancer STAR Act.

The most important research organization in the country, the NIH is apolitical, and its largest area of study involves cancer. Its funding is particularly important because, since adult and childhood brain tumors are relatively rare, there is little profit for pharmaceutical companies in funding research. The STAR Act is a piece of bipartisan legislation that, if passed,

will advance pediatric cancer research and child-focused treatments, improve the tracking of childhood cancer, and enhance the quality of life for survivors. It will also create a database of pediatric brain tissue samples that will support a variety of medical research programs.

For our part, Making Headway was there to represent the needs of children with brain tumors, as well as their parents, friends, and communities. We met with staff at the offices of New York legislators Sen. Kirsten Gillibrand, Sen. Charles Schumer, Rep. Elise Stefanik, Rep. Nita Lowey, and Rep. Tom Reed II, and we were very encouraged by their strong support.

Over the past 20 years, medicine has seen astounding advances, yet the complexities of brain tumors, combined with a lack of funding, have resulted

in no significant new treatments. Over 700,000 people—30,000 of them children—are living with a brain

tumor. We hope you'll also consider contacting your representatives in Washington to encourage their support of the NIH and STAR Act. Visit www.makingheadway.org/advocacy to learn more.

Almost everyone had a direct, personal connection to somebody with a brain tumor.

I don't worry about the little, insignificant things anymore

By Alexis Zachem

I am THAT girl who had a brain tumor. Before you start pitying me, let me make one thing abundantly clear. I love being the girl who had a brain tumor. No, not for the attention I get for it, and definitely not for the surgery and recovery. I like who my tumor made me and what it made me realize about myself.

Before I became a brain tumor girl I was average. Smart, but never the smartest. Skinny, but definitely not the skinniest. All I wanted was to distinguish myself from everyone around me. I thought I could do this by being the prettiest or smartest, but found myself disappointed that I fell short every time. At the end of freshman year, as I sat on the sidelines of a lacrosse game, I was hit in the nose by a ball traveling 75 miles per hour. I was rushed to the emergency room to have facial reconstruction.

I thought to myself, what could get worse than this? I can't have shattered nasal plates and a deviated septum because I need to be pretty. I can't spend months inactive, because I need to work out to be skinny. One thing I've learned about life is it can always be worse. Right before my surgery, my doctor pulled my parents aside and gave them the news that had everyone entering the room in tears.

I HAD A BRAIN TUMOR! An innocent 15 year old who was too shy and insecure to hurt a fly! I vividly remember the feeling when they told me; that feeling of your heart dropping to the floor as your stomach tightens and throat closes. I thought it was the end. I would never live to go to college, drive a car,

meet my husband or start a family. I couldn't have been more wrong.

The way I see it, people face tragedy in two ways. You can be the victim or you can be the survivor. I am a survivor. I fought my tumor and I beat it. I had a 10-hour surgery, spent 5 nights in the ICU, went on dozens of medications and have 6 titanium plates in my skull and a 9-inch scar, but I won!

I don't like it when others know what I went through. I don't like being looked at differently because I fought a deadly illness. But I do love who my surgery made me. Now I am passionate about everything I do. I appreciate every moment of every day because I understand how precious life is.



I have raised over \$50,000 for Making Headway through planning and executing an annual spin-a-thon. I started a social media campaign called "brain freeze for brain cancer" that gained international attention and had thousands of shares. I mentor kids currently battling brain tumors, and help their families through the experience. I donate toys and clothes to the hospital. I have a blog, braintumorgirl.com, that helps kids understand what to expect when having brain surgery. Nothing makes me happier than doing these things.

My surgery gave me a new perspective on life. I don't worry about the little, insignificant things anymore. I know how lucky I am to simply be alive and I use that to make everything I do productive.

Alexis is now studying neuroscience at Duke University. Her goal is to become a pediatric neurosurgeon or neurologist, and change the patient-doctor interface for kids undergoing brain surgery.



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foundation

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.

Making Headway would like to thank Victoria Murphy and Alexis Zachem for sharing their stories.

Managing Editor
Robin Hardman