



making headway
foundation

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

makingnews

Fall/Winter 2017

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Letter from our Chairman & Founder

This newsletter describes many services and programs Making Headway funds. All are aimed at easing families' journeys through a devastating disease. Nevertheless, the stress parents face with their sick children is constant and ongoing: worries about medications, symptoms, family issues, medical bills, and more.

Through several free-of-charge family events throughout the year, Making Headway aims to give families a respite from this relentless anxiety. One such recent event was the annual Family Yacht Cruise. What a beautiful day the parents and children had, cruising on the Skyline Princess down the Hudson River to the Statue of Liberty. There, thanks to the efforts of Tom Ryan, whose son is a patient of Dr. Jeffrey Allen, an NYFD fire boat greeted us with a spectacular display of water shooting high into the air from every pump on board. As we turned around and headed up the East River, a delicious lunch was served on both decks, followed by dessert—including 150 cupcakes baked and decorated by my wife, Maya. It is so heartwarming to see the relaxed faces of the children and their families, enjoying the day and forgetting everything else for just a few hours. Our thanks go out to the Stadtmauer family, whose generosity every year helps make this cruise possible.

Edward P. Manley

Funding Update

Making Headway is pleased to announce new or renewed funding for five significant projects and grants that directly assist families impacted by a pediatric brain or spinal cord tumor:

Pediatric Neuro-Oncology Fellowship.

Once again Making Headway's funding for our annual fellowship will allow a promising young doctor, Dr. Fernando Suarez, to participate in evaluation, treatment, and clinical trials at NYU Langone Medical Center, preparing for a career in pediatric neuro-oncology.



Neuropsych Testing.

Children with brain tumors often experience developmental, cognitive, social and emotional problems, from the tumor, surgery, and radiation treatment. The Hassenfeld Center's Pediatric Neuropsychology Program proactively assesses young patients in order to recommend interventions such as school support, speech therapy and behavioral counseling. By funding a full-time pediatric neuropsychologist, we have enabled access to this testing for all newly diagnosed patients.

Research Tissue Bank. Making Headway's ongoing support for the Pediatric Brain and Nervous System Tumor Research Registry and Tissue Bank was renewed again this year, allowing researchers from around the world to access rare tissue samples that can add significant value to their work finding better treatments and a cure.

Family Aspects to Recovery. This long-term study evaluates the impact of socio-economic status, home environment, parenting and parental distress on pediatric brain and spinal cord tumor patients. The goal is to find ways to help children with brain tumors before neuropsychological problems develop.



Massage Service.

Massage therapy can promote not just relaxation but critical physical healing. Making Headway recently funded the hiring of Blossom Beason, a professional who is certified in pediatric massage therapy and oncology massage to work with both children and their parents.

Fellowship Alumna Update



Dr. Devorah Segal was a Making Headway-funded Pediatric Neuro-Oncology Fellow in 2015-2016.

We asked her recently to bring us up to date on her work, and here's what she had to say:

"I am now an associate professor of pediatrics and child neurology at Weill Cornell Medicine. I'm doing mostly general pediatric neurology with a sub-specialty

focus on neuro-oncology and neurogenetics, including neurofibromatosis type 1. I am also working on writing up the research I did during my fellowship to submit it for publication, and am slowly getting involved in some neurosurgery/ neuro-oncology research at Cornell. My fellowship year at NYU was a time of real professional growth, and helped prepare me for some of what I do now. I remain very grateful to have had that opportunity and to be able to apply what I learned to the care of my patients."



Generosity Was Par for the Course

September 25 was an unseasonably warm day—almost too hot for golfing, but that didn't stop the many friends and Making Headway supporters who turned out to play, dine, and vie for prizes at the 5th annual **Brian McCabe Drive for a Cure Golf Outing**.

The event, organized by Eileen and Mike McCabe in honor of their son Brian, brought in \$52,000 for Making Headway's programs.



Covering the Distance—on Stationary Bikes

We mentioned the second annual **Race For ACE** spin-a-thon in the last issue of *makingnews*, but the event occurred too close to deadline to feature the results. We're amazed and deeply grateful that an incredible 914 donors contributed a total of \$115,469 in support of Making Headway, bringing new meaning to the concept of spinning gold.



Announcing an Exciting New Grant

Making Headway is delighted to have received a \$10,000 grant from the NYS Department of Health to support our educational and psychological counseling services as we expand them into Westchester County. Making Headway is grateful to NYS Assemblyman David Buchwald, who advocated for this program.

A Letter from our Executive Director



October 1st marked my one-year anniversary at the Making Headway Foundation. When I started, it was clear that this organization had a remarkable mission and an impressive track record of successful programs and services for families. But over the past year, I have learned that Making Headway is much more than a list of services, research grants, and events. It provides vital resources and a safety net, offers a listening ear and a shoulder to cry on, and shows love and support for every child. As a father, a son, and a brother, I recognize this passion as something that can only be described as "family."

For 20 years, Making Headway has pushed the limits of what services are "necessary" in order to treat children as more than just patients, and overcome social, medical, and psychological challenges. Twenty years ago, we fought for child-life specialists; integrative therapies like art, music, and yoga; and psychological care for the whole family. If the hospital did not provide these services, Making Headway filled in the gap. The success of these programs was clear, and they inspired many other hospitals to make them part of their own standard of care. However, there is much more that needs to be done.

As described on page 6, Making Headway has launched an ambitious

plan to expand our services to new locations, including Westchester County and Long Island. I look forward to my second year as Executive Director, overseeing this expansion to ensure that children diagnosed with a brain or spinal cord tumor receive the specialized resources and care they need to achieve their academic potential.

Daniel Lipka
Executive Director

Taking a Break



Todd Shapera Photography

Mother Nature gave us two beautiful days for Making Headway's annual **Family Fun Day** and **Family Yacht Cruise**. Hundreds of children turned out with their families for the events, held each year to provide some much-needed fun and relaxation to those impacted by brain and spinal cord tumors. At the

23rd annual Family Fun Day, kids who have spent too many hours of their lives in and out of hospitals took a day to simply act like kids—rock climbing, playing arcade games, taking in an incredible live animal show, dancing, and more—while stressed out parents and siblings enjoyed a bit of respite and camaraderie, as well.

A few months later, they came back for our Family Yacht Cruise, where they could escape their worries with support and love from their friends and family. We sailed through New York Harbor on a warm fall day, enjoyed a special FDNY water show, and bonded under the gleaming eye of Lady Liberty.



Annual Winter/ Spring Theatrical Event—2018

Sunday, April 8, 3:00pm
New Victory Theater
209 West 42nd Street
New York, NY

Save the date for another magical day out for the whole family at Making Headway's annual winter/spring theatrical event. On Sunday, April 8th, you're invited to enter a world of light and air—of flying umbrellas, giant kites, tremendous

balloons, and confetti that transforms into stars. Air Play was created by the Acrobuffos, a husband and wife team who have performed their unusual blend of circus and street theater in 18 countries. Telling the story of a sibling pair who journey through a surreal land of air, it is suffused with sculptural artistry, music from around the world, and a plentiful dose of humor. Visit MakingHeadway.org/airplay to get tickets or to donate.

Horace Greeley All- Athlete Walkathon

November 5th, 11am-1pm
**Horace Greeley High
School, Competition Field**
70 Roaring Rock Road
Chappaqua, NY

It's that time of year again! The students of Horace Greeley High School will be limbering

up and taking to the field for the 4th annual All-Athlete Walkathon. Show up to enjoy food, music, and the opportunity to cheer on these big-hearted young sports stars, all while supporting the event's beneficiaries, the Making Headway and Gardner Marks Foundations.

Shopping for a Cause

December 8, 6:00pm
ICD Contemporary Jewelry
75 South Greeley Avenue, Chappaqua, NY

Who says you can't combine holiday shopping with champagne, finger foods, and a great cause? Kick off the season by dropping by this 4th annual fundraiser, where you can browse among fine jewelry crafted by international designers, secure in the knowledge that 20% of proceeds will be donated to Making Headway. MakingHeadway.org/ICD

So Many Ways to Do Your Part

Interested in supporting Making Headway? Direct donations of any amount are always welcome, but there are also many other ways to make a difference. Making Headway staff are here to help guide you through the process and make your idea come to life. For example:

- Getting married? Celebrating a birthday? Many generous donors have shown their support by asking invitees to donate to Making Headway in lieu of gifts. It's not only a great way to raise funds, it's a wonderful way to spread awareness about our work.
- Add a whole new dimension to holiday—or everyday—shopping. When you make your purchases through AmazonSmile (www.smile.amazon.com) or iGive (www.igive.com), you can designate a portion of the proceeds to go to Making Headway. It won't cost you a penny more!
- Host your own fundraising event. Have a party, organize a bowl-a-thon, ask friends to sponsor you in a race. We'd be happy to help you make a plan or answer your questions. Call our office at (914) 238-8384 or email dan@makingheadway.org.



Coming in 2018: Making Headway Expands Educational Services



This past summer, Making Headway conducted a comprehensive review of regional children's hospitals to better understand the needs of children diagnosed with a brain or spinal cord tumor and how Making Headway can help. We looked at everything from the medical care provided to educational

services to the availability of therapies like art and music.

Over the next year, and with the continued support of our donors, *Making Headway will start to expand services to more hospitals, including our first direct programs in Westchester County and*

Long Island. Our first step focuses on an important unmet need: education and school re-entry. For children diagnosed with a brain tumor, standard

Making Headway will expand services to Westchester County and Long Island.

treatments can have devastating effects. Surgery to remove the tumor, as well as radiation therapy, inevitably damage or destroy healthy brain cells. As a result, a majority of children develop mental and/or physical disabilities and often struggle when returning to school. Over the past decade, Making Headway has successfully put together a team of expert educational advocates to work with these families, and ensure that each child gets the custom educational services and resources he or she deserves and is entitled to. Next year, Making Headway will begin making this service available to more children at more hospitals in NYC and in the surrounding areas.

The Forgotten Illness

Childhood cancers of the central nervous system (CNS), which includes the brain and spinal cord, are rarely recognized as a critical health issue for children. While illnesses like leukemia and asthma dominate headlines, the fact is that **brain and spinal cord cancers killed more children in the past year than any other specific type of illness.***

None of the countless new medical technologies developed in the last dozen years has translated into better results for children with CNS cancer: just as many children die of this disease today as 15 years ago. One reason for this is that only a fraction of funding for medical research goes toward pediatric CNS tumors.

Families impacted by a pediatric brain or spinal cord tumor already understand how critical this issue is, but this is a disease that everyone needs to pay attention to. If we're to help future generations of children, the time to start supporting research is now. Making Headway will continue to invest in cutting-edge medical research projects and programs, but these projects are only possible because of the generous support from thousands of individual donors. If you are interested in learning more about pediatric brain and spinal cord tumors, or want to donate, please call (914) 238-8384 or visit www.MakingHeadway.org/donate.

*Data collected from wonder.cdc.gov, Underlying Cause of Death, 1999-2015, ages 1-17. Information was grouped according to the CDC sub-chapters, within the ICD-10 113 Cause List.



EIGHT YOUNG SCHOLARS GET A BOOST

Every year, Making Headway awards \$5,000 college scholarships to outstanding young adults who had been diagnosed with a brain or spinal cord tumors. This year, Making Headway awarded six scholarships in addition to the two available through the Scott J. Reisser Fund. The Scott J. Reisser Memorial Scholarship Fund was established by Fritz and Joanne Reisser to honor the memory of their 22-year-old son, who succumbed to a brain tumor just short of achieving his dream of college graduation.



Surgery to remove a brain tumor at age seven left sports enthusiast **Zachary Grace** with mobility problems. Many years

and countless hours of rehabilitation later, Zachary says, "If I had to describe myself in one word, that word would be tenacious." True enough! Having received his Associate's Degree at Ocean County Community College last spring, he's continuing his pursuit of a journalism career at Duquesne University.



While a student at Westhampton Beach High School, **Victoria Blydenburgh** was known for both her strong academics and

her commitment to helping others. She enjoyed opportunities to work with children, and she designed and sold a cancer awareness bracelet to benefit advocacy organizations. A nominee for the National Honor Society and the U.S. Presidential Scholar's program, Victoria is now a freshman at SUNY Oneonta.



Mikayla Stajuana celebrated her 17th birthday in the ICU, having been diagnosed with a benign brain tumor just

days previously. The experience solidified her decision to enter college as a pre-med, focusing on neurology. As a dance major at LaGuardia High School for the Performing Arts, Mikayla was named to

both the ARISTA and Science National Honor Societies. She has now begun her college adventure at Fordham University.



Hannah Ceretti, whose tumor left her with hearing loss, is deeply interested in the social, cultural, linguistic, educational,

and psychological issues encountered by the deaf community. A deaf studies major at SUNY New Paltz, Hannah spends holidays and school breaks working with students with disabilities through the NYC Department of Education.



When a fifth grade teacher tried to exclude brain tumor survivor **Aaron Algava Czik** from an accelerated math

program try-out, the indignant young scholar brought his case to his school principal. In the end, he became one of only two students in the school to be accepted into the program. The recipient of numerous academic awards, Aaron is currently working on a double major in economics and statistics at the University of Chicago.



As a student at New Dorp High School, **Alexia Shay** achieved academic honors in numerous subjects and was

named to the National Honor Society. Diagnosed with a tumor at age eight,

Alexia says she learned she can achieve anything she wants as long as she keeps trying her best. What she wants to achieve now is a career designing video games, and she's on her way as a freshman at Rutgers University.



Bogdan Kompaneyets's recovery from the tumor that left him in a coma was called a miracle, but he begs

to differ: the real miracle, he says, was the NYU Langone Medical Center staff, from doctors and nurses to physical therapists and teachers—as well as "Fairy Godmother Maya from Making Headway." Back at high school, Bogdan received a range of honors, including an NYS Assembly Certificate of Merit, and is now continuing his education at Kingsborough Community College.



For some, the saying 'What doesn't kill you makes you stronger' is simply just a saying without a deeper meaning, but I'm living

proof that these words really are true." At nine years old, **Taylor Coyle** was diagnosed with a very rare form of brain cancer and her life was changed forever. In the years that followed, Taylor realized that she loved working with and helping other children in the hospital. She is currently pursuing a career as a Child Life Specialist and will be attending the University of North Carolina at Pembroke.

Real Families, Real Impact

It's been nearly 16 years since Roselle Tunison first found herself in an ambulance with her 6-month-old daughter, Chloë. Chloë had experienced a brain hemorrhage, and she'd shortly be diagnosed with a brain tumor. It was the beginning of a grueling journey, with myriad ups and downs, that continues to this day. But fortunately, it was also the beginning of Roselle and her family's relationship with Making Headway.

When her kids were young, Roselle would need to bring not only Chloë but her twin brother, Johnny, on the lengthy trips from their Long Island home to the hospital in Manhattan. (First, Beth Israel and, later, NYU Langone Medical Center.)

"The playroom is what made it doable," she says. "It was so welcoming and warm. I could connect with other mothers going through the same thing there. For the kids, waiting for the doctor was arts and crafts time."

Making Headway supports families for as long as necessary, whether that means an afternoon or a lifetime. Roselle has many stories to tell about her warm interactions with Drs. Allen and Kothbauer (members of Making Headway's medical advisory board) and the Making Headway team. There was the time she and Johnny were waiting for Chloë to awaken after yet another surgery. It had been a long,

stressful day and they were both tired and hungry, but she didn't want to leave the waiting room. Suddenly, Maya appeared, bearing cupcakes!

There were the many times "the yoga fairy," Annie Hickman, was on hand to help the children spend their waiting time with fanciful activities. There was support from psychiatrist Dr. Hess and psychologists Dr. Greenleaf and Dr. Donnelly. And there was assistance from education specialists Patty Weiner and Sabina Bragg. Roselle remembers warmly the period when Bragg (a member of Making Headway's Ongoing Care Team at the time) helped the teachers and administrators at Chloë's middle school understand the child's special challenges: "Most schools don't know anything about kids with brain tumors. They don't realize that certain behavior problems are typical, and they blame the parents or something else. Sabina joined in our phone calls and made sure I was being heard," Roselle explains.

Chloë still has her struggles at school and at home. The road hasn't been easy for the Tunisons. But Roselle credits Making Headway for making everything a whole lot better than it might have been.

"What really stands out about Making Headway is the warm, compassionate care. There are days when you feel like you're just going to give up because nobody understands what you're going through. Making Headway understands."



"There are days when you feel like you're just going to give up because nobody understands what you're going through. Making Headway understands."
—Roselle Tunison.



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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 the Tunison Family for sharing their story.

Managing Editor
Robin Hardman

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