One Survivor’s Tale
A message from Charles McMahon, Making Headway Foundation
Board Member

I was just starting my senior year of high school in September 2004 when the headaches started. A particularly bad episode led to my doctor requesting an MRI and, after a series of tests and consultations, I learned that I had been diagnosed with a pineal germinoma. This is a type of brain tumor that is most prevalent in children, so, as a 17-year-old, I was treated at the Children’s Hospital in Los Angeles.

The Children’s Hospital oncology ward is where I was first faced with the unfortunate reality of childhood cancer. During my five month treatment regimen, I was repeatedly amazed to see the other seriously ill children playing, smiling, and laughing. This helped me realize the value of providing a special kind of care and support with the goal of easing the suffering of patients and their families. I was incredibly fortunate that my tumor was responsive to the treatment and I am blessed to have made the transition from patient to survivor.

When I moved to New York in 2010, I was honored to be introduced to Dr. Jeffrey Allen, who connected me with Making Headway Foundation. The foundation’s mission is to support children with brain and spinal cord tumors, and I have seen firsthand the value of this goal. Making Headway makes a difference in the lives of patients and their families by providing support services and funding projects and research. While there are significant benefits from all of Making Headway’s efforts, I find that the most rewarding achievement is bringing smiles to the faces of children and families who are undergoing an extremely traumatic experience. I am very proud to be a part of this amazing organization and I have been truly touched to see the foundation’s positive impact on patients’ lives.

This year is very special for me, as it marks my 10th year cancer-free. While this is a celebratory occasion for me, childhood brain and spinal cord tumors continue to afflict thousands of kids and families each year. I would like to invite everyone to enjoy this newsletter, which includes stories about Making Headway events and supporters, staff and programs. Thank you for supporting such an important cause. I wish you all the best.
A New Way to Help Out

The free-standing fundraising events people organize year-round in support of Making Headway are a wonderful way to contribute to our mission, but they aren’t the only way. Many people ask if they can fundraise for us while they participate in marathons, bike races, ironman events and other such activities. Others encourage donations in lieu of presents for special occasions, such as weddings and birthdays.

Individual fundraising of this kind is a great way to help us help the families we serve. Now Making Headway has a dedicated web page that allows you to register your event or special occasion, and create a customized page that makes it easy for your friends and family to give directly online. Recently, two pairs of individuals took advantage of this opportunity to do their own fundraising for Making Headway:

• Over the summer, Robert Nuzzo and his partner formed “Team Trek Kilimanjaro,” hiking the famous mountain to raise money in honor of Robert’s 4-year-old nephew, Dean, who is recovering from treatment for a brain tumor. The two raised over $13,000 for Making Headway, and this amount will increase through matching gifts from many of the donors’ employers, including Nuzzo’s own employer, Goldman Sachs.

• In July, Steve and Noah Friedman, husband and son of Sallie Sanborn, a long-time, valued member of the Making Headway Ongoing Care Team, competed in the New York City Triathlon. Steve and Noah turned the grueling competition into a fundraising event, raising $3,235 for Making Headway.

You, too, can provide a unique kind of help for families who have a child with a brain or spinal cord tumor. As you get ready to train, celebrate or compete, consider registering your occasion as a Making Headway Fundraising Event. To learn more, please call the Making Headway office at (914) 238-8384, or email us at info@makingheadway.org.

Hearts Were Heavy, But a Tradition Continued

It was a bittersweet evening for the many regular attendees of the Thomas D. Fitzgerald III Memorial Fund’s annual Mardi Gras Bash. Following the untimely death last spring of one of the event’s principal organizers, Thomas Fitzgerald, his family decided to hold the event as planned in April. Fitzgerald and his family had created the memorial fund in memory of their son, who succumbed to a brain tumor in 2003. This year’s “bash” had the same fabulous food, music and auctioneering as ever, but had an added special poignancy as guest after guest paid warm tribute to Fitzgerald. The event brought in $3,500 for Making Headway.
One For the Record Books
One year after members of the One Life Club at Scarsdale High School first blew our wheels off with their immensely successful Cycle-a-thon—raising $11,438 and earning a “Youth in Philanthropy” award from the Westchester Chapter of the Association of Fundraising Professionals—the teens have left their own record in the dust. Proceeds from their second annual spin event, in May, came in at nearly double: $21,798! The sold-out studio at Scarsdale’s Flywheel Sports was electric with excitement as the young fundraisers cycled their way to a generous new gift for Making Headway.

Back to the Bronx
The annual Nicky and Thomas Docu Memorial Golf Outing returned again this year to the Pelham Bay & Split Rock Golf Course. As is always the case at this iconic event, the crowd was there as much for the fun and camaraderie—and the barbecue—as it was for the sport. Generously organized by Tom Docu (brother of the late Nicky) and friends-of-the-family James O’Reilly and Keith Weiner, the June event raised more than $8,000 for Making Headway.

Team Amy to the Rescue
When John Crabtree’s wife, Amy, died of a brain tumor six years ago, the grieving husband founded the Amy Marie Crabtree Foundation (aka “Team Amy”) in her memory. Amy had always loved children, so it was natural that the foundation would become a strong supporter of Making Headway. Late this summer, Making Headway was the fortunate beneficiary of two different events at John’s Chappaqua restaurant, the renowned Crabtree’s Kittle House:

• In August, the Crabtree family and Team Amy held their fifth annual Amy’s Birthday Celebration Fundraiser. The lovely summer picnic included scrumptious barbecue and an array of wines and beers, as well as Amy’s Signature Sangria. As is traditional, the foundation used the event as an occasion to announce annual grants; Making Headway was proud to become the first organization ever to receive a repeat grant, accepting $5,000.

• Then in early September several dozen diners turned out for the annual Sparkle for a Cause event, where they dined on small plates, sparkling beverages, and delicious entrees while enjoying live music and the warmth of an outdoor fireplace. The evening brought in $1,746 for Making Headway.

Above: Matteo Tuminello at the Hassenfeld Children’s Center.
Top left: Alexis Zachem (left) and Fazl Shaikh (right) with a friend at the Cycle-a-thon fundraiser.
Middle: Rob Greenstein, New Castle Town Supervisor, and Edward Manley at the Sparkle for a Cause event.
Bottom left: Event organizers Jim O’Reilly (left) and Tom Docu (right) with a golfer at the Nicky and Thomas Docu Memorial Golf Outing.
**When Pins Fly**

After Lauren Cummins passed away from an inoperable brain tumor at the age of 17 last April, her cousins the Kaltens decided to host a bowl-a-thon in her memory. Family members named the event **HPH Bowl-a-thon** in honor of how Lauren had lived her life: happy, positive and healthy. Nearly fifty people arrived at Homefield Bowl, in Yonkers, on August 22 to remember this loving and energetic young girl and try their luck on the lanes. But the highest score went to Making Headway, which received more than $2,100.

**New Location, New Games—Same Old Good Times**

Nobody was sure quite what to expect of this year’s Making Headway **Family Fun Day**. Ever since its launch, in 1993, the annual party for young patients and their families had been held on the Manley’s lawn in Chappaqua. This year, the site changed, and about 230 people of all ages came instead to LIFE, The Place to Be, an event venue in Ardsley, New York. The new spot, recommended by Board Member Greg Taubin, turned out to be a winner. Guests were delighted with the on-site bowling alleys, rock climbing wall, laser tag, arcade and more. They laughed at mime Chip Bryant, and at clowns Looney Lenny and Adam Auslander. They made faces in the free photo booth provided by Kleb Kuznetsov and Todd Shapera, and feasted on a sumptuous lunch. An ice cream sundae bar and Maya Manley’s famous baked goods topped off an excellent day.

**Hot Music and Cold Water on a Summer Evening**

As Making Headway began its 20th anniversary year, we were honored to be the featured charity for the final evening of the **Chappaqua Summer Concert Series**. Hundreds of area residents turned out for the July event, enjoying a trip down memory lane courtesy of 80s tribute band, The Ronald Reagans. They learned about Making Headway and heard personal moving stories from pediatric brain tumor survivor, Alexis Zachem and from Fazl Shaikh, whose best friend, Jack Reyna, passed away from a brain tumor. Best of all, they had the opportunity to try their hand at dunking an assortment of brave souls into a bracingly cold dunk tank. Making Headway’s Executive Director, Catherine Lepone, Ryan Tucker, a brain tumor survivor, and an array of other eager volunteers stepped up to take one for the cause, raising $763 for Making Headway.

**Oh What A Day!**

The sky looked a bit ominous on the morning of September 20, as people of all ages gathered for Making Headway’s annual **Family Yacht Cruise** around Manhattan. But when the clouds parted, it turned into a warm, breezy, beautiful day. Those on board, families that have been helped by Making Headway, enjoyed a delicious lunch, topped off by Maya’s home-made treats. They clowned around with Looney Lenny, and watched, spell-bound, as a fireboat from the New York City Fire Department zig-zagged alongside, then zipped to the Statue of Liberty and orchestrated a spectacular water cannon display. It’s a special treat each year for the families, made possible by retired firefighter and friend Tom Ryan. The cruise, itself, was generously funded once again by Marisa and Richard Stadtmauer. As one young attendee commented, the day could only have been more perfect if it had started all over again from the beginning.
Helping Kids Get Back on Track at School

Sabina Bragg knows a thing or two about the way schools work. One of several Making Headway education consultants, she has master’s degrees in both special education and school administration, and is currently working on her PhD in educational psychology. She also understands the learning challenges faced by children who’ve experienced treatment for a brain tumor. For seven years before joining Making Headway, Bragg worked as an in-hospital teacher for the NYC Department of Education.

Bragg was teaching at the Hassenfeld Children’s Hospital at NYU Langone Medical Center when she got pregnant with her first child more than three years ago. She planned to resign, in order to focus on motherhood and research. But after delivering her daughter at NYU, she got a surprise visit.

“Maya literally came to me right after I gave birth and asked me to join Making Headway. She told me I could do the work from home when I was ready. I was thrilled.”

Bragg had already worked closely with Making Headway and hospital staff. She considered them her friends and colleagues, and was greatly impressed by their immense efforts on behalf of the children. As a hospital teacher, she, too, had done her best to help the kids in any way she could. But she had often been frustrated, finding she had little authority to help parents through problems they faced within the school system. Her job at Making Headway is different. Bragg now sees herself as a “fixer,” working with families, teachers and school administrators to get kids the support they need.

Finding Creative Solutions

Bragg does her homework: studying a child’s records, observing in the classroom, talking to teachers and administrators and—most importantly—listening to parents. Although she credits her success in part to her ability, as a peer, to build relationships with teachers and principals, she makes it clear whose side she is on in the end. She fights until she gets what is best for each child. Lately, she has found solutions in technology.

“Apps are fun, and, since everyone uses their devices these days, they don’t make the kids self-conscious,” says Bragg.

Technology can be a boon to students who need extra help getting organized or processing information; it supports them while fostering independence. For example, a child who needs extra time for changing classes can get a reminder from a smart watch, rather than relying on a teacher’s intervention. A child that needs to hear information repeatedly can manage the process him or herself with text-to-speech software. Or a child that needs help organizing long-term projects can schedule each step on a calendar app.

Creative approaches like these, along with the experience, training and tenacity to get them adopted by schools, have spelled success for most of Bragg’s efforts. Nearly three years into her new role, she is still amazed and grateful to have the opportunity to continue working with colleagues she’d thought she was leaving, and to make a difference in so many people’s lives.
**Gracious Giving**

Throughout the year, Making Headway receives numerous gifts from individuals, families and friends, organizations and companies. These gifts help us fulfill our mission. No matter how great or small, we are honored by each contribution and sincerely thank you. Some examples of gracious giving include the following:

The fact that members of the “senior class” of CA Montessori Children’s Center are mostly five years old didn’t stop them from doing their part in memory of alumna Lauren Cummins. The kids, who attend a child care center for employees of CA Technologies, raised $402 in a Senior Class Bake Sale; the company generously matched this amount, bringing in a grand total of $804 for Making Headway.

Newlyweds Michael Gluck and Dina Schwartz made their wedding doubly joyous by turning it into an occasion for giving. The thoughtful couple donated $1,018 to Making Headway in memory of Sarah Antonoff, a close friend of Dina’s family.

Abbey Solomon hosted a special shopping event in her Scarsdale home, inviting friends to purchase stylish jewelry, clothing, fashion accessories and more from Designs that Donate and Ali Weiss Jewels. The event brought in $1,255, in honor of Alexandra Talbot, a brain tumor patient.

The Children’s Future Fund held its 6th Annual Christian Brito 5K Run at Passaic’s 3rd Ward Park, and the Brito family kindly requested that a portion of the proceeds—$1,250—benefit Making Headway.

When Nina Frorieip’s organization, Clock Wise Productions, found it had some money left over in the budget of a completed project, she and her colleagues generously decided to donate the extra $235 to Making Headway. When the time came to celebrate Nina’s birthday, she asked for donations to Making Headway in lieu of gifts, raising another $909.

The nights are starting to get a bit chilly, but that won’t bother the children in treatment at Hassenfeld Children’s Center one bit. Once again, they’ll be able to snuggle up in soft, hand-crocheted blankets and hats from Corinne and Bob Jeziorski, and dive under warm blankets hand-crafted by Ethel Thomas and members of her Linus Blanket Group at the Plainview Reformed Church.

When Brady Allen celebrated her 10th birthday at Le Jardin du Roi, she encouraged guests to bring gift cards for distribution at the Hassenfeld Children’s Center. Brady’s mother, Wendy Egan, a manager at Le Jardin, along with the Chappaqua restaurant’s owner, Joe Quartararo, are both long-time supporters of Making Headway. Their special request was met with enthusiasm and generosity, making Brady’s a very special birthday, indeed.

Middle school lunchrooms don’t always have the best reputation, but young members of the Mount Sinai Middle School Student Council showed just how wrong that preconception can be. For weeks, the students sold grey “Mount Sinai Strong” bracelets during lunch, in memory of their classmate, Ryan Zinna; they then donated the $213 in proceeds to Making Headway.

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They’re Off and Running!

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. This year, Making Headway was able to award seven scholarships in addition to the two available through the Scott J. Reisser Fund, enabling a total of nine deserving young people to continue their education with a $5,000 grant apiece:

• Following a busy high school career that included volunteering and staffing both the yearbook and the literary magazine, Sophia Casale is continuing her studies at Stockton University, with plans to become a speech therapist in the public schools.

• A freshman at Rochester Institute of Technology, Bailey Gribben is majoring in computer technology engineering. During high school, he was National Ambassador for the Children’s Tumor Foundation and president of the National Honor Society.

• While in high school, Alan Khatsernov started a cancer awareness club and worked as a counselor at Sunrise Day Camp, for children with cancer and their siblings. This fall, he’s entering the Honors College at the University of Massachusetts, Amherst.

• A sophomore at Rochester Institute of Technology (RIT), Brandon LaFever plans to become a pediatric neuroscientist. In high school he acted in school musicals and sang in the all-county chorus; now he sings with the nationally renowned RIT acapella group, Eight Beat Measure.

• Having endured about 100 MRIs herself, Riley Magner is now a freshman studying medical imaging at Rhode Island College, so she can help other children going through the same thing. In high school she was a peer mediator, and worked as volunteer photographer at a camp for kids with cancer.

• A sophomore at Iona College, where he was proud to make Dean’s List as a freshman, Brian McCabe is pursuing a business degree. When the weather cooperates, he is also an avid snowboarder.

• A member of the Quinnipiac University Honors Program, Nathan Orsini received an Outstanding Academic Achievement Award in Communications. He is currently on medical leave but plans to continue his studies in the spring.

• In high school Halie Palmer was a member of the National Honor Society, Tomorrow’s Teachers, and the yearbook club, and also a mentor for the Heroes and Cool Kids program. This fall she’s entering Edinboro University, with dreams of becoming a museum curator.

• A second-year student at the Tiferet Center in Ramat Beit Shmesh, Israel, Netanya Stein is pursuing a career in social justice, while also finding time to volunteer at an after-school center for children with severe special needs.
Did You Know?
Making Headway Helps with Funeral Expenses

When one’s child passes away as the result of a brain or spinal cord tumor, there can be no talk of consolation. For most people, this is, and will remain, the very worst moment of their lives. At such a time, the last thing families should have to worry about is how to cover funeral costs. Yet for many people, this is also a time of great financial difficulty. Family members may have lost work time or had to give up working altogether to be with their child through all the ins and outs of doctors’ appointments, procedures, and missed school. And of course, there are often medical expenses to contend with, as well.

In the face of this, Making Headway is grateful to be able to provide one small bit of concrete assistance to families mourning the loss of their child. For those in deepest need, we provide up to $5,000 in funeral expenses. We provide this support for any family with a demonstrated need, paying funds directly to the funeral home, as long as their child has been in treatment in the New York metro area. So far, in 2015 alone, Making Headway has paid out a total of $42,000 in funeral expenses, giving families one less thing to worry about during a difficult time.

Introducing Our Newest Board Member

You may already know Audrey Manley. The oldest daughter of Making Headway founders Edward and Maya Manley, Audrey has a master’s degree in art history from Columbia University and has worked in communications and marketing for the Morgan Library, among other places. But she’s also been active in Making Headway since its founding, from stuffing envelopes to planning events to serving as a managing editor of this newsletter. The work has been close to her heart ever since high school, when her younger sister, Cynthia, was diagnosed with a brain tumor. Now, Audrey is excited to be rolling up her sleeves for a stint on the Board of Directors—and we’re excited to have her.

Save the Dates!

November 8, 2015
Put on your sneakers, do some stretches and grab a water bottle. It’s time for the Horace Greeley All Athlete Walkathon at the Horace Greeley High School Competition Field, in Chappaqua, New York.

November and December (various dates)
Get started on the holiday shopping (and sneak in a nice warm pullover for yourself) during Family Britches’ Cashmere for a Cause shopping days. The Chappaqua, New York, store will donate $10 to Making Headway for every cashmere sweater sold on these days.

December 10, 2015
Not done with the holiday shopping? Stock up on bling during Shop for a Cause day at ICD Contemporary Jewelry, also in Chappaqua, New York.

February 21, 2016
Think Fred Astaire. Now, think Hip Hop. Tapping your feet yet? Then get yourself to the New Victory Theater in Manhattan for Untapped!, the dance-extravaganza that is this year’s Making Headway’s winter theater event.

Left: Audrey Manley with her son, Otto. Below: Magdalena Bielawska with Dr. Jeffrey Allen.