



Seventeen Years and Counting

A message from Edward Manley, Founder and President, Making Headway Foundation



It's hard to believe that just seventeen years ago Clint Greenbaum, Maya and I established the Making Headway Foundation. Our mission from the outset was care, comfort and cure for families of children diagnosed with brain and spinal cord tumors. With an invitation from the late Fred Epstein, a world-renowned pediatric neurosurgeon, we started our efforts at the brand new Institute for Neurology and Neurosurgery (INN) at Beth Israel Medical Center.

Thanks to the help of many loyal families, our first fundraising event raised over \$350,000, which we used to fund such enhancements as special equipment that helps children relax by watching videos or listening to music during an MRI; the creation of three educational videos for parents; and part-time Child Life Specialist, Rehabilitation Technician and Music Therapist positions. Despite having no paid staff of our own, we were on our way.

We have come a long way since that humble beginning. When the INN closed in 2004, we transferred our efforts to the New York University Langone Medical Center (NYULMC). Thanks to the generosity of an ever-increasing group of donors, we've raised over \$17 million to date. We've used only 13 percent of this to cover administrative and fundraising expenses, spending the balance on programs. To promote research, we've established a \$2.5 million endowed professorship in pediatric neuro-oncology, committed \$1 million to a new neuro-oncology laboratory at NYULMC and supported clinical trials.



But numbers alone can't tell the story. For families, the devastating diagnosis of a child's brain or spinal cord tumor is the beginning of a difficult journey. While their child receives excellent medical care, family members often need guidance and caring support along the way to navigate the maze of issues they face. Our Ongoing Care Program started with just one psychologist to help families cope with their child's illness. Today we offer families the free-of-charge services of four psychologists, three educational consultants and one psychiatrist. To relieve the stresses of their lives, we invite them to events such as a Family Fun Day and a yacht cruise. We provide four scholarships yearly to surviving college-age children. And in the sad event that a child dies, we provide bereavement counseling and assistance with funeral expenses.

In the years ahead we will continue expanding the variety of services for children and their families.

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

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Making Headway Foundation is a 501(c)(3) not-for-profit foundation.

Making Headway Foundation works closely with the Stephen D. Hassenfeld Children's Center for Cancer and Blood Disorders at NYU Langone Medical Center in New York City. Our services are available to all pediatric brain and spinal cord tumor patients and their families throughout the tri-state area, regardless of where they are treated.





Putting a New Spin on Tradition

For fifteen years, Jeannie and Greg Trunz hosted an annual *All-is-onE Tulip Festival Dinner* in memory of their daughter, Allison. This year, they gambled on something new. They still hosted their event at the lovely Swan Club in Roslyn, Long Island. It was a mild evening in late April and the grounds were once again bursting with tulips. The food was as delectable as ever.

But this time, guests were invited to try their luck at a *Tulip Festival Casino Night*. From spinning roulette wheels to the clattering of dice, fun and excitement were the name of the game. Who was the biggest winner? Making Headway, of course, to the tune of \$60,000.

Not For Dads Only

As often happens, this summer's *Family Fun Day* coincided with Father's Day and families took full advantage of the opportunity to celebrate. Close to 450 people showed up for the June 16 event, hosted, as always, by Edward and Maya Manley. There were activities for every age and interest, from pony rides to manicures, swimming to crafts to a petting zoo.



Guests laughed at the antics of Looney Lenny, Adam the Clown and mime, Chip Bryant. They feasted on barbecue followed by scrumptious, home-baked desserts. And they enjoyed the glorious summer day, as a predicted rainfall didn't arrive until the last guest had departed.



Late Summer Sparkle

Dozens of guests did their best to extend summer as long as possible this year, showing up at Crabtree's Kittle House in Chappaqua the evening after Labor Day for a garden party. The event, which featured sparkling-wine cocktails and tapas-style food, was one of a series of *Sparkle for a Cause* evenings sponsored by restaurant owner, John Crabtree, and the Team Amy Foundation. Held outdoors in the tranquil garden dreamed up by his late wife, Amy, who died three years ago of brain cancer, the affairs raise awareness and funds for a different non-profit each week. Making Headway was delighted to be the beneficiary of this particular late summer gathering which brought in \$7,500.



Front cover:

Top: Edward Manley.

Middle: Patients and family members enjoying the annual Family Yacht Cruise.

Bottom: Casey Yang at Family Fun Day.

This page:

Above left: Laurie and Steve Alstad at the Tulip Festival Casino Night.

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Above right: Julia Bis at Family Fun Day.

Below left: Anna and her sister Joanna Benthall at Family Fun Day.

Left: Board member David Almeida (middle) with his guests at the Sparkle for a Cause event at Crabtree's Kittle House.

Sun, Sand and the Sound

Fundraising was a day at the beach for the more than seventy friends and supporters who gathered on September 22 for the second annual *A Day In The Park To Honor Holly Kensicki Lind*, a three-mile walk along Long Island Sound. The event, in memory of a young woman who passed away two and a half years ago from a pediatric spinal cord tumor, took place at Sherwood Island State Park in



Westport, Connecticut. In addition to moving comments by Holly's sister, Katie, and Holly's husband, Keith, it included breakfast and a lot of serious sand castle-building for the many youngsters on hand. It was a lovely way to share time and memories and the \$30,000 it raised for Making Headway was an added bonus. 🌱

Water, Water Everywhere

It was a warm day in mid-September when more than 200 patients and family members set sail for the annual Hudson River *Family Yacht Cruise*. As has become tradition, the families—all of whom have been helped by Making Headway—were entertained by the antics of Looney Lenny, dined on a sumptuous lunch, and then sat back for the show of their lives in the form of a water cannon display set against a magnificent view of the Statue of Liberty. The display, arranged by retired firefighter and friend, Tom Ryan, was courtesy of the New York City Fire Department and the whole wonderful afternoon was thanks to the generosity of Marisa and Richard Stadtmauer. 🌱



Passing the Torch

With the tragic loss of Tom Docu last February, the inevitable question arose: what would become of the annual *Friends of Nicky Docu Memorial Golf Outing*? Tom had hosted the highly-anticipated event each year in memory of his son and in support of Making Headway. Friends and supporters needn't have worried. Tom's son, also named Tom, took on the mantle of his dad and, with the help of other family members and Jim O'Reilly, a founder of the event, pulled it off without a hitch. Over 100 golfers showed up at the Van Cortlandt Park Golf Course on a warm June day to play a round and dine together. The re-christened *Nicky and Thomas Docu Memorial Golf Outing* brought in \$12,000 for research. 🌱



Building Awareness and Thanking Our Supporters

September is Pediatric Cancer Month and Making Headway has been busy! We teamed up with another Chappaqua-based charity, A Kids' Brain Tumor Cure (AKBTC), to give local businesses an opportunity to show their support with posters, special ribbons, and informational cards. The ribbons, which intertwined grey (for brain cancer) and gold (for pediatric cancer) in an elegant bow, were hung on doors of businesses in Chappaqua and Millwood on September 26, Pediatric Brain Cancer Awareness Day. We also partnered with AKBTC to host a booth

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Top: Organizers of the A Day in the Park to Honor Holly Kensicki Lind event.

Middle: Jim O'Reilly and Tom Docu, who organized the Nicky and Thomas Docu Memorial Golf Outing.

Bottom: The Wehr family on the annual Family Yacht Cruise.



Michael Schwartz: A Survivor's Story



At age two and a half, Michael Schwartz was diagnosed with a medulloblastoma—or malignant brain tumor. It was a day his father, Sam, will never forget.

“It was Friday the 13th, believe it or not,” says Sam. “Our pediatrician was out of town so it was a substitute pediatrician, who we had never met, that made the diagnosis.”

Devastated, Sam and his wife, Mindy, started asking around for a surgeon. The name that arose more than once was that of the renowned Dr. Fred Epstein, and they gave him a call.

Dr. Epstein, who at the time worked at New York University Hospital, successfully removed Michael's tumor. In an older patient, the next step would have been radiation, to eradicate any cancer cells lurking in neighboring tissue. But radiation was too dangerous for a toddler, so Dr. Epstein, along with Michael's oncologist, Dr. Jeffery Allen, recommended a long course of chemotherapy, instead.

Michael seemed to do well with the chemo, making it all the more horrifying when the first CAT scan following the completion of his treatment showed that his tumor had recurred. Once again, Dr. Epstein successfully removed it and this time, since Michael was already over the age of four, he and Dr. Allen recommended radiation. The radiation was accompanied by a course of high-dose chemotherapy that was so aggressive it led to septic shock, landing the poor preschooler in intensive care for four harrowing days.

But the combined treatment had done the trick. Michael was cancer-free. Sixteen years later, he still is.

New Challenges Arise

Now a twenty-one year old college sophomore, Michael has almost no memories of those long-ago days. He had emerged a bright, happy, sociable kid. However, radiation therapy for brain tumors nearly always takes a toll on cognitive abilities, and Michael's case was no exception. He was doing just fine in kindergarten, but it gradually became clear that he would eventually face some learning challenges his classmates didn't.

Mindy Schwartz pulled out all the stops, working tirelessly to get her son the assistive services he needed. By second grade, she had arranged for a Board of Education-assigned aide to provide him with one-on-one assistance in the classroom. But as he made his way through third grade, it became clear this wouldn't be enough. Although he was keeping up with the help of his classroom aide, Michael's unique learning issues were starting to affect his self-esteem. At the aide's recommendation, the Schwartzes transferred him to Stephen Gaynor, a school specializing in bright children who learn differently.

It proved an inspired move.

“I can't tell you how valuable that school was for him. Very small classes, not super-competitive, very individualized attention. He got really confident,” Sam says.

But most schools, even specialized ones, don't have a lot of experience with kids who've had brain tumors. The learning issues for these kids are different, and, according to Sam, the teachers don't really understand what they are. So it



Top: Michael Schwartz

Bottom: Sam and Michael Schwartz.

was at this point that the staff of Making Headway began playing a major role in Michael's life.

The Schwartzes were already quite familiar with Making Headway; in fact, when Michael was first diagnosed they started a research fund, which remains the primary vehicle for research-specific fundraising at Making Headway. (Today, Sam Schwartz is also on the organization's board.) During Michael's second course of treatment, they enjoyed the playroom and many of the other on-site services and amenities that Making Headway helped to fund.

But it was the educational consultants on Making Headway's Ongoing Care Team that made the biggest difference in young Michael's life. Experts from that team came to his school and met regularly with teachers and administrators there. They were very concrete.

"They'd explain, this is Michael's issue and we think the best way to teach him would be like this," says Sam.

Not only did members of the team work with the teachers continuously to ensure they were teaching him in the most effective way, they started meeting with Michael, himself, regularly, for specialized tutoring after school. His schoolwork, and with it his self-confidence, soared.

Moving Into the Mainstream

Michael stayed at Stephen Gaynor for five years, at which point all agreed he was ready for a mainstream school. Nonetheless, everyone was just a little bit nervous when he entered an independent middle/high school, York Prep, in eighth grade. How would he fare in this environment, competing with kids that didn't face his same obstacles to learning?

They needn't have worried. Michael was an honor student right off the bat.

Throughout high school, Michael continued to see Making Headway consultants after school. He needed a few other accommodations, like extra time on tests. But with this bit of help, he excelled.

"I had some really difficult courses in high school. I definitely wouldn't have done as well if it wasn't for [Making Headway's] support in those classes. I don't think I would have been an honors student



Top: Mindy, Sam, Michael and Jackie Schwartz at Michael's graduation.



Bottom: Michael and Sam Schwartz.

if I hadn't continued seeing the Making Headway consultants after school," says Michael.

By the time college came around, he was ready. In the fall of 2012, Michael enrolled in the business school at American University in Washington, D.C. He and his family chose American in part because it offers a first-year program specially geared to kids with learning issues. They study the same rigorous curriculum as everyone else, but have ongoing guidance and support during their freshman year to ensure they are adjusting well and keeping up. Nonetheless, the first couple of weeks were especially difficult, Michael reports.

Luckily, the Making Headway team had taught him well: thanks to them, he had the skills he needed to succeed.

"They taught me I have to work harder than most people, that's just the way I've got to do it. In college, I figured out what I needed to do pretty quickly, and I credit them for that," he says.

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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:

Cronin's Golf Resort in Warrensburg, New York, has a tradition. Patrons wrap quarters in dollar bills and toss them to the ceiling. Besides creating an unusual lounge décor, the custom is a great way to collect funds for an annual gift to those in need. When owner, Jack Cronin, decided to give this year's gift of \$2,073 to brain tumor survivor and golfing regular, **Gabe Lipinski**, 12-year-old Gabe elected to pay it forward. He generously donated the funds to Making Headway.

Ten-year-old **Elisabeth Eiff** has been cooking up some kindness with her new online business, *Hopeful Treats* (www.hopefultreats.webstarts.com). Elisabeth donates half the profits from her sale of home-made baked goods to Making Headway in memory of her friend, Lily Taubin. Recently she also held a bake sale; the talent and dedication showcased in the two generous activities brought in a total of \$135.

Fazl Shaikh is only a freshman at Scarsdale High School but he's already making his mark, founding a club to fundraise in memory of his great friend, Jack Reyna. The club, *One Life*, has sponsored sales of bracelets and baked goods, held a soccer tournament and more, and recently presented Making Headway with a check for \$1,000.

Dale Garone, whose daughter, Lea, is a brain tumor survivor, organized friends to dine at a local Ruby Tuesday. Through that restaurant's "Community GiveBack Program" twenty percent of the cost of their meal was donated to Making Headway, bringing in \$374 and making for an especially memorable dinner.

Ten years ago, when **Jake Cappello** was just four years old, his younger brother, Josh, underwent treatment at Beth Israel and enjoyed time in the playroom there. Jake has never forgotten the way Making Headway made the whole family feel better and made his own time at the clinic "feel like a vacation." So when he needed a project for Junior National Honor Society, he wasted no time in taking up a collection of new books and donating them to Making Headway.

For some of the participants in Temple B'Nai Abraham's Early School Walk-a-Thon, walking itself is a recently-acquired skill. Children ranging in age from two to five years old walked laps around the gym, raising \$2,442. The walk-a-thon, which was held indoors because of rain, was organized by **Elyse and Michael Dub**, whose daughter, Elaina, is a student at the school.

Once again the children of Hassenfeld Children's Center have been blanketed in cuddly warmth, as soft hand-made blankets arrived from both **Corinne and Bob Jeziorski** and the **Linus Blanket Group**, led by **Ethel Thomas**, of Plainview Reformed Church. And thanks to Talbot family friend, **Felicia Zacks**, children in the Playroom are not just feeling warm but engaged, enjoying boxloads of new toys and books. 🌱



Top left: Gabe Lipinski.

Bottom right: Elyse Dub with her daughter Elaina.

Below top: Jake, Jared and Josh Cappello.

Below bottom: A display at the Temple B'Nai Abraham's Early School Walk-a-Thon.



Maya Manley Wins “Woman of Distinction” Award



We're proud to announce that Making Headway Founder and Secretary, Maya Manley, has been honored with a “Woman of Distinction” award

by New York State Senator Greg Ball. Ball created the award to recognize accomplished and outstanding women of his district, which includes parts of New York's Westchester, Dutchess and Putnam counties. The twenty-two honorees, selected from nominations submitted by local residents during Women's History Month, were saluted in a special “Hall of Fame” on September 8. They will continue to be honored as part of a travelling “Wall of Fame” to be displayed throughout the district.

Senator Ball commented, “While all those nominated have worked and volunteered without want of recognition, their efforts have not gone without notice or appreciation. Within their communities, each of these women honored today has effected meaningful change in the lives of those whom they sought to improve.”

OMG!

Last spring we reported that three lucky teenagers were on their way to the *OMG! Cancer Summit for Young Adults* in Las Vegas, thanks to a scholarship from Making Headway. The scholarship funds were the proceeds from last fall's *Chelsea Cohen Memorial Bowl-a-Thon*, organized by Barbara Rittner



and her son, Daniel Cohen. The *OMG!* summit is a combined oncology conference and social networking event for young adult patients, survivors, caregivers, professionals and advocates.

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Four Deserving Young Scholars Are On Their Way

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. Each year, Making Headway Foundation matches the Scholarship Fund's \$10,000 contribution, enabling a total of four deserving young people to continue their educations with \$5,000 grants each. This year, the scholarships go to:

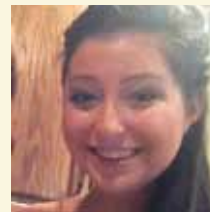
- **Aaron Gaberman.** Recipient of both the Evan Angell Memorial Award for outstanding life achievement by a high school sophomore and the Bank of Fairfield Community Spirit Award, Aaron will pursue a Bachelor's Degree at Marist College.
- **Jason Fiore.** Jason is an engineering major at Stevens Institute of Technology, where he is a member of the National Honor Society and consistently on the Dean's List.
- **Fernando Morales.** Fernando hopes eventually to influence the development of new medical approaches for the treatment of children with brain tumors; he's entering New York Institute of Technology this fall.
- **Meaghan Tully.** An honor roll student and athlete, Meaghan is pursuing the next step in her education at Rockland Community College.

Congratulations, Aaron, Jason, Fernando and Meaghan!

Top left: Maya Manley.
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Bottom left:
Participants Steve Hazlett (center) and Ashley Skiba (right) meet a fellow cancer survivor at the *OMG!* Cancer Summit for Young Adults.

Below: Scholarship winners Aaron Gaberman, Jason Fiore, Fernando Morales and Meaghan Tully.



Seventeen Years *(continued)*

In addition, we plan to devote more resources to basic and translational research in order to identify the genetic and molecular causes of brain tumors and develop new diagnostic tests and targeted therapies.

Thank you to our donors for sharing our vision of care, comfort and cure, enabling us to help thousands of families and children during our seventeen years of existence. We look forward to serving just as many during the years to come. 🌱



Building Awareness *(continued)*

at the Chappaqua Rotary Club's Annual Community Day. Children and adults stopped by to learn about our work and the local businesses that support it, do some sidewalk art with the chalk we provided and carry home a brand new frisbee. Special thanks to the Chappaqua-Millwood Chamber of Commerce for their assistance in promoting these events and Amy Weinstein, Executive Director of AKBTC. 🌱



OMG! *(continued)*

The three teens have now reported back on what a wonderful time they had. Here are excerpts of their comments:

- *I had the time of my life and learned so much and met so many amazing people. There were over twenty brain tumor survivors there—it was so great to share stories and learn about each other. And the best part [was making] amazing new friends.*
- *The trip was wonderful, I had a blast. I met a lot of great people and got a lot of useful information about cancer and its effects.*
- *Never in my life could I have imagined being in Las Vegas and meeting the most amazing people, and being able to relate to each and every one of them. It's a very profound experience when you think you're alone but realize you are surrounded by family.* 🌱

Michael Schwartz *(continued)*

Michael completed his first year at American with a 3.5 average and is now busily making his way through sophomore year. Although he hasn't chosen his major yet, he thinks he will pursue some form of marketing. He's hoping to go abroad during part of his junior year—maybe to Italy or Eastern Europe. In the meantime, he's working hard but still finding time to hang out and shoot some hoops with friends. 🌱

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Making Headway thanks Catherine Lepone and Linda Mudford-Lewis for their generous help with this newsletter. Special thanks to Mindy, Sam and Michael Schwartz for letting us tell their story.

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

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Top: Steve Hazlett at the OMG! conference.

Middle: Edward and Maya Manley at the Chappaqua Rotary Club's Annual Community Day.

Bottom: Looney Lenny the Clown and Edin Pejinovic at Family Fun Day.