



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

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

Top: Dr William Carroll, Maya Manley, Dr. Jeffrey Allen, Sam Schwartz and Edward Manley at the signing of the Endowed Professorship for Dr. Allen.

Bottom: Juliana LoPiccolo with her mother, Chantal.

Making Headway Endows Professorship at NYU and Expands Research Efforts

A Message from Sam Schwartz, Vice President of Research and Board Member

We are pleased to inform you that Making Headway has pledged \$2.5 million to NYU School of Medicine to endow the Otto and Marguerite Manley and Making Headway Foundation Professorship in Pediatric Neuro-Oncology. The endowed professorship, one of only three Pediatric Neuro-Oncology endowed professorships in the United States, was made possible by Otto and Marguerite Manley's significant bequest to Making Headway. While named for the parents of Making Headway founders, Edward and Maya Manley, the endowed professorship is really a tribute to the entire Foundation and all it has done to improve the lives of children with brain tumors.



The income from the endowment will be used to enhance NYU's Pediatric Neuro-Oncology Program by attracting and retaining world-renowned doctors in the field. It will also provide funds for teaching and clinical and basic research. The endowed professorship further strengthens Making Headway's relationship with NYU Medical School and will ensure NYU's commitment to a strong Pediatric Neuro-Oncology Program in perpetuity. We greatly appreciate the commitment of Dr. William Carroll, Director of NYU's Cancer Institute, to enhance NYU's Pediatric Neuro-Oncology Program.

All of us at Making Headway are delighted that the first recipient of the endowed professorship is Dr. Jeffrey C. Allen, MD, Director of NYU's Pediatric Neuro-Oncology Program and Medical Advisor to Making Headway. There is no more deserving recipient than Dr. Allen. One of the leading authorities on pediatric neuro-oncology in the country, he has dedicated his life to children afflicted with brain and spinal cord tumors, working tirelessly on their behalf for more than 25 years.

In addition to the endowed professorship, Making Headway is currently funding a \$580,000 research program at NYU Langone Medical Center. The program consists of five projects that focus on various aspects of pediatric brain tumors, with the objective of moving the field one step closer to finding a cure. The research projects include: Hypoxia-Induced CXCR4 Functions as Potential Clinical Targets in Pediatric Brain Tumors (David Zagzag, MD, \$150,000); Sonic Hedgehog Pathway Mutations in Medulloblastoma (Howard Weiner, MD, \$100,000); Micro-MRI of Mouse Medulloblastoma Progression and Response to Therapy (Daniel Turnbull, PhD, \$100,000); Feasibility of Active

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Announcing a New Addition to Our Ongoing Care Team



We are pleased to welcome Susan Leslie, PhD, to the Making Headway Ongoing Care Team. An educational consultant, Susan studied at

SUNY College at Purchase, New York, and the CUNY Graduate Center in New York City. She has a great deal of experience working with families trying to navigate educational issues in the face of neuropsychological problems. Susan, who lives in Weston, Connecticut, will be helping our families who reside in that state. 🌱

First Scott Reisser Memorial Scholarships Awarded

We are delighted to announce that Megan Lerner, of Freehold, New Jersey, and Jordan Bayarsky of Brooklyn, New York, have been named the first recipients of this new award. A member of both the National Honor Society and the French Honor Society, Megan is a freshman at Rutgers University. Her interests include medicine and psychology. Jordan, who graduated high school with a GPA of 99 and a perfect attendance record, will be entering Binghamton University next spring. He is interested in law and teaching. Best of luck to you both! 🌱



Top left: Susan Leslie.

Top right: Peter Howe, from the Good Dog Foundation, with Lily Langbein and Brianna Badalamenti.

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Immunotherapy for Brain Tumors Using Dendritic Cells Transfected with Messenger RNA Amplified from Tumor Cells (David O'Neill, MD, \$160,000); and *Role of ID-1 in Hypoxia Proliferation and Differentiation of Neuroblastoma* (Lawrence Gardner, MD, \$70,000).

Making Headway's next research goals are to establish laboratories at NYU dedicated to pediatric brain tumor research and the development of new therapies. These efforts will require funding in the range of \$3–\$6 million. It will take a lot of work and effort but with all of your dedicated support we know we can reach these goals.

On a personal note, it has been nearly 14 years since my own son, Michael, was diagnosed. Since that time, we have established the Michael Schwartz Research Fund at Making Headway and all of the funds we have raised from family and friends have been dedicated to pediatric brain tumor research. The Schwartz family could not be more pleased with Making Headway's expanded research efforts. While my wife, Mindy, and I know how fortunate we are to have a 16-year-old cancer survivor, we will never forget Mikey's friends in the hospital who lost their lives at such a young age. There can be no more noble cause than finding a cure for pediatric brain tumors. 🌱

Bottom: Faith Griffin and her brother, Elijah, with Looney Lenny, the clown.



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. Here are some examples of gracious giving:

High-schoolers **Jake and Timmy Helman** took advantage of their school's fundraising day to sell Making Headway bracelets. The young men, who attend the Kent School in Connecticut, raised an impressive \$1,000 in honor of their friend, **Ryan Tucker**.

And for the fourth year in a row, **Tyler Epple's** school made February special with its "Hearts of Hope" fundraiser. In honor of Valentine's Day, Tyler and his mom sold \$1 paper hearts to students at **Abbey Lane Elementary School**. The hearts, signed by the students, festooned a special Hallway of Hope during the month of February—and Making Headway received \$203 from the generous initiative.

Young people spending time at the Hassenfeld Children's Center recently have had some wonderful new toys and games to play with, thanks to a number of generous donors:



Top: Renee Etra with Mengna Jiang.

Bottom: Annie Hickman, yoga teacher, with Malik Townsend and Fardouci Akhtar.

- **Florence Webber**, owner of the Ridge-wood Dance Studio in Queens, delivered three gigantic bags of toys, while **Ira Klein**, another friend of Making Headway, shipped three boxfuls via UPS. Three turns out to be a magical number, indeed!
- In the case of **Kai Pien**, it was a tenth birthday party that provided the magic; the youngster generously requested his friends to give toys for Making Headway in lieu of birthday gifts.
- Thanks to the work of longtime Making Headway friend **Jeanne Egan**, the **North Shore Kiwanis Club** donated 25 teddy bears as part of their "Hug a Bear" project. **Local high school students** added a personal touch by wrapping them and including a note with each bear.
- Finally, **Tony Ousouljoglou** and his fellow employees at Wells Fargo Insurance Services designated Making Headway as a recipient of their March "Jeans Day" donations. (Once a month, employees can wear jeans to work in exchange for donating to a selected cause.) Tony, who says that his daughter, **Emily**, always enjoys the playroom toys when she visits the Hassenfeld Children's Center, asked that some of the more than \$600 raised be used to replenish the playroom's toys, games and arts and crafts supplies. 🌱



Families Who Have Not Forgotten

Last December, Ralph Arbia and his daughter, Kim Madsen, threw a *Holiday Party* at the Westlake Golf Club in Jackson, New Jersey. Guests enjoying a sumptuous buffet were joined by a particularly jolly guest of honor: Santa, himself, dropped by to distribute presents to every child in the place. Making Headway also received a gift, to the tune of \$18,300.

Nearly 200 people feasted, danced and adorned themselves with colorful beads at the second annual *Mardi Gras Bash*, hosted by Lisa and Tom Fitzgerald last February. The event, held at Cortlandt Manor in Westchester, was a fundraiser for the Thomas D. Fitzgerald III Memorial Fund; Making Headway was the fortunate beneficiary of \$4,000.

It was another beautiful spring day at Point Lookout, New York, when about 300 caring people showed up to enjoy the breezes and get a little exercise for a cause. The 10th annual *Little Bit of a Walk and Fun Run*, organized by Diane and Pat Ryan in memory of their daughter, Elizabeth, brought in \$24,000 for Making Headway.

The eleventh annual *“All-is-onE” Tulip Festival Dinner Dance*, hosted, as always, by the gracious Jeannie and Greg Trunz, honored the hard-working members of Making Headway’s Ongoing Care Team. The event was held at the lovely Swan Club, where Silent and Get Lucky Auctions helped boost proceeds to over \$136,000.

Grateful for Making Headway’s support of

their son, Jacob, Larry and Carolyn Krawitz helped organize the sixth annual *Murray Prawer Memorial Mitzvah Walk*, which is held by Temple Beth Rishon in Wyckoff, New Jersey. The pledge walk took place on May 4, earning an impressive \$8,250 for the Foundation.

And once again, golfers, friends and family gathered throughout the summer to tee-off with a purpose. First, about a hundred sports and barbeque lovers showed up at the Van Cortlandt Park Golf Course in the Bronx to enjoy the fifth annual *Nicky Docu Memorial Golf Outing*. The outing raised an impressive \$19,400, but the check that Christine and Tom Docu presented to Making Headway was for \$20,600. The difference? That was thanks to Nicky’s classmates at *St. Margaret of Cortona School*. Upon graduation, the thoughtful and generous young people presented Nicky’s parents with funds they had raised in their friend’s memory, as well as a poem they had written about him.

A few weeks later, it was time for the fourth annual *Kyle A. McKay Golf Classic*, where about 120 golf enthusiasts enjoyed lunch and time on the greens before being joined by several dozen more for a buffet dinner and silent auction. The event, organized by Lauren and Don McKay in honor of their son, Kyle, was held at the Crab Meadow Golf Club on the North Shore of Long Island. It raised over \$27,000 for Making Headway.

Most recently, 140 golfers gathered at the sixth annual *Fore A Difference Golf Tournament*, hosted by Tracey and Stephen Casale with friends, Ralph Arbia and his daughter, Kim Madsen. Held at New Jersey’s Hanover Golf Club, the event also featured delicious snacks, from hot dogs to shish kebabs. At the end of the day, another \$43,000 had been earned for Making Headway. 🌱



Top: Steve Casale, Ralph Arbia and Kim Madsen at the Fore A Difference Golf Tournament.

Left: Don and Lauren McKay with their son Kyle at the Kyle A. McKay Golf Classic.

Making Headway and the Pediatric Hematology/Oncology Program at NYU Langone Medical Center

By William L. Carroll, MD, Director of Hassenfeld Children's Center and NYU Cancer Institute

It has been seven years since I had the privilege of assuming the post of Chief of the Pediatric Hematology/Oncology Program and Director of the Stephen D. Hassenfeld Children's Center for Cancer and Blood Disorders. At the time, I saw an enormous opportunity to be part of an already excellent program and to help build it into one of a small group of top-tier centers nationwide. Our strategy was to provide cutting-edge care to all children in our community and to specifically gear our research efforts to areas of critical need (our "flagship" programs).

One essential focus of our strategic plan was to develop new methods of minimizing the extraordinary physical, emotional and spiritual burden that the treatment of a life-threatening disease has on the child and, importantly, on the child's whole family. The Hassenfeld Center has always been a leader in the delivery of psychosocial care, and our group of doctors, nurse practitioners, nurses, social workers, child life specialists and psychologists wanted to take our efforts to a new level.

We had just initiated these efforts when I had the extraordinary opportunity to meet Maya Manley and her team who were part of the Pediatric Neuro-Oncology Program at Beth Israel Medical Center. At the time, I was recruiting Dr. Jeffrey Allen to NYU to lead our Pediatric Neuro-Oncology Program. In Maya I immediately recognized a person who shared our vision of a program that focused on delivering 360-degree care to our patients and families, embracing a model that emphasized wellness, as opposed to a disease-based approach. Little did I realize then that she would become a leader in our vision to transform our program, building on our long-term success in this area.



Left: Christian Brito with his parents, Juan and Judy.

Ed and Maya Manley and the rest of the Making Headway Foundation joined forces with us to enrich the lives of children and their families. Their biggest contribution has been the unselfish personal commitment of Ed and Maya, themselves. Maya leads by example, taking time to work directly with our children at the Center. Her spark, enthusiasm and warm, gentle touch have a profound impact on our families and staff. She has transformed our environment into a growth and enrichment center where children get the most sophisticated medical care available while at the same time growing emotionally and intellectually.

Unfortunately, insurance companies do not pay for the essential components of psychosocial care. Without the support of Making Headway—which sustains a large part of our psychosocial program—our children would be deprived of one of the most important aspects of care. Making Headway's support of our Child Life Program, Neuro-Psychology, Nutrition and Nursing means that our children receive the psychosocial care they richly deserve.

While we have made progress in our battle to improve cure rates for childhood cancers, there are some kinds of tumors for which more improvement is urgently needed. Brain tumors are the second most common cancer in children and cure rates are substantially lower than for many other childhood tumors. These cancers

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often evade the same treatments used so successfully for other forms of childhood cancer. Recently the Making Headway Foundation has teamed up with NYU's Division of Pediatric Hematology/Oncology and the NYU Cancer Institute to fund basic laboratory research to discover the underlying biological pathways that drive tumor growth and resistance to treatment. It has funded a "tumor bank" that interested researchers can use to analyze samples for specific mutations that catalyze the development of these tumors as well as to screen new agents that may kill brain cancer more effectively. For the past two years, Making Headway has funded pilot programs so that investigators can develop the preliminary data needed in order to apply to external funding agencies like the National Cancer Institute. This has had a huge pay-off by encouraging talented investigators to focus on experiments directly related to improving outcomes for children with brain tumors.

There is no doubt that a major factor in the remarkable growth of NYU's Pediatric Cancer Program is the support of the Making Headway Foundation. The work done by members of our community has enriched the lives of children and families cared for in our program, and the results of our research are being shared with scientists and physicians worldwide in our goal of curing and preventing brain tumors. In spite of our success to-date, the best is yet to come. We cannot thank Making Headway enough for its support. 🌸



Meeting and Greeting at Making Headway

By *Linda Mudford-Lewis*,
Office Administrator

Like most members of the Making Headway "family," I remember vividly the day I first met Maya Manley. I was new to our church and I had volunteered, with some trepidation, to help out at the annual rummage sale. One of my assignments was to help Maya bundle up hundreds of coat hangers to be reused the following year. For those who know Maya, it will go without saying that she welcomed me warmly. We chatted as we worked and as other church members passed, Maya would say, "Meet Linda, my new friend from New Zealand!" I made many new friends that day and was easily able to decide that this was the church for my family.

Getting to know Maya led to my taking a job at the Making Headway office six years ago. It was a great decision. I absolutely love my job: it's close to home, flexible, interesting and rewarding. But my favorite part of the job is meeting the children and their families. Every year I look forward to Family Fun Day, where I sit at the end of the Manley's driveway with my husband, Burn, and greet all the guests. It is so wonderful to get to know everyone, to watch these amazing children as they grow year to year and to see how excited they are to be attending such a magical event. My other favorite event is the Yacht Cruise, when I welcome many happy and enthusiastic families who are anticipating a few relaxing hours cruising around the harbor. Yet another place I "meet and greet" is the Annual Tulip Festival Dinner Dance at the Swan Club. There, I get to see many of the fantastic parents that support, and are supported by, Making Headway.

Throughout the year I am in contact with many families on the phone and am pleased to be getting to know so many of them. As the Foundation continues to grow, I look forward to "meeting and greeting" for many years to come! 🌸

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

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Left: Nurses Eileen Gillespie, Cat Gamble, Jessica Tahaney and Sarah Kramer.