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Making Headway 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.

**Efforts to Launch a Dedicated Neuro-Oncology Research Laboratory at NYU Langone Medical Center**

*A message from Jeffrey C. Allen, MD, Otto and Marguerite Manley and Making Headway Foundation Endowed Professor of Pediatric Neuro-Oncology and Director of Clinical Neuro-Oncology, NYU Langone Medical Center*

*These are the best of times for scientific discovery and the most challenging of times to ensure that pediatric brain tumors receive the attention of the scientific community. Technological advances in the past decade have allowed scientists to probe our DNA code and the formation of proteins that control the behavior of normal and cancer cells.*



*Given access to tissue from a brain tumor, scientists are capable of identifying mutated "normal" genes in cancer cells that may provide a survival advantage to a cell population, allowing it to multiply, locally invade and in some cases metastasize or spread elsewhere in the body. These genes then are transformed to become oncogenes ("accelerators") or in some cases genes are deleted (tumor suppressor genes or "brakes").*

*Keeping pace with the discovery of these mutations is a mutually intense effort to develop drugs to suppress these aberrant behaviors. The drugs that are emerging are much more specific and in many cases, less toxic than "shotgun" chemotherapy, which affects all proliferating cell populations, both normal and neoplastic. In some cases, a population of cancer cells relies on a very limited biologic pathway to gain advantage. We call this process "oncogene addiction" and interruption of this vulnerable pathway can produce miraculous clinical responses—as we have seen with the drug imatinib and chronic myelogenous leukemia. Pediatric and adult brain tumors may be equally vulnerable to "molecular targeted therapies."*

*Progress in this area is limited by the number of scientists motivated to conduct research in this field, the availability of private and national funding and the provision of resources to conduct this research by academic institutions throughout the world. Several individuals at NYU Langone Medical Center (NYULMC) have been working hard to create a laboratory research program dedicated to pursuing basic research in central nervous system tumors that will advance the discovery process of brain tumor biology and generate potential new treatments that can be studied in patients with refractory brain and spinal cord tumors. Although there are unique differences in some forms of brain and spinal cord tumors in children and adults, there are more similarities than differences. Furthermore, there is a likelihood that tumors discovered in adults may have begun in some form during childhood. Thus, we wish to combine efforts with our adult neuro-oncology colleagues at NYU, such as Dr. John Golfinos, Chairman of Neurosurgery. (continues on next page)*

*Top: Dr. Jeffrey Allen with Nicholas DeLaurentis at Hassenfeld Children's Center.*

## Dedicated Neuro-Oncology Research Laboratory

*(continued from first page)*

William Carroll, MD, prior Director of the Division of Pediatric Oncology at NYULMC and now Director of the NYU Cancer Institute, and I have been slowly and methodically seeking sources of funding, generating support and enthusiasm within our administration and casting a broad recruitment net for a laboratory leader to launch a new Translational Neuro-Oncology Research Laboratory. We have already secured over \$2 million of outside funds from the Ira Sohn Foundation and Making Headway Foundation, which are excited about this potential to start a pediatric translational laboratory. Fortunately, the Dean of NYULMC was the former Director of Neuroradiology at NYU and is very supportive of programs to care for neuro-oncology patients. We met with Dean Robert Grossman several months ago along with representatives of these foundations and members of the development office. Dr. Grossman expressed his strong support for building a new Brain Tumor Center starting with a translational laboratory. He authorized the formation of a search committee for the senior laboratory scientist to lead this laboratory and he committed laboratory space and institutional resources. He charged the search committee to identify 3-5 viable candidates within a 6-12 month period and he would select a leader.

The search committee is led by Dr. Robert Schneider, Director of Translational Research at the NYU Cancer Institute. Dr. Carroll and I are members. Ads have been placed in prominent scientific journals



*Left: Shaindy Holtzer.*



*Below: Crafts, games and snacks in the Hassenfeld Children's Center playroom.*

*Bottom left: Aaron Caceres having a short nap in the playroom.*

and we are about to begin the interview process. Once established, the NYULMC and Cancer Institute are committed to recruiting several additional clinical investigators in adult and possibly pediatric neuro-oncology to facilitate the translational or clinical research process. Given the already outstanding base of laboratory investigators and clinicians as well as NYULMC's new Neuroscience Institute, I expect us to be one of the top programs in the country dedicated to advancing knowledge in this area. Clearly, the existence of this Translational Neuro-Oncology Research Laboratory will accelerate the discovery process and provide hope for both children and adults afflicted with these devastating diseases. It will also be the culmination of my program-building efforts in an academic career dedicated to the care of children with brain and spinal cord tumors spanning over 35 years. I hope many of you will share this excitement and support this initiative. 





### When a Child's Sibling is Ill: Supporting the Well Child at Home and at School

by Sallie Sanborn, MS, CLS  
Psychotherapist, Making Headway's  
Ongoing Care Team

When a child's sister or brother is diagnosed with a critical or chronic illness, the impact on the child is great. Parents can support the well child by understanding his or her reactions and doing what they can to ensure the school community is kept "in the loop."

A medical diagnosis brings on changes involving the entire family. The sibling of an ill child experiences loss—the loss of the familiar. Children relate to the world through their senses. When a family member becomes ill, the things they see, hear, smell and feel are thrown into a whirlwind of unfamiliarity. While we all want to protect our children, we can't do so by withholding information. Doing so would leave the child alone to sort through the experience in silence and likely develop serious misconceptions. Instead, we can help our well child best by sharing the same information regarding diagnosis, hospitalizations, procedures and possible outcomes that we share with our ill child.

We can also help our well child by sharing this information with his or her teachers. The more they know about the specifics of what the family and child are going through, the more appropriately they can respond.

Another way to support our child in this situation is to understand that it is perfectly natural for his or her behavior to change. Young children, in particular, can only show us how they feel through their behavior. They don't have the words or experience to respond any other way. I would worry if a child in this situation did not exhibit some behavioral changes. Understanding what to expect and why can help parents and teachers respond in an appropriate manner.

In addition, the more the teacher knows about what the child was like before the diagnosis—his or her personality, strengths and vulnerabilities—the more he or she can recognize and understand behavioral changes. Teachers, after all, are accustomed to tailoring their lessons to a child's capabilities, style and stage of development.

Finally, children often have physical and emotional reactions to the stress of illness in their family. Reactions may include lack of energy, over-activity, changes in eating habits, stomachaches, headaches, muscle weakness, chest pains and difficulty breathing. The child may become forgetful, confused, less productive, have difficulty concentrating or sleeping and exhibit shock or disbelief.

There is no timetable for the effect an ill sibling will have on a child. Situations change constantly, along with the child's developmental understanding. Waves of sadness, fear, anger and jealousy will come and go, surfacing at predictable and unpredictable times. This will naturally affect the child's behavior both at home and at school. Teachers, too, will react differently, based on their own life experiences and beliefs.

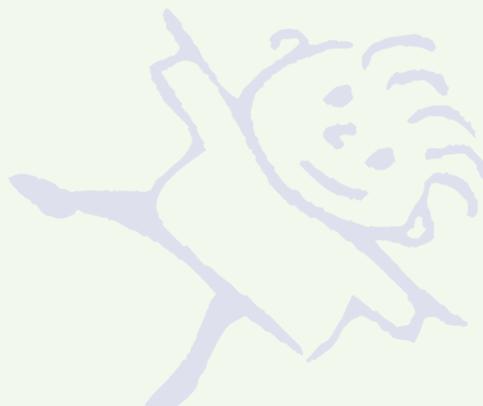
The more families can work with teachers and schools, keeping the lines of communication open, the better they can support their well child. 🌱

Sallie Sanborn, a psychotherapist and Child Life Specialist, is a member of Making Headway's Ongoing Care Team. She also has a private practice, where she specializes in working with children whose lives have been touched by illness, injury or loss. For more information about Making Headway's Ongoing Care Team and other support services, please call our office at (914) 238-8384 or email [info@makingheadway.org](mailto:info@makingheadway.org).



Above: Annie Hickman, yoga teacher at Hassenfeld Children's Center, with Michael Nunez, on right, and Shimon Cohen.

Top left: Alan Steffen with Rocco the dog. Rocco comes from a group called Animal Assisted Therapy.



## Introducing Our New Director of Development



We are pleased to welcome the most recent addition to our Making Headway team. Catherine Lepone, who has accepted the newly-created position of Director of Development, comes to us with more than 25 years of experi-

ence in both the non-profit and for-profit sectors. She served as the Executive Director for The Paralysis Project of America and has also held positions on the development staffs of such organizations as the Huntington's Disease Society of America and the NephCure Foundation.

Catherine's experience with fundraising for rare disease research, her work with a charity that focused on central nervous system diseases and her special events experience combine to make her uniquely qualified to help us reach our goals here at Making Headway.

Raised in Yonkers, New York, Catherine attended the University at Albany where she received a BS degree in Marketing Research. She moved to California shortly thereafter and worked in the business world for more than 10 years before realizing that working for charities was much more personally rewarding and more aligned with her philosophy of life. Her recent move back to the east coast has allowed her to become reconnected with her roots here in Westchester and the tri-state region.

Catherine will be responsible for managing and coordinating the dozen or more special events that occur each year and will also seek out new sources of funding for Making Headway through individual donations, corporate grants and sponsorships.

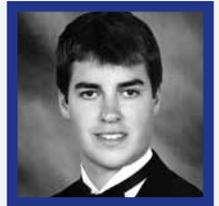
Welcome, Catherine! 

## Four Young People Win \$5000 Scholarships

Once again, four talented young brain tumor survivors are pursuing their dreams this fall thanks, in part, to the Scott J. Reisser Memorial Scholarship Fund and Making Headway Foundation:

- Varsity athlete **Cristino Chavez** will be attending The College at Old Westbury. Cristino, who competed on the track and cross country teams at Glen Cove High School, is hoping the next finish line he crosses will be college graduation. His goal is to get a degree in art history and become a curator.
- Daniel Fischer** is getting ready to study Sports Management while minoring in Business Management at Towson University. "I could not be more excited about my future prospects working in a field that intrigues and interests me," says Daniel. "I am grateful to have this opportunity and to also have a deep appreciation of being able to go to college, an otherwise simple rite of passage for most eighteen-year-olds."
- Krystle Narine's** goal is to get her BA in social work with a certificate in Child Life. The sophomore will graduate from Nassau Community College this fall, then continue her education at SUNY Stony Brook. Her interest in Child Life grows from her own experience: "I realized that I would like to help other sick children with cancer and other serious illnesses because I can relate and understand their pain. I am challenged by learning disabilities, yet I try to envision myself as a caregiver, a social worker or child life therapist. I want to share my artistic talent through art therapy and bring joy to someone in pain."
- Working with children is also the plan for **Jennifer Pulgrano**, who will pursue a special education degree at Nassau Community College. Jennifer is a graduate of Division Avenue High School in Levittown, New York, where she was kept more than busy as Secretary of SADD ("Students Against Destructive Decisions") and Vice President of the Cooking Club as well as through her membership in Best Buddies, the Key Club, Fashion Club and Art Club. As if that's not enough, Jennifer is active in the Girl Scouts and is currently working on her Gold Award.

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, the Making Headway Foundation matches the Fund's contribution to enable more deserving young people to take advantage of it. Congratulations, Cristino, Daniel, Krystle and Jennifer! 



From top:  
Scholarship recipients  
Cristino Chavez,  
Daniel Fischer,  
Krystle Narine and  
Jennifer Pulgrano.

Top left:  
Catherine Lepone, new  
Director of Development  
at Making Headway  
Foundation.



## A Spring Tradition Continues

After a summer of horrific weather, it may be hard to remember there was once a lovely spring. But lovely, it was, on May 5, when crowds gathered once again for the annual *All-is-onE Tulip Festival Dinner* hosted by Jeannie and Greg Trunz in memory of their daughter, Allison. It was the 14th year for the dinner, which was held, as always, amongst flower-filled grounds at the beautiful Swan Club. This year's event journal honored Dr. Sharon Gardner and Nurse Practitioner Kelly Ann Cervone. Dr. Gardner is an eminent researcher and a pioneer in the treatment of infants with primary malignant brain tumors. At Hassenfeld, she and Ms. Cervone are an inseparable team, combining their talents in ways that magnify the benefit for the children and their families. In addition to honoring Dr. Gardner and Ms. Cervone, guests enjoyed a delicious meal and had fun with silent and "Get Lucky" auctions. In all, the event brought in over \$100,700 for Making Headway.

## When the Spirit of Giving is Par for the Course

- For the seventh consecutive year, the greens of the Crab Meadow Golf Club did double duty, as sportsmen and women hit the fairway for a cause. The occasion was the annual *Kyle A. McKay Golf Classic*, sponsored by Don and Lauren McKay in honor of their 8-year-old son, who has been in remission for a number of years. This year's event was held on June 13, a beautiful day, and in addition to perfecting their swings (or watching their loved ones do so), participants enjoyed lunch, cocktails and dinner. After dinner came golfing awards and a silent auction. The event raised an impressive \$29,000.
- Less than two weeks later, on June 24, it was time for the 8th annual *Nicky Docu Memorial Golf Outing*. As always, Christine and Tom Docu remembered their beloved son with a year of planning, searching the city for just the right balls, clubs and apparel to distribute as prizes to the many friends and supporters who always attend. They came out in force again this year, arriving at the Van Cortlandt Park Golf Course in the Bronx ready for action, despite a threat of rain. As if in response to such spirit, the clouds stayed away until the last foursome had returned. Altogether, it was a hole in one for Making Headway, which gained \$22,500 for its research initiatives.

## What's a Little Wind and Rain Among Friends?

What do you call a golf tournament without the golf? The ninth annual *Fore A Difference Golf Tournament*, that's what. When Hurricane Irene flooded the grounds of the Westlake Golf and Country Club in Jackson, New Jersey, participants were undeterred. They showed up anyway at the August 29 event to enjoy a sumptuous dinner and comic entertainment. Held as always in honor of Sophia Casale, brain tumor survivor and active young teenager, the proceedings were organized by Tracey and Stephen Casale with friends, Ralph Arbia, Joe Samaritano and Ralph's daughter, Kim Madsen. This was a tournament that everyone won, including Making Headway, enriched by \$36,000 and a lot of good feeling.

## And save the dates for these upcoming events:

January 14, 2012: "Twelve Angry Men" performed at the third annual *Night at the Theatre* at the Merrick Theatre and Center for the Arts, Merrick, New York.

February 26, 2012: Making Headway's *Annual Winter Show* is in a new venue this year: Watch for BRAZIL! BRAZIL! at the New Victory Theater, Manhattan.

March 31, 2012: The 14th annual *Little Bit of a Walk and Fun Run*, at Point Lookout, New York.

May 2, 2012: 15th Annual *All-is-onE Tulip Festival Dinner*, at the Swan Club, Roslyn, New York.

June 22, 2012: the 9th annual *Nicky Docu Memorial Golf Outing*, at Van Cortlandt Park Golf Course, Bronx, New York.



From top to bottom:

Dr. Sharon Gardner and Nurse Practitioner Kelly Ann Cervone.

Golf foursome braves the rain to play in the Nicky Docu Memorial Golf Outing.

Tom Docu presenting a prize to a golf tournament participant at the Nicky Docu Memorial Golf Outing.

Paula Barth and Joe Samaritano at the Fore a Difference Golf Tournament.



## 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:

Myriad examples of snuggling were in evidence up and down the halls of Hassenfeld Children's Center as children curled up in the latest batch of hand-made blankets contributed by members of the Plainview Reform Church Project Linus Group in Plainview, New York. The project is championed at the church by long-time Making Headway supporter, **Jeanne Egan**.

Once again **Michele and John-Claude Hallak**, owners of upscale New York and New Jersey Hallak Cleaners, proved they have no hang-ups about fundraising—they continued to promise customers a ten cent donation to Making Headway in exchange for every returned hanger. A good part of the \$2,000 they presented recently was the result of this thoughtful and creative effort.

Friends and neighbors in the community of Point Lookout, Long Island generously dropped off items for the **Kreutzberg and Ryan families** to sell in a yard sale benefitting Making Headway. Some kids even parted with their old toys for the cause, which brought in a total of \$246.

Guests at the wedding of **Chris and Renee Ravanello** were happy to do without traditional wedding favors when they realized a donation had been made to Making Headway, instead. The newlyweds donated \$400, commenting, "Making Headway has been an amazing resource for us after Chris's medulloblastoma diagnosis in January, 2010. Thank you!"

**Cathryn Soupios** and **Patrick Riley** also started married life in the spirit of giving, donating \$500 to Making Headway in lieu of wedding favors at their July wedding.

Two newly-minted nonagenarians celebrated the milestone in style by re-directing gifts to Making Headway. Friends of **Mildred Sankey** gave \$550 in lieu of presents in honor of her 90th birthday—as well as in memory of Mildred's grandson, Nicholas Docu. And those celebrating **Herb Goldberg's** 90th honored him and his granddaughter, Alexandra Talbot, with gifts totaling \$618 for the Talbot Family Research Fund.

On the other end of the spectrum, members of the newest generation got into the act on the occasion of their own birthdays:

- **Sarah Rose Kohan**, born the night before her dad, Sami, entered NYULMC for a bone marrow transplant, celebrated her first birthday in the spirit of giving. "Sara has everything she needs," Sami said, explaining their decision to ask for donations in lieu of gifts, "There are other kids who really need the help." The generous plan garnered \$245 for Making Headway.
- "Making Headway helped our family a great deal before, during, and after Owen's stay at NYU. We can't think of a better way to honor Owen on his 6th birthday..." read the card inviting friends and family of **Owen Dodd** to celebrate the occasion with a donation. Just as they had for his fifth birthday, the youngster and his family then dropped by to deliver the checks (\$565 this time) along with some really great games, toys and activity sets for the Playroom.
- Sixteen was even sweeter than usual for **Kelly Rose Gubitosi** and **Emily Tyree**, who kindly suggested donations to Making Headway in lieu of birthday gifts. The two friends of the Talbot family raised \$9,565, which they designated for the Talbot Family Research Fund.
- An apple for the teacher? **Michele Ventura's students** at John F. Kennedy High School, in Plainview, New York, were sure they could do better than that! They held a bake sale in honor of Ventura's daughter, Julia, raising \$300 for Making Headway.
- **Children at The Early Childhood Center**, in Fairfield, Connecticut, devoted their May monthly charity drive to Making Headway. Staff and students wore gray in honor of Brain Tumor Awareness Month and the children donated a variety of highly useful items, including bubbles, notebooks, coloring books, markers, Play-Doh, and stickers—not to mention a \$25 check.
- And who says wisdom is the province of the old? Bronxville Middle School eighth graders **Katie Toal**, **Briana Alberghine** and **Caitlin Lillis** created a business as part of a home economics project. They made and sold chocolate-covered strawberries and pretzels, then donated the \$83 in proceeds to Making Headway. Says Katie, "We chose to donate our money to Making Headway because we realized how hard it is for people to get over something like a child's cancer. It's horrible and it affects everyone around them." Katie, a close family friend of 11-year-old Jack Reyna, who was diagnosed with a pediatric brain tumor last year, also launched a program called "Coins for Cancer" as part of her confirmation project. She sought contributions from family members, friends and classmates, bringing in an additional \$250.

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

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*Above: Paige Reiger and Isabel Kreutzberg at the Kreutzberg and Ryan family yard sale to benefit Making Headway.*