

**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: Children enjoying a balloon show at Family Fun Day.*

*Below: Nadyah Saleh and Katherine Marciano at Family Fun Day.*

## A Message from Maya Manley, Parent Advisor and Friend

*What I call “my life’s work, my mission” has been an ever-evolving, transforming process. It started simple—volunteering at an institution for mentally retarded children. It was my own daughter’s brain tumor diagnosis, 23 years ago, that jolted me but also grounded me in what I was really meant to be and am still in the process of becoming. In time, I learned that what I do best happens in the hospital playroom: being and sharing with parents; doing arts and crafts with their wonderful children.*



*Each child teaches me something new, something from his or her world that I am so blessed to be a part of. Their sheer joy, enthusiasm and willingness to participate in playroom activities are intrinsic strengths they can draw on to cope with the uncertainty that—depending on where they are with their treatment—engulfs their lives. The privilege of witnessing their own transformation—from fear to joy, from doubt to trust, from alone to connected—is not something I take lightly.*

*But still, a hospital is still a hospital. I long to see the children in the fresh air and green grass, running and laughing, swimming and playing. That’s why every year, more than anything, I look forward to our annual Family Fun Day. I have a dream come true: thanks to the enormous support of my family and friends from near and far, I get to organize a day of fun for my hospital families and children, and also get my own daughters home—usually for a whole week! It moves me to no end that my own family is so dedicated to our Family Fun Day. This year, Catherine and her good friend Bernie came from California. Audrey and her husband, Thomas, brought my darling grandchildren, our toddler, Esmé and her baby brother, Otto. What a bustling home it was—baking, cooking, organizing, and delegating mixed with babysitters, sleeping and crying children. (Cynthia, chief decorator of all baked goods and arts and crafts specialist, could not come this year.)*

*I cannot imagine a Family Fun Day without our good friends, Nina Froriep, who we met on a mountain top in Switzerland, and Tom Dean, our long time family friend. These gems arrive at the crack of dawn each year and stay until the last chair is put away. I wish I could say that I step back and take in the magical spectacle of our yard coming alive, but it’s mostly a blur—(Continued on next page)*



*(Continued from front page)*

a joyous, marvelous, happy blur. This year's Family Fun Day was on Father's Day and what dad couldn't feel special taking his family to what has become for many, an ideal family outing. As usual, the food was plentiful, the pool was warm and wet, manicures and massages have been worked into the mix along with face painting, arts and crafts and, of course, those crazy hats by Wacky Wendy's factory. In between sharing laughs and meals, parents quietly caught up with each other, shared their stories—joyous, heartbreaking and everything in-between. It's true that special friendships that began in the hospital continue on the lawn. How fitting it all seems to share this on the longest day of the year.

It only takes one Family Fun Day to get hooked: a young mother who came for the first time said, "I feel so good seeing and being with other families. I did not seem so alone any more, I gained hope!" And a young boy who has had such a hard time at the hospital told me that there was only one problem with Family Fun Day: way too much fun! This is the ultimate compliment and a wonderful end to a wonderful day.

### **Cheerleaders at Home, Advocates at School: What Parents Can Do to Support Their Child's Academic Success**

*By Rebecca Mannis, PhD*

There are a number of factors contributing to the challenges children with brain and spinal cord tumors face in their academic development: missed instruction due to treatment, cognitive difficulty related to a tumor's location or brain tissue manipulated during surgery, post-radiation syndrome, chronic fatigue, and/or learning disabilities associated with chemotherapy. While each child's academic challenge is unique, the goal for children is the same: to reach his or her academic potential.

Similarly, parents of a child who has been diagnosed with a brain or spinal cord

tumor face unique challenges but they share the same role. Their role in their child's academic success is crucial because learning disabilities associated with a brain or spinal cord tumor can be so subtle. At home, parents need to be cheerleaders, encouraging and affirming their child's perseverance. At school, they need to be top-notch advocates. A parent's role in their child's educational success often includes:

- keeping detailed records of all testing, Individual Education Programs (IEP), and medical records
- writing a 1-page summary of the child's medical history and its impact on the child's learning style
- updating and sharing that history at the start of the academic year with ALL teachers and related service providers
- being aware that their child requires specific neuropsychological testing, rather than the traditional educational and psychological evaluations that school districts provide to children with developmental learning problems
- asking medical professionals for letters supporting specific needs that their child has such as a barrier-free school, a break for rest in the middle of the day, a health para-professional to help with moving around a busy hallway, or preferential placement on a bus route to limit the length of a bus ride
- keeping a log of observations about their child's experience at school and with homework/preparing for tests at home
- becoming familiar with services and accommodations that are appropriate for children with Traumatic Brain Injury
- being aware of the reauthorization of the Individuals with Disabilities Education Act (IDEA)—usually every five years—and the impact it might have on their child's IEP



*Top: Chip Bryant entertaining kids at Family Fun Day.*



*Above: Kyra Torch with painted face and Wacky Wendy hat at Family Fun Day.*

Parents, you know your child the BEST; you can listen to his or her concerns the BEST; and you can advocate for them the BEST. To find out how educational consultants Rebecca Mannis, PhD, and Patty Weiner, MS, CCLS, can support your child's education or to make an appointment, call Making Headway at (914) 238-8384.

## Gracious Giving

Throughout the year, countless contributions are received by Making Headway from individuals, groups, organizations and companies. No matter how great or small, we are honored by each contribution and sincerely thank you. Some examples of this year's gracious giving include the following:

**Frances Barbuto, Sophie Trotter's** neighbor, donated \$100 received for her magical quilts.

**Heidi and Ira Rosen** raised \$800 from a benefit rock concert in their home.

**Marisa and Richard Stadtmayer** funded the second annual cruise on *The Jewel*. 142 Making Headway family members enjoyed a fresh lunch and spectacular views of downtown Manhattan.

**Adam the Clown** provided quips and seasick gags.

In memory of **Tyler Romano, Susan Marynowski** raised \$1,120 from her swim-a-thon while **Jen and Joe Abatiello** gave \$300 in lieu of wedding favors.

**Frances Ratsimore, Peter Barbieri's** aunt, and her co-workers at Symrise Corp. donated 12 barrels of toys. **Jennifer Dowd**, a friend of the **O'Toole-McIntyre family**, organized a holiday toy drive at Goldman Sachs. Five-year old **Matthew Thaxton** raised \$355 for his used toys. **Howard Berner's** synagogue donated toys.

**Danielle Stein** donated \$250 in honor of her Bat Mitzvah. **Andrew Greenbaum** donated \$575 in honor of his Bar Mitzvah.

**Alex Bloom**, Michael Schwartz's friend, proposed that his classmates at **The Birch Wathen Lenox School** support Making Headway. They raised \$90. **Winthrop Intermediate School 232** collected pennies and donated \$900. *The Hearts of Hope* fundraiser at **Tyler Epple's** school raised \$500. **Summit Lane Elementary School** raised \$150 on one of their dress-down Friday's.

**Nina Froriep** ran the New York City Marathon for Making Headway, raised \$10,000, almost tripling what she raised in 2002. You go, Nina!

In lieu of birthday gifts: \$545 came from **Hannah and Spencer Newman** who requested donations be made in memory of **Fallon O'Toole McIntyre**. **John Tilas, Hannah Klitsberg's** grandfather, celebrated his 90th birthday and suggested guests make donations which they did to the tune of \$650.

**E\*Trade Financial Corporation** donated \$2000 as part of the *Award for Excellence in Leadership* given to their employee, **Paul Vienick**. **Christina Labricciosa**, organized a *Dress Down Friday* at work and donated the proceeds—\$500.

## Cheerio, Tena! G'day Linda!

Making Headway families will all miss office administrator, Tena Walton who has moved back to England with her husband, Keith. We wish them both the best of luck in their retirement. Self-described as "the English one with the funny accent at the end of the telephone," Tena did so much to make the office organized and cheery. She had a wonderful, warm way with parents, listening to their worries and helping where she could. Fortunately, Tena's friend, New Zealander Linda Mudford-Lewis, had come on board part-time a while ago. When Tena announced her decision to leave, Linda assumed her duties and made a seamless transition to full-time—right down to the "funny accent at the end of the telephone." 🌸



Above: *Nina Froriep (second from right) being honored for her NYC Marathon fundraising efforts at the home of Swiss Ambassador Raymond Loretan and his wife Mrs. Carol de Quay Loretan. Also pictured: Dr. Jeffrey Allen, Maya and Edward Manley.*

## Parents Who Have Not Forgotten

Once again, Robin and Chuck Magner hosted **Riley's Walk**. On a lovely Saturday in September, 150 participants walked around Boston Harbor and raised \$22,600 for research.

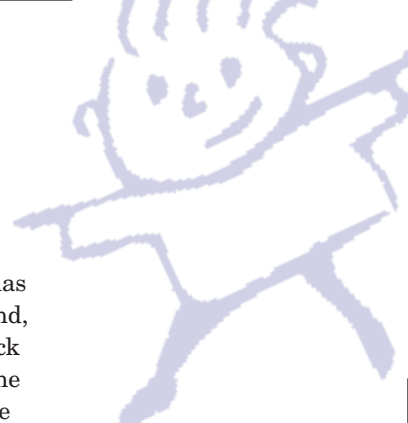
Last year's annual **Fore A Difference Golf Tournament**, hosted by Tracey and Stephen Casale, had an especially memorable contribution! Not only did 125 golfers help raise \$47,500, but Tracey gave birth to Olivia one week after the tournament.

Cheryl and Chris Coutts and Chris and Jim Caci hosted a record crowd of 326 attendees on the fifth annual **Casino Night**, raising \$49,400.

The April showers stopped just in time for Diane and Pat Ryan's **Little Bit of a Walk and Fun Run**. The 100 participants raised \$22,500 for research.

Jeannie and Greg Trunz hosted 269 guests this year at their 8th annual **Tulip Festival "All-is-on-E" Dinner Dance** at the Swan Club on Long Island. They raised \$150,700.

Bottom: *Riley Magner (on right) with her friend at Riley's Walk.*



## Superkids

Stories by Elizabeth Buttke

### SOPHIA

#### Ever looking on the bright side



At eighteen-months old Sophia had barely begun to explore the world when her parents, Tracey and Stephen Casale, noticed some-

thing was wrong with Sophia's right eye. "It was moving back and forth, kind of jiggling," Tracey recalls, as she and Stephen retrace the journey that began when they looked into their daughter's eyes and, for the first time, felt something other than pure joy.

Concerned and apprehensive, they took Sophia to her pediatrician. He immediately recommended a visit to a neurologist, who ordered an MRI. The diagnosis was one that no parent would ever want to hear: optic chiasmatic glioma. Sophia had a benign tumor on her optic nerve, which caused irreversible damage to the nerve, permanently affecting Sophia's vision.

"When the neurologist gave us the results of the MRI, we had a hard time believing what she was telling us," Stephen says. The neurologist, however, knew exactly what she was talking about. Just six months earlier, she had a patient with the very same diagnosis as Sophia. She recommended they take Sophia to an ophthalmologist, and also referred them to Dr. Jeffrey Allen, who treated her previous patient with positive results.

Even so, Stephen says they were so confused they wanted to explore other options as well. But every doctor they consulted assured them that Sophia would be in the best possible hands with Dr. Allen at the INN.

Because Sophia was so young, Dr. Allen recommended chemotherapy instead of radiation. Although the family's life revolved around Sophia's treatments and

subsequent MRIs to track the progress of the therapy, seeing how well Sophia responded to it all made things easier for Tracey and Stephen.

Nothing really affected Sophia—not even losing her hair—because she was too young to know or care about chemo's side effects.

As a result, Sophia grew up like any other little kid, learning and discovering all the wondrous things that a two- or three-year old experiences for the first time. And then some. Between age three and five, Sophia attended The Lighthouse School for the Blind, to help her prepare for a future that looked more and more promising with every favorable MRI result.

Now eight years old, Sophia has been totally off chemo for the past two years, and her MRIs continue to bring her parents good news. Sophia is happily ensconced in a regular class in public school. She has a vision therapist, and has been learning Braille since last year. The school system also provides an Orientation and Mobility Teacher, a one-on-one para, and Active Physical Ed to help Sophia learn and live to the fullest.

Which is exactly what she does. The past year has been full of joy for Sophia—from the removal of her Medi-port to the arrival of the sibling she has always wanted, her baby sister Olivia. Then, in May, came one of the most important moments in Sophia's life: her First Communion—followed by a fabulous fun-filled party that Sophia enjoyed so much she never wanted the day to end.

For Tracey and Stephen, every moment with Sophia is truly special. Tracey says "Sophia could just sit there and watch a parade go by and the smile on her face and the joy that we see on her face, you just can't compare anything to that."

Except, perhaps, Sophia's laughter. For what she lacks in sight, she more than makes up for in sound. The joyous, lyrical sound of Sophia's laughter is like music to everyone's ears.

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

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*Top: Sophia Casale with her baby sister Olivia.*

*Below: Nichole Allen with her baby Tyler.*

