



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

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In a strong collaborative spirit, Making Headway works closely with the Institute for Neurology and Neurosurgery (INN) at Beth Israel Medical Center in New York.

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

*Below: Dr. Jeffrey Allen with Khalil Smith.*

## Education Support Services Funded By Making Headway

*A Message from Edward Manley, President*

*I am continually in awe of how you, our donors, so generously support our efforts at Making Headway. The funds you give enable us to continue to provide and expand our programs and services to the growing number of families we serve.*

*One, in particular, is increasingly in demand: the serious challenges recovering children face in school. Most children with brain tumors experience some kind of learning disability as a result of the tumor itself and the medical interventions such as surgery, chemotherapy and radiation. Quite often, disabilities are so subtle and so unlike "typical" learning disabilities, teachers and parents have a difficult time catching them and an even more difficult time accommodating the child's learning needs. Getting the school district to understand and support these educational needs is more often than not an uphill battle. The worst part about it is the child's self-esteem. Already challenged from physical limitations, the demands of medical interventions and—for school-age children—the significant amount of missed school-time, a child's sense of self can take a precarious dive if someone sensitive and trained doesn't intervene. Parents who are still reeling from the devastation of their child's diagnosis, let alone the treatment, find themselves once again at the bottom of a towering mountain. They need someone they can trust and rely upon.*

*For many years we have offered the services of Rebecca Mannis, PhD, our educational counseling specialist, to help these children and assist their parents in understanding what services, testing, and supplementary materials will optimize their child's educational program. But knowing what your child needs is not enough. Getting the schools up to speed and to participate in accommodating these subtle issues can wear down the strongest parent. Your continued donations have enabled us to strengthen our educational support services with the addition of an outstanding school advocate.*

*We welcome Patty Weiner, MS, CCLS to our support service staff. Patty is Director of the Child Life Program at Bank Street College of Education in New York City. Her specialty in school advocacy means that she works with schools to ensure not only that they provide the proper accommodations to each child's educational program but that they also implement these accommodations as required by Federal law.*

*Because of you, our donors, Making Headway remains in the day-to-day and the hearts and minds of all the families who join me as I thank all of you for your belief in our work, for your confidence in our ability to serve the children and their families and for your continued and generous donations.*



## Support Staff Supporting Nurses: A Unique Environment Yields Excellence and FUN

Erin Hartnett joined the team at the INN 1½ years ago and says that never, in 30 years of nursing, has she felt such love and support. This is a common observation from nurses at the INN. The Day Hospital (better known as the playroom) on the 5th floor is “nursed” by Erin and her colleague, Eileen Gillespie. They join the nurses who care for inpatient children on the 10th floor in attributing the unique feel at the INN not only to the amazing kids and their families, but also to the support staff funded by Making Headway.

There is so much more to nursing at the INN than administering chemo; so much more than tracking the doses of each patient, minding laboratory results, attending to medical needs. In many ways, the nurses take on full force questions, concerns, heartbreak and anxieties of patients and their families. What a difference it makes to the nurses to know that there is someone to help them do their jobs in a way that makes the medical seem secondary to the fun going on. Kids literally run down the hall to get to the playroom. They are greeted by child life specialist Jose, an institution of fun! Erin says that Jose has that magical, mysterious way of connecting to each child and making him or her feel special. There’s one baby who absolutely needs to sit on music therapist Yelena’s lap while he’s being accessed for chemo. She sings sweet coos to him and his parents are so grateful to see joy in a situation that for them, should be anything but. Erin watches psychologist Jean speaking soothingly to parents as if she had all the time in the world knowing full well that Jean is hard-nosed when advocating for



*Left: Nurse Practitioner Erin Hartnett and Tali Zabari.*

*Bottom: Nurse Eileen Gillespie and Carlos Pagan.*

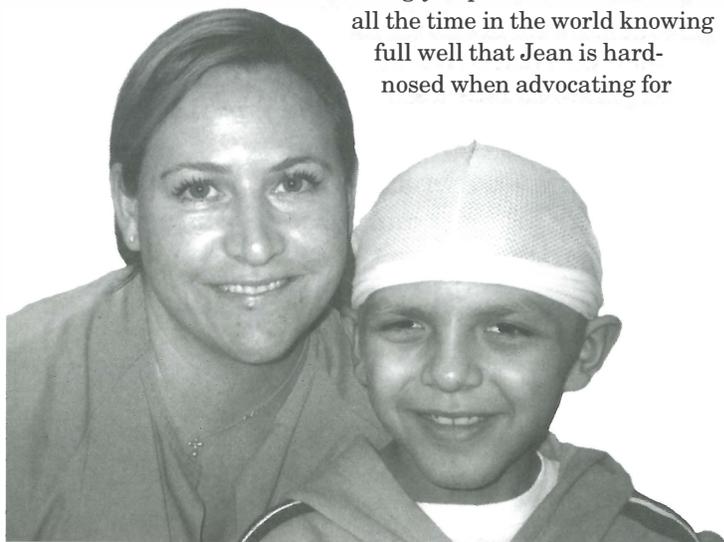
*Below: Tyler Romano with his dad Chris. Peter Barbieri.*

their needs. And just when the room is packed and the nurses wonder how they will get through, Adam the Clown bursts in and teaches folks the famous Butt Dance. (Nothing relieves stress more!)

And that’s where the nurses are so relieved. They appreciate the presence of Making Headway founder and volunteer, Maya, in all of this. Says Erin: “Maya has an ability to nourish the patients and staff—body and soul. She notices when we’re not taking lunch and feeds us, she compliments us and makes us feel good about what we do.”

On the 10th floor, nurse Bridget Connolly says support services from Making Headway free her to concentrate on the immediate medical issues. “I don’t have to worry as much about the kids’ emotional and developmental needs because I have Adam or Yelena to do that.” Nurses rely on Making Headway’s support services especially in the five bed ICU where children are unable to visit the playroom. “It takes a tremendous strain off parents to watch their child laugh and be soothed,” Bridget says. When parents are freed to relax a little it becomes a win-win-win situation.

All of the INN’s nurses love that the kids have such positive associations with their hospital experience. It’s not that anyone hides the gravity of the situation, but it becomes secondary when there’s so much comfort, kindness and hilarity. When given the choice, kids will choose laughing over crying. It’s true that it’s this amazing spirit that transforms the nurses’ job from making a living into living a privilege. How wonderful then, they feel, that support from Making Headway’s incredible cast of characters allows this spirit to take off. 🌱





### One Ship, 200 Families and a Snowstorm Equals Success

A snowstorm did not deter over 1,000 people from enjoying this year's fundraiser, Gilbert & Sullivan's *HMS Pinafore*. The afternoon performance provided laughter and enjoyment on a dreary day, raising \$500,000 for Making Headway programs. 200 Making Headway families share the success. Each year around the holidays, on top of their busy schedules, they take time they don't have. They send invitations to friends and family asking them to buy tickets and make donations. For many, the letter that accompanies the invitations lets folks know their child's progress. Making Headway is honored to have become part of their lives. Without the help of Making Headway families, the magnificent result of this event would not be possible. We are most grateful to all of them. 🌱

### Casino Night: Honoring Friendship, Benefiting Making Headway

Even before they were born, Nicole Caci and Morgan Coutts were destined to be best friends. Meeting at Lamaze class as expectant parents, it's not surprising that their parents bonded. The true surprise came over time: their values and interests—even what makes them laugh—were so similar. They truly enjoyed each other. They went on vacations together, celebrated birthdays and shared holidays. And they shared heartache. The Caci's were beside Chris and Cheryl when Morgan was diagnosed with a



brain tumor at 2 years old.

Two years later, the Caci's proposed the idea of *Casino Night*. Since then the friends gear up yearly to make *Casino Night* a success. In 4 years, they have raised \$194,000 for Making Headway.

Now 8 years old, Morgan and Nicole are still best friends. *Casino Night* honors their friendship because they brought the families together in a friendship that will last forever. 🌱

### Family and Friends Fore a Difference

Tracey and Stephen Casale's *Fore a Difference Golf Tournament* is a family affair filled with friends. "They have been there for us since day one," says Stephen referring to their daughter, Sophia's diagnosis in 1998. "If Tracey or I couldn't make it to the hospital, someone else volunteered. Once they stepped in the playroom, they could see the Making Headway magic and they understood what we meant."

When they had the idea for a golf tournament fundraiser, everyone helped. From arranging and displaying to setting up and breaking down, family and friends come together to honor Sophia and raise money for Making Headway. They marvel at how something distressing became transformed into something joyous, celebratory and gratifying.

Stephen strategically chose the end of September for the event but the planning is a constant. From determining the golf course, finding sponsors, organizing raffles, ordering the luncheon, making remembrance pins out of golf tees (Tracey's specialty!), *Fore a Difference* is a year-long process to improve upon their success. The first two events alone raised nearly \$100,000.

"This year, we'd love to get more Making Headway families," says Stephen. Last year the Coutts brought foursomes as did Brian McCabe's dad, Michael. This September, the tournament is a week earlier to accommodate Sophia's expectant sibling in October. "There's no way Tracey will miss this," says Stephen. Next year one more family member will join the Casale tradition that has made all the difference. 🌱



Above: Golfers at the Fore a Difference tournament.

Top: Jake and Augusta Greenbaum with their Uncle Randy, Aunt Stella, and cousins Andrew and Jemma at the HMS Pinafore performance.

Bottom: Jim Caci, Cheryl and Chris Coutts, and Chris Caci at Casino Night.



## Superkids

*Stories by Elizabeth Buttke*

### KYLE

#### Determined to win

Before Kyle was even born, brain cancer reared its ugly head into the MacDonald family's happy life. Mary and her husband Jack were just three months away from welcoming Kyle into their loving home. Already the proud parents of two wonderful sons, five-year-old John and Ryan, two and a half, they eagerly awaited Kyle's arrival. But a devastating diagnosis arrived first. The boys' Dad had an anaplastic astrocytoma. Suddenly life in the MacDonald household was chaotic—filled with crises. By the time Kyle met his Dad for the first time, Jack had already lost much of his personality. His memory and judgment were impaired, and his ability to function was severely limited.

Fortunately, Kyle was just what the family needed: a huggable, happy baby with a great personality. As Mary Jean puts it, "Kyle was the one who found a way to make us laugh instead of cry. His happy, mischievous spirit gave our family the joy that is often buried when cancer strikes."

When Kyle was 7, he started having headaches and began to fear he had what his Dad had. Repeated visits to the doctor brought repeated reassurances that Kyle's headaches were merely headaches. Until the unthinkable happened. An MRI confirmed what Kyle had suspected all along. He, too, had brain cancer. Having grown up with the effects of his Dad's cancer all around him, Kyle knew what cancer could do to him. He asked questions no 7-year-old should ever have to ask. "Will I be able to remember things? Will I be

able to think, to play the piano, to snow-board, to be me?"

Mary Jean told Kyle that he had a different kind of cancer, a medulloblastoma in the back right cerebellum, and she assured him he would get better after treatment. He believed his Mom and never again showed any fear. "Kyle became such a great patient," says Mary Jean, "even the nurses would laugh when he'd say they could practice sticking needles on him, because he convinced himself he could do it and he wasn't scared."

Immediate surgery was followed by almost two years of chemotherapy and radiation. Although Kyle was embarrassed at first about losing his hair, he gradually became more confident about telling people he was wearing a hat to conceal his bald head. Along the way he got an unexpected boost from his brother Ryan, who took it upon himself to speak to classrooms full of kids and tell them Kyle's baldness was due to the strong medicine he had to take, so they shouldn't make fun of him. Mary Jean believes what helped Kyle most was not only the treatment he received at the INN, but the healing support he found there. She credits Child Life Specialist Jose, and Adam the clown—who are funded by Making Headway—Hale, a volunteer, and all of the nurses and doctors for creating "a place where Kyle was cared for, supported and healed while having great fun."

There was also the constant support of family, friends and neighbors, and the strength of Mary Jean herself that helped Kyle become the thriving eleven-year-old he is today. He plays ice hockey, soccer, basketball and baseball. He plays the piano and writes music. He's a rock-climber and an award-winning snow-boarder. And, egged on by his brother John—who has become passionate about promoting health and awareness of cancer—Kyle is expected to run the survivor's lap in an American Cancer run that John's high school is holding.

Kyle has already outrun cancer, so one lap is sure to be a piece of cake. 🍷

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Making Headway thanks Tena Walton and Linda Mudford-Lewis for their generous help with this newsletter. Special thanks to Elizabeth Buttke for her contribution.

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

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*Top: Kyle MacDonald with Adam the Clown.*

*Below: Brian McCabe in disguise.*

