



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: Edward Manley

Center: Lauren Richmond with Maya Manley at the new Hassenfeld Children's Center.

Bottom: Josefa, Luis and Paula Santiago on the annual Making Headway yacht cruise. Photo courtesy of R.S. Walton Photography.

Looking Forward

A Message from Edward Manley, President



More than halfway through our eleventh year, we can look back with pride at our numerous accomplishments. With the help of our many supporters, we have provided countless families with comfort and resources in the face of devastating circumstances. We have done what we can to make their hospital stays more comfortable and provided them, free-of-charge, with much-needed psychological and educational counseling services.

This is work we will continue to do, but at the same time we are always looking to build on it and move ahead. With that in mind, I'd like to share with you three exciting new developments. First, I'm delighted to announce we have completed moving our programs into the new Hassenfeld Children's Center. This magnificent facility is focused on wellness, with comfortable treatment rooms and a much larger playroom—a delightful new setting for the arts and crafts and other activities that have already begun enlivening the Center.

Second, as we continue to grow and enhance our services, we have decided to build on our ability to meet families' needs by appointing our first Executive Director, Joanne Reisser. Joanne comes to us with extensive experience in non-profit administration and fundraising. She will work at broadening our fundraising base and preparing a strategic plan to guide our future efforts. Welcome, Joanne!



And finally, after nearly eleven years of care and comfort, the time has come to expand our focus on the third "c" in our mission: cure. The Board has agreed to commit \$580,000 in funding for five research projects at the NYU Medical Center. The objective of these projects is to learn more about the underlying reasons for pediatric brain tumors. The funding is the first step in our eventual goal of endowing a Making Headway Research Laboratory dedicated to pediatric brain tumor research.

As you know, but as I cannot say enough, none of our efforts, our programs and our successes would have been possible without the generous support of you, our donors. We are forever grateful for your confidence in our work. 





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:

Five years after **Samantha Robbins** lost her best friend, **Sarah Antonoff**, she once again held a garage sale in her dear friend's memory, this time raising \$561 for Making Headway.

Maira Hernandez-Kinloch held a Scrapbooking Party. Party-goers not only came away with an armful of memories, but raised \$565 for Making Headway.

Congratulations to **Bob and Gail Trunz**, who recently celebrated their 50th wedding anniversary! The parents of Swan Club owners and longtime Making Headway supporters **Greg and Jeannie Trunz**, Bob and Gail asked friends and family to give to the Foundation in lieu of gifts; bringing in \$500. Meanwhile, **Lissa Parsonnet**, a member of Making Headway's Ongoing Care Team, celebrated her 50th birthday in Phoenix, Arizona, by running her first half marathon, in the process raising \$1,675. Way to go, Lissa!

Apparently, for some young people it is never too early to think about giving to others. Just ask **Samantha Frederick**, who gave Making Headway \$250 from her Bat Mitzvah gifts, and **Max Lefkowitz**, who gave \$1,300 in honor of his Bar Mitzvah. Or talk to survivor **Nikki Batsford**, who took the time to hand-knit 24 beautiful dolls for distribution to patients at NYU.

Students at **Roaring Brook Elementary School**, in Chappaqua, New York, contributed more than 100 games, dolls, art supplies and other playthings to a Making Headway toy drive. The shiny new toys will be kept on hand for distribution at events such as birthday parties, end-of-chemotherapy celebrations, and—of course—the 15th annual **Family Fun Day**.



Left: The Casale Family with Edward Manley at the annual Fore A Difference Golf Tournament.

Bottom: Kevin Bishinkevich with Looney Lenny the clown.

Families Who Have Not Forgotten

Support for Making Headway was par for the course at two recent events: 105 golfers teed off for the 5th annual **Fore A Difference Golf Tournament**, hosted by Tracey and Stephen Casale. The event, which included a silent auction and a mouth-watering buffet, was held at the Bergen Hills Country Club in New Jersey, raising a grand total of \$43,690. And balls were flying at the fairway during the third annual **Vincent Mannino Memorial Golf Outing**, sponsored by the Holy Name Society of Staten Island's Our Lady of Pity Church, where participants took swings to raise another \$5,000 for Making Headway.

Numerous guests enjoyed a deliciouso **Evening of Tapas and Spanish Wines** at Café Panache in Ramsey, New Jersey. Fritz and Joanne Reisser hosted the event, which raised \$11,345 for the Scott Reisser Memorial Scholarship Fund. Celebrants at the Thomas D. Fitzgerald III Memorial Fund **Mardi Gras Bash** were festooned in beads as they danced, feasted and bid on an array of tantalizing auction items. The lively event in Peekskill, New York, brought in another \$6,000.

Meet the Beatles—Again

We may be well into the 21st century, but for a few brief hours on January 28th it was 1964 again, and the British Invasion was in full swing. Twelve hundred Making Headway friends and families swayed and sang along to **Strawberry Fields—A Beatles Tribute Band** during two performances at the Kaye Playhouse in New York City. The Beatles impersonators, who might have stepped right from the stage of The Ed Sullivan Show, sang such classics as *Yesterday*, *I Want To Hold Your Hand*, and *All You Need Is Love*. The event raised \$500,000, and a groovy time was had by all. 🌻



What Should We Tell the Children About Diagnosis and Treatment?

By Sallie Sanborn, MS, CLS,
Making Headway Ongoing Care Team



When a family is faced with a new and difficult diagnosis, the impact reverberates throughout the household. Every diagnosis is a family diagnosis, affecting all family

members. Parents struggle with what, how and even whether to tell their child and his or her siblings about the medical diagnosis and treatment plan. My role, along with others on the Ongoing Care Team, is to help families make good choices about what and how to tell their children.

Parents, depending on their own experiences, are often afraid to tell their child the truth about their diagnoses. They may not want to use words like “cancer” or “tumor.” But it is important to explain the changes in his or her body. Often parents use words such as “boo-boo,” “bump,” or “sick,” but we all get boo-boos and get sick without necessarily needing chemotherapy, radiation and hospital stays.

As parents, it is difficult to see our children sad or upset, but just as we do not deny children happy experiences, we must give them the tools to deal with sad or difficult ones. A lack of information is a source of worry for our children, just as it would be for us. Although some children don’t want to know as much as others, it is important to answer the questions they ask. Children feel empowered when they have the knowledge to deal with their situation, letting them be the victor instead of the victim. The power of knowing the truth also allows them to maintain trust in their parents and in their health care throughout their lives.

Another reason to tell children the truth is that they need to hear it from their parents before they hear it from someone else or overhear it in a conversation. One 10-year-old girl told me about overhearing



For more information about Making Headway’s Ongoing Care Team and other support services available, please call our office at (914) 238-8384 or send an e-mail to info@makingheadway.org.

Top left: Sallie Sanborn.

Top right: Lily Langbein with her dad Dennis.

Bottom: Lauren Lam with her mom Kelly.

her mother discuss her diagnosis before she had been told herself. When I asked her how that made her feel, she said, “I didn’t know who was protecting me.”

Children will go through the experience of their diagnosis and treatment with or without our help. We can hold their hands, but if we are honest in our touch, the support is immeasurable.

*In addition to her invaluable role as part of Making Headway’s Ongoing Care Team, Sallie Sanborn has a private practice working with children who are experiencing the illness of a family member. She is featured in author Patty Dann’s recently-published memoir, *The Goldfish Went on Vacation: A Memoir of Loss (and Learning to Tell the Truth About It)*, for which Sallie also wrote an Afterword.* 🌸





Paving the Way to a Secure Future

Parents of a child with a brain or spinal cord tumor have so much to manage that ensuring their child's financial security and future well-being usually drops to the bottom of the list. Yet protecting their child in this way is critical. With the help of an estate planning attorney and financial advisor or insurance professional it need not be as overwhelming as it seems. Here are some of the strategies these professionals can help with:

- **Family protection:** A family may need this protection to cover financial losses if a parent dies or becomes disabled. Remember that the costs involved in such a case are not just a possible loss of income, but the loss of caregiving time the parent has been providing.
- **Mortgage protection:** Being forced to move after the death of a parent may be emotionally and physically difficult if a child has special needs for housing, such as ramps or extra-wide doors. Life or disability income insurance can help to pay the mortgage so families don't have to leave their home.

- **Education funding:** Children with brain or spinal cord tumors may have special educational needs that carry additional costs, such as customized learning materials. Or, parents may want to be putting aside money for higher education in a college savings plan.

- **Retirement funding:** Preparing for retirement is critically important. With an adequate income later on, parents will be in a better position to help their child when he or she reaches adulthood.

- **Wills and trusts:** A child with a brain or spinal cord tumor may have to be provided for differently into adulthood. A Special Needs Trust provides for the child's care without disqualifying him or her from eligibility for Social Security, Medicaid and other such government benefits. Some attorneys also recommend that parents of children with special needs supplement their will with a detailed "Letter of Intent," outlining their specific wishes for their child's care.

- **Guardianships:** It's important for parents to appoint a guardian to care for their children and have power of attorney in the event of their own death or disability. In the case of a child with a brain or spinal cord tumor, parents will want to consider whether the chosen guardian is willing and able to take on the extra responsibilities involved in their child's care.

Remember, there are professionals whose job it is to help simplify this kind of planning. By taking care of these issues now, all families can ensure their children are provided for into the future. 🌱



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

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Photo courtesy of R.S.
Walton Photography.*

*Bottom: India Kotis with
her mom Ayun.*

