



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

Founders

Edward Manley
President

Maya Manley
Secretary

Clint Greenbaum
Treasurer

Making Headway Foundation, Inc.

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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.

Top: Edward Manley and Mikey Schwartz.

Middle: In the spirit of things—Clint and Jake Greenbaum at Kaleidoscope.

Bottom: Debbie and Tony Costanzo at Casino Night 2001.

A Message from Edward Manley, President



What a wonderful year we have had! Fund raising receipts reached a new level, our programs were expanded, new friends helped our cause, and we assisted many more families on their journey through their child's illness.

Thanks to over 200 dedicated people who helped us sell tickets and secure contributions, our fall fund raising event, Barnum's

Kaleidoscope, was a sell out! How wonderful it was to see the smiles on the faces of over 700 children and their family members who attended free of charge. We raised over \$500,000—a new record! Casino Night 2001 is another success story. Organized once again by Chris and Jim Caci and Cheryl and Chris Coutts, proceeds were up almost 50% over last year, enhanced by many superb gifts for the auction as well as new table sponsors.

Our programs continue to grow. To provide information of vital interest to parents, three educational seminars were conducted during the year, covering such topics as growth hormone therapy, educational remediation, and nutrition alternatives. In New Jersey, we developed a unique new format for our support groups, offering three concurrent groups for parents, children who are patients, and their siblings. This permits the entire family to attend and take part in the healing process together.

Plans for the coming year include new investments in research programs under the supervision of Dr. Jeffrey Allen, Chief of Pediatric Neurology at the INN, funding of a pediatric neuro-oncology fellow, and expanding our services to Long Island.

I would like to extend my sincere thanks to our former Administrator, Joan Fyfe, for three years of devoted service to Making Headway. She was instrumental in raising the Foundation's operations to new professional levels and developing new programs. We wish her all the best in her new endeavors.

In closing, I would like to express my heartfelt thanks to the many friends who believe in Making Headway. From our generous donors, to our friends who give of their energy and time, to the doctors, nurses, and staff at the INN who welcome our efforts, we are indeed truly grateful.

My warmest regards to all of you.



Gift of Music

To celebrate five years of remission, gifted pianist Matthew Zachary threw a big bash. In January, over sixty family members and friends enjoyed an evening of food and original music performed by Matthew. In lieu of gifts, Matthew asked that donations be given to Making Headway. Last December, Matthew performed at Rose's Turn, a cabaret theater in New York City. He donated all performance proceeds to Making Headway. His new album, *Every Step of the Way*, is coming out in April. We applaud and thank him. 🌻

Honors & Awards

Edward and Maya Manley were awarded the Citizen of the Year Award by the Chappaqua Rotary Club in honor of their work for Making Headway. Dr. Jeffrey Allen, Chief of Pediatric Neurology at the INN, was also honored this past year for his dedication and work for children with brain tumors. The Pediatric Brain Tumor Society honored him for excellence in pediatric clinical research and the Children's Brain Tumor Foundation awarded him with a certificate of appreciation for his many years of commitment, support, and service. Dr. Fred Epstein, Co-Director of the INN, was featured on a special ABC-TV presentation of Nightline hosted by Ted Koppel, which profiled his mission to provide children with life-saving care in a unique environment. 🌻



Kids Giving Graciously

Thanks to: Josh Cohen who generously arranged for a portion of his Bar Mitzvah gifts to be donated to Making Headway; the Forest Lake School third grade classmates of Joshua Don, who made a donation to honor the memory of his sister Rachel Don; and Liz and Katherine Friedland—the daughters of Dr. Patricia Brous-Friedland, an anesthesiologist at the INN—who, with their friend Kira Cypers, sold lemonade and washed cars to benefit Making Headway. The gift of giving starts at any age. 🌻

And the Winner Is . . .

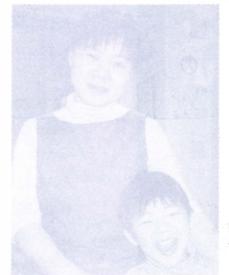
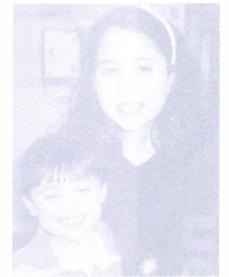
Making Headway is pleased to announce this year's winners of the Poster Painting Contest: Katherine Vallone, age 11, and Ion Balaurea, age 10. Their beautiful artwork is featured on the invitation and journal covers for the annual Tulip Festival Dinner Dance fundraiser to be held April 26, 2001, at the Swan Club on Long Island. 🌻

Special Thanks

Special thanks to: the Chatlos Foundation of Longwood, FL, and the Frueauff Foundation of Little Rock, AR, for their generous grants in support of Making Headway's After Care Program; CIBC World Markets Corp., for generously sharing a portion of the commissions they generated during their *Miracle Day* last December; and to Pat Imbriale, for nominating the Foundation as the beneficiary of the Staten Island Board of Realtors' annual golf tournament. 🌻

Passings

Linda Barnes, Making Headway's Westchester therapist, passed away unexpectedly in February. We extend our heartfelt condolences to her family. 🌻

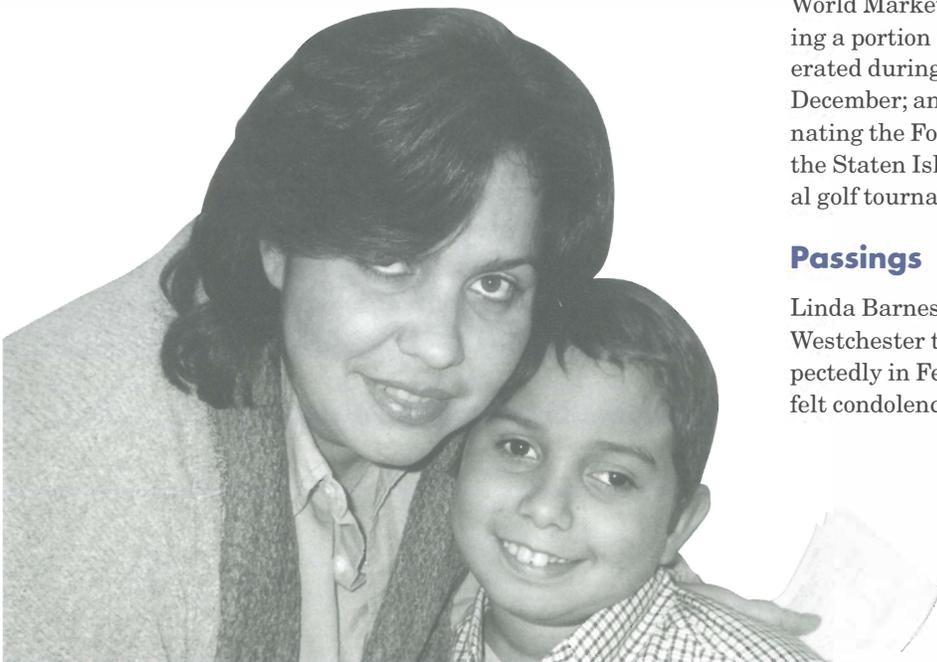


Top: A new 'do'?
Cherraine Davis and
Child Life Specialist
Jenna Aranoff.

Middle: Sisterly-
brotherly love, Megan
and Ryan Lerner.

Middle: Raymond Tang
and his mom.

Bottom left: Robinson
Abreu with his mom,
Amalfi.



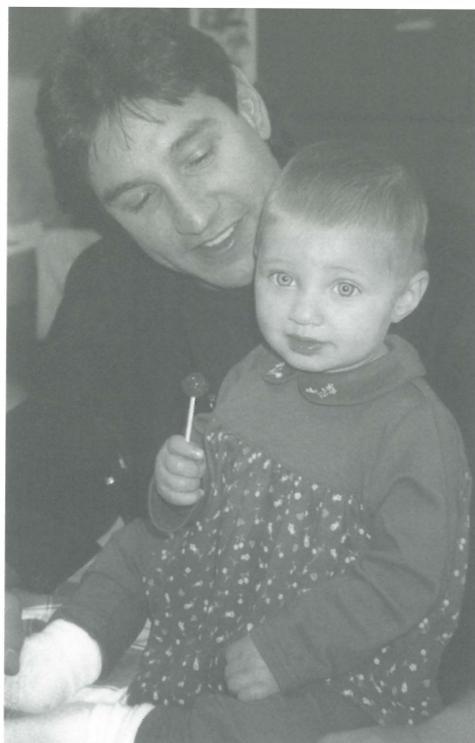
Advocacy: Getting Your Child the Education She/He Needs and Deserves

By Dr. Rebecca Mannis, Learning Specialist

For many children with brain and spinal cord tumors, a number of challenges begin when they least expect it—when they start to feel physically stronger and return to school. The illness, surgery, and recovery process, including chemotherapy and radiation, combined with missed school, can have a large impact on learning. Unfortunately, it is very common for these children to experience a number of academic problems.

Children's specific learning issues are quite individual. Based on research that has followed children like ours for the past twenty years, we do have a good sense of some common challenges. These range from difficulty in concentration and the ability to juggle a variety of tasks (executive functions), to slow intake (processing) of information and production of work, to memory retention problems and fatigue. Applying information learned in one area to a new or different context can also be very difficult. Furthermore, these children are often very sensitive to the stimulation of noisy and unstructured environments, making recess, lunchtime, and class transitions very tough. Socialization problems are also an issue for them, as they are not able to process information as quickly as their peers, and cognitive deficits make it difficult for them to follow subtle social clues from their classmates.

It is excruciating for a child who has already endured such pain in the hospital to return to school only to face these new challenges. This can also be a trial for our children's well-intentioned teachers who



are often unequipped to understand the specific learning issues that our children have and what sort of assistance they are entitled to under Federal law. Unfortunately, school districts often decide on eligibility for services and accommodations based on incorrect criteria, such as those for the more common learning disabilities.

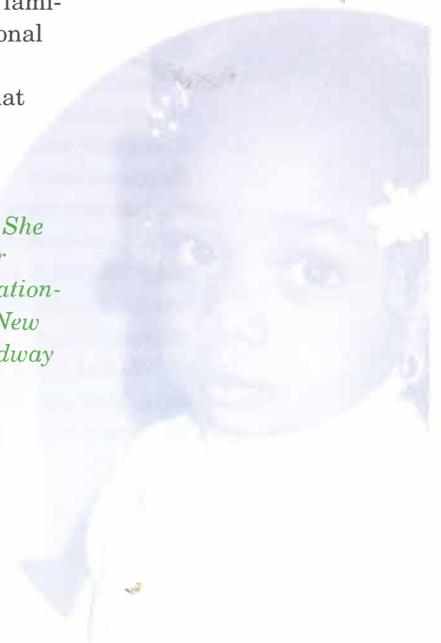
Assistance comes in many forms. It may entail receiving special "related services," such as speech and language, or a resource room for reading skills. It may involve getting extended time on tests, or the use of a computer in the classroom. Furthermore, it may require placement in a particular type of classroom, specific methods of instruction, or ongoing collaboration with the educational team. As a learning specialist, my job is to work with children and their families to better assess what the educational needs are and to assist the schools in understanding how best to provide that support.

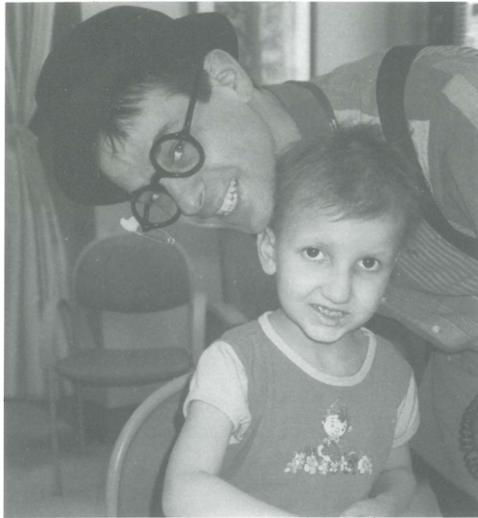
Dr. Rebecca Mannis is part of Making Headway's experienced support team. She is available to work with you and your child to identify ways to address educational difficulties. Her office is located in New York City. Please contact Making Headway for more information or to make an appointment. 🌸

Top: Happiness is a lollipop— Gina Quondamatteo with her dad, George.

Bottom left: Nurse Practioner Kathleen Murphy and Milina Pagan.

Bottom right: Shenique Downie.





Superkids

Stories by *Elizabeth Buttke*

SHANNA

Nothing bothers her pretty little head

Four-year-old Shanna was a bundle of energy, as happy and active as any little girl could be. Then suddenly her mom, Mary Church, started noticing that Shanna was having difficulty going up and down stairs. She was complaining of dizziness. She was afraid she was going to fall. She even started walking sideways.

Shanna's pediatrician suspected a vision problem, and sent her to an ophthalmologist—who found nothing wrong. Two days later, when Shanna stopped using her right arm, her pediatrician sent her to see a neurologist.

A CAT scan revealed a large mass, and Shanna was immediately taken by ambulance to the INN—where less than 48 hours later, Dr. Epstein removed a malignant medulloblastoma from Shanna's brain.

That was more than enough for any child to endure. But it was just the beginning. Shanna's surgery was followed by six weeks of radiation and close to a year of chemotherapy.

"We had a real rough time," her Mom says. "And yet, all through her treatment, Shanna really looked forward to going to

the INN. She enjoyed spending time with Maya and Jenna and Honey and just about everybody there. Including the doctors and nurses." Shanna had such a good time in the playroom, in fact, that she would stay there all day if her Mom let her. As Mary tells it, "Sometimes we closed up the playroom."

For Mary, Making Headway was a help in more ways than one—with everything from emotional support to important learning experiences, such as the informal discussion on growth hormone therapy that Mary attended. Now that Shanna has finished her treatment, however, trips to the INN are much less frequent but still eagerly anticipated.

Not surprisingly, the close bond between Shanna and her single Mom has become even closer as a result of what they have been through together. Still, Mary is amazed at how Shanna kept her cool throughout the ordeal—even when she lost her hair.

Mary says, "I told her that even though she didn't have that beautiful long hair anymore, she still had a very pretty little head for us to look at. And that seemed to make her very happy."

Now five and a half years old, Shanna is starting school and already mapping out her future. She wants to "be a mother and have six twins."

Needless to say, inside that pretty little head Shanna Church has a mind of her own—one that even a big, bad brain tumor couldn't suppress. 🌻

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Making Headway thanks Catherine Manley and Tena Walton for their generous help with this newsletter. Special thanks to Elizabeth Buttke and Dr. Rebecca Mannis for their contributions.

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

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Top: Shanna Church and one of her favorite people, Adam the clown.

Bottom: All in the family—Leonor Lopez and her children, Cindy and William.

