



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

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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: All smiles—Elisa, Jake, Clint, and Augusta Greenbaum.

Middle: Mindy Schwartz, Mary Dale and Jeffrey Allen, and Sam Schwartz at the Tulip Festival Dinner Dance.

Bottom: Ready, Set, Go! Walk-a-thon supporters, including members of the Casale family.

WHAT GIVES? A Message from Clint Greenbaum, Treasurer

The IRS or the Bible. Russian Roulette. Prove yourself to be worthy.

These are answers to Jeopardy-like questions that I often think about. Consider the questions:

- *What causes people to give to charity?*
- *How do people choose their charities?*
- *How do I get more people to give more money to Making Headway?*



Most charities are self-serving. Suitably, people give to their own churches, temples, schools, and organizations. Others give because a friend or a business associate has asked them to. Solicitations for most health-related charities come from those who either have or were afflicted with the disease. In the case of Making Headway, the families are generally too young to both shoulder the burdens of the disease and significantly contribute or fund raise. Getting the general public to give is expensive and difficult.

What does Making Headway do to address this dilemma? We believe in being lean and mean. Sponsorship covered 100% of the expenses of two of our most recent fund raisers. The annual "All-is-onE" Tulip Festival Dinner Dance, sponsored by the Trunz family, raised \$135,000, and the "Little Bit of a Walk" walk-a-thon, sponsored by the Ryan family, raised \$13,500. As a result of such generosity, Making Headway's total 1999 fund raising expenses were only 6% of total receipts, with administrative costs at only 9%. This means that 85% of every dollar goes to the services and programs that Making Headway provides. This is an excellent achievement for a smaller sized charity.



Elsewhere in this newsletter you will read how well your contributions are being spent. What I wanted to show you here is how efficient Making Headway is.

But Making Headway can do even better. How?



- **GIVE US YOUR E-MAIL ADDRESS!** Internet correspondence is much cheaper than snail mail. Contact us through our website at www.makingheadway.org.
- **TRY TO GIVE MORE** and get your friends to give more!
- **PLEASE** help us keep our fund raising expenses down and our donations up! We'd rather spend the organization's money on helping the children who need it! 

Meet Linda Barnes



Please join Making Headway in welcoming the newest member of its support team—Linda Barnes, Certified Social Worker (CSW). A graduate of Columbia University's School of Social Work, Linda has practiced individual and family counseling for more than twenty years. Formerly the director of an outpatient mental health clinic for a major social service agency in Westchester, NY, she has worked with a wide spectrum of people and issues. Now, as part of Making Headway's support team, Linda is available to counsel individuals and families in the Westchester area. To help families deal with the devastating effects of a brain tumor, she will focus on maximizing each individual's personal strengths and existing skills for coping. Office, home, or telephone visits are available. Her services are provided free of charge by Making Headway. Please call our office for more information. 🌸

Helping Us Help You

Linda Barnes is also currently leading a series of parent focus groups in the Westchester area. These focus groups will assist Making Headway in establishing services and programs that are most helpful to families with children undergoing treatment. Your input is very valuable!



Top: Dr. Jeffrey Allen getting a great big hug from Emily Ousouljoglou.

Middle: Big blue eyes and a sweet smile—Lori Dombrowski.

Middle: Picture perfect—Nurse practitioner Marianne Mariniello and Jennifer Pulgrano.

Bottom: Giggling gals—Child life specialist Jenna Aranoff with Alexandria Valentin and sisters Khiabet and Balkis Leal.

The next focus group is planned for Wednesday, October 18, 2000. Please call Making Headway to participate. 🌸

Research Update

The Director of the Albert Einstein College of Medicine Cancer Center, David Goldman, MD, has asked Dr. Jeffrey Allen, Chief of the Division of Pediatric Neurology at Beth Israel Medical Center, to help develop a Neuro-Oncology Program on the campus. Dr. Allen's goal is to recruit accomplished basic scientists who are presently engaged in other types of cancer research to conduct pilot studies in brain tumor biology. Hopefully, new approaches to the treatment of brain tumors in children and adults will emerge. Incentives to stimulate this research effort include access to a human brain tumor tissue bank and the provision of seed money from the **Michael Schwartz Research Fund** of Making Headway. We will keep you abreast of the progress of this effort. 🌸



Making Headway Sponsors Educational Seminar Series

To provide parents with as much up-to-date information about treatments as well as health, school, and social issues, Making Headway recently established an educational seminar series. The speaker for the first program, held this past August, was Dr. Charles Sklar, Pediatric Endocrinologist and Director of the Long Term Follow-up Programs at Memorial Sloan-Kettering Cancer Center. Dr. Sklar spoke with a group of parents about growth hormone (GH) deficiency in children who have had treatments for brain tumors, how GH is administered, studies summarizing the results of GH therapy, and its related risks. An informal question and answer session followed the presentation.

Additional educational seminars, on topics such as educational advocacy and nutrition, are planned for later this fall. Please call Making Headway if you would like to attend or need further information. The seminars are offered free of charge. 🌸



Save the Dates:

Casino Night 2001
Friday, February 2, 2001

Little Bit of a Walk
Sunday, April 1, 2001

Tulip Festival Dinner Dance
Thursday, April 26, 2001

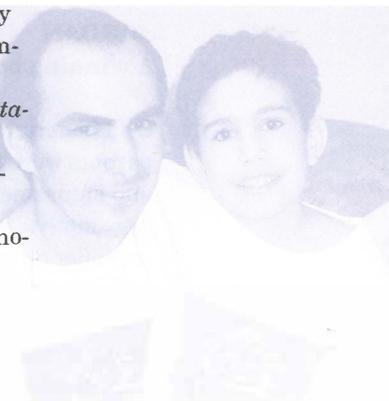
A Family Affair: Support for Parents, Patients, and Siblings

Taking its commitment to children and families very seriously, Making Headway has established a unique new idea of combining support for the entire family. In New Jersey, we now offer monthly *simultaneous* support group meetings—one for parents, one for patients, and one for siblings—designed to promote patient and family adjustments to life after the diagnosis of a brain or spinal cord tumor. These concurrent groups eliminate the need for childcare or complex family scheduling while encouraging a sense of family healing.

Parent Group: Headed by Dr. Lissa Parsonnet, the group discusses ways to deal with immediate issues and concerns such as family stress, different coping styles, school problems, and alienation from friends.

Patient and Sibling Groups: Psychologist and art therapist Dr. Grace Zambelli, and art therapist Cheryl Wilczak head the patient and sibling group respectively. Each uses a variety of art projects and games to help children cope with the effects of their own or their siblings' illness and the feelings generated by the illness. Social skills are also emphasized in the patient group.

Please call the Making Headway office for a meeting schedule or more information. 🌸



Above: Matching shirts, matching smiles—Luis and Josh Gonzalez.

Left: Mother and daughter—Kim and Gabriella Feltre sharing a hug.



Superkids

Stories by Elizabeth Buttke

JORDAN

A winning boy in more ways than one

On Memorial weekend 1998, when most parents were taking their kids to the beach and amusement parks, Wendy and Mark Abramowitz were setting out on the scariest roller coaster ride of their lives.

Even the devastating loss of Mark's father to a sudden heart attack, and the death of Mark's mother after a long battle with cancer—all in just four years—could not have prepared them for what they were about to endure. Their elder son Jordan, just short of his sixth birthday, was diagnosed with a malignant brain tumor.

Jordan was a healthy, happy, little boy who loved playing soccer, Nintendo and computer games—and being big brother to two-and-a-half-year-old Alec. When Jordan started having headaches, his doctor thought they might be from allergies. But when the usually unflappable Jordan continued to complain about the pain, his parents took him to his pediatrician, who ordered a CAT scan.

"That's when our lives changed," says Wendy. The scan revealed what doctors believed to be a benign tumor, and the next day Jordan was in surgery in a Long Island hospital. At the time Wendy thought, "We just had to get the surgery

over with, and we'd be on our merry way."

Sadly, it didn't turn out that way. Jordan had a malignant medulloblastoma. Long bouts of radiation and chemo lay ahead of him; months of fear awaited his parents.

But on their first visit to the INN, where Jordan would soon begin treatment with Dr. Allen, Wendy's initial encounter with Maya Manley was so reassuring that she knew immediately Beth Israel was the right place for Jordan to be. Not only because of the doctors, but also because of the care Jordan would get from the nurses and from Honey, Jenna, Tina, Marcia, and Maya in the playrooms.

That care proved to be more valuable than Wendy and Mark could ever have imagined. For just eight weeks after Jordan's remarkable recovery from surgery, his headaches returned. Incredibly, a CAT scan revealed there might be another tumor.

Surgery was scheduled with Dr. Fred Epstein, and it seemed to Wendy that they were starting all over again. Fortunately, no tumor was found.

But in spite of that setback, through it all Jordan proved to be an amazing little boy who was filled with an enormous inner strength that surprised even his mom. He never complained about his treatments, his stays in the hospital or being pricked and prodded by needles. Even the MRI didn't scare Jordan a bit. He simply relaxed and enjoyed watching a video on the special viewing equipment provided by Making Headway. And he charmed everyone he met.

Now 8 years old, Jordan is doing so well that Wendy says "I'm the luckiest mom in the world." 🌸

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

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Top: Alec and Jordan Abramowitz.

Bottom: Clowning around! Adam Auslander and Tess Ryan.

