



**MAKING
HEADWAY**



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

Fall 1997

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

Officers:

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Making Headway is a 501 (c) (3) non-profit foundation



**A first anniversary message from Edward Manley
President of Making Headway**

It is hard to believe, but Making Headway is about to begin its second year. What a fruitful year the first one has been! Our first fundraising effort was a huge success; we have put our first support programs in place; and we have already begun to make a difference in the lives of so many children and families.

With all of their needs in mind, and hope in our hearts, Making Headway is well on its way to realizing our objective: to provide a continuous program of complementary care and humanistic support for families of children with brain and spinal cord tumors and other serious neurological illnesses.

We are pleased and honored to be able to focus our resources and energies at the Institute for Neurology and Neurosurgery at Beth Israel Medical Center—working with Dr. Fred Epstein, Dr. Jeff Allen and the entire INN pediatric staff to enhance hospital programs and services. We are co-funding Dr. Marcia Greenleaf, a health psychologist, for three days a week, to help parents deal with their child's medical illness and related situational stress. Quality of life improvements include a second child life specialist to staff the day hospital playroom, and a recreational therapist to permit the tenth floor playroom to be open for longer hours seven days a week. To continue critical support programs for families after their children leave the hospital, we offer free support groups.

None of this good news would have been possible without the generosity of our donors, and all of the families who volunteered to help sell tickets for our first fundraising event last Fall: Walt Disney's "World on Ice," featuring the movie "Toy Story." We raised over \$300,000 for our work and, through the sale of sponsor tickets, were able to invite over 1,500 sick and underprivileged children and their family members, free of charge, for an exciting afternoon of fun.

Clint, Maya and I thank you. The staff at INN thanks you. The children thank you. Their families thank you. We all look forward to your continued support—so we will not only be able to fund humanistic support, but also clinical research, training fellowships and education.

What a wonderful second year this can be!

Making Headway INNights

When the Institute for Neurology and Neurosurgery (INN) opened at Beth Israel Medical Center, it filled what I have long considered to be a crying need. Ever since my early days as a physician, I have been aware that even with the most advanced medical treatments and state-of-the-art technology, much of what goes on in the brain is beyond a neurosurgeon's reach. A patient's fears, anxieties and emotions respond to a different kind of care.

I can excise a life-threatening tumor from the brain of a small child, but the secret places in a child's mind—where monsters and the boogeyman live—are out of bounds. Not only that, diagnosis of a child's brain tumor fills the parents' minds with monstrous fears and anxieties that are as great as, or greater than, those of their child.

No scalpel, no amount of surgical skill, is a match for the torments generated by the child's and the parents' brains in the face of devastating neurological disease. The only way to slay the dreaded "dragons" that reside within is with very large doses of understanding, compassion and love—to be administered as frequently as possible.

At Beth Israel's INN, that is not a prescription we take lightly. It is a deep-rooted philosophy that forms the basis of everything we do. While the medical treatment we render must be as good as, or better than, that which is available anywhere else in the world, we believe it is also critical that patients and their families be cared for in a warm, friendly, comfortable and comforting environment.

This "marriage" of technology to humanity is seen throughout the INN—where the most sophisticated equipment and medical treatments are combined with state-of-the-*heart* caring.

Dr. Fred Epstein: On Care and Caring



Technology and related medical expertise make recovery possible. But in the real meaning of the word, recovery only evolves over time—through the interaction of technology and nurturing individuals who assume responsibility for the patient and family.

Led by the nurses, all of our personnel are a vital part of the healing process: social workers, psychologists, nutritionists and physicians, to be sure. But I am always impressed by how much patients appreciate the concerned and caring attitude of our house-cleaning staff, who never fail to say "Good Morning" and ask about the child as they straighten up the room.

In other words, every single member of the INN team has an important role to play. Recognizing this enables us to deliver the comprehensive care that meets all of the family's needs, and promotes the well-being of our patients.

Our association with Making Headway not only unites kindred spirits in terms of motives, goals and long-term aspirations, it enables us to translate so many concepts into reality. These include psycho-social support and funding for quality of life projects which are beyond the budgetary scope of the hospital program. The caring support that Making Headway makes possible is a valued part of the care we provide.

We look forward to a long and rewarding future together, as we continue to work with Making Headway—to make life for every child at the INN better every day.

Dr. Epstein shown here with Rabbi Mychal Springer and Mikey Schwartz, says "The caring support that Making Headway makes possible is a valued part of the care we provide."

Dr. Epstein, a world famous pediatric neurosurgeon is the director of the INN.

Making Headway makes way for INNcredible kids

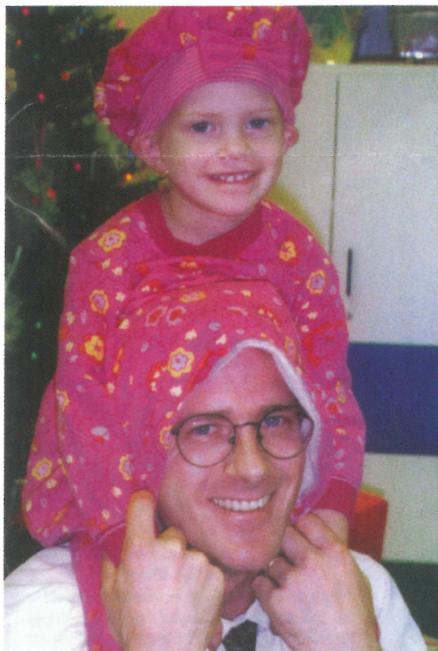
Like the kitchen in your home, the playroom is the heart and soul of the INN's pediatric floor.

More than just a place for playing, it is where everybody gathers to chat, commune with each other, console or be consoled. Through the generosity of our supporters, Making Headway is funding a recreational therapist, which allows the playroom to be open for longer hours, seven days a week - as well as a second child life specialist to staff the day hospital playroom.

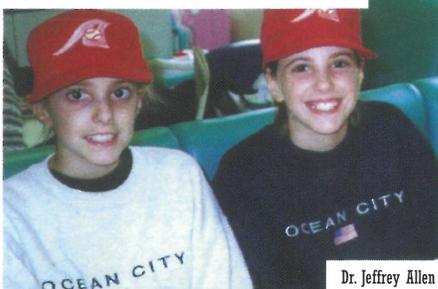


Jamie Lane shows off his own private transportation system, riding the halls on his IV pole.

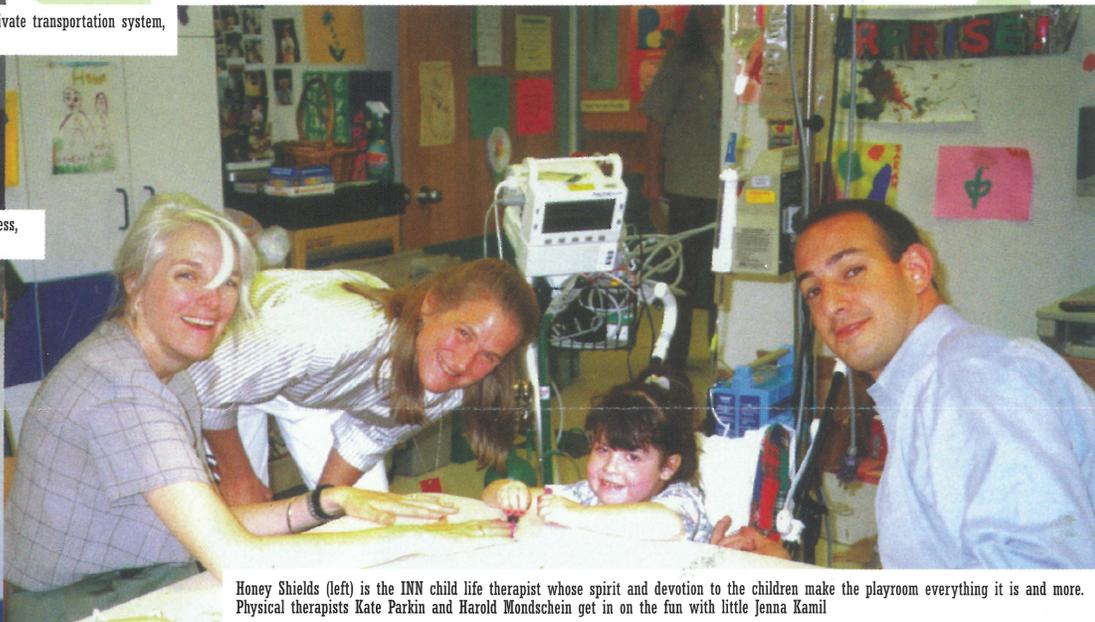
When Allison Trunz fashions a matching hat for her Dad out of her dress, she shows she sure can match his constant clowning around.



Which twin is the patient? Elizabeth. Which one is she? Only Elizabeth and Kathryn Marciano know for sure!



Dr. Jeffrey Allen with one of his many friends (and fans), Kelly Ann Reilly

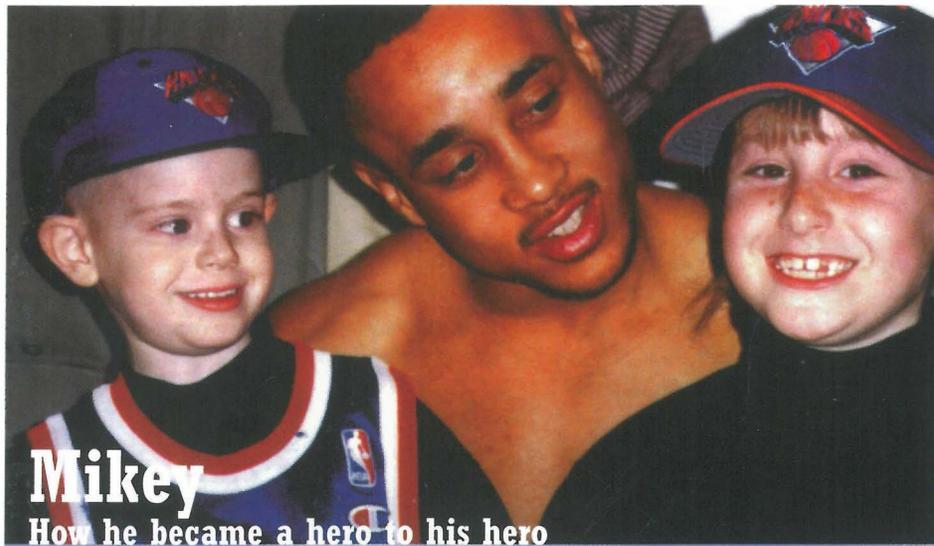


Honey Shields (left) is the INN child life therapist whose spirit and devotion to the children make the playroom everything it is and more. Physical therapists Kate Parkin and Harold Mondschein get in on the fun with little Jenna Kamil



Five-year-old Beenu in the playroom: her favorite place to be at the INN.





Mikey
How he became a hero to his hero

Four-year-old Mikey Schwartz may be barely knee-high to his favorite all-time Knicks hero, John Starks, but as everyone who knows Mikey knows: there is no shortage of bravery in this little boy.

Weeks prior to a bone marrow transplant to treat a recurrent brain tumor, and mid-way through the 1996-97 NBA season, Mikey had the opportunity to meet his hero in the Knicks locker room. Sitting on Stark's lap while they talked about the evening game, Mikey had a ball – and proudly introduced Starks and his teammates to sister, Jackie.

Memories of that exciting time stayed with Mikey throughout his treatment and helped him maintain a positive attitude – especially during the most difficult weeks of his transplant.

In fact, Mikey had enough good feelings to share them with another patient four months later, his friend John Starks. No sooner has Mikey completed chemotherapy and radiation treatment, when he visited the Knicks player in the hospital – where Starks was recuperating from hand surgery.

Man to man, they chatted about Stark's surgery, the outcome of the season and the Knicks' tough loss to the Miami Heat. When they finally said goodbye, Mikey and Starks gave each other the "thumbs up" sign, acknowledging that they were both on the road to recovery.

Making Headway INNspirations

Marisol and Robert

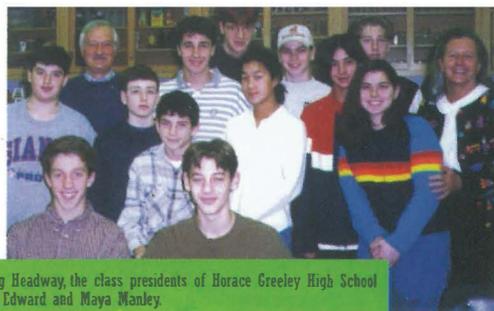
From tears of sorrow to tears of joy

When Marisol Lopez met Dr. Robert C. DaRosso (currently a pediatrician on staff at the INN at Beth Israel North), he was treating Marisol's brother, Luis, for a brain tumor, at NYU Medical Center. Sadly, Luis succumbed to the disease on January 17, 1994.

Four months afterward, Robert and Marisol had no contact with each other – until their paths crossed again. A friendship grew, a relationship began, love developed, and much to the delight of all who know both of them, Robert and Marisol were married on Saturday, April 12, 1997. In memory of Luis, the happy couple danced on their wedding day to "The Wind Beneath My Wings", and dedicated the song to Luis – who not only was there in spirit, but also in their hearts.



Dr. Robert DaRosso and his bride, Marisol, honeymooning in the Caribbean.



Donating their time and money to Making Headway, the class presidents of Horace Greeley High School in Chappaqua take a break to pose with Edward and Maya Manley.

"One man's junk is another man's treasure."
The Northern Hudson Valley Candlelighters organize a rummage sale each year in April. Proceeds go to families who have children with cancer. Please donate anything and everything you no longer want. Call Maya Manley at (914) 238 - 4917 to arrange for pick-up.

Something for Everyone
Support groups led by Dr. Marcia Greenleaf are held outside the hospital for parents, young survivors and siblings. For more information on meeting times and place, call (212) 523 - 8877.

SAVE THE DAY!
Our second annual Making Headway fundraiser is Walt Disney's "World on Ice" featuring the movie "Hercules", on Sunday, November 9th. Details to follow.

Happenings



When the members of Class 6C at the Solomon Schechter School of Westchester held a bake sale, it was a treat for Making Headway which received the proceeds of the sale in honor of Sara Weinger, whose brother Aaron helped put the event together.

Bulletin Board

Breaking news....
Dr. Fred Epstein is organizing an international conference on ependymomas in November 1997. The latest developments in treating this type of tumor will be discussed at the conference, which will attract hundreds of specialists from around the world. Making Headway will provide funding to publish the proceedings of the conference as a supplement to the Journal of Pediatric Neurosurgery.

Next Newsletter Deadline
News items for the next Making Headway Newsletter must reach us by December 1, 1997. If you have any questions, call the office at (914) 238 - 8384.

Thanks to our friends who made this newsletter possible through the donation of their services:
Liz Butke - writing and editing,
Matthew Clark - graphic design