



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.

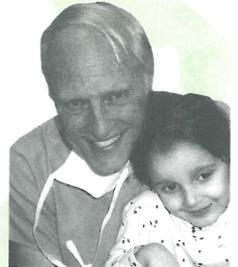
Making Headway is a 501(c)(3) not-for-profit foundation.

Top: Dr. Fred Epstein and Emily Ousouljoglou.

Bottom: Dr. Jeffrey Allen with Michael Schwartz, Sophia Casale and Billy Anthony.

A Message from Edward Manley, President

September 2001 was significant in several ways. The tragic events at the World Trade Center Towers affected us all deeply. We honor those who courageously led so many to safety, and remember all those who lost their lives. Closer to home, Dr. Fred Epstein, Director of the Institute for Neurology and Neurosurgery (INN) suffered a serious accident while riding his bicycle. He is making slow but steady progress in his recovery, but his presence and leadership at the INN are sorely missed. We keep him in our prayers.

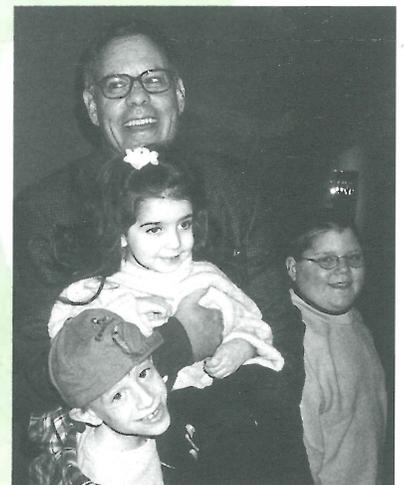


On a more positive note, September 2001 marked Making Headway's 5th birthday. We can be very proud of our accomplishments during this relatively short period:

- *over \$1 million in grants awarded to the INN for projects and programs which enhance the excellent medical care provided by the doctors, nurses and staff.*
- *over \$500,000 of Ongoing Care services provided to help families adjust to life once their child comes home from the hospital including support groups, counseling services, seminars, and bereavement groups.*
- *average administrative/fund raising expenses kept under 11% of receipts.*

I am pleased to report that our winter fund raising event, The Pirates of Penzance, succeeded well beyond our expectations. We filled almost every seat with 300 of those given to the families of the New York City Police and Fire Departments. The proceeds will enable us to continue our programs of supportive care.

In closing, I would like to thank our Board members, both active and honorary, for their efforts in helping Making Headway continue its many programs. We are also so grateful to Tena Walton who keeps the office running with her dedicated service and wonderful sense of humor. Our accomplishments would not have been possible without the kindness and generosity of our donors. We thank you for helping us realize our mission to positively touch the lives of all the children and families we serve.



Two Neurosurgeons and a Swiss Family Carry Out Fred Epstein's Vision

Last year four-year-old Benjamin Külling was diagnosed with a spinal cord tumor and treated in his native Switzerland. The surgeons in Zürich removed a small portion of the tumor, leaving his legs paralyzed for two months. Concerned when the tumor continued growing during nine months of chemotherapy, Claudia and Daniel Külling began to search the internet. Dr. Fred Epstein's name came up repeatedly and they arranged to see him when he attended a conference in Zürich. Meeting him, Claudia and Daniel were as moved by his depth of compassion as they were by his extraordinary expertise. Viewing Benjy's scans, Dr. Epstein detailed what his team could do to remove most of the tumor and what to expect afterwards.

Scared and hopeful at the same time, the family prepared for their trip to New York in mid-September. Then came September 11th. Near despair, Daniel and Claudia had to strengthen their resolve not only to put Benjy through another surgery but to do it in a city reeling from its own disaster. They bought new tickets and were scheduled to leave the first week of October. Then came September 30th. Unbelievably, Dr. Epstein had been in a dreadful accident. The family was crushed.

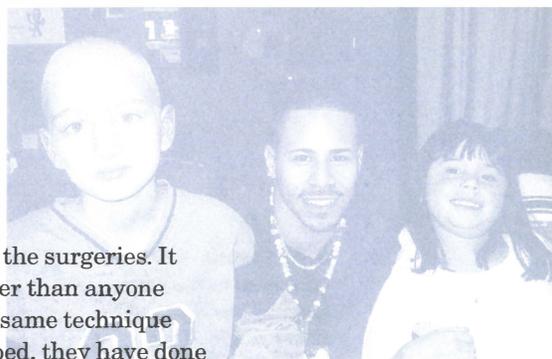
On this side of the Atlantic, the attending pediatric neurosurgeons, Dr. George Jallo and Dr. Karl Kothbauer, were faced with their own painful heartbreak as their dearly loved mentor lay in a coma. Both had been training with Dr. Epstein for years to

eventually take over all the surgeries. It happened so much earlier than anyone had planned. Using the same technique that Dr. Epstein developed, they have done more spinal cord and brain tumor surgeries in children than the majority of neurosurgeons in the US and overseas. Yet their presence at the hospital was significantly eclipsed by their world-famous mentor. How could they assure families of their incomparable qualifications?

When Dr. Kothbauer called the Küllings, they were moved by his kindness and willingness to speak with them at length. His experience seemed obvious and yet they asked what so many parents in their place have asked, "If this were your child, what would you do?"

Daniel, Claudia and Benjy arrived in New York in October. The surgery was exceptionally complex. For Claudia and Daniel, it was eleven hours of waiting and wondering. For Dr. Jallo and Dr. Kothbauer, it was an occasion to feel how deeply they had internalized Dr. Epstein's guiding voice. They removed most of the tumor and two days later, Benjy took his first steps.

The experience at the INN mirrored Dr. Epstein in every way. Here was the finest medical care in a loving environment. The Küllings never felt alone. Back in Zürich, Claudia spoke fondly and longingly of the INN. She laughed recalling how funny Dr. Jallo is and sighed anticipating the chemo Benjy will now undergo in Zürich—without the playroom, without Adam the Clown, without Maya's arts and crafts, without the extraordinary difference Making Headway had made in their stay. She wished they could be in New York and in a way they are. The care and support they received is memorialized by the wondrous toy they sent upon their return to Zürich—a four foot high, hand-crafted wooden marble run which stands at the entrance to the day-hospital playroom. It delights and mesmerizes children when they visit and reminds us all what an inspiring role the children and their families play in making the INN the special place it has become. 🌱



Above: Child-Life Specialist Jose Acevedo with Jesse Cassel and Oriana Cerrud.



Above: Dr. George Jallo and Dr. Karl Kothbauer.

Bottom: Daniel, Claudia and Benjy Külling.





Giving Graciously

Throughout the year, countless contributions are received by Making Headway from individuals, groups, organizations, and companies. These gifts help us in fulfilling our mission to provide care, comfort, and support to families of children with brain and spinal cord tumors. No matter how great or small, we are honored by each contribution and sincerely thank you. Some examples of this season's gracious giving include the following:

Maira Hernandez-Kinloch, whose son Matthew was treated at the INN, held an afternoon tea in celebration of her birthday. In lieu of gifts, Maira asked friends to donate to Making Headway—she raised over \$2,000.

Adam Auslander, our clown at the INN, recently celebrated his birthday and also asked that his friends donate to Making Headway. We have received over \$700.

When **Alex Lynch** began radiation treatment, his parents promised the six-year-old one dollar for each treatment. By the time he'd finished his treatments, Alex had squirreled away a telling pile of bills into a hospital envelope. Later, Alex set up a lemonade stand, stashing away even more money from his profits. Over \$50 in bills and change was stuffed into the now tattered envelope which Alex generously donated to Making Headway.

Research Update

In response to a request for proposals related to pediatric neuro-oncology, research scientists at the Albert Einstein College of Medicine submitted four applications at the end of last year. The Grant Review committee recommended one project for funding, which the Board has approved: a two-year, \$100,000 grant to Dr. Eliot Rosen, in which he will investigate and identify the genes that cause human glioma tumors to be resistant to chemotherapy and radiation therapy, hopefully leading to new treatments. **The Michael Schwartz Research Fund** of Making Headway will fund half of this project. 🌱

Superkids

Stories by *Elizabeth Buttk*

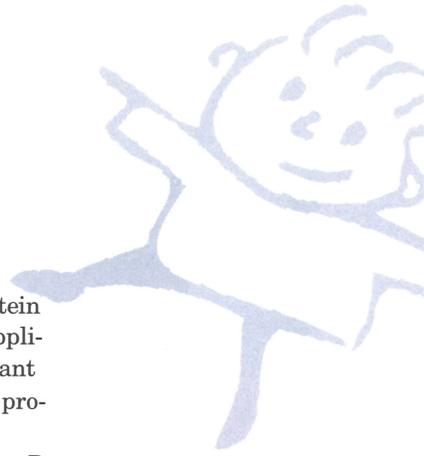
STEPHANIE A real gem

For most teenagers, birthdays are fun times to remember. And so they were for Stephanie Garwin, until the day she turned fifteen—the day she learned she had a malignant brain tumor. Since then, birthdays for Stephanie have been bitter-sweet. But the day Stephanie calls “life-changing” was April 3, 1995—the day of her surgery.

“I was kind of led to believe that after my surgery I'd be fine,” Stephanie says. “But what I thought was not what happened.”

Although her tumor was successfully removed, Stephanie was on a regimen of medications and hormones that caused unwelcome weight gain, some vision problems and learning difficulties, and she found it hard to relate to her peers. She was unable to do all the things they did, and her experience made her priorities very different from theirs.

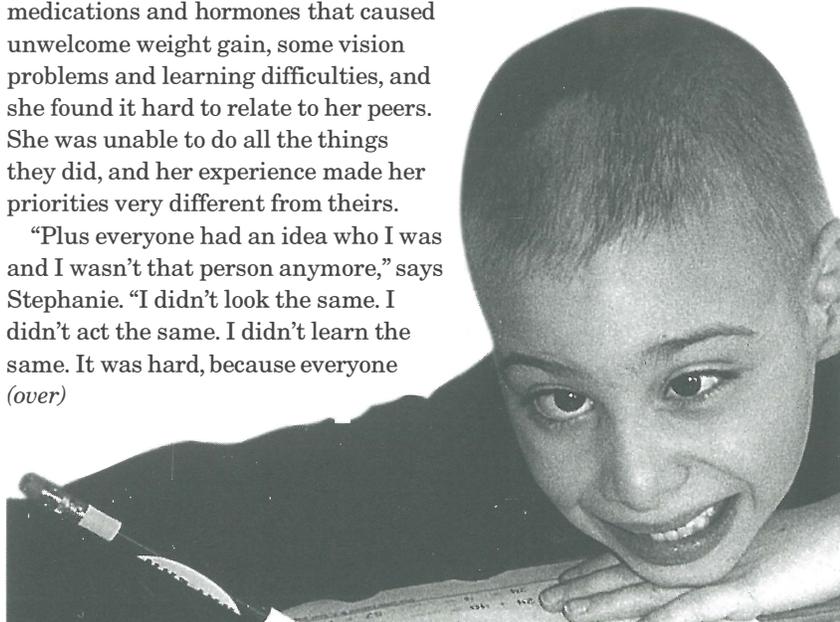
“Plus everyone had an idea who I was and I wasn't that person anymore,” says Stephanie. “I didn't look the same. I didn't act the same. I didn't learn the same. It was hard, because everyone
(over)



Top: *Alex Lynch and Adam the Clown.*

Above: *Kyle MacDonald with his mom Mary Jean.*

Below: *Jake Harary.*





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had something to compare me to. So I was really looking forward to going away to college...to go someplace where no one knew the so-called old Stephanie, and just knew me from me."

In spite of learning difficulties and physical impairments, Stephanie did well in college. She was proud of her SAT scores, and maintained a good GPA. "But I think it's important for people to know that in order to do that," Stephanie says, "you have to put in a lot of hard work and get to the right people who can help you. You may have to go to special classes and therapy. In my case it was cognitive remediation. But I know there are a lot of other things."

"Making Headway was just beginning when I was diagnosed, and probably one of the best things for my family was getting involved—because we met people who were in the same situations. The psychologists Marcia Greenleaf and Lissa Parsonnet helped my whole family tremendously, and helped us understand a lot of what we were going through. And also the Manleys, because their daughter had a similar thing. So it was so important for us...to know that you're not alone makes a big difference."

After about a year and a half of college, Stephanie began to have more trouble walking, more trouble learning, and a lot of fatigue. On a visit home for her sister's birthday, she told her family she didn't feel well. When her Mom found her unconscious on the floor, another life change was soon to follow. Stephanie was confined to a

wheelchair, and unable to return to college. While the setback made Stephanie feel more dependent than ever on her family, she soon found the wheelchair was liberating—allowing her to do so much more than she could when lack of stamina and endurance limited her. As a result, Stephanie wants other young patients and their parents not to think of having a wheelchair as giving up. She says, "When I went from a manual chair to a scooter to a power chair, my parents felt that each step was kind of a negative thing, and I guess in some ways it was. But it put me further in my independence. It's me enabling myself to do more on my own, and to enjoy life instead of just working hard to get there."

That same positive outlook is very much in evidence when Stephanie talks about her newfound talent for making jewelry—which came to light when she worked with beads in occupational therapy. Making jewelry is not just fun for Stephanie, it is serious business. She is working on her Fall line, has hired a marketing consultant, and hopes to be in the jewelry business in a big way.

"I think it's amazing, and it shows what wonderful things can happen and *do* happen through difficult times," says Stephanie. "And how through this you can find what you love, and I think that's so important...finding something like making jewelry, which brings me so much joy. It's so interesting to me, what can come of an illness. I think it's important to realize that not everything is bad."

Wise beyond her 22 years, Stephanie hopes reading about her experience will help other young brain tumor patients and their parents. She says, "It may mean changing and evolving and adapting your goals, your hopes, your dreams...it doesn't mean you're still not going to get there... but the road is going to be different. And as the child's situation develops, the parents are going to have to change and evolve also. That's a lesson that my parents have had to learn, and are still learning." And what a teacher they have in Stephanie. 

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

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Top: Stephanie Garwin.

Below: Brandon Boston with his mom Janice.

