



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

Founders

Edward Manley
President

Maya Manley
Secretary

Clint Greenbaum
Treasurer

Administration

Tena Walton
Linda Mudford-Lewis
Office Administrators

Making Headway Foundation, Inc.

115 King Street
Chappaqua, NY
10514-3460
Tel: (914) 238-8384
Fax: (914) 238-1693
www.makingheadway.org

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.

Below: Maya Manley and Carlos Saavedra.

A Message from Maya Manley, Parent Advisor and Friend

When our daughter Cynthia was well into remission (having been treated by “wonderful” Dr. Allen as she still calls him), I decided to become a volunteer at NYU Hospital. Because my own experiences at hospitals had been so negative, I wanted to make a difference.

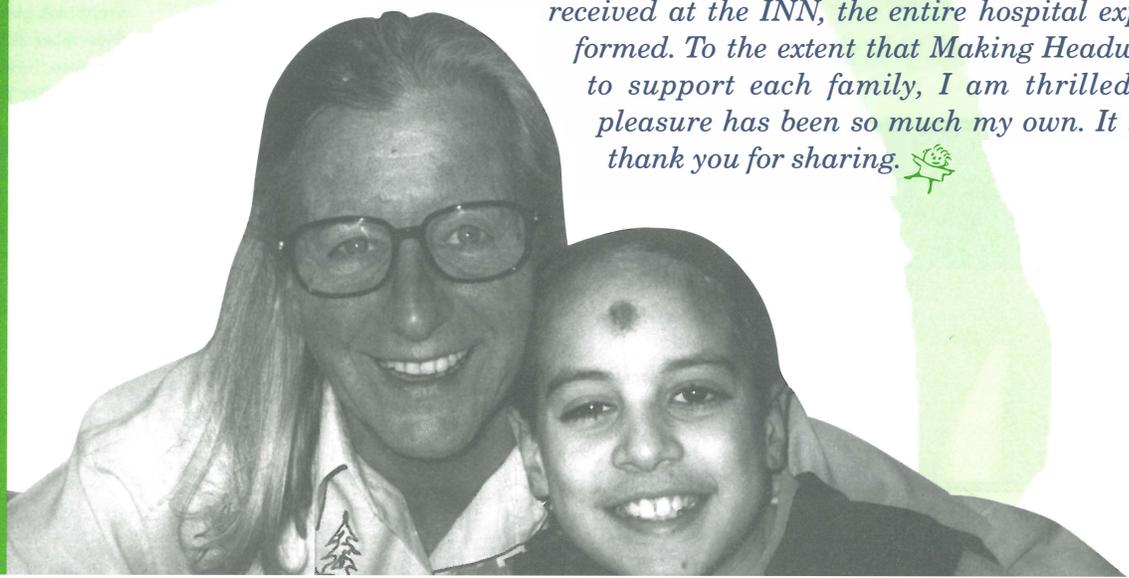
Working with children who have brain or spinal cord tumors and their families quickly became as important to me as my other work—being Edward’s wife and a mother to four grown children. I simply needed both to have a meaningful and content life. With this volunteer work growing from our experience with Cynthia, the groundwork for Making Headway was laid.

What Edward and I have tried to accomplish these six years with Making Headway! We wanted to create a program where parents coming to the hospital with their child would be welcomed, embraced, respected, understood, and even fed. (How often parents come having eaten nothing since the night before because their child couldn’t eat before an MRI!) We wanted to create an environment where parents never felt abandoned, hopeless or helpless.

We were thrilled when Dr. Allen and Dr. Epstein invited us to enhance their unrivaled medical care with a program for the emotional and psychosocial well-being of families. In 1996, we began working together at the newly built INN. Your support of Making Headway has turned that shared vision into a reality.

Today when children come to the playroom, they are embraced by Jose, the Child Life Specialist. He plays every board game under the sun, figures out every video game and computer program and keeps the arts and crafts table going with endless possibilities. When a young child or even a baby is anxious, Yelena, the Music Therapist, calms them with her soothing songs. Helping to sort the torrent of emotions and feelings, psychologist Jean Donnelly is on hand at the INN while outside the hospital, psychologists Marcia Greenleaf, Lissa Parsonnet and Sallie Sanborn lead support groups and offer individual sessions. Rebecca Mannis, our Education Specialist, assesses school-age children and advocates for their needs. And when all else fails, Adam the Clown makes even the most intense parents laugh.

When a sense of trust and an expectation of fun, comfort and care are firmly established in children and parents alongside the superior care received at the INN, the entire hospital experience is transformed. To the extent that Making Headway has been able to support each family, I am thrilled. But really, the pleasure has been so much my own. It is I who wants to thank you for sharing.



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:

Child Life Specialist at the INN, **Jose Acevedo** and his friends ran the Achilles Marathon raising \$338 for Making Headway.

To fund Making Headway's educational remediation services, **CIBC World Markets Corp.** generously designated \$22,000 of the commissions they earned during their *Miracle Day* last December.

The Foundation was honored to be included in the Bat Mitzvah of **Jackie Schwartz** who, in lieu of presents, asked her friends and family to donate to Making Headway. We have received nearly \$2,400 from Jackie. What a promising start to young adulthood!

LILAC, the Long Island League to Abolish Cancer, hosted a fashion show and dinner for the benefit of Making Headway. More than 200 people attended, and the event raised over \$15,000, which will be earmarked for medical research.

We're never too old to anticipate what this year's birthday presents will bring which is why it's so touching when individuals decide to give rather than receive. In honor of their birthdays, **Lauren Hennessy**, **Barry Klitzberg** and **Paola Greenfeld** donated \$350. Far off in Switzerland, **Monique Trumpy** celebrated her 50th birthday by asking friends to donate to Making Headway. Over 3,000 Swiss Francs were raised (this converts to more than \$2,000!). In memory of Elizabeth Ryan, **Catherine Whelan** celebrated her 6th birthday by helping children with brain tumors. She donated the \$75 raised in lieu of birthday presents.

The **Frueauff Foundation** awarded Making Headway a grant of \$15,000 to help fund a one year pediatric neuro-oncology fellowship at the INN under the direction of Dr. Jeffrey Allen.



Top: President and Senator Clinton with the Davis Family.

Bottom: Sarah Antonoff and nurse practitioner Kathleen Murphy.

Special Guests on a Special Day

This year marked the 10th annual **Family Fun Day** given at the Manley's home. A spectacularly beautiful day set the scene for a summer tradition among Making Headway families. All day, the pool sparkled amid enthusiastic splashes. Many took a break to enjoy yummy snacks before heading up the lawn to play badminton or ping pong, pet the animals, have a manicure, get a hilarious hat made, laugh at the balloon show, learn how to juggle, and catch up with special friends outside the hospital.

After sitting down to the sumptuous supper, two new guests arrived. President Clinton and Senator Clinton were identifiable, if not by their faces, then at least by their name tags: "Hello, my name is *Bill*" and "Hello, my name is *Hillary*." They graciously shook hands and smiled for photos while marveling at the lovely yard transformed into such a special world.

Sitting by the pool as day turned to evening, you could look out across the lawn dotted with joyous children, luminous jugglers, and tranquil parents. Up past that friendly house where the sun was setting and amid the gentle strains of music, you could see the place shimmer and feel that all was well. 🌸

Events

Much of what Making Headway is able to do, is fueled by annual events, often sponsored by our families and their friends.

Last Spring, the annual **Tulip Festival Dinner Dance** at the Swan Club raised \$159,000. Hosted by the Trunz family, the evening fulfilled its promise of elegance, commemoration and celebration. This year's journal was dedicated to Dr. Fred Epstein. The 7th Annual **Tulip Festival Dinner Dance** will be held on April 10th, 2003. Save the date!

Last Spring, the annual **Little Bit of a Walk** sponsored by the Ryan family raised a record \$22,300 in an aerobic 1.6 miles! The 5th annual **Little Bit of a Walk** will be held at Point Lookout, Long Island on April 6th, 2003. Save the date!

A new event, **Fore a Difference**, is teeing off thanks to the Casale family. The golf event took place on September 30th in Emerson, New Jersey shortly after we went to press.

Casino Night is back! Organized by the Coutts family, it will be held on February 28, 2003 at Wayne Manor in New Jersey. Come roll the dice, all you heavy rollers!



The Sibling Experience

By Audrey Manley

Twenty years ago, my parents took me to the end of our driveway to tell me about my sister's illness. I heard the words: brain tumor, surgery, radiation, chemotherapy. Struggling to comprehend what this meant for Cynthia, for me, for our family, I watched as my mother began to cry and my father reached to comfort her. I stood there witnessing their grief as a complete outsider.

Feeling like an outsider is not unusual for a sibling. As exhausted parents care for the sick child, the others are often left to fend for themselves. It is not that we are less loved, just that we are healthy. When parents withhold information, we're left in the dark where things can look much worse. When parents reveal their concerns, we are left with the realization that those who always reassured us and made us feel safe, are scared too. It's heartbreaking to experience the lonely shore of what had seemed a boundless ocean.

After my sister's operation, my father took us to the hospital to visit her. I did not recognize the girl in bed with bandages, tubes and machines. Cynthia had been the family clown, the one with the mischievous grin. I looked at a complete stranger. I was overcome with worry. Would she die? Would we all get sick? It became too much. The last thing I remember was the city lights in the window behind her bed as I fainted. Two ICU nurses and my mom had to drag me outside.

My mom was consumed for the next several months. She would come home, shower, nap, pack fresh clothes, and leave again. Our joyful, wonderful, fun-loving mother had become a shadow of her former self. She was so sad, it broke my heart. My father did his best to replace my mom but the house felt lonely and empty.

When Cynthia came home, the house was no longer empty but it was no less lonely. People kept coming by to visit her. They brought her gifts and lavished her with attention. It wasn't long before

Cynthia got used to it. It was hard to watch my parents turn a blind eye to behavior they had never tolerated before. Life had become unfair and I was angry. It was hard not to be jealous and envious. I found myself hating Cynthia. And then, horrified with my feelings, I felt guilty. It was a vicious and agonizing cycle.

What I realize today is that everything I felt was normal. Any child who has a sibling diagnosed with a brain tumor feels something similar. The issue is less about *what* we are feeling and more about *what to do* with the feelings.

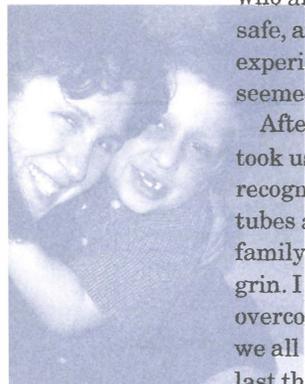
When Dr. Marcia Greenleaf asked me to help her establish a *sibling* support group for Making Headway, I jumped at the chance. If I could ease another's suffering by making it safe and even productive to feel, I knew it would be healing for me as well.

Drawing on her work with cancer patients and their families, Marcia facilitates the group and provides concrete strategies to deal with feelings and issues. I serve as the link, often opening meetings by talking about my own experiences. Everyone has the opportunity to tell their story. We make wish lists. We problem-solve. We eat pizza. We laugh. It's a packed hour but I think everyone leaves feeling good. I know I do.

What happened to Cynthia was the unthinkable. But with her diagnosis and treatment, something happened to me too. It changed my life and shaped it in powerful ways. I'm still learning thanks to the courageous kids who participate in the *sibling* support group. 🌱

Sibling Support Groups

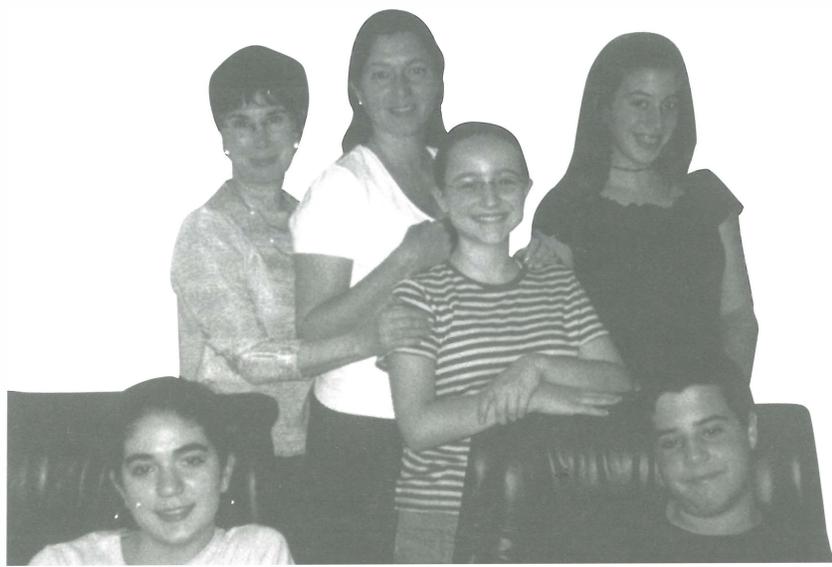
Monthly *sibling* support groups are available. Please call the Making Headway office at (914) 238-8384 to find out about the next one in your area.



Above: Alex and Chris Chametsky with dad Todd and step-mom Vivian.

Left: Renee Etra and John Buczynski.

Below: The sibling support group.





Superkids

Stories by Elizabeth Buttke

MORGAN An angel on earth

From day one, Morgan was a very special little girl. Her parents, Cheryl and Chris Coutts, had tried for almost six years to bring her into this world. They endured two miscarriages, and surgery for Cheryl, before they finally were able to hold Morgan, safe and secure, in the loving warmth of their welcoming arms.

“We had a perfect life going,” says Chris. Then shortly before Morgan’s second birthday, she developed an ataxic gait and bouts of vomiting, which doctors attributed to an inner ear infection. But when her symptoms worsened, Morgan’s pediatrician ordered an MRI.

The diagnosis that followed was shattering. Morgan had a very large tumor on her cerebellum, and she needed immediate surgery. The doctor had already called Dr. Fred Epstein, who was about to leave for Europe. Instead, Dr. Epstein rushed into surgery that afternoon, to remove the malignant medulloblastoma that threatened Morgan’s life.

“That started our journey,” says Cheryl. “A journey into a world of chemotherapy, a world of very sick children, and a world that I wish no parent (or child) would ever have to experience. But while we were in that world, I believe we made the very best of it.”

Although Morgan underwent six rounds of intensive chemotherapy at the INN, Cheryl says, “She has really good memories of the hospital, and Making Headway has done amazing things. Honey constantly supplied us with music and video tapes, so that we could sing and dance our way through chemotherapy.”

Even at Memorial Sloan Kettering, where Morgan later had to go for a bone

marrow transplant, called a stem cell rescue—in which her own previously harvested stem cells were utilized to rebuild her body—the Coutts looked to many of the people at Beth Israel to help them through the ordeal. “Like Maya and Honey who came to visit us,” says Cheryl. “It was so touching. We were in another hospital, but still they didn’t forget about us. Even though they had plenty of other kids to take care of, they gave us support in so many ways.”

But it was the incredible strength of little Morgan that made Cheryl and Chris strong. No matter how treacherous their journey became, Morgan never lost her amazing love of life. Not even when two carefree, cancer-free years were suddenly cut short by a routine MRI that revealed Morgan’s tumor was growing back.

After researching all of the treatment options, Chris and Cheryl decided on proton beam therapy—a relatively new radiation treatment that led them to move to Boston, one of the few places it was available. And, true to her upbeat nature, Morgan led them *through* Boston: from yummy clam chowder at Samuel Hall, to fun swan boat rides in the pond and exploring all the shops on Market Street. All this, in between daily radiation under anesthesia.

Now, three years later, Morgan is a beautiful and healthy seven-year-old, with two younger sisters, and thankful parents who once again are learning to rejoice in the present and believe in the future. When they reflect on the past, it is with great appreciation for “many little miracles along the way” and all the wonderful people who shared their journey—including Dr. Allen, Dr. Epstein, Tania, all the doctors and nurses at Beth Israel, Ed and Maya and Making Headway. Chris also special credit to his in-laws for their unwavering support. “They are really quite remarkable people,” he says.

Chris recalls what his mother-in-law told him on the day of Morgan’s birth: “An angel was born today.” As anyone who knows Morgan can tell you, every day of her life proves it. 🌱

Making Headway Foundation, Inc.

115 King Street
Chappaqua, NY
10514-3460
Tel: (914) 238-8384
Fax: (914) 238-1693
www.makingheadway.org

Making Headway thanks Tena Walton and Linda Mudford-Lewis for their generous help with this newsletter. Special thanks to Elizabeth Buttke for her contribution.

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

Managing Editors:

Maria Jerskey
Audrey Manley

Photos:

Maya Manley

Design:

Cara Galowitz Design Associates

Printing:

H & S Graphics

Top: Morgan Coutts.

Bottom: Daniel Rios with his dad Hiram.

