



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

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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.

**"You Don't Know Me, But Thank You for Making Headway!"**

*A Message from Clint Greenbaum, Treasurer*

*Living two hours east of the City, I rarely get to meet the parents of children who use the services provided by Making Headway. When I do, I usually hear, "You don't know me, but thank you for Making Headway!" Hearing this makes all the work that my wife, Elisa, and I do behind the scenes for Making Headway worthwhile.*

*I want to take this opportunity to let you, our contributors and especially my 600 friends who donate, know that your giving isn't just to keep on my good side, but that it really does matter. Making Headway makes a horrible situation a little less horrible. It's bad when an adult is sick; it's earth shattering when a child is.*

*Thirteen years ago Elisa and I discovered that our three-month-old perfect boy was not so perfect. When I heard there was a tumor the size of a small grapefruit in the center of his tiny head, I literally fell to the ground. My parents had both died of cancer so I knew the drill: the operations, chemotherapy and hospital treatment. I didn't know if I could do it again and I was scared about the outcome.*

*Jake had excellent care but the experience was no joy ride. We were lucky: at 1½ years old, Jake was considered cured. By then Elisa and I had vowed to help others going through the same nightmare.*

*Nine years ago we moved to Westhampton Beach, had our daughter Augusta and became active in the community. Last December, Jake celebrated his Bar Mitzvah. While the brain tumor left Jake with no speech and significant learning disabilities, he wowed an overflow crowd using his communication device. He was very, very proud.*

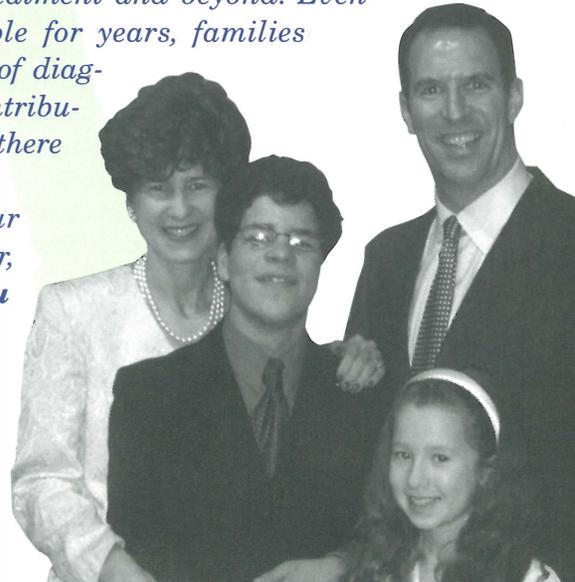
*We're sure Jake has forgotten everything about his sickness, but Elisa and I were scarred for life. We would do anything to make it easier for the "new Jakes" and their families. Reading through each issue of this newsletter, it's obvious that other parents—even patients, siblings and friends—feel the same.*

*Making Headway is made up of a large group of parents who have not forgotten. At different times they've resourced our many services both in and out of the hospital, during treatment and beyond. Even when a child's tumor has been stable for years, families continue to grapple with the outcome of diagnosis and treatment. Thanks to our contributors, Making Headway continues to be there for them.*

*You may not realize how much your dollars help. They help a lot! Remember, "You don't know me, but thank you for Making Headway!"*



*Bottom right:  
The Greenbaum family.*



## 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 year's gracious giving include the following:

Our Swiss friend, **Nina Froriep**, raised \$3,645 for Making Headway when she ran the entire NYC Marathon sponsored by her friends. At a more leisurely pace in Boston, **Robin and Chuck Magner** organized *Riley's Walk*, named for their daughter. On September 7, 2002, they raised an amazing \$23,700 which was donated to Making Headway in honor of **Dr. Fred Epstein**. At their request, it has been designated toward research.

On the occasion of her marriage, **Michelle Casale** honored her cousin, **Sophia Casale**, by forgoing wedding favors. Instead, Michelle and her husband, **Vincent Oliveri**, donated \$2,000 to Making Headway. To honor their grandson, **Timmy, Michael and Anne Martin**, celebrated their 45th wedding anniversary by asking friends and family to make gifts to Making Headway. \$1,295 was raised and their son, **Michael**, matched this gift himself for a total of \$2,590.

Each year, Temple Israel of New Rochelle holds *The Jill A. Konweiser Memorial Softball Challenge*. Thanks to **Pamela Garfinkle**, a member whose father is a patient at the INN, Making Headway was this year's recipient of \$1,360. **Quality Connections**, a Long Island-based social group of single parents, raised \$1,095 at their Holiday Party in December 2002. **Petrillo Stone Corporation** of Mount Vernon, NY, in lieu of Christmas gifts for their clients, donated \$5,500 to Making Headway.

To honor her 7th birthday, **Lila Smyth**

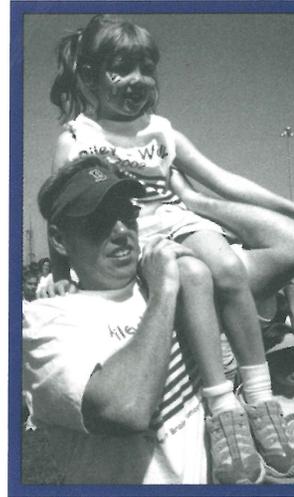
asked her friends to send gifts to Making Headway. We received \$1,185. Gifts in honor of **Jake Greenbaum's** Bar Mitzvah amounted to \$2,856. We also received donations from **Meredith Schepp** and **Josh Kramer** on the occasion of their Bat and Bar Mitzvahs.

**Maira Hernandez-Kinloch, Matthew's** mom, had another birthday party this year and asked her friends to make donations for Making Headway. Last year's amount of \$2,000 was topped by this year's: 3,030. **Dr. Isidor Pugatsch** of Switzerland is INN patient **Benji Killing's** grandfather. In lieu of a party for his 75th birthday, he donated 750 Swiss Francs (about \$580) to Making Headway.

Our new friends, **Jackie and George Sabatini** and their colleagues at work raised \$1,000, purchased toys and delivered them to the children at the INN. **Melissa Billings** and **Kate Branch**, a teacher and nurse respectively at the **Roaring Brook School** in Chappaqua, worked with the 40 members of the **5th Grade Children's Service Organization** to make 700 yummy candy packs for the children who attended *The Mikado* performance in January.

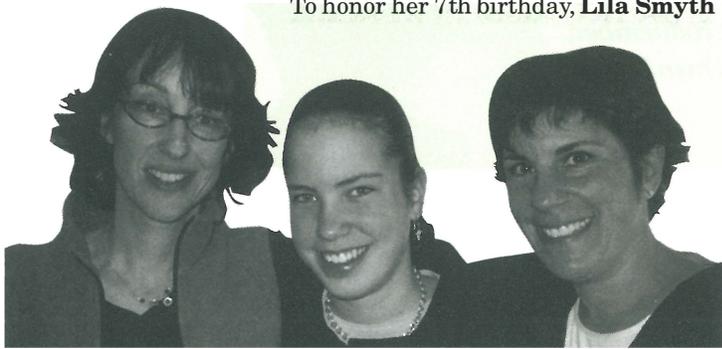
In memory of her best friend, **Sarah Antonoff, Samantha Robbins** organized a huge tag sale with items donated by local merchants, friends and family. She raised and donated \$1,200. Additionally, Samantha and the **7th Grade Advisory Group** ran a school store during recess and raised \$1,000 that they donated to Making Headway. Inspired by Samantha's efforts, the **Beatman Foundation** donated \$1,000. Each year the proceeds from **Jericho High School's** fashion show are donated to charity. This year high school senior **Rebeca Wanderman** (see related article on page 6) asked the committee to donate the \$3,000 raised to Making Headway.

**Bridget Lavery**, president of the National Junior Honor Society at Kawameeh Middle School, in Union, NJ, and club members raised \$1,000 for Making Headway at their annual bowl-a-thon in honor of her cousin **John Buczynski**, a patient at the INN. 🌱



Above:  
Chuck and Riley Magner  
at Riley's Walk.

Bottom:  
Shira Antonoff with  
Samantha Robbins and  
her mom Lisa.





Mary Dale and Jeffrey Allen.

### Dr. Jeffrey Allen Honored

“Never have we known a doctor with more integrity or noble intent. Your devotion to each child guides your work and inspires all of us,” said Edward Manley to a standing ovation as he introduced Dr. Jeffrey Allen, the honored guest at this year’s *Tulip Festival Dinner Dance*. After a few characteristically, light-hearted quips, Dr. Allen shared his motivation for becoming a pediatric neuro-oncologist at a time when the profession scarcely existed: his son, Justin, who died in 1980 just shy of his 7th birthday. Among the voluminous ads that honored Dr. Allen in the *Dinner Dance Journal*, one page—with a precious photograph of Justin and dedication by Mary Dale Allen—expressed what every parent, child and colleague comes to feel about a man who sets the standard for “doctor” in every sense of the word. “The depth of your love for our son has been transformed into the gift of care for your patients and their families.”

### Major Fundraising Event a Great Success!

On Sunday, January 19th, four months of hard work culminated in the foundation’s major fund raising event of the year: a performance of Gilbert & Sullivan’s *The Mikado* at the City Center in New York City. More than 1,100 seats were filled by children and their families who laughed at the slapstick comedy when they weren’t marveling at the verbal acrobatics and

ridiculously delicious plot line. To make the event a financial success, 150 Making Headway families and friends did a magnificent job selling tickets to their friends and family—not an easy task at the end of the year and so close to the holidays! Their generous efforts resulted in a total of \$510,000 being raised and a cheery afternoon in the depths of winter.

### Family Fun Day 2003

Once again—for the fourth year in a row!—Maya and Edward Manley’s *Family Fun Day* was rain-dated. Once again, 150 soggy phone calls were made to 150 disappointed families. And once again, it was worth the wait when, one week later, the overcast morning cleared into one of the best *Fun Days* yet! While the sun smiled down on all of us, it was the smiles of delight and expectations-fulfilled that lit the day. It only takes one *Family Fun Day* at Maya and Edward’s to establish a family tradition—rain date and all! While it’s a pleasure for everyone in the magical way of magical days (when else do you see Dr. Allen playing tag or children patiently waiting over an hour for a wacky hat?!), it’s also a profound experience to share so much joy with a group of people whose common experience has made them Making Headway families. See you next year!



Above:  
Nurse Eileen Gillespie  
and Caroline Giles.



Molly Solomon and  
Jared Cappello.



Wacky Wendy, the hat maker and onlookers at Family Fun Day.



## Fore a Difference

Last September the first annual *Fore a Difference Golf Tournament*, organized by Sophia Casale's parents, Steve and Tracey, took place at Emerson Golf Club in New Jersey. The crisp morning warmed up into a perfect, cloudless day and by evening, \$46,480 had been raised for Making Headway. An equally spectacular day is planned as we go to press for September 29th. 🌻

## Tulip Festival Dinner Dance

The snow had barely melted as the tables were set for the 6th annual *Tulip Festival Dinner Dance* given in memory of Allison Trunz this past April. The tulips hadn't had a chance to bloom yet but everyone—looking beautiful and feeling handsome—had a magical evening. The keynote speaker was Dr. Fred Epstein whose very presence embodied the experience of struggle and love that brings us together each year. The Journal honored our deeply loved, deeply admired Dr. Jeffrey Allen and at the end of the evening, \$169,000 had been raised. 🌻



## Casino Night

Once again the annual *Casino Night* fundraiser in honor of Morgan Coutts, hosted by her parents Cheryl and Chris and good friends Jim and Chris Caci, was an outstanding success. Attendees played blackjack, roulette, craps, and took chances on silent and tricky-tray auctions, all in the name of Making Headway. By the end of the evening, the sold out crowd had raised \$55,600. Thank you to all who attended and all who donated prizes and their time. 🌻



## Little Bit of a Walk

Despite a forecast of a blizzard on its way, the 5th annual *Little Bit of a Walk* went ahead as scheduled April 6 under gorgeous skies at Point Lookout, NY. A record number of walkers—over 700!—helped raise \$22,500 for organizers Diane and Pat Ryan in memory of their daughter, Elizabeth who died of a brain tumor when she was 9. As usual, the money raised was allocated to research. 🌻

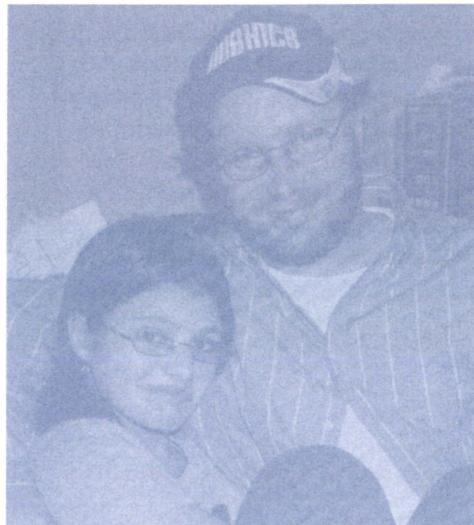
*Above:*  
The crowds at the start of Little Bit of a Walk.

*Center:*  
Chris Coutts, Edward Manley, Cheryl Coutts and Chris and Jim Caci at Casino Night.

*Bottom:*  
Kelsey Hawkins and her dad Stuart.

## Nicky's Big Hit Fundraiser

On June 1st, Nicky Mangione's parents, Teri and Frank, organized *Nicky's Big Hit Fundraiser* in honor of their son. Together with co-owners Sharon and Sal Agostinelli, they donated the use of their Long Island Baseball Academy. The kids enjoyed the batting cages; received individual instruction on pitching and hitting; devoured pizza and hot dogs; and diminished a 6 foot long submarine sandwich. The *Big Hit* was a big hit with a whopping \$3,775 raised for Making Headway. 🌻





### Individual Therapy: One of Many Facets of Support

*By Sallie Sanborn, Child Life Specialist*

What does it mean for a child or sibling to be able to write a book about having a brain tumor, or make drawings to illustrate different ways to take medicine or deal with frustrated or angry feelings?

For many years I have worked as a Child Life Specialist in a hospital setting and for the past 14 years have worked in private practice, with a focus on the psychosocial needs of children and families with medical issues.

My work combines technical awareness of medical procedures with an understanding of children's developmental levels and corresponding needs. It is my belief and experience that healing and growth can emerge from pain, illness and injury. I utilize talk and play therapy to help elicit children's feelings about their own or a family member's illness. We draw (a lot), play games (a lot) and talk (a lot). Emma Plankl, a pioneer in the field of child life and author of the classic "Children and Hospitals" wrote, "When we listen to the stories children tell and look carefully at the pictures they draw, we learn a lot about what illness means to them."

Illness affects each child and family uniquely and therefore requires a range of nurturing approaches. These can include support before, during and after a hospitalization; therapeutic play; guided medical play; home and hospital sessions; consulta-

tions with schools; and providing information and insight to families and schools regarding feelings and behavior of children as they cope with illness, injury or loss.

Sometimes when children are ill or affected by family illness, they need a special person just for themselves, to talk it out, play it out, draw it out and write stories about it. I feel honored every day to be working with the Making Headway families and staff. 🌱

### Teenage Program

When you put "teenager" and "brain tumor survivor" in the same sentence, the result is combustible. That's why Making Headway has funded a new program at the INN for teenage brain tumor survivors. Run by Honey Shields, Director of Child Life, the program addresses issues of social isolation by enabling kids to experience the kinds of activities that brought them joy pre-diagnosis. It makes all the difference when they are socializing with peers in the same boat. Each month, the group spends a day out in the city together. It might be for a baseball or basketball game; a visit to Chelsea Piers; maybe a show. It almost always includes pizza! While the teens are having fun, their parents have the opportunity to meet with Dr. Marcia Greenleaf for their own peer support group (because when you put "parents" in the same sentence as "teenager" and "brain tumor survivor," poof!). 🌱

### Support Services

Child Life Specialist Sallie Sanborn is available for individual counseling with your child as well as family therapy. The Teenage Program occurs monthly. Please call the Making Headway Office at (914) 238-8384 for details.

*Above:*  
Sallie Sanborn.

*Below:*  
The Teen Group at a baseball game.





## Superkids

Stories by Elizabeth Buttke

### REBECA

Positive-ly unstoppable.

The day Debbie and Harold Wanderman's baby girl began to crawl, she set more than her little legs in motion. She started her parents on a search for answers that lasted four long years.

As they watched Rebeca make her way across the floor, they noticed that she kept rubbing her left leg into the carpet. When the puzzling behavior persisted, so did their concern. Time and again, they consulted their pediatrician about it. But the doctor thought it was merely dry skin.

When Rebeca started walking, Debbie's experience as an Occupational Therapist kicked in. She felt sure something was wrong—even after the pediatrician said Rebeca walked just fine.

Consultations with doctor after doctor led to test after test, as they considered a range of possibilities—from Lyme disease to multiple sclerosis. Still, they found nothing wrong.

But when Rebeca began screaming out in pain as she played, or even just laid in bed, her parents consulted even more doctors. One after another, they said it was only growing pains—or simply Rebeca's way to get more attention after the birth of her baby brother. "Then an orthopedist thought maybe she had a hairline fracture," says Debbie. "But the X-rays showed nothing. So the orthopedist recommended an MRI."

When the MRI revealed a tumor inside the spinal column of then four-year-old Rebeca, the Wandermans were determined to take their child "to the ends of the world to find the best doctor." Their research brought them to Dr. Fred Epstein, who

quickly turned their fears into hope. Rebeca's surgery was so successful that eight years later when she had to write a school essay about her hero, Rebeca wrote about Dr. Epstein.

Little did Rebeca know then that two years later her hero would again save her life. In September 1999, after a routine MRI, Dr. Allen told the Wandermans that Rebeca's tumor was growing back. Once again, Dr. Epstein removed as much of the tumor as possible. And once again, Rebeca faced a long recovery regimen designed to get her to stand and balance and walk and function.

"The nurses and doctors and everyone at the INN were really fabulous," Debbie says, recalling the caring and compassion of everyone they met.

Debbie especially remembers how "Making Headway was there to support so many children. Maya has always been there with her wonderful words of encouragement, the phone calls, follow-ups, to make sure that you're okay, and psychologically handling it."

Now three years past her second surgery, 18-year-old Rebeca enjoys a close and mutually supportive relationship with her very protective 17-year-old brother Scott and her baby sister 11-year-old Nicole. She plays tennis, shoots hoops and works out regularly.

This September, Rebeca will enter Emory University with more wisdom than you would ever expect from one so young—until you meet Rebeca, in her own words from her college essay:

"Though I have undergone years of pain and frustration, I choose not to dwell on my condition. My illness has limited my physical ability; it does not define me. In fact, it has served as a catalyst in motivating me to achieve the unattainable. I've realized that I must shape my own life, make choices, set goals, and aspire to be the best that I can be. Those curveballs that life has thrown me have only made my will to succeed stronger. I strive to do my best, and even in the hardest of times, I never surrender."

Needless to say, Rebeca has come a very long way. Just think how far she is going to go! 🌱

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

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

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