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

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

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

*Top: Big smiles from Lila Smyth and Edward Manley.*

*Middle: Chris and Cheryl Coutts with guest Joe Dolan at the blackjack table.*

*Bottom: Sophia Casale giving Dr. Jeffrey Allen a new hair style.*

**A Few Words from Edward Manley, President**

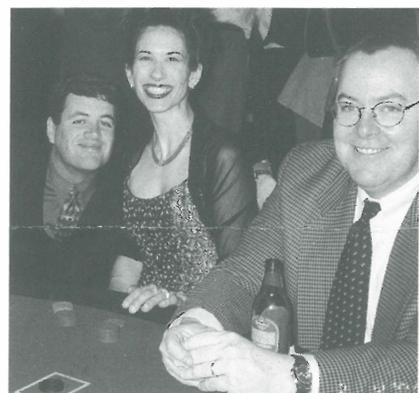


*Welcome to the year 2000! There is much exciting news to share in our first newsletter of the millennium.*

*Our fall fund raising event, "The Flying Fruit Fly Circus," was a great success. All three performances sold out and we invited about 700 children and their family members to attend free of charge. Best of all, we raised \$450,000, a sum beyond our expectations and one which reflects the hard work of the countless*

*families who helped sell tickets. Special thanks go to Elisa and Clint Greenbaum, Mindy and Sam Schwartz, and Tracey and Steven Casale for their outstanding efforts.*

*The year began with a bang. In early February, Jim and Chris Caci devoted many hours organizing an exciting new event, "Casino Night 2000." The evening honored their friends, Chris and Cheryl Coutts, whose daughter Morgan recently completed treatment for a brain tumor. Over 230 people attended and enjoyed an evening of roulette, craps, and blackjack, accompanied by a raffle and silent auction. Almost \$26,000 was raised on behalf of Making Headway.*



*I would like to send you our thanks for your immeasurable kindness and generosity which touches the lives of all the children and families we serve. In addition to continuing programs already in place, your contributions have enabled us to offer new services to both parents and children. For example, we have hired a new therapist, Dr. Lissa Parsonnet, to provide support services for families in northern New Jersey. Furthermore, Adam Auslander has joined our team to provide entertainment for children and families at the Institute for Neurology and Neurosurgery (INN) at Beth Israel. You can read more about both of them in this issue.*

*Our plans for the coming year include an expansion of our support services. We are currently conducting a series of parent focus groups from which new services will be developed. Keep a lookout for our fall newsletter and other upcoming events. Until then, warmest regards.* 🌸





### Meet Adam

For Adam Auslander, entertaining people is a way of life.

After graduating from their highly acclaimed clown school in 1988, Adam spent a year with Ringling Brothers and Barnum & Bailey Circus touring major U.S. cities. He describes it as one of the greatest experiences of his life. "Doing something fun, wacky, and creative" was encouraged every day. Adam has also worked with the Big Apple Circus, appeared on the Rosie O'Donnell Show and the Late Show with David Letterman, and annually trains the clowns for the Macy's Thanksgiving Day Parade. His professional experience also includes acting in a wide variety of commercials, short films, and off-Broadway productions.

Having spent the past seven years as part of the Big Apple Circus Clown Care Unit, Adam is no stranger to hospitals. He has entertained kids and adults at Columbia Presbyterian Hospital, New York University Hospital, and Memorial Sloan-Kettering Cancer Center, among others.

Last fall, Making Headway asked Adam to become part of its team to provide support services at the INN. "I'm a clown," says Adam, "and it is wonderful to see how I, in my own way, contribute to a child's experience in this place."

Using a large repertoire of entertainment approaches—including stand-up comedy, improvisation, magic, music, juggling, puppetry, and hat and card tricks—Adam divides his time between the waiting and reception rooms, the day and inpatient playrooms, and the ICU, providing relief and diversion for parents, siblings, and staff. "I love this work," he says. "There

is nothing more rewarding than to have a kid in the worst possible circumstances say to me 'I love you,' or 'You're so funny.'"

Adam says he is extremely happy to be a part of Making Headway's support network for kids and their families undergoing treatment. We thank him for providing brilliant smiles, side-splitting laughter, and moments of pure joy. 🌸

### And the Winner Is . . .

In April, Making Headway Foundation held its third annual "All-is-onE" Tulip Festival Dinner Dance in Long Island. To illustrate this year's invitation and journal cover, the Foundation organized a Poster Painting Contest this past fall. All children, from ages 3 to 18, who are or were patients at the INN, were eligible to participate.

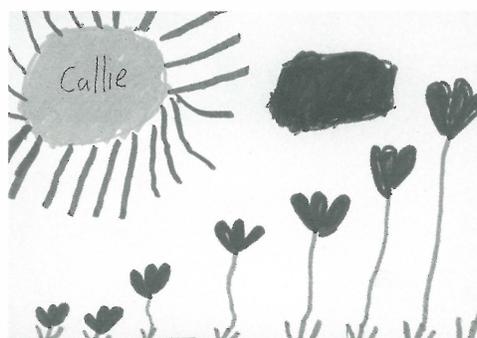
"We had an overwhelming response to the contest," said Joan Fyfe, Making Headway's Administrator and one of the contest judges. "It was a very difficult process to make a final pick as each poster submitted was uniquely beautiful."

After much deliberation, two first prize winners were chosen and will be awarded a \$75 savings bond. Elizabeth Marciano's drawing is featured on the invitation and Callie Hacker's drawing is featured on the journal cover. 🌸

*Top: Dara Helfant and Adam Auslander having fun together.*

*Middle: Shanna Church making a very important phone call.*

*Bottom: Prize-winning posters by Elizabeth Marciano and Callie Hacker.*



## Making Headway's After Care Program: Providing Guidance, Understanding, Compassion, and Support

*Is your child having difficulty in school?  
Do your other children feel left out?  
Are you worried and unable to relax?*

When your child is diagnosed with a brain or spinal cord tumor, emotional upheavals can be as disruptive as the disease itself, causing devastating effects to your entire family. Each family member—including patient, siblings, and parents—experiences a startling variety of reactions, and deals with them differently at various stages.

Once your child has undergone diagnosis, surgery, and post-operative treatments, such as chemotherapy and radiation, your family is faced with the day-to-day reality of recovery. Learning to cope on your own, trying to regain a more “normal” life, often requires a different sort of help as you are now faced with a new set of problems. Your child may experience attention, concentration, and behavioral problems. Siblings may feel abandoned, scared, and angry. You may feel overwhelmed and isolated.

Making Headway recognizes the importance of providing help and support for you and your family at this stage.

Free of charge individual counseling, support groups, and a learning specialist are on hand to help you handle school, social, and family stress.

## Meet Making Headway's Experienced Support Services Team:

### Marcia Greenleaf, Clinical Advisor/ Health Psychologist



Dr. Greenleaf holds monthly support groups in New York City for parents, patients, and siblings and is also available for one-on-one counseling either by phone or in person.

### Lissa Parsonnet, Psychotherapist



Dr. Parsonnet is available for one-on-one counseling for parents, patients, and siblings in northern New Jersey. Monthly support groups in the same area are being planned.

### Rebecca Mannis, Learning Specialist



Dr. Mannis is available to work with you and your child to identify ways to address educational difficulties such as concentration and memory. Her office is located in New York City.

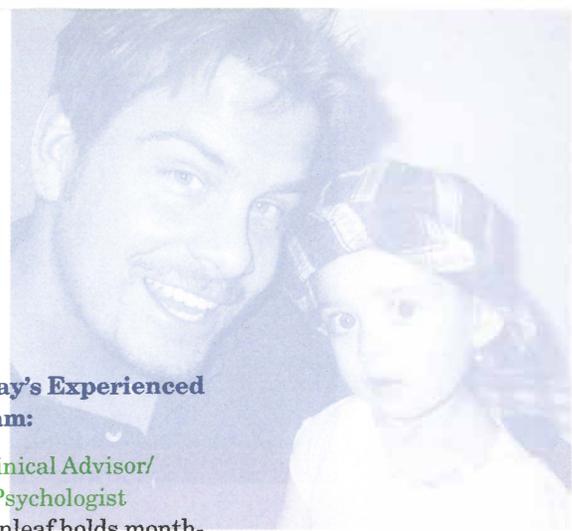
**Support Groups** for patients, parents, and siblings are offered monthly in New York City and shortly in northern New Jersey. Discussions cover issues such as fear, confusion, anger, and isolation. Learn to develop skills and strategies that will help you and your family better cope with stress.

**Individual Counseling** can be arranged at your convenience in both New York City and northern New Jersey. If you feel uncomfortable discussing issues in a group, one-on-one sessions are a more private and intimate option. Office visits and/or telephone consultations are available.

**Learning Specialist** appointments for children experiencing difficulties when returning to school are offered in New York City. This is particularly helpful for children experiencing problems concentrating, retaining information, and following instructions.

*Top: Chris Stevens with his daughter Ciara in the INN playroom.*

*Bottom: Cherraine Davis playing doctor with her dad Keith.*





## Superkids

Stories by *Elizabeth Buttke*

### Scott

#### He won't let anything get him down

"As my handsome boy comes bounding through the door, bursting with energy, it's hard to believe he's not in perfect health," says Joanne Reisser. But the sad fact of the matter is, almost five years ago at the age of 11, Scott was diagnosed with a brain tumor.

When that unimaginable news first came to light, it cast his family in the darkest shadow of their lives. Scott's then 14-year-old sister, Liz, tearfully asked if her brother was going to die, echoing out loud the unspeakable fear that Joanne and her husband Fritz harbored in their minds.

Although Scott had been erupting in uncontrollable temper tantrums from the time he was two, neither his parents nor the many doctors they consulted ever attributed his behavior to a brain tumor. Even when Scott started having seizures many times a day, the Reissers were told it is not uncommon for kids to develop epilepsy during the pre-adolescent stage.

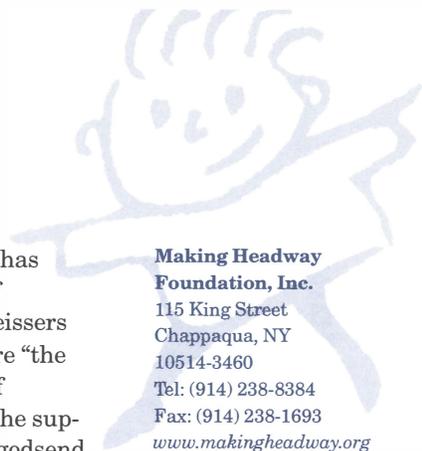
An MRI finally revealed the horrible truth. Scott had a massive brain tumor that had probably been there since birth. From the depths of despair, the Reissers' spirits soared into the heavens when Dr. Fred Epstein told them the tumor was benign and could be removed.

As Scott recuperated from surgery that removed 95% of the huge tumor, Joanne spent day after day in the hospital. She recalls her first meeting there with Maya Manley, saying, "I could not know then how much I would come to rely on her and all the Making Headway angels."

Because Scott's relentless tumor has caused him to undergo two bouts of chemotherapy since surgery, the Reissers have come to appreciate all the more "the incredible overwhelming support of Making Headway," says Joanne. "The support groups especially have been a godsend to me. Marcia Greenleaf is a gifted therapist and it's wonderful to have such a caring professional to count on. I can cope so much better with the fear and uncertainty, and be able to share those feelings with other parents."

As for Scott, he has never stopped doing the things he loves: going to skateboard camp and tennis camp, playing on a silver medal-winning national roller hockey team, and learning to ice skate so he could make the school ice hockey team.

He also loves watching his favorite pros snowboarding in Utah on the video machine Making Headway installed in the MRI. Besides being a lot more fun than just looking around and listening to those awful loud noises, it's a great way for Scott to pick up some cool snowboarding tricks for himself. 🌱



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*Top: Joanne and Scott Reisser.*



*Middle: Kedar Mertz enjoying a song with Tina Brescia, music therapist.*

*Bottom: Maya Manley and Anthony Bodah enjoying cupcakes they have just decorated.*