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

A Few Words from Edward Manley, President

Making Headway has made great strides forward during the past year. I invite you, our supporters, to read about the Foundation's programs that have benefited so many children and their families.

A View from Inside

A Message from Joan Fyfe, Administrator



As we mark the end of Making Headway's third year and my second year as Administrator, I am struck by what an extraordinary period the past twelve months have been for the Foundation.

Last year, we sent a survey to all families on our mailing list and the response was overwhelming. Many important issues and needs, both old and new, were identified. The largest request was for information. In response, we provided a list of information and referral services in the tri-state area, courtesy of the United Way of Westchester-Putnam. We also mailed all families a copy of Exceptional Parent magazine's "1999 Resource Guide." It includes a wealth of information on available resources and organizations.

A second need was for individual counseling and support groups in northern New Jersey. We have completed our interviews, and will have a therapist available this fall. Making Headway's web site—www.makingheadway.org—is up and running, and lists the dates of our monthly support group meetings. Being online extends Making Headway's outreach even more—requests for information have come from Peru, Brazil, and Asia.

Plans are underway to provide other services requested in the survey. In the upcoming year, under our After Care Program, we aim to include seminars and workshops for parents and a therapist in Long Island. We must, however, be prepared to meet the changing needs of our constituency. If you see a need that should be addressed, please don't hesitate to call me. The information you provide is very important as we work to improve our services.

During this dynamic and exciting time, some things have remained absolutely constant. We continue to be blessed with Making Headway's co-founders, Maya and Edward Manley and Clint Greenbaum, whose work has inspired so many, and with wonderful volunteers such as Greg and Jeannie Trunz, who chaired the successful Dinner Dance, Sam and Mindy Schwartz, who have raised substantial funds for research, Diane and Pat Ryan, for organizing the walk-a-thon, all the families who helped us sell tickets to our "Christmas Carol" fund-raising event, and so many more who never fail to give above and beyond the call of duty. Thank you one and all.

Last, but certainly not least, my sincerest thanks to you our donors. Making Headway's success is due, in large measure, to your support and trust. You are the foundation on which we are able to build.

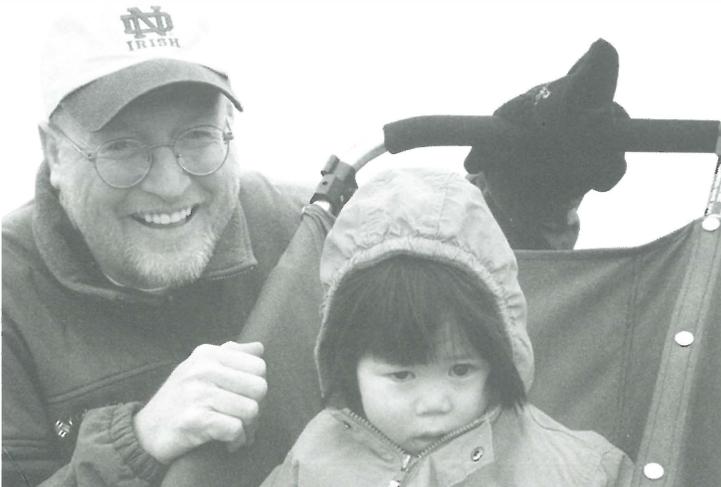


Sun, Sea Air & a Little Bit of a Walk

Imagine the smell of salty, fresh sea air. Imagine rows of small, quaint houses. Imagine a group of dedicated people rising early on a Sunday morning for a good cause. On April 11, 1999, approximately five hundred people did just that, and over \$10,000 was raised for Making Headway.

Held at Point Lookout, New York, a village on the south shore of Long Island, the *Little Bit of a Walk*, a 1.6 mile walk-a-thon, was organized by Diane and Pat Ryan in memory of their daughter Elizabeth, who passed away on December 22, 1997, of a brain tumor.

The walkers included people of all ages—ranging from grandparents to teenagers to babies in strollers. T-shirts commemorating the event, a light breakfast, and music were all donated anonymously. Thanks to all of you who gave up your regular Sunday routine—whether it be reading the paper, going to Church, or simply sleeping in. The steps you took will provide leaps and bounds for others in need.



Stop & Smell the Flowers

Amid forty-thousand tulips, Making Headway celebrated its second annual Tulip Festival Dinner Dance and Silent Auction—named “All-is-onE”—at the Swan Club in Glenwood Landing, New York, on April 22, 1999. This magical evening raised approximately \$100,000, which will fund Making Headway’s After Care Program and other INN projects.

The evening included a wonderful cocktail hour just as the sun was setting, followed by a superb dinner. Heartwarming speeches were made by Greg Trunz, host and owner of the Swan Club, and Dr. Jeffrey Allen, Chief of Pediatric Neurology at the INN, among others. Irresistible dance tunes were provided by the Herb Carlin Orchestra. The journal brought smiles, laughter, and tears as people leafed through it during the evening, discovering messages of love and support.

It would not be an exaggeration to say that everyone went home happy!

Bah, Humbug!

Ebenezer Scrooge, Tiny Tim, and all the ghosts were present for Making Headway’s major fund-raiser, a performance of Charles Dickens’ classic tale, *A Christmas Carol*, held on December 6, 1998, in the theater at Madison Square Garden. The event raised \$370,000, exceeding our expectations as well as last year’s total, and will fund the three ongoing positions in the Child Life Department at the INN as well as other projects.

Through the sale of sponsor tickets, over 1,700 children and their family members were invited—*free of charge*. One hundred and twenty-five INN families and forty families whose children were patients at other New York hospitals attended the performance. A large number of sponsor tickets were also given to children’s organizations and special schools.

The afternoon was filled with oohhhs and aahhhs, laughter and smiles. Scrooge be gone!

Above: Dr. Fred Epstein, Director of the INN, and members of the INN team, having a good time at the Dinner Dance.

Left: Enthusiastic walkers holding a painting of Elizabeth.

Below: Smiles from walk-a-thon supporter Kevin Heneghan and his daughter.

Save the Dates:

New Fall Event
Flying Fruit Fly Circus
 Saturday, December 11,
 Sunday, December 12,
 and Sunday, December
 19, 1999

Little Bit of a Walk
 Sunday, April 2, 2000

**Tulip Festival Dinner
 Dance**
 Thursday, April 13, 2000

Since its inception three years ago, Making Headway has focused its efforts on establishing a continuous program of complementary care and humanistic support for families of children with brain and spinal cord tumors and other catastrophic neurological illnesses. The programs and support services listed below cover care *before surgery, during the hospital stay, and after the child returns home.*

At the INN:

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. To date, we have approved over \$600,000 in grants for support and quality-of-life programs which make the hospital stay significantly more comfortable for both parents and children, while enhancing the excellent care provided by the doctors, nurses, and staff.

Making Headway funds three ongoing positions in the Child Life Department: a Music Therapist, a Child Life Therapist, and a Recreational Therapist.

New projects funded during the past year include:

- A full time psychologist, to help parents cope with the devastation of their child's illness and to assist the staff in addressing the stresses they face in dealing with sick children.
- A Welcome Kit for each family entering the hospital, consisting of a tote bag, t-shirt, baseball cap, toiletries, and information covering the hospital stay.



- An ultra-low temperature freezer, for preserving brain tumor specimens for research.
- Our first project sponsored by the Michael Schwartz Research Fund: "The Pathogenesis of Disseminated Low Grade Glial Tumors in Children," under the direction of Dr. Jeffrey Allen, Chief of Pediatric Neurology.

After Leaving the Hospital:

Our After Care Program continues the care and support once the hospital stay has ended, as parents are left to cope by themselves, trying to return to a more "normal" life. Making Headway has provided \$130,000 for free of charge support groups, individual psychological and educational remediation counseling, funeral expenses, and periodic bereavement groups.

Serving as the Foundation's Clinical Advisor, Dr. Marcia Greenleaf leads four support groups:

- *Parents of children within one year of diagnosis*
- *Parents of children one year after diagnosis*
- *Youth group for teenage brain tumor survivors*
- *Siblings of brain tumor children*

Dr. Greenleaf also provides individual counseling for parents and children who do not feel comfortable in a group session.

So many children who survive a brain or spinal cord tumor experience learning difficulties when returning to school. Learning Specialist Dr. Rebecca Mannis is on hand to assist parents and children in identifying ways to address these educational difficulties.

Making Headway offers all the After Care Program services free of charge. For more information and support group schedules, please contact the office at (914) 238-8384.



Above: Dr. Marcia Greenleaf enjoys a moment with Matthew Greenzweig.

Below Left: Drs. Epstein, Berenstein, and Allen, and others, receiving the Welcome Kits.

Below Right: Jerry Cifrodelli getting a kiss from INN Administrator JoAnn Baldwin.

"The availability of such post-treatment therapies is probably as important and in some cases more important than the more readily identifiable medical treatments. It has been demonstrated time and time again that the emotional healing is just as important as the physical healing. I would hope to attend many more of these worthwhile sessions."
—Lou Greenzweig, father of a brain tumor survivor, after attending a support group for parents sponsored by Making Headway



Making Headway Relocates

Having outgrown the home office, Making Headway moved to larger quarters in Chappaqua nine months ago. See end page for our new address.

It's a Wrap!

Many thanks to Pat Bartimoccia and the other volunteers of the Northern Star Quilt Guild. They donated forty children's comfort quilts to Making Headway. The quilts are being used to keep children warm and cozy while undergoing chemotherapy treatments at the INN day hospital. Thanks also to Jennifer Sappell, who created a beautiful quilt in honor of Making Headway. It hangs in our new office for all to admire.

Wedded Bliss

Congratulations to newlyweds Marianne and Dan Marinello, Jennifer and Christopher Crotty, and Bridget and Dan Connolly! Our thanks to all three couples, who made generous donations to Making Headway in lieu of wedding favors.

Rites of Passage

Congratulations to Daniel Chertoff, Daniel Fink, and Aaron Weininger on the occasion of their Bar Mitzvahs, and to Ashley Newman and Brooke Schepp on the occasion of their Bat Mitzvahs! All five generously arranged for a portion of their gifts to be donated to Making Headway.

A Bevy of Babies

Congratulations to several parents on their new arrivals: Sydney Beth Coutts, born March 30, 1999, to Chris and Cheryl Coutts; Matthew Robert DaRosso, born June 20, 1999, to Dr. Robert and Marisol DaRosso; and Anthony James Lane, born June 27, 1999, to Jim and Patty Lane.

Bears, Books & Baseballs

Inspired by a similar gift given last year, Andrea Seidman delivered a van full of toys she collected at her child's school for Making Headway to distribute at the INN. Barbara O'Donoghue also collected a multitude of toys and delivered them to the INN's playroom in honor of Making Headway. Thanks to both for their generous donations.

And the Award Goes To . . .

Congratulations to JoAnn Baldwin, who was recently recognized by the entire INN staff for her outstanding work. Congratulations also to Maya Manley, who was awarded a lifetime membership in the New York State PTA in recognition of her work for children through Making Headway.

On the Corporate Side

If your company has a matching gift program, simply fill in the form and send it to us—we'll do the rest. In addition, if your company has a United Way Campaign you can designate your gift for Making Headway. Our number is 028207.



Above: Edward Manley, Making Headway's President, and Andrea Seidman.

Above Left: Rachel Don and her sister Becky wrapped in a comfort quilt.

Below: INN Psychologist Dr. Jean Donnelly and Child Life Specialist Jenna Gelfand giggling with Balkis Leal.



A Little Fairy Dust

Who better than Peter Pan to lead us up, up, and away, off to Never-Never Land, where dreams come true?

Sheilah Beckett, a world-renowned illustrator of children's books, certainly thought so. Working for eight weeks, she created a sixteen-foot painted mural of Peter Pan and Tinkerbell leading Wendy and her brothers into the night sky. She donated this work to the INN in honor of Making Headway.

The wonderfully playful and colorful mural hangs on the wall outside the operating room at the INN. The mural helps to fill children's minds with images of fairies and flying before they enter surgery, and hopefully inspires sweet dreams during.

Thank you, Sheilah!

Superkids

Stories by Elizabeth Buttke

Megan

How she got to be a whiz at MRIs

For the first half of twelve-year-old Megan's life, she seemed to be as healthy and happy as her younger brother Thomas. Then in April 1993, Megan's eyes started to hurt, she was getting nauseous at night and throwing up in the morning. After treating her for what seemed to be an allergy, Megan's parents, Ellen and Tom Rasmussen, noticed a tremor in Megan's hands as she reached for things.

Their doctor thought it was probably from "too much allergy medication." But when an eye doctor spotted swelling behind Megan's eyes, a subsequent CAT scan revealed hydrocephalus and "some sort of blockage." Then an MRI resulted in a devastating diagnosis: their beautiful little girl had a brain tumor.

Dr. Fred Epstein and Dr. Jeff Allen were consulted, and decided the tumor was so deeply situated that surgery was not an option. "They felt we should just watch and wait," says Ellen. The waiting was hard on Megan's parents, but the watching was even harder on little Megan—who had to endure MRIs at her local hospital every three months at first, then once a year.

In 1997, when the MRI showed a significant increase in tumor size, Dr. Allen started Megan on chemotherapy at the INN—where she was delighted to find even the dreaded MRI had a friendlier face, thanks to its accompanying video machine funded by Making Headway.

Recalling Megan's seventeen-month ordeal with chemo, Ellen says "My whiz kid of a daughter, who's in the gifted program at school, kept on getting almost straight A's that whole time. And she packed everything she could into the first three days of the week, because she knew she'd be sick Thursday afternoon, usually Friday, and sometimes on the weekend."

In spite of enduring all that, and the loss of her thick, wavy Rapunzel-like hair, Megan came shining through—and the chemo reduced her tumor to about the size it was before its alarming growth.

"It would have been much harder," says her mom, "if Megan didn't have someplace to go that was fun. But she loves the playroom at the INN." In fact, often when Megan would be done with her treatment, she'd say "Oh, we can't go yet, because I have to finish this"—referring to one of the art projects (or maybe the basket of candy) provided by Making Headway's Maya Manley, who, Megan says, "is one of the most important people in the hospital!"

Left: Detail of Sheilah Beckett's amazing mural.

Below: Megan showing off her bubble gum skills.





Intensive Caring: On the Way Back
By Dr. Marcia Greenleaf

Families who have had their lives shattered by a child's brain or spinal cord tumor, or some other catastrophic neurological disorder, can find enormous comfort in a safe, secure hospital setting. But when the child is discharged, feelings of fear and uncertainty can be overwhelming for all concerned.

Suddenly the future is filled with unknowns. There is no simple guide book to lead the children, their siblings, and their parents on the most difficult journey of their lives. But there is help. Like outstretched hands and open arms, Making Headway's After Care Program welcomes all those who feel lost and alone in the face of such frightening, confusing times.

As a health psychologist, my role in the After Care Program is to help parents understand what is happening—and to help each member of the family develop the skills and strategies they will need to feel grounded and secure in the midst of the turmoil.

Because each child has a different rate of recovery, there is no set formula for the recovery process. Problems with mood swings, memory, concentration, and attention vary as much as the children who exhibit them. Parents and siblings also have different rates of recovery from the stress of illness in the family. As each person involved struggles with different kinds of issues in an attempt to re-enter his or her own world, unexpected happenings occur. When problems are overlooked or not identified, actions and decisions can cause even more problems and more stress.

Whenever necessary, I will refer parents to another member of the Making Headway network: Rebecca Mannis, Ph.D. Besides teaching recovering chil-

dren how to best manage their return to the classroom, Dr. Mannis is an effective advocate who helps ensure that the child's school system provides everything he or she needs.

By sharing what we have learned from the many hundreds of families who have walked this way before, Making Headway's After Care Program enables us to make every step of the way back a little lighter for all those who follow.

Here's a Thought . . .

By Maya Manley

An island. That's how I always think of the playroom at the INN. A friendly place for children to undergo their therapies *while* having fun. The staff and volunteers work hard to furnish an environment which encourages the children's self-esteem and—through music and art projects—sparks their creativity. For the parents, the playroom has also become a special spot. It provides them with an opportunity to meet other parents, to share information, and to gain hope.

I have always felt very strongly that one of Making Headway's main goals should be to provide these "islands" of comfort and support, whether at the INN's playroom or at a support group. Based on my own personal experiences with my daughter, I know this is not a journey any family should have to undergo alone. Both parents and children need places in which they can feel secure and loved.

For me, one of the best parts of the day in the playroom comes at about six o'clock. The children have been poked and prodded and have endured procedure after procedure, yet they still wish to linger. "Just a few more minutes" is like music to my ears. It makes me believe that this "island" truly has become a sanctuary.

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Above: Meow! Lila Hollensteiner in her favorite role from "Cats."

Left: Maya Manley with Susan Olshansky in the playroom.

