

MAKING HEADWAY NEWS



Fall 1998

Looking Back—Looking Forward

A Message from Edward Manley, President of Making Headway



Edward Manley with a special friend,
Claire Santiago

Another successful year is behind us here at **Making Headway**. Our fundraising surpassed that of the prior year, we added new support groups, offered individual psychological and educational consulting programs, and funded many needed projects at the Institute for Neurology and Neurosurgery (INN) at Beth Israel Medical Center in New York City. Above all, we helped many new families cope with the diagnosis of their child's illness, and made their lives more comfortable while undergoing surgery and treatment.

The achievements of this past year could not have been accomplished without the generous support of our donors as well as all the families who sold tickets to our principal fundraising event, Walt Disney's "World on Ice," which raised a record \$350,000!

Kudos go to Joan Fyfe, who joined as the Foundation's Administrator last August to help us prepare for future growth. She has streamlined the organization and made it operate on a much more professional level.

This newsletter—**Making Headway**'s second—includes information about our realized and projected goals, our fundraising events of the past year, and some thoughts from Clint Greenbaum, our Treasurer.

It also introduces you to the touching stories of two children and their families, as well as including other news and events.

We approach our third year with enthusiasm, energy, and the confidence that **Making Headway** can and will do much more for the children and their families. What a wonderful situation to be in!

On a Personal Note

A Message from Clint Greenbaum, Treasurer of Making Headway

Every adult I have ever met has had his or her share of personal misfortune or tragedy. As we all know, that's life. But when tragedy strikes a child, no attempts at explanation—and no amount of consolation—can diminish the darkness it brings.

For the parents, it seems the darkness will never end. But all of us who have lived through the nightmare have found that glimmers of hope, and moments of happiness, can and do shine through the gloom—especially every time a smile lights up the child's face.

My son Jake was only three months *new* when we discovered that he had a rare malignant brain tumor. Through a combination of medicine and miracles, Jake has survived. Today, in spite of the deficits he has due to his illness, Jake is a very happy and active eight-and-a-half year old.

My wife and I are thrilled to have our Jake healthy and whole, and we know how fortunate we are. But we want so much more. We want *all* children who suffer the tragedy of brain and spinal cord tumors to be free of pain and suffering.

That is exactly why we are so involved with **Making Headway**. The Foundation not only helps children who are seriously ill today; its goal is to help children of tomorrow as well. Ultimately, **Making Headway** also hopes to fund research—to help find a cure for this dreaded disease. To that end, **Making Headway** is run as a very lean foundation. About 92% of every dollar donated is available to fund program activities. Some of the ways **Making Headway** puts your donations to good use are highlighted in this newsletter. We hope you will take a few minutes to read about them.

I know **Making Headway** is just one of approximately 600,000 charitable organizations in America, and I know there are only so many that any one person can support. But what can be more worthy than helping to give children not just a better life, but life itself.



Ready with a smile, Jake and Clint Greenbaum

Founders

Edward Manley, President
Maya Manley, Secretary
Clint Greenbaum, Treasurer

Administration

Joan Fyfe, Administrator

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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.

The Year in Review

The Tulip Festival: A Dancing—Dining—Delight

On April 23, 1998, **Making Headway** held its inaugural Tulip Festival Dinner Dance and Silent Auction at the Swan Club in Glenwood Landing, New York; over \$107,000 was raised. Congratulations are due to the organizing committee of this unforgettable event, to the 311 guests who attended, and to the many donors who contributed.

Guests were warmly greeted by the gracious co-chairs of the event, Greg and Jean Trunz, owners of the Swan Club. The Trunzes generously offered their facility as the site for the event, named "All-is-onE" in honor and in memory of their daughter, Allison, who passed away on August 12, 1997, at the age of four, of a malignant brain tumor. Greg and Jean said, "our daughter's strength, courage, and love of life touched and forever changed all those who knew her. It is our hope that the evening will raise substantial funds for **Making Headway** and by doing so ease the suffering of some desperate families."

The evening began with a festive cocktail hour, while guests had an opportunity to look over the various items donated for the Silent Auction. A selection of California red wine, spa packages, a VCR, a microwave, various pieces of silver and gold jewelry, and tickets to the Rosie O'Donnell show (complete with limousine escort) were among the items bid on quite competitively!

Dinner was served in the main dining room, interspersed with a welcome speech by Greg Trunz; remarks by Dr. Fred Epstein, Director of the INN, where Allison Trunz had her treatment; and an inspiring talk about siblings by the Reverend Jack Miller. Dr. Marcia Greenleaf, Clinical Advisor to **Making Headway's** After Care Program, introduced Matthew



Left to right: Carol and Harold Mondschein, with co-chairs Greg and Jean Trunz

Greenzweig—a brain tumor survivor—who received a standing ovation after playing his original composition for piano entitled "Recovery." Joan Fyfe, **Making Headway's** Administrator, gave a brief commentary on the organization of the event, recognizing its committee members. Edward Manley, President of **Making Headway**, spoke about the mission and goals of the Foundation and highlighted its achievements of the past year. The Foundation's Secretary, Maya Manley, shared some of her experiences with the children and the parents she comes into contact with throughout the year during her weekly work in the playroom at the INN.

While dessert was being savored, Glenmar Studios presented a video they had created exclusively for this event, which included images of countless children and families enjoying themselves at the INN, at **Making Headway's** "Walt Disney's World on Ice" benefit, and at the 1997 Family Fun Day.

Throughout the evening, guests enjoyed music by and danced to The Herb Carlin Orchestra, led by Herb Cohen and featuring vocals by his wife Anne. Herb and Anne are parents of a brain tumor survivor.

All proceeds from the Tulip Festival Dinner Dance, the Silent Auction, and the accompanying journal will be used by **Making Headway** to fund humanistic support programs and quality-of-life improvements for the pediatric floor at the INN.

Save the Dates:

- The second annual Tulip Festival Dinner Dance and Silent Auction to benefit **Making Headway** will take place on Thursday, April 22, 1999.
- This fall's major fundraiser will be a musical production of Charles Dickens's "A Christmas Carol" at Madison Square Garden on Sunday, December 6, at 5 p.m.



Mary Jane Newman with members of Lilith and Musica Antiqua

Lilith: Female Voices Join in Song to Benefit Making Headway

Mary Jane Newman directed the inaugural concert of Lilith at the Weill Recital Hall at Carnegie Hall, in New York City, on Thursday, May 28, 1998. Lilith was accompanied by Musica Antiqua, New York, the critically acclaimed period-instrument orchestra. A portion of the concert's proceeds was donated to **Making Headway**.

Lilith is a fourteen-member women's choir that explores seventeenth- and eighteenth-century contrapuntal music. This young and vibrant ensemble created a distinctive and spiritually profound listening experience. The concert featured material from Lilith's upcoming debut Vox CD release "Hymns to the Goddess."

After the concert, **Making Headway** hosted a champagne reception to thank the artists and to acknowledge their gracious donation. In attendance were many **Making Headway** supporters.



Cheryl and Morgan Coutts enjoying a special moment together in the INN's playroom



Making Headway Makes a

The Realization of Making Headway's Efforts

Since its inception in 1996, **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 cover care *before* surgery, *during* the hospital stay, and *after* the child returns home.

It is through the generous donations of its supporters that **Making Headway** has provided the following services:



Child Life Specialist Jenna Gelfand giving some tender loving care to Jamie Kocher

At the INN:

A Health Psychologist

who helps parents deal with the crisis of their child's illness and prepares children for surgery and other frightening procedures

A Recreational Therapist

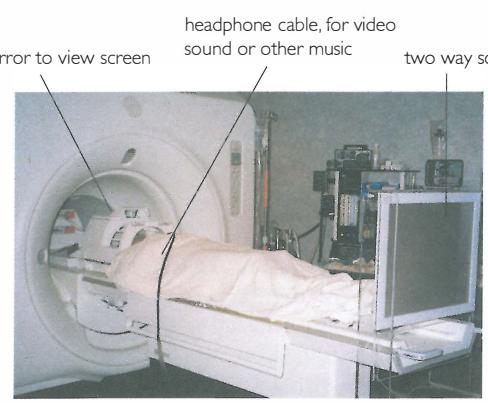
who keeps the in-patient playroom open on weekends, so that children and their parents have a place to play and relax

A Licensed Music Therapist

who uses music therapy with children to reduce their anxiety and pain, and to promote feelings of happiness and serenity

A Child Life Specialist

who staffs the day hospital playroom, interacting and playing with children while they undergo treatments



Magnetic Resonance Imaging (MRI) with relaxation system

MRI Relaxation System

While undergoing the MRI exam, patients—particularly children—are often anxious. Sedation is frequently necessary, sometimes causing delays and further anxiety. The MRI Relaxation System permits a child to watch a video while undergoing the exam. If a child prefers to listen to music, there is also an AM/FM radio and a CD and cassette stereo system. The MRI Relaxation System reduces or eliminates the need for sedation and, more importantly, helps anxious patients to relax by taking their minds off the procedure. INN staff members have noted considerably fewer delays since its installation.

Hercules: A Show of Strength



The Kiernan family enyoing "Hercules"

Making Headway's major fundraiser was Walt Disney's "World on Ice," featuring the story of "Hercules." Held November 10, 1997, at Madison Square Garden, the event was tremendously successful! The theme was particularly appropriate in light of the Herculean courage demonstrated by the children and families undergoing the ordeal of brain and spinal cord tumors. It also reflected the Herculean efforts displayed by the nurses, volunteers, friends, and doctors who have helped **Making Headway** become such an outstanding success.

All 2,500 seats were filled, and the event raised just over \$350,000, exceeding all expectations, and surpassing last year's total by seventeen percent. Approximately one hundred volunteers helped the Foundation sell tickets.

Through the sale of sponsor tickets, **Making Headway** was able to invite 1,800 sick and/or underprivileged children and their family members to the event—*free of charge*—for an afternoon of fun and excitement. Over one hundred families, whose children are patients at the INN, and sixty families, whose children are patients at other

New York hospitals, attended the performance. Sponsor tickets were also given to the following organizations: Friends of Karen; Green Chimneys Children's Services; Inner City Schools of New York City; Camphill Village for mentally handicapped children and adults; HeartSong; and Westhampton Beach BOCES School.

Making Headway gratefully acknowledges all those who made this day possible. There is no way to describe the joy, excitement, and fun this day delivered for so many.

Difference 1997-1998



Purchase and Installation of Washer/Dryer

on the in-patient floor, so that parents no longer need to leave the hospital to wash their child's favorite pajamas and blanket

Purchase of Wooden Play Furniture for the day hospital playroom—including a little kitchenette, an ironing board, a play wash machine, and a doll house—to provide a variety of play activities for children while they undergo treatment

Development and Production of Education Videos

to help families face the unknown—often the hardest part of treatment, to ease children's fears, and to educate parents about medical procedures, including:

- Preparation for Surgery
- Radiation Therapy
- Treatment for Spasticity

Getting the Word Out

with the publication of the proceedings of Dr. Fred Epstein's (Director of the INN) international conference on the treatment of ependymoma, a type of childhood brain tumor, in the *Journal of Pediatric Neurosurgery*

After Leaving the Hospital:

After Care Program

to meet the families' needs for services once their child leaves the hospital

Making Headway sponsors an After Care Program to help families and patients understand the challenges they face in the post-operative and recovery phase, and to help them develop the resources to deal with these challenges.

The program currently includes four support groups led by Dr. Marcia Greenleaf, the Foundation's Clinical Advisor:

- Parents of children within one year of diagnosis
- Parents of children one year after diagnosis
- Youth Group: Brain and spinal cord tumor survivors
- Siblings, eight years and older

For those parents who do not feel comfortable in a group session, Making Headway provides individual psychosocial counseling with Dr. Greenleaf.

In addition, as so many children who survive a brain or spinal cord tumor experience learning difficulties when returning to school, Dr. Rebecca Mannis, a Learning Specialist, is available to assist parents and children in identifying ways to address these difficulties.

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



From left to right:
Conference participants
Drs. Jeffrey Allen, Mark
Rosenbloom, Fred Epstein,
Dan Lefton, Paul Griebman,
and Larry Kun

Helping Making Headway

Your support is needed both now and in the future.

To make a donation or to find out ways in which you can help, please contact Making Headway at (914) 238-8384.

Seen and Heard: Things You Should Know

Michael Schwartz Research Fund

In celebration of his continued progress, **Making Headway** has established the Michael Schwartz Research Fund. Contributions accumulated in this fund will be used to support medical research projects aimed at finding the cause of, and a cure for, brain and spinal cord tumors.



Michael Schwartz,
an inspiration to us all

Making Headway's New Offices

Making Headway will be moving into larger and more convenient offices in Chappaqua, NY. Stay tuned for more information and don't worry—the old address and telephone number will remain valid after the move.

On-Line News

Making Headway makes its debut on the world wide web this fall. Look for us, along with links to additional resources, at the following address:
<http://www.makingheadway.org>
As always, we can be reached by telephone at (914) 238-8384.

New Arrivals

Congratulations to Greg and Jean Trunz, whose daughter Kathryn Nicole was born on July 12, 1998, at 10:28 a.m.

Games Needed

Any and all new and safe games that can be donated to the INN playrooms are most welcome. Computer games (Sega, Nintendo, etc.) are a definite plus.

Public Relations Coup

Dr. Bob Schepp graciously created a permanent display poster (seen at the Tulip Festival Dinner Dance) and a twelve-foot banner for **Making Headway**.

Gallons of Gifts

At their annual Hanukkah/Christmas Party, Patrick and Mary Whalen requested that in lieu of holiday gifts, guests bring presents for kids. Donated to **Making Headway**, these gifts (stuffed animals, play toys, board games, etc.) have been given to children and their siblings at the INN throughout the year. We graciously thank the Whalens for this thoughtful—and useful—contribution.

Brave Warriors

Stories by Liz Buttke

Kristen

Why Everyone Thinks
She's the Cat's Meow

Kristen was a chubby-cheeked, happy baby who rarely cried. Who could ever guess what her future held? In 1993, the phone calls started. Her teacher asked if her eyesight had been checked recently. Her dancing instructor asked if her parents had noticed her right leg behaving differently. Then her mom walked her to the school bus and Kristen couldn't squeeze her hand as she held it. "Within forty-eight hours, we were in the operating room—after receiving a diagnosis of Juvenile Pilocytic Astrocytoma," says Kristen's mother, Janet. Although benign, its location made total removal impossible.

After two years of quiet, a slight growth appeared. Fortunately, Kristen responded to the vincristine/carboplatin protocol. At the end of eighteen months, there was a twenty-five percent shrinkage—and once again, the wait.

"But this time," says Janet, "we had all the loving support of our friends at the INN. Kristen is actually going to miss seeing them every week. She trusts the doctors to help her, and has a radar somewhere within her that never lets her feel sorry for herself, and is rarely down about anything."

During treatments, Kristin found friendship and fun in the playroom at the INN, where volunteers organize daily craft projects to help children have fun during their hospital stay. More recently, she was spotted thoroughly enjoying herself while splashing around in the pool at the Family Fun Day hosted by Ed and Maya Manley. A picture of her playing in the pool was published in the local Westchester paper covering the event.

"I truly believe Kristen was born to bring out the best in those around her," says her mom, who feels that Kristen's innate compassion has developed even more "because she has been treated with such kindness herself over the last four years, by all the professionals trying to eradicate her tumor, and by all the support personnel who work to calm any fear she has in her often bumpy road to survival. We also appreciate the support given to us by *Making Headway*, day and night."



Left: A beautiful smile from Kristen Butler
Right: Family bonding; Arlene, Adam, and David Gaynes

Thanks to all of them, Kristen's smile continues to brighten her Floral Park, Long Island, home—bringing joy to her father and mother, Steve and Janet, her sister Elizabeth, and her cat Mel.

Adam

A Little Boy Who is A Big Role Model

Not yet six years old, Adam has already made quite an impact on the world around him. Since his diagnosis at age fifteen months—when an MRI revealed what doctors believed to be a congenital brain tumor—Adam has been poked and prodded and stuck with more needles than most adults feel in a lifetime. Yet through it all, he has continued to laugh and love and gobble up life so happily that no one would ever suspect what Adam and his family have endured.

For Arlene and David Gaynes, Adam's mom and dad, there were many fearful moments—like wheeling their son down for biopsy surgery and a procedure to relieve the pressure on the brain—after Dr. Jeffrey Allen diagnosed a benign Astrocytoma. Then it was coming to grips with the fact that Adam had to begin a very long and difficult sixty-week program of chemotherapy. But no matter how nightmarish the situation became for Adam's parents, their remarkable little boy never lost his spirit, his smile, his sense of fun, or his positive attitude.

When Adam played ball in the hospital hallway and his brother Taylor accidentally tripped over the intravenous (IV) cord, pulling the IV needle out of his chest, Adam said "Don't cry, Mommy. I'm okay."

When he took his favorite toy jeep to "show and tell" in nursery school, and a classmate unexpectedly asked about his Mediport, Adam simply shifted gears. He pulled his tank top off to show and tell the class how "I get medicine through my boo-boo machine to fix the boo-boo in my head."

As the first child ever to go through the chemotherapy program at the INN,

Adam arrived there on the very first day when things were still in disarray. Since then, the INN has become a haven for parents like Arlene and David, who find comfort in the companionship of other parents they meet in the hospital and at *Making Headway* gatherings, as well as in the warmth and friendship of the INN staff. Adam, in particular, loves doing projects with Maya Manley and other children in the day hospital at the INN.

"We finished chemo in May 1997," says Arlene. "And while I didn't want Adam to be on chemo anymore, I found that I actually missed Beth Israel. It's a place like no other—everybody from the volunteers to Maya and Heather and Honey and Carrie to Dr. Allen, Dr. Siffert, Dr. DaRosso. I could go on and on—all of them are constantly working to make these kids' lives easier and better." Adam's father David says, "We never missed a treatment. We needed to be there for our boy and we needed to be there for ourselves."

As for Adam, he not only got the loving support he needed at the INN—he gave as much as he got. "He's been the positive force that has kept us going," continues David. "He's our hero. He has a lot of qualities that I, as his father, hope to have some day."

Editor's note: Since this article was written, Adam has relapsed. Arlene and David, however, told us that they have seen positive results from his chemotherapy treatments. Adam's strength and courage in facing treatments continues to astound us all.

• • •



Chemotherapy or not, fire trucks are all that count for Gene Jerskey seen here with his dad Charles Long

End Notes



Splish-splash, Jesse Bartimoccia

Poolside Reflections

I was fortunate enough to be able to be part of the Manleys' sixth annual Family Fun Day on Sunday, June 21, 1998, as a lifeguard.

There was a sign posted at the pool club where I work, asking for anyone interested in lifeguarding at the picnic. I was delighted at the opportunity and called the Manleys immediately.

When the day came I was extremely nervous. I knew these children were special, and very delicate. I wasn't sure what to expect. I was scared that I wouldn't be able to give all the children the care they needed and deserved.

When I arrived at the Manleys', I saw that some of the children had lost their hair from chemotherapy and others needed wheelchairs, and extra attention. Despite my nervousness,

the children welcomed me into their games and activities. Their sweetness and gentleness astounded me. They played together and helped each other out. They were never rude or harsh. Their cheerful attitude made the day special for everybody—including me.

The parents and families were very supportive, and you could tell they were very proud of their kids. The siblings of children were very understanding and patient. They were friendly and they helped me out a lot by helping kids in and out of their floats, and by playing games with them while they were in the water. One thing that made me happy was that there were children at the picnic that had survived brain and spinal cord tumors. They serve as examples for

children and families who are going through the same situation, and show that it does get better, and that there is hope.

When the day was ending, I was sad to see the children go. They had been so friendly, and I had gotten to know them rather well.

Hopefully next summer I will be able to attend the seventh annual Family Fun Day, where once again families will gather together to spread love, and keep hope alive.

Written by Josephine Gutierrez, a senior at Horace Greeley High School, Chappaqua, NY

Editor's note: The sixth annual Family Fun Day was hosted by Edward and Maya Manley at their home in Chappaqua, New York, on Sunday, June 21, 1998. They were happy to welcome over 300 people, mainly families and children from the INN, for a day featuring swimming, gymnastics, a petting zoo, a ventriloquist, a magic show, and other fun and games, as well as a barbecue. They wish to thank all the volunteers who helped make this day possible.



Children enjoying the ventriloquist show at Family Fun Day



Katie Goldman, creative at every occasion

Helping Making Headway Through United Way

If you are making a donation to the United Way—either on your own or through your company—you can choose to designate your contribution to Making Headway. Every little bit helps! For further information, please contact Making Headway at (914) 238-8384.

How To Reach Us

Making Headway welcomes news and commentary. Please send articles and news items to: Making Headway News, 35 Alpine Lane, Chappaqua, NY, 10514-1615, or via fax (914) 238-1693, and include a daytime telephone number. Submissions may be edited for length, style, clarity, and content.

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