



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

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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.

Top: Tena Walton, Office Administrator.

Bottom: Gene Jerskey and Allynn Gooen at Family Fun Day.

**A View from Inside
A Message from Tena Walton, Office Administrator**



A friend heard that I was looking for a part-time job not too far from home and mentioned my name to Maya and Edward Manley. After a couple of interviews I began working for Making Headway. And for those of you who have phoned the office, I'm the lady with the funny English accent!

My background is in the secretarial field. I worked at the United Nations in New York for a number of years, first as Secretary to the Secretary-General and then as the Personal Assistant to the Administrator of the United Nations Development Programme. One of the best things about working at the UN was the feeling at the end of each day that one had tried to make a difference. And that is how I feel about Making Headway. I have been so moved by the families with whom I have come into contact—you are truly amazing.

I have had a number of opportunities to be involved with Making Headway families—first with the Coutts and Caci families for Casino Night and then with the Ryan family for their Little Bit of a Walk. Meeting the Trunz family at their magnificent Tulip Festival Dinner Dance—where I also met the Greenbaums—was also a great pleasure. All these events are incredible examples of what families do to help other families.

I also spent a most exciting afternoon at Maya and Edward's Family Fun Day, held at their home in Chappaqua, where I got to really know some of the children. Who could fail to be touched by each one? Sitting at the welcome table, I saw the joy in the eyes of the children when they were greeted by Adam the Clown (on stilts) and heard them shout "Adam, Adam!" Then they came dashing up to the table to ask "Where's Maya?" One mother said to me, "This is such a special day, because our children get to meet one another outside of the hospital in beautiful surroundings." I realized how very fortunate I am to have been given the privilege of working where I do. What I do is really administrative work, but what each Making Headway family does on a daily basis is a source of true inspiration to me.

The past nine months have been a wonderful experience for me. I look forward to getting to know more of you better. Please know that if there is anything at all that I can do at any time, I'm just a phone call away.





Honors & Awards

At the 2001 *Tulip Festival Dinner Dance*, Making Headway's Board of Directors announced—as part of the Foundation's fifth anniversary—the creation of an Honorary Board of Directors. This was established to recognize and honor those individuals who have been instrumental in helping the Foundation grow and achieve success. This year's honorees are Elisa Greenbaum, Greg and Jeannie Trunz, Sam and Mindy Schwartz, and Reverend Jack Miller. At the same time, the Board elected Dr. Jeffrey Allen to be the Foundation's Medical Advisor. His scientific expertise and advice in research and medical matters are a welcome addition to Making Headway. 🌱

Walking, Dancing & Running

This year's *Little Bit of a Walk*—a 1.6 mile run/walk at Point Lookout, NY—was held on April 1, 2001. Organized by Diane and Pat Ryan in memory of their daughter Elizabeth, this beloved seaside event raised over \$15,300 to benefit Making Headway.

On April 26, 2001, under starlit skies and amidst 40,000 tulips, guests danced the night away at the annual *Tulip Festival Dinner Dance*, in Glenwood Landing, NY. Sponsored by the Trunz Family, the event raised over \$135,000 to benefit Making Headway.

Ready, set, go! The Hoboken, NJ, Police Department held its annual *5K Run/Walk Against Crime and Drugs* on August 6, 2001, to benefit Making Headway. This year's proceeds were over \$12,000. 🌱

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. We are honored by each contribution, no matter how great or small, and sincerely thank you. Some examples of this year's gracious giving include the following:

Students of Briarcliff High School, Briarcliff Manor, NY, raised \$500 in memory of Lara Chwatt.

Babylon Evening Homemakers, Holtsville, NY, held a Chinese Auction raising \$250 in honor of Ryan Szynklarz.

Students and staff of the Martha B. Day School, Bloomingdale, NJ, raised \$446 in memory of their fellow student Lori Jean Dombrowski.

Ella Cohen, of Mamaroneck, NY, asked her friends to give contributions in lieu of birthday gifts. Over \$295 was received.

Students of Saint Athanasius School, Brooklyn, NY, held a bake sale and "dress down" day in honor of Sophia Casale, raising \$500.

Students of Central Boulevard School, Bethpage, NY, raised \$135 in memory of Eric Grappone.

Woods Road Elementary School, Babylon, NY, held a 5K run in honor of Ryan Szynklarz. The event raised \$2,400 which has been earmarked for research.

Cast members of NBC TV's "Ed" bartended at NYC's La Nonna and raised over \$1,000 in tips. Thanks to Rosalie Joseph, Tom Fontana, and Janet Butler of ABC TV for arranging the evening.

Congregation Sons of Israel Religious School, Briarcliff Manor, NY, organized a fundraiser in memory of Lara Chwatt. Over \$1,900 was raised.

Genesis Diagnostic Imaging, Lynbrook, NY, held a fundraiser, featuring former NY Jets, which raised \$500.

Jacquie and George McClelland, of Southboro, MA, in lieu of favors for their daughter Lindsay's wedding, made a donation of \$300, in honor of TJ Marriott.

Spyros Orfanos, of Upper Montclair, NJ, asked his friends to give contributions in lieu of birthday gifts. Over \$3,900 was donated.

Research Update

Earlier this year, after a series of meetings between Dr. Jeffrey Allen, the Foundation's Medical Advisor, and Dr. David Goldman, Director of the Albert Einstein College of Medicine (AECOM) Cancer Center, Making Headway's Board of Directors approved a commitment of \$400,000 to be spent over a two-year period to fund research projects in pediatric neuro-oncology within the AECOM community. A request for research proposals has been circulated at both AECOM and Beth Israel Medical Center. A Neuro-oncology Grants Committee will be established to develop an equitable process to review applications. The Board's goal is to foster medical research that will seek to determine the cause and cure of brain and spinal cord tumors in children. The Michael Schwartz Research Fund of Making Headway will fund half of all approved research projects.

Top: Matt Davis with his parents Matthew and Marylee.

Q & A: Getting Your Family the Support They Need

By Dr. Lissa Parsonnet, Psychotherapist

Q: Why Should We Go to a Support Group?

A: Nothing prepares a family for the diagnosis of a brain tumor—especially if the diagnosis concerns a child. The diagnosis marks the beginning of a journey through an emotional, social, and medical maze in which there are few street signs, mile markers, or road maps. Newcomers to this maze may feel that they have entered with the wrong kind of car, with insufficient insurance, and without a reliable mechanic. To further complicate matters, the family and friends who usually provide advice and guidance cannot fathom this maze. This intensifies the sense of being lost, isolated, and in the dark. Recognizing the need for specialized support, Making Headway has developed a **Family Support Program** in northern NJ designed to promote patient and family adjustments to life after diagnosis.

Q: How Will My Family Benefit from Participating?

A: Studies have demonstrated the effectiveness of support groups in improving mood, adjustment, and pain. Support groups create a sense of community: members have an opportunity to be understood and heard by others in a similar situation, providing a sense of belonging. Through this community, people are able to forge connections, establish bonds, and find hope.

Q: How Does the Making Headway Family Support Program Operate?

A: Because the diagnosis of a brain tumor has different impacts on patients, siblings, and parents, Making Headway offers *three* concurrent support groups: one for children with brain tumors, one for their siblings, and one for the parents. All groups are professionally led and utilize strategies which are age appropriate.

The *patient* group uses art, play, and discussion to address feelings of isolation and being “different,” as well as the desire for independence. In one session, the children played *Chutes and Ladders* using medical terminology and procedures—including needles, surgeries, and CAT scans—to increase the children’s comfort with the medical world.

The *sibling* group has addressed a wide range of feelings, including neglect, guilt, fear, and resentment, also through art, play, and discussion. In one session, the children drew pictures of different faces—each face symbolizing a specific emotion—in order to help them distinguish and articulate their feelings.

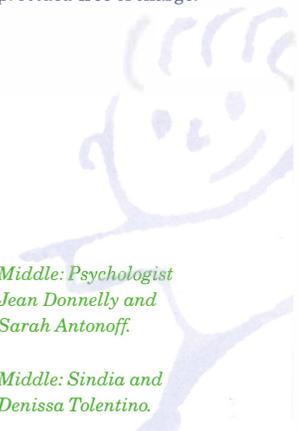
Parents bear a tremendous burden. They are responsible not only for the care of their sick child and well children, but also for maintaining their productivity at work, operating the household, and nurturing their spouse and themselves. Managing, balancing, and coping with these many responsibilities is a primary focus of the parent group. The group discusses and devises strategies for dealing with behavioral and disciplinary problems, school difficulties, sleeping problems, marital stress, social isolation, resentment, understanding and navigating the medical system, and fear of recurrence. 🌻

Dr. Lissa Parsonnet leads the parent group. The children’s groups are led by Art Therapist Cheryl Wilczak and Art Therapist and Child Psychologist Dr. Grace Zambelli. They are all part of Making Headway’s experienced support team. Dr. Parsonnet is also available for individual counseling. Please contact Making Headway for more information or to make an appointment. These services are provided free of charge.

Middle: Psychologist Jean Donnelly and Sarah Antonoff.

Middle: Sindia and Denissa Tolentino.

Bottom: Child Life Assistant Marcia Graham and Ashley Wagner.



Superkids

Stories by Elizabeth Buttke

NETANYA

A tiny tot full of courage

The term “the terrible twos” took on a horrible new meaning for Abby Landau and Steven Stein, when their daughter Netanya was just two years and three months old. It all started on a bright sunny day in the playground, when Abby asked a friend if she noticed anything different about Netanya’s right eye—which appeared to Abby to be different in size and shape from the left eye. When her friend confirmed Abby’s suspicion, a visit to the pediatrician quickly followed and immediately thereafter, a CAT scan.

The bad news came with a glimmer of hope. Although they found a major mass attached to the optic nerve behind the eye, the configuration of it led the doctor to believe it might not be malignant.

The local pediatric ophthalmologist recommended that Netanya be taken to see specialists at an eye hospital in Philadelphia—where an MRI was promptly done. Afterward, Abby recalls, “They had Netanya in a room behind closed doors...we heard her screaming hysterically, she was so afraid...we asked if we could go in to comfort her and they would not let us in.”

That kind of treatment was a far cry from what Netanya and her parents later found at the INN. Because chemotherapy



was warranted to reduce the size of the tumor, and possibly avoid surgery, a pediatric neuro-oncologist in Philadelphia recommended Dr. Allen at the INN—only a half-hour from Netanya’s home.

Speaking of their initial visit, Abby says, “Dr. Allen sent Steve and me into the playroom to get a sense of what it would be like if Netanya were to start chemotherapy and be a patient at the INN. We were completely moved by the warmth and happiness we felt in the room, with so much love and attention being given to the kids.”

All through Netanya’s treatment, Abby found the doctors and nurses as well as the people from Making Headway so extraordinary, she says, “I’d come home and tell my friends that I’d never seen a place that would make kids feel so welcome and so wonderful.”

She recalls how Maya and Child Life Specialist Jenna Aranoff always made Netanya and her older sister feel like princesses in the playroom, like it was the only place they wanted to be. And when Netanya eventually had surgery to remove the tumor, Abby says “her eye was bulging so much...it was an extraordinary disfigurement, and it was a beautiful thing how beautiful Maya and Jenna and everybody made Netanya feel.”

Now that Netanya is a healthy, happy five-year-old, Abby and Steve will never forget the “warmth and giving” they found at the INN. And nobody at the INN will ever forget Netanya. How, even at two, she never flinched when she had to endure stinging eyedrops. How, by the time she was four, she was able to lie perfectly still for MRIs with no sedation, happily watching videos on the special VCR Making Headway has provided. And how such a little girl with such a big tumor had more than enough courage to meet the challenge head-on. 🌱

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

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Top: Maya Manley with Ashley Kummer and her little sister.

Bottom: Netanya Stein and her mom Abby.

