When Silver Means Survivor
A Message from Clint Greenbaum, Founder and Treasurer, Making Headway Foundation

Usually, 25 years is called a Silver Anniversary, but in the case of our son Jake’s upcoming milestone, we’re going to call it the Survivorversary.

The incredibility of discovering that our perfect, three-month-old first child had a rare malignant brain tumor still shocks us 25 years after the fact. But such news is devastating no matter how old a child is. It’s devastating to the child, the parents, the siblings, the extended family, friends and classmates.

Nothing is more scary than the diagnosis of a brain tumor. Today, just about everything can be transplanted: a heart, a liver, lungs . . . but not a brain. Plus, due to the brain’s functions and complexities, treating brain tumors is much more difficult than treating any other kind of cancer. Finally, add one more tragedy to the situation—when a brain tumor happens to a baby, a toddler or to a teenager.

This is why Elisa and I never stop trying to help others who are going through what we experienced. For the past 25 years we’ve asked everyone we know to pitch in with their financial support so that Making Headway can implement its long list of services and programs. We’re so grateful for the many, many people who have stepped up over the years to back this vital cause.

Reading this issue and past Making Headway newsletters, how can you not be impressed by the work that this Foundation does? Please give, and if you do, maybe you’ll want to donate in honor of a young man who not only makes everyone smile, but has inspired countless people to fight the horrors of brain tumors: Jake Greenbaum, on his 25th Survivorversary.

Top: Jake Greenbaum.
Middle: Elisa and Jake Greenbaum.
Left: Elisa Greenbaum, Dr. Jeffrey Allen, Jake, Clint and Augusta Greenbaum.
More teams than ever showed up to play in the event, held in honor of young Chris Conetta, a brain tumor survivor. The smell of roast pork wafted over the field and by day’s end players, friends and family had cheered on their teams and feasted on barbecue. Victory went to the tournament’s newest team, the Sox, but Making Headway took the prize, at $10,295.

They Get a Kick Out of Helping

For more than a week in October, high schools across both Suffolk and Nassau counties in Long Island participated in Kicks for Cancer, a soccer-based fundraiser in memory of Hauppauge High School student, Courtney Tomkin. As always, the week’s showcase event was an evening of games featuring Hauppauge’s own Lady Eagles girls’ soccer team and their male counterparts, the Eagles. This festive evening included not only the sport, itself, but activities and food the whole family could dig into, and hundreds of people filled the stands. Making Headway has always been one of the beneficiaries of this event, organized by the Tomkin family; friend Alexis Gonzalez and her family; and Lady Eagles coach, Jesseca Kulesa. Traditionally Kulesa brings the team to the Hassenfeld Children’s Center to personally deliver the check. This year, however, Mother Nature had other ideas—after two intrepid attempts to travel from Long Island in the face of snow storms, the team was forced to send its $18,100 by mail.

I Love Rock and Roll

Last fall, after hearing about Making Headway’s work during Pediatric Cancer Awareness Month, Dr. Margie Strelzyn-Witt was determined to contribute. So she solicited the help of her husband, Barry Witt, who plays in Big Mannequin, a rock ‘n roll cover band. Together with her son, Dylan, Margie organized an evening of music and fun at Mount Kisco’s MTK Tavern. The result was a packed house; not just friends but the whole community turned out to eat, drink, and rock out—altogether bringing in over $7,000 for Making Headway.
Attention Must Be Paid

Audience members at the Merrick Theatre and Center for the Arts on March 1 were riveted by an anguished Willy Loman and his family in Arthur Miller’s classic, *Death of a Salesman*. But it was more than just a night of great theater. Organized once again by Jeanne Egan with the support of the North Shore Kiwanis, *A Night at the Theatre* benefited Making Headway to the tune of $1,375.

The Gift of Music

On April 6, friends and fans of acclaimed recording artist Lina Orfanos gathered for *Finding Hope in Music*, a private concert dedicated to raising funds for Making Headway. Orfanos, a brain tumor survivor famous for her talented vocals in Greek, English, French, Hebrew, Italian and Spanish, partnered with her friend Dina Krambovitis to organize the event. In addition to Orfanos, the evening featured four-time Grammy Award-winning master drummer, Glen Velez, with rhythm vocal wizard, Loire; Harry Antoniou, winner of the X Factor in Greece; and nearly two dozen other singers and instrumentalists. The gifted musicians made it a night to remember for lucky audience members; their generosity was also a gift to Making Headway, which came away with $5,000.

Ladies and Gentlemen, Prepare to be Amazed . . .

There was not an empty seat to be had at the New Victory Theater in New York City on April 6, as an enthusiastic crowd laughed and gasped through *Bello Mania*, starring the wild antics of the world’s favorite clown. The audacious Bello Nock hails from a multi-generational European clown family and is the youngest person ever to be inducted into the Circus Ring of Fame. His motto is, “No audience member should need more than the edge of his seat.” World-famous he may be, but that didn’t stop Bello from greeting attendees, posing for pictures and signing autographs. Making Headway’s annual theatrical event brought in more than $520,000 in contributions and ticket sales, allowing us to fill the hall with excited young patients and their families.

Let the Good Times Roll!

It may have been a full month into Lent, but Mardi Gras was still in full swing at the eighth annual *Thomas Fitzgerald Memorial Fund Mardi Gras Bash*. Held on April 5 at the Colonial Terrace in Cortlandt Manor, New York, this year’s party benefited not just Making Headway but “Friends of Karen” and the family of Dan and Janine Callahan, whose son Sean is battling cancer. Friends and co-workers of the Fitzgeralds—who organized the event—performed the services of DJ and auctioneer, donated one-of-a-kind auction items, and helped out in countless other ways. With $4,000 earmarked for Making Headway, it was a festive and generous way to welcome the spring!
**My Journey With Maya and The Making Headway Foundation**

*by Marcia Greenleaf, PhD*

*Health Psychologist, Clinical Director:*

*The Making Headway Ongoing Care Team*

My work with pediatric brain tumor patients began with a call from Maya Manley. She was looking for someone to help her daughter Cynthia, who had been diagnosed with a brain tumor. One of my specialties was hypnosis and stress management for medical patients, but pediatric brain tumors were new territory. At that time, the medical focus on cure—while critical—didn’t include helping the patient and family live with the impact of the diagnosis or deal with post-treatment needs.

Maya went on to help found the Making Headway Foundation and now actively pursues her own work with children and their families. But in 1982 she was dealing with her own trauma as the mother of a child with a brain tumor. With Cynthia, Maya and I began our journey. There were no guidelines or rules to follow in this highly specialized area. We were on our own. In the late 1980s, Maya became determined that I was to help other families deal with the struggles she and her family were facing. She was my guide, giving me suggestions from her personal experience, her intuition and her heart. No textbook could match those variables.

Maya taught me that a family in crisis wouldn’t be able to accommodate to my schedule. Rather, I needed to accommodate to theirs. She encouraged me to introduce Making Headway’s programs to parents by phone when I couldn’t meet with them in person. She insisted we would develop our own rules: we would bend to meet each family’s needs as they were presented to us.

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**Every Situation is Unique**

Families in this situation experience so many fears, conflicts and problems, it’s normal to be overwhelmed. We didn’t have a magic wand to reverse reality, but we learned how to lessen the impact of it. We agreed that families needed practical strategies and emotional support, not traditional psychotherapy. It became clear that parents need information to understand what’s happening to their child; to manage in a medical setting; and to deal with the impact on a spouse, on healthy children, on extended family and friends. It also became clear that all family members need practical tips and strategies to help the ill child re-enter life and cope with interpersonal dynamics both at home and in the outside world. Our families were struggling to adjust to a new, (unwanted) normal.

We learned there is no one single time to provide support for families going through something like this; we learned to respond now. There isn’t waiting time when a family faces first time shock at diagnosis; first time surgery; first time post-surgical treatment; first time post-treatment getting the child back to school; first time with healthy siblings acting out in anger; first time with the ill child throwing a tantrum in public; first time parents can’t agree on treatment decisions; first time recurrence. At any given moment, each member of the affected family needs answers to diminish his or her confusion and mental anguish.

And it isn’t just the “first times.” Chronic problems also shock. The second, third and fourth times any of these things occur—all require extra guidance and support. Everyone hopes to put the whole experience behind and move on. But even after treatment is completed, medical follow-up care, educational remediation, physical rehabilitation and social problems create ongoing stress for the child along with everyone connected with that child. The whole family continues to be out of balance. It’s beyond unfair.

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Gracious Giving

Throughout the year, Making Headway receives numerous gifts from individuals, families and friends, organizations and companies. These gifts help us fulfill our mission. No matter how great or small, we are honored by each contribution and sincerely thank you. Some examples of gracious giving include the following:

It was one of the fiercest winters on record, but children visiting the playroom at Hassenfeld Children's Center were kept snug and warm, thanks to a plethora of hand-made gifts:

- Right around Thanksgiving, Lucy Rutigliano, Connie Citrola, Marija Validzic and Kathleen Rice sent a packet of lovely hand-crafted blankets.
- The box arriving from Corinne and Bob Jeziorski was overflowing with hand-crocheted hats as well as blankets.
- And members of the Linus Blanket Group, which Ethel Thomas organizes at the Plainview Reformed Church, sent their own cozy home-made blankets on two different occasions, as well.

Newlyweds Peter and Katie Bellotti skipped the wedding favors, opting instead to give Making Headway $200 in honor of their flower girl, 7-year-old cousin Katie Hanson.

The kids in Ms. Dorio's fourth grade class at Wampus Elementary School put their creativity to work on holiday gift bags in honor of their friend, Alexandra Talbot. Grown-up friend Felicia Zacks then delivered the bags—which were loaded with toys, crafts and books—to Making Headway; they were soon in the hands of the delighted children at Hassenfeld.

Every Friday evening in Nyack, New York, artists of all stripes partner with local businesses to strut their stuff. This is how several local musicians found themselves playing at the Maria Louisa Boutique, which in turn donated the $150 proceeds to Making Headway.

It’s not unusual to associate Bar and Bat Mitzvahs with gift-giving, but this year several young people put a new spin on the concept:

- Brain tumor survivor Jacob Krawitz honored his own big day by giving a gift of $3,000 to Making Headway.
- As a Bat Mitzvah project, sisters Brooke and Daniela Schwartz chose to hold a bake sale in honor of their cousin, Alexandra Talbot. The sale raised awareness as well as funds for Making Headway, bringing in $758.
- Gene Dunn made good use of his four studios—Brooklyn Vindhya Yoga, Brooklyn Brazilian Jiu-Jitsu LLC, Brooklyn Brazilian Jiu-Jitsu II and BBJJ III—to organize fundraisers. Held in memory of family friend, Alan Steffen, who passed away this past Christmas Eve, the events raised $2,330 for Making Headway.
- Marie Flavin-Brouder apparently believes that giving is always in fashion. The entrepreneur dedicated the grand opening of her chic new shop, M Boutique, in Chappaqua, New York, to Making Headway, donating $400 from the evening’s sales.

When Megan Mathews set up shop on the online artisans' website, etsy.com, to sell her handmade mosaic frames, she didn’t have personal profit in mind. Naming the online store “Holly’s Hobbies” in memory of her friend Holly Lind, Megan announced she would donate 100% of the proceeds to Making Headway. Her beautiful work has already brought in $300.

Last fall, Thomas J. O’Connell asked family and friends to sponsor him on a fundraising climb to Mt. Everest basecamp, generously donating the $3,850 in donations to Making Headway. Here is what he had to say about his journey:

After almost a year of planning, training and talking myself into it, I finally reached the Mt. Everest Basecamp on November 12, 2013. Another item to check off the proverbial bucket list. Every so often I find myself in need of a challenge, something that will push me beyond my own preconceived limits.

Fourteen days of climbing to altitudes as high as 18,800 feet through the majestic Himalayan Mountains, nearly 100 miles round trip by foot, to see what very few people have the opportunity to see: the beauty and tranquility of Nepal and the highest point in the world. Memories of a lifetime, not only of my destination, but also of the people who helped make the journey possible and incredibly special.

I’ve been quite blessed in life. The challenges and limits I face and have faced are of my own doing, not like the children and families who face the challenges of illness and misfortune. As a member of the Claudio Reyna Foundation board, I saw firsthand what Making Headway does—the comfort and care they provide in a child’s hour of need and a family’s moment of distress and despair.

So it was with great pride and pleasure that I dedicated this year’s climb and fundraising effort to the Making Headway Foundation. I know in my heart that they will continue on, selflessly providing support to those who face incredible challenges—challenges that may seem impossible. I know we all have many demands and requests for our time and money. I simply ask that you consider Making Headway in the future as a worthy cause for your generosity.

Thank you and God bless you.
Parenting can be a daunting task, especially when dealing with unexpected obstacles. The path to recovery can be challenging, as seen in the story of Maya and her family. Maya’s journey is a testament to resilience and the importance of support and community. Parents need to remember that they are not alone in this journey, and reaching out for help can be crucial. The Ongoing Care Team at Making Headway is here to support families and provide resources to help them navigate the post-treatment phase. By working together, families can find the strength to move forward and find upward progress.