



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

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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.



Tee Time and More

On October 7, nearly 100 golfers once again hit the fairways at the beautiful Pelham Bay and Split Rock golf courses for a day of play and celebration in honor of young brain tumor survivor, Brian McCabe. Rain threatened—and at one point even interrupted the proceedings—but it didn't dampen the enthusiasm of the golfers, who not only played but enjoyed a hearty breakfast, a light lunch, and a lovely reception in a special, tented pavilion.

Brian, now 17, gave an eloquent speech; his parents also spoke, and everyone bid on a range of enticing auction items. The second annual **Brian McCabe Drive for a Cure** was chaired by Brian's dad, Mike McCabe, and pulled together by an array of volunteers including the Casale, Murphy, and Taxter families as well as members of the extended McCabe family. It drew corporate sponsors including Douglas Elliman Property Management, Hercules Corporation, A.C. Klem, DNA Contracting and Belkin Burden Wenig & Goldman, LLP. Not only did it turn out to be a lovely experience for all, but it brought in nearly \$50,000 for Making Headway.

Coming in Swinging

The Conetta family's annual **Swing for a Cause** whiffle ball tournament was held a bit later than usual this year. October 19 was a nippy fall day, with glorious colors just beginning to adorn the trees surrounding the Federal Little League Park in Stamford, Connecticut.



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.

Top left: Mike McCabe, Brian McCabe and Jimmy Brennan at the second annual Brian McCabe Drive for a Cure.

Bottom Left: Chris Conetta, Pete Conetta, Rick Ackerman of Henckel Corp, and Lynn Conetta at the Swing for a Cause fundraiser.

Below: Hauppauge's Lady Eagles girls' soccer team at the Kicks for Cancer fundraiser.

Members of Big Mannequin, a rock 'n roll cover band playing at MTK Tavern.

Dr. Margie Strelzyn-Witt and her son Dylan, with Maya and Edward Manley of Making Headway, at MTK Tavern.



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. 🌱



Left: Bello Nock and Lea Garone at the Bello Mania fundraiser.

Below: Liliana Ponce (lower right) with family members at the Bello Mania fundraiser.

Matt Lewis, daughter Elizabeth, and mother-in-law Maryanne Parker at the Thomas Fitzgerald Memorial Fund Mardi Gras Bash fundraiser.

Bottom Left: Musician performing at the Finding Hope in Music fundraiser.



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.

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.

(continues on back page)



Top: Marcia Greenleaf.

Below: Mark Bis with his daughter Julia at Family Fun Day.

Back page: Greg Licciardi at Family Fun Day.



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.



Above:
Marie Flavin-Brouder at the opening of M Boutique.

Below:
Thomas J. O'Connell at Mt. Everest basecamp.

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.



My Journey With Maya

(continued from page 4)

Following the Child

After finding the right medical team, managing the life of the whole family in and out of the medical setting and scheduling follow-up appointments, parents are exhausted. Many develop a hyper-vigilant stance that gets triggered anew by every MRI, every cold virus and every unexpected obstacle. There is cultural pressure to bring the ill child up to speed at home and in school.

However, brain surgery and post-surgical treatment invariably create deficits in the capacity of a child to process new information and the ability to respond to social cues. Any brain lesion slows down communication signals in the brain. As painful as it may be when one's child cannot keep up with peers or adapt to social situations, it is helpful to treat these circumstances as indicators of capacity overload—rather like a circuit breaker that shuts off when the electrical load is too high. Learning new information, playing with other kids, lunching in a noisy cafeteria, making decisions and controlling impulses—any one of these may put more demand on a child's brain circuitry than it can bear. Compounding these problems, many children whose illnesses have been successfully treated are left with physical deficits affecting such things as balance, vision, hearing and hormone production.

Different families use different solutions and coping strategies, depending on the child's age, type of tumor, treatment protocols, family resources, geographical location and their ability to confront the "new normal." This can be hard. Parents may lament: *Why doesn't last year's solution work this year? Why can't my child behave like other children? Will my child ever catch up?* There may be hand-wringing and loss of sleep.

Those parents who are most successful navigating these waters are amenable to learning countercultural, counterintuitive parenting skills: they follow the child. "Follow the child" translates into observing behavior as data to understand

their child's biological, social, intellectual and emotional capacities. If their child acts out, they examine the situation to see if external demands or challenges are too overwhelming. While it's countercultural to follow a child's behavior instead of directing the child to fit in, parents find that when children aren't stressed to go beyond their brains' capacity to process, they thrive. Ironically, downward (read "realistic") expectations lead to upward progress.

Parents Need Support Too

If you're a parent of a child with a brain tumor (or a survivor), it's natural to want to move on. No one is "bad" or "crazy" for wanting "it" to be over, for losing sleep before every MRI, or being hyper-vigilant when simply being observant and alert is enough. On this journey, I've learned how important it is for parents to pay attention to their own circuit breakers. Irritability, anger and fatigue signal you're stretched beyond your capacity. There are things you can do about that:

- **No**, you can't disappear or go on holiday. But **yes**, you can change your standards, cut back and find ways to rest and get personal time-outs.
- **No**, keeping it to yourself or complaining won't work. But **yes**, setting clear limits will help.
- **No**, acting like a victim or fussing will not lead to being rescued. Nor will it work to hope others will "get it" and understand. But **yes**, you must deliver clear and clean (not emotionally-charged) communication, expressing your limits and needs.

It's not selfish—it's "self-is." When the primary caretaker goes down, everyone goes down. The ship sinks. It's important to keep your "self" intact.

Today there are hospital programs providing information and support that didn't exist when Maya and I started our journey. To augment hospital services, The Making Headway Ongoing Care Team has experts who can help you with practical strategies at each phase of your journey; teach parenting skills; advise on sibling issues; and advocate for educational adjustments unique to families coping with pediatric brain tumors.

It may be disconcerting to have to depend on so many others for the care of one's own child, but no one person has all the expertise to manage the bio-psycho-social jigsaw puzzle you're facing. Reaching out will help you help your child and the whole family. As Maya says: "We walk with the parents. No parent should face this journey alone."

If you're the parent of a child with a brain or spinal cord tumor (or dealing with the aftermath of a tumor), call the Making Headway office and let them know your concerns. They will direct you to the right experts. 

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Making Headway Foundation works closely with the Stephen D. Hassenfeld Children's Center for Cancer and Blood Disorders at NYU Langone Medical Center in New York City. Our services are available to all pediatric brain and spinal cord tumor patients and their families throughout the tri-state area, regardless of where they are treated.

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

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