



making headway foundation

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

makingnews

Summer 2018

02 New Family Liaison

Caralyn Perlee joins the Making Headway Team in a special role.

07 Making Headway and the Hassenfeld Center

A synergistic partnership that continues to redefine patient care.

12 Real Families, Real Impact

Diagnosed with a brain tumor as a child, Jessica Surita shares her story.



03 Air Play—Making Headway on Broadway



09 Head to the Hill



08 Promising New Treatment for Deadly Brain Tumor



05 Family Fun Day



Letter from our Chairman & Founder

Dear Friends,

For the past 22 years Maya and I have been involved on a daily and personal basis with establishing and shepherding the Making Headway Foundation. Through the years we have worked with many of you to launch critical new programs that bring direct help to thousands of sick children and their families. In the process we have worked to secure a firm financial footing so that Making Headway can continue to grow and prosper.

Now it's time for both of us to take a few more steps back. I feel confident that we have a strong team in place to gradually take over our roles. In fact, I think they will succeed beyond our greatest dreams. Dan Lipka will lead the Foundation as it continues to achieve its crucial mission. Caralyn Perlee will show the same loving care for the children as did Maya at the hospital, and Jennifer Samuels will make sure that the administrative and financial tasks are tended with care and efficiency.

Maya will continue to do her beloved work at Hassenfeld until she is no longer able. And, since our home is just five minutes from the office, I will remain on call to help as needed.

None of this promising new day would be possible without the donors and friends who have come on board to help sail the ship. We are unspeakably grateful to each of you for the important ways you continue to contribute your time, passion and resources. Nothing the foundation has done—or will ever do—can happen without you.

Maya joins me in saying to you each day, with all our hearts, "Thank you, Thank you, Thank you."

Edward P. Manley

Welcoming Our New Family Liaison

Making Headway is pleased to introduce Caralyn Perlee, our new Family Liaison. Caralyn joined us in January and her role is to be there for the families, much like Maya Manley. The warm, personal and often long-term relationships Maya forms with families are a unique feature of the Making Headway Foundation, and as she moves closer to full retirement we're committed to ensuring this vital aspect of our work continues for future generations. That's where Caralyn comes in.

A professional child life specialist, Caralyn worked at Hassenfeld from 2012 to 2016, getting to know members of the Making Headway team quite well. In particular, her path often crossed with Maya's in the playroom. A year after she left NYU, Making Headway reached out to her to see if she'd consider taking on the new role. Caralyn, who had been working in Europe, accepted with pleasure.

While Caralyn is eager to carry on the in-hospital support Maya is known for, and can be seen walking the floors and frequenting the playroom on Tuesdays and Thursdays, she has big ideas for broadening the role as well. As a full-time family liaison, she'll be at the hospital two days each week, freeing up the other days for supporting families in other settings, including in-home. She is also keenly interested in exploring some other directions, such as doing more work with siblings, providing more one-on-one support, and addressing the special challenge of teenagers.

"For teens, friendships play a crucial role in development and well-being, but children with brain and spinal cord tumors often struggle to fit in socially. My experience at Hassenfeld has taught me that teens are increasingly less likely to participate in groups aimed at peer support," Caralyn says, adding that she is currently researching alternative models that have been used in other settings to support older children.

Clearly, Caralyn has much to contribute to Making Headway and the families we serve, and we look forward to continuing our work and growing our impact with her on our team.

"I have seen firsthand the life-changing impact that Making Headway has had on countless families, and I could not imagine a more fulfilling and fitting career and purpose for myself."





Sometimes It's Good to Be a Little LAX

Eighteen of the best girls' lacrosse teams in the country travelled to Cold Spring Harbor, Long Island on April 21 for the fourth annual **Gains for Brains** lacrosse showcase. It was a brisk, sunny day, the action was spirited, and the event drew an enthusiastic crowd. Journalist Andrew Rappaport and his wife Laura organize this event each year in memory of Courtney Tomkin, whose story of battling cancer greatly moved him when he interviewed her in 2008. As always, proceeds from this year's showcase will go to support Making Headway's mission, including providing psychological services and education advocacy for the children and their families.



Uplifting in Every Sense of the Word

A sold out crowd of nearly 500 packed Broadway's New Victory Theater on April 8 for our spring theatrical event, **Air Play**. The exhilarating afternoon featured flying umbrellas, colorful confetti, shimmering silks, and buoyant balloons. It was a lighter-than-air extravaganza that kept audience members of all ages laughing and gasping, in turns.

Air Play was one of the most entertaining Making Headway-sponsored winter theatricals in the 20+ year history of these events. As always, it was an opportunity not just to enjoy a spectacular show but to relax in the comfort of shared community. "This was the first stress-free hour I've had in over a year," one mother commented. Making Headway invests in programs that provide medical research, but just as important are events like this, which provide emotional support and some much needed time to simply enjoy life.



Putting Their Hearts into Dancing

It's never too late to celebrate Mardi Gras, at least according to the scores of party-goers who thronged to the 12th annual **Thomas D. Fitzgerald Memorial Mardi Gras Bash** on April 7. The event, held at the Mansion at Colonial Terrace in Cortland, New York, once again featured DJ Big Al spinning tunes that kept the crowd dancing all night. Lisa Fitzgerald, along with her daughters, Kylie and Tauri, do the hard work of putting this fundraiser together each year in memory of Thomas Fitzgerald III and Thomas Jr. As a result of their generous efforts, other families benefit from Making Headway services and enjoy events like our annual Family Fun Day.



Taking a Swing for Research

On June 1, friends and family gathered for the 16th annual **Nicky and Thomas Docu Memorial Golf Outing**. The event, which helps raise funds to support research programs aimed at finding better treatments, honors Nicky Docu, who passed away from a brain tumor at the age of 10. Making Headway was there for the family 16 years ago and continues to support them to this day.

Race for Ace

The 3rd annual **Race for ACE** was organized by Andy Ecker's family and friends to honor his brave fight against brain cancer, which he sadly lost in July of 2015, and to support the Making Headway Foundation. Race for ACE also recognizes Andy's legacy as a passionate Michigan fan, mathematical genius, hardworking employee of Macquarie Capital, winner of every board game ever played, welcoming and loyal friend, loving big brother, amazing son, and all around remarkable guy. Andy's mother, Making Headway Board member Susan Rubin, led the team to make this event so memorable.

Hundreds of supporters participated in the race, which started at Flywheel Sports in downtown Manhattan and finished with food and drinks at Solas. Over 600 people donated to Making Headway through this event, enabling us to support critical programs and services.



A Letter from our Executive Director



The mission of the Making Headway Foundation continues to inspire me to further develop and expand

our programs, in order to provide a more robust level of care to families. Over the past 22 years, Making Headway has developed and funded an array of customized, family-based programs specifically for those who have experienced the impact of a pediatric brain or spinal cord tumor. Our additional investments in hospital staff and research grants (see page 8) have directly or indirectly affected over 10,000 children. Recently, I have been fortunate to spend time with families and learn even more about the impact of our work, which guides our vision for the future. This vision includes the hiring of a dedicated Family Liaison to work with and

directly assist families in need. It also includes expanding our education programs to three new children's hospitals, growing our college scholarship program, increasing public education and advocacy, developing new services for families, and making new, more collaborative research investments.

Pediatric brain and spinal cord tumors remain the most common and deadliest form of childhood cancer. The more researchers learn about this disease, the clearer it becomes that they are faced with one of the most complex challenges in the medical world, involving dozens of genetically unique tumors, each with different symptoms, treatments and outcomes. Finding better treatments and a cure will always be our long-term goal, but addressing the unmet, immediate needs of families is our top priority.

Not long ago, I was able to spend some time with Josh Cappello, who survived a brain tumor as a child and is now planning to go to college. When asked what he remembered of his treatment, Josh listed a string of things: Jose Acevedo from the playground, Family Fun Days, Adam the Clown, the prize box, and so on. He didn't recall one negative experience or painful procedure—what better testament to how the work of Making Headway can change a child's entire experience of a brain tumor? In honor of Josh's experience, and hundreds of others, I will continue Making Headway's legacy: to work passionately toward Care, Comfort, and a Cure for all the families.

Daniel Lipka
Executive Director

Family Fun Day

On June 17th, Making Headway hosted our 25th annual **Family Fun Day** for children diagnosed with brain or spinal cord tumors and their families. A crowd of over 300 joined us for free music, animals, food, and fun at the world-

famous Bronx Zoo. Family Fun Day was once again held on Father's Day, as a way to celebrate family and bring everyone together. Making Headway is so proud to provide this gift each year for our families.



"My kids really enjoyed the clown, the gifts and the face paint. The best part for my girls was getting their nails done!! Thank you so much for all the time and effort you put in to making this event a smashing success!"

"It was truly wonderful. The kids had so much fun! They loved Looney Lenny and his funny tricks, the games, the cupcakes, hotdogs, ice cream. They really indulged and didn't want to leave. My husband and I loved the lemon sorbet and the manicure. The ladies that did the face paintings did such good jobs. We loved the t-shirts! Thanks to all those that helped make this happen. It couldn't have been better!"



"We absolutely loved the location and the face painting, crafts, and animal station were fun for our 5 year old... The zoo was amazing and we truly appreciate being included."



"The gathering was great, everyone was socializing with each other, we all are one big happy family. Thank you Making Headway Foundation. Especially to Edward and Maya for their work in helping us and also for such wonderful events."

"The kids had a ball, music, gifts, food and the zoo.... it was the best event this summer."



"Loved it. The space was generous. Lots of choices for food. And the bonus was being able to spend the rest of the day at the zoo. So grateful for such a lovely day."

"As always it was a great day, with our family and friends. My children can't wait for the next event, God bless you all."



Making Headway Family Yacht Cruise
Sunday, September 16th
11:30am–3:00pm
Chelsea Piers (Pier 60)
New York, NY
makingheadway.org/cruise

If you or a family member has been touched by Making Headway, leave your cares behind and join us for our annual

sail on the waters off Manhattan, sponsored by Richard and Marisa Stadtmauer. Enjoy entertainment for all ages, delicious food, good company, and breathtaking views—including the traditional water cannon show, courtesy of Tom Ryan, whose son survived a brain tumor.



Brian McCabe Drive For A Cure Golf Outing
Monday, September 24
7:00am–3:00pm
Pelham Bay and Split Rock Golf Course
Bronx, NY
makingheadway.org/mccabe

Fall is a beautiful time of year to hit the greens. Join us for golf, food, camaraderie, and fun at this sixth annual outing, organized by Eileen and Mike McCabe in honor their son Brian.

Woodlawn Run for a Cause
Saturday, September 15
10:00am
St. Mark's Church
7 St. Mark's Place
Yonkers, NY
<https://goo.gl/9XRqXS>

Zip up your jogging suit and reach for your sneakers. This year,

Making Headway is proud to be one of two beneficiaries of this annual 3.1 mile race. Running not your style? Come anyway—you're more than welcome to walk the course, which finishes at Indian Field.



Powder Puff Scores for Making Headway
Each year, the junior and senior girls of Harrison High School in Harrison, NY, compete with each other in a rousing game of flag football. This event, called **Powder Puff**, also serves as a fundraiser, with the senior class choosing the charity that will benefit. We're delighted that Making Headway was the chosen beneficiary this year. The seniors took the prize in a close game on June 5, and everyone had a great time.

So Many Ways to Do Your Part
Interested in supporting Making Headway? Direct donations are always welcome, but there are also many other ways to make a difference. For example:

- Many generous donors have shown their support by asking for donations to Making Headway in lieu of gifts for birthdays or weddings.
- When you make your purchases through AmazonSmile (www.smile.amazon.com) or iGive (www.igive.com), you can designate a portion of the proceeds to go to Making Headway.
- Host your own fundraising event. Call our office at (914) 238-8384 or email dan@makingheadway.org.

Making Headway and the Hassenfeld Children's Center: A Powerful Partnership

For over 15 years, Making Headway Foundation has shared a unique vision and partnership with the NYU Langone Stephen D. Hassenfeld Children's Center for Cancer and Blood Disorders. The Hassenfeld Center, one of the leading facilities of its kind, serves one of the largest concentrations of children with brain or spinal cord tumors in the country.

Making Headway's unique relationship with the Hassenfeld Center began with a vision shared by Dr. Jeffrey Allen; former Hassenfeld Director, Dr. William Carroll; and Edward and Maya Manley. When the Manley's daughter, Cynthia, was diagnosed with a brain tumor, it was Dr. Allen who treated her. The treatment saved Cynthia's life, but in the process the Manleys grew to see that families impacted by a pediatric brain tumor need much more than just great medical care. The Manleys, along with Clint Greenbaum, whose child also survived a brain tumor, would later co-found the Making Headway Foundation. Their goal was to raise funds to provide care and comfort for children with brain and spinal cord tumors, while funding medical research geared to better treatments and a cure. Drs. Allen and Carroll shared their dream, and a life-long partnership was born.

When Dr. Allen took a leadership role at the Hassenfeld Children's Center in 2002, Making Headway set to work doing its part to make this facility the best in the country. Dr. Allen proposed medical research innovations and staffing that Making Headway quickly embraced, such as a Brain Tumor

Bank, an endowed chair in pediatric neuro-oncology, a pediatric neuro-oncology fellowship, a clinical trials research administrator and more. For her part, Maya's personal experience as the parent of a survivor led to the funding of quality-of-life programs that were rare at the time. The foundation invested in additional child-life positions, a masseuse, a yoga specialist and staffing of vital services such as support for school re-entry. Over the years, Maya has also personally volunteered nearly 10,000 hours in the playroom, supporting the children and their families.

"The Making Headway Foundation and especially having Maya Manley present two days a week has been life changing for children with brain and spinal cord tumors. When these children come in for their medical appointments, Maya greets them with a warm smile and



"Although our goal is focused on providing the best medical care possible, we understand that your child needs more than just a treatment plan. We care for the whole family and extend our goals beyond merely conquering disease. We work to eradicate the physical, emotional, and psychological burden of a disease while looking toward the future," says Maya.

a soft voice that welcomes them to come to the playroom and do a craft. This immediately eases the children and they relax into a playful activity that Maya has thoughtfully organized and prepared for them," commented Hassenfeld Senior Social Worker Patricia Ryan-Johnson.

In all, Making Headway has awarded 68 grants totaling over \$9.1 million to the Hassenfeld Children's Center, with the result that Hassenfeld has grown into one of the most comprehensive pediatric medical facilities in the nation.

**HASSENFELD
CHILDREN'S
HOSPITAL
OF NEW YORK
AT NYU LANGONE**

The unique culture and resource that Making Headway's partnership with NYU has helped to establish

has had far-reaching ramifications. Recently, NYU Langone opened a brand new inpatient facility in Manhattan, the Hassenfeld Children's Hospital. The new hospital will provide one of the country's most modern and technologically-advanced resources for children with serious illnesses. Making Headway continues to serve as an essential partner in this venture.

As we begin to expand Making Headway's services to other children's hospitals in the region, we look to the success of our continuing partnership with the Hassenfeld Children's Center as a guide for the future. By working together toward common goals, we have helped more than 1,500 families, and raised the bar for family care.

MAKING HEADWAY, MAKING PROGRESS.

Since our inception, Making Headway has invested in cutting edge research projects designed to find better treatments and a cure for pediatric brain and spinal cord tumors. Here are updates on our recent investments.

Drs. Papagiannakopoulos, Snuderl and Aifantis are developing models that will enable the characterization of the molecular events underlying pediatric tumorigenesis and will assist the development of new therapeutic strategies tailored to fight those glioma driver mutations. Their findings will have a great impact on identifying precision medicine-based therapeutic strategies for the treatment of pilocytic astrocytoma (the most common type of brain tumor in children).

Dr. Richard Possemato is performing an in-depth metabolic analysis of pediatric gliomas. He has identified a possible new therapeutic approach, and his team is currently investigating its potential applications for use in immunotherapy.

Dr. Stephen Sands has continued his long-term study evaluating the impact of socio-economic status, home environment, and parenting and parental distress on pediatric brain tumor patients. The project aims to create a more accurate protocol for early-intervention, so doctors can better help children before they experience significant neuropsychological decline. To collect sufficient data, this study currently involves the collaboration of 36 children's hospitals.

Testing a Potential New Treatment

In January, the NYU Langone Medical Center launched an exciting new clinical trial. Led by pediatric neuro-oncologist **Dr. Sharon Gardner**, the trial is exploring the effects of a new drug on children with a class of tumors that contain a devastating mutation. Brain and spinal cord tumors with this mutation, known as H3 K27M, have proven completely resistant to treatment by any other means, and they are particularly prevalent among children. The survival rate for children with DIPG, one of the most common tumors with this mutation, is less than one percent.

Clinical trials on adults with the mutation have been underway for some time, and they've shown promising results. One 22-year-old woman experienced a 96 percent reduction in the size of her tumor. Another patient had tumors that completely disappeared. And while this is the first pediatric clinical trial, a handful of children have been treated with the drug under the "compassionate use" protocol, and some of them have also responded well.



Dr. Gardner explains that this is a Phase 1 trial, meaning it focuses on the drug's safety, and she's optimistic about how it's going so far.

"I think it's fair to say the drug has been tolerated quite well to-date," she says, noting that the children participating have so far experienced only minor side effects. In addition, the regime itself is relatively unobtrusive: participants take the drug just once a week, orally, and can do so from home.

While no one can yet speak to the drug's efficacy, Dr. Gardner is enthusiastic about the possibilities:

"There is no cure for this kind of tumor. None. We're hopeful that this new therapy can improve this dire prognosis for these children."

The new drug, ONC201, is manufactured by pharmaceutical company, Oncoceutics. The trial will involve about 45 children, who will be treated by ONC201 alone or in combination with radiation, depending on their medical history.

Making Headway Covers the Costs

The children participating in the new clinical trial led by Dr. Gardner have come for treatment from homes all over the world. While Hassenfeld Children's Center has generally paid for their airfare, staff were concerned that families would need to cover the cost of staying in New York City—an expensive proposition. So, they turned to Making Headway. Following a visit to the beautiful, newly refurbished Ronald McDonald House

in Manhattan, Making Headway was delighted to agree to cover the costs of staying at the facility for all families participating in the clinical trial, for as long as they need it.



Betker Family



On May 7–8, Making Headway Foundation once again went to Capitol Hill to advocate for programs and funding that could make all the difference for children with brain tumors. The trip was part of Head to the Hill, an annual event organized by the National Brain Tumor Society. This year, over 250 people from 33 states assembled in our nation's capital to fight for resources in support of brain tumor research.

While Making Headway staff have participated in the event in the past, 2018 was the first year we were joined by some of our families. Making Headway sponsored each family, covering all costs for travel, accommodations and food, because we realized how important it was for these families to be there representing the needs of children with brain tumors. Historically, almost all of the advocates at the event have been affected by an adult brain tumor, and we knew that a vital component was missing. Malignant brain tumors are very rare among adults, but they are the most common and deadliest type of childhood

cancer. We are so proud that four local families, each impacted by a childhood cancer, were able to share their stories with our nation's leaders.

The Making Headway contingent included: Maria Barbieri and Randi Bayarsky, each of whom has a son who survived a pediatric brain tumor; Rachel Cappello and her son Joshua, who survived a brain tumor as a toddler; and brain tumor survivor Jessica Surita, who was joined by her brother, Jason. (You can read more about Jessica's story on page 12.) Rounding out the team were Making Headway's Executive Director, Daniel Lipka, and Family Liaison, Caralyn Perlee.

Each of the families and staff members joined with teams that were helping policymakers better understand this community's urgent needs. They spoke of legislation that is critical to ensuring the availability of treatments, increasing scientific research, and promoting the discovery of a cure. In total, the Making Headway team met with four U.S. Senators and eight Members of Congress.

Rachel Cappello called the experience powerful, adding: "Josh and I spoke to our senators and representatives from Connecticut about a cause dear to our hearts, the Childhood Cancer STAR Act. This act will provide pediatric brain tumor research, lead to better treatments for our youngest patients, and help increase the quality of life for survivors."

Jessica Surita told her story at all four meetings she attended, inspiring a great deal of interest among policymakers when she discussed her childhood medulloblastoma and subsequent struggles with the long-term effects of treatment.

"It was great to use my own voice and have people listen when I talked about the difficulties I have from treatment side effects," said Jessica.

Research into these kinds of debilitating and often lasting side effects could be funded by the National Institutes of Health, if legislators allocate the monies for it.

As Making Headway grows, we hope to amplify our voice and impact in order to help as many families as possible. Head to the Hill was an empowering experience for each of the families, and we know they will continue to advocate for themselves and others throughout the country.

UPDATE: On May 22nd, only three weeks after Head to the Hill, Congress passed the Childhood Cancer Survivorship Treatment Access and Research (STAR) Act. This is one of the most comprehensive childhood cancer bills ever introduced. It will both advance pediatric cancer research and address the ongoing needs of survivors. Making Headway is proud to have been part of the successful advocacy team and very grateful to all the families who made this possible.

MAKING HEADWAY AWARDS MORE SCHOLARSHIPS THAN EVER BEFORE

In 2018, Making Headway expanded our scholarship program to include significantly more winners than any previous year. Fourteen inspiring young survivors of brain or spinal cord tumors will each receive a \$5,000 college scholarship. Making Headway funded 12 of the scholarships, with the Scott J. Reisser Fund providing funding for two more. The Scott J. Reisser Memorial Scholarship Fund was established by Fritz and Joanne Reisser to honor the memory of their 22-year-old son, who succumbed to a brain tumor just short of achieving his dream of college graduation.



Lionel Chen
Bergen Community College. *Diagnosis:* Medulloblastoma at age 5.



Victoria Kay
Five Towns College. *Diagnosis:* Temporal Brain Tumor at age 12.



Taylor Coyle
UNC at Pembroke. *Diagnosis:* Medulloblastoma at age 9.



Jacob Krawitz
Muhlenberg College. *Diagnosis:* Medulloblastoma at age 6.



Georgie D'Avanzo
Syracuse University. *Diagnosis:* Oligodendroglioma Tumor at age 5.



Edward McCarthy
Mount Saint Mary College. *Diagnosis:* Anaplastic Ependymoma at age 14.



Zachary Grace
Duquesne University. *Diagnosis:* Medulloblastoma (PNET) at age 8.



Emily Ousouljoglou
Marywood University. *Diagnosis:* Medulloblastoma at age 4.



Christine Panza
Northeastern University. *Diagnosis:* Brain Stem Tumor and NF2 at age 9.



Tariku Smith
Northeastern University. *Diagnosis:* Optic Brain Tumor at age 7.



Noelle Sollivan
Kean University. *Diagnosis:* Astrocytoma at age 10.



Mikayla Stajuana
Binghamton University. *Diagnosis:* Pineocytoma at age 16.



Lucas Sundwall
Quinnipiac University. *Diagnosis:* Low grade intradural astrocytoma at age 7.



Anya Zach
Indiana University. *Diagnosis:* Pediatric Pilocytic astrocytoma at age 23.

PAST SCHOLARSHIP WINNERS:

“Looking back, not only did Making Headway help me pay for my college education, but it also provided some unexpected and much-needed closure. Since I was diagnosed with a brain tumor more than 15 years ago, I carried the physical and emotional burden with me for most of my life, through multiple surgeries and seemingly endless hospitalizations. Being able to use my experience to

apply for scholarships finally allowed me to let go of my demons. I feel like I am no longer sick or “a person who had a brain tumor,” I am just a person. I am a writer, I am a storyteller, I am a student, a professional, a young person who has accomplished so much in life, and a person who has so much more to accomplish. I am not my illness anymore, and that is a blessing that I will always be grateful for.” — **Katherine Nelson, 2014 scholarship winner.**

“This award came at a critical time as my parents and I were uncertain that I would be able to continue due to financial constraints. I’ll never forget the day that I opened the letter. It was truly unbelievable and allowed me to continue my dream of one day being able help young people and their families with pediatric neurological brain disorders and to work with others in the field to find, once and for all, a cure for cancer” — **Brandon LaFever, 2015 scholarship winner**



Dear Making Headway,

I cannot thank you enough for my scholarship to attend **CancerCon** 2018, but I will try. As a 21-year pediatric cancer survivor, I do not have peers who truly understand what my reality is. There are times where I feel extreme fatigue—not the kind of fatigue that “just take a quick nap!” will fix—the kind where you’re lying on the couch and it literally feels like you’re becoming one with the

cushions. I have seen and lived through things that some of my best friends will (hopefully) never have to experience in their lives. When I found StupidCancer.org a few years ago, my eyes were opened to the fact that there were actually other people my age who just get it...

My experience at CancerCon 2018 was unlike anything I have ever experienced... The first night I met another woman in her 30s. The next morning, at the scholarship welcome breakfast, we sat together at a table with seven other women, all of us in

our 30s. I couldn’t believe there were so many of us!

...As we continued attending sessions together and sharing meals, I learned that I am not alone. This group of women, my “CancerCon Squad,” has become my family.

Excerpts from a letter from Whitney Hadley. In 2018 Making Headway sponsored Whitney to attend CancerCon, the annual, international gathering of the young adult cancer movement. To read her full account of her experience, visit www.MakingHeadway.org/cancercon

CHARITY CUT-A-THON

To celebrate 25 years in business, the talented and generous Lillian Schon, proprietor of **Lillian’s Hair Salon** in Westhampton Beach, NY, hosted a **Charity Cut-A-Thon** on June 3. She and her team offered \$25 haircuts—no appointment necessary: “No wash, no blow—just cut and go!” To make it extra special, Lillian got permits to set up tables and chairs outside her Main Street shop, added a catered lunch, hired some folks costumed as the Marios Brothers and Frozen’s Elsa and

Anna, collected over 30 raffle prizes, and arranged for WLNG radio to broadcast live from the event.

100% of proceeds from the Cut-A-Thon went to Making Headway. An annual donor, Lillian is the long-time friend and hairstylist of Making Headway board members **Elisa and Clint Greenbaum**, as well as their brain tumor-survivor son, **Jake**, and their daughter **Augusta**.

Thank you, Lillian—we wish you continued success in your business!



Fazl Shaikh started the One Life Club in honor of his friend Jack Reyna.

In 2013, Fazl Shaikh lost one of his best friends, Jack Reyna, to a pediatric brain tumor. Fazl was a freshman at Scarsdale High School, where he and fellow student Alexis Zachem (a brain tumor survivor) started the **One Life Club**. Throughout their high school career, One Life held a number of events, raising over \$40,000 to support Making Headway. This year, Fazl entered Middlebury College with the same passion and dedication that he has shown for years, starting a new chapter of the One Life Club. Fazl and club co-president, Jacob Ellen, have assembled a 26-member team and are hard at work. They have already raised thousands of dollars and are planning a 5K run, t-shirt sales, and a soccer tournament. Making Headway is so proud of Fazl and his commitment to honor his friend by making a positive impact.

Real Families, Real Impact

One morning in 1995, eight-year-old **Jessica Surita** awoke with a pounding headache. When she tried to get up, she found she couldn't hold her head up. Her mother rushed her to the hospital, where she was diagnosed with medulloblastoma—a massive malignant tumor. Treatment would eventually encompass radiation, two rounds of chemotherapy, several blood transfusions, and eight surgeries. In the process, Jessica would experience cardiac arrest twice, and—once—a stroke that left her temporarily paralyzed. She also suffered a long list of side effects from the treatment, including hearing and memory loss, vision problems, two bouts of shingles, kidney stones, thyroid problems, diabetes, and more.

Jessica's cancer went into remission seven years later. Because of her memory loss, she doesn't remember much from those early days, but she does remember Making Headway. She remembers Maya Manley, a warm presence who did crafts with her in the playroom. Jessica loved to do silly things like dress up her IV bag in costume. The nurses were not always amused, but Maya was.

"She thought everything I did was hilarious," says Jessica.

Maya continued to play an important role in Jessica's and her family's lives, but that was only one aspect of Making Headway's impact. Dr. Jean Donnelly, a Making Headway psychologist, also played an invaluable role in Jessica's recovery.

At school, things were not going so well. She'd missed quite a bit, and she was struggling with the disabling side effects triggered by the treatment. Members of the Making Headway team worked with her and her family, connecting them to a school in Westchester that would give her the support she needed. Jessica thrived at the new school, graduating with honors, and even giving a commencement speech.

She also looked forward to Making Headway events. She even re-learned how to swim during the annual Family Fun Days. In 2018 Jessica joined Making Headway to advocate for brain tumor research on Capitol Hill in Washington, DC (see page 9).

Jessica is not the only one who remembers Making Headway fondly. Her mother, Glorey Moreno, says it made all the difference:

"We went through a lot with her. Such a bad time. They were always there to talk to. It just means so much to have someone there for you—a shoulder to lean on."



Making Headway Foundation provides care and comfort for children with brain and spinal cord tumors, while funding medical research geared to better treatments and a cure.

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Making Headway services are available to all pediatric brain and spinal cord tumor patients and their families throughout the tri-state area.

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

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