



Caring For Patients While Exploring Promising New Treatments

A Message from Dr. Sharon Gardner, Associate Professor of Pediatrics, NYU Langone Medical Center

As a pediatric oncologist, my number one goal is to provide the best possible care for my patients. Of course, no one person can provide this care alone—as the saying goes, it takes a village. I feel very fortunate to work at a world class facility like the Stephen D. Hassenfeld Children’s Center for Cancer and Blood Disorders. I can count on the combined expertise of doctors, nurses, psychologists, social workers, child life specialists, financial counselors and the Making Headway Foundation team to provide children and their families with help and support from every angle.



A child is a parent’s most precious gift. Yet it hardly needs saying that parents of a child who is ill carry a tremendous burden. They may feel scared and helpless; they may be afraid to speak up and ask for what they need. I try to get to know the entire family so that I can better understand their situation and their needs. I try to ease their burden by being flexible with my schedule and making myself available to them.

In addition to providing care for my young patients and supporting their families, I conduct research. My work focuses predominantly on developing new therapies for children and young adults with central nervous system tumors. When I first came to NYU about eighteen years ago, my work involved developing treatments that enhanced the child’s recovery by pairing intensive chemotherapy with a therapeutic approach that made use of the ill child’s own stem cells. The goal was to eliminate or at least decrease the amount of radiation these very young children would have to undergo. I also used this approach in older patients with recurrent brain tumors who had received radiation as part of their initial therapy. As a result of that early work, this approach is now considered the standard of care for many patients.

More recently, I have focused on stimulating the patient’s own immune system to attack their tumor. This is similar to the concept of vaccination. However, instead of using vaccines to prevent illness, I am exploring the possibility of using vaccines to get rid of tumors. My team and I have already completed our initial trial in children, which

(continued on back page)

*Top: Dr. Sharon Gardner.
Todd Shapera Photography.*

*Left: Lobsang Chodak
with his daughter Emma.
Todd Shapera Photography.*

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Out for an Autumn Drive

On a cool day in October, an intrepid group of golfers and other friends gathered at the Split Rock/Pelham Bay Golf Course for the fourth annual **Brian McCabe Drive for a Cure**. In addition to lively competition and camaraderie on the links, there were a couple of tasty meals and some off-link competition, too: guests bid on auction items ranging from an elegant dart board set to a ball signed by legendary Yankee closer Mariano Rivera. The altogether pleasant day was organized, as always, by Mike McCabe, and this year it broke its own fundraising record, bringing in \$56,215 for Making Headway.

Laurels All Around

October's annual **Kicks for Cancer** event also surpassed its personal fundraising best. The week-long sports extravaganza is held each year in memory of Hauppauge High School student, Courtney Tomkin. As always, this year it featured soccer matches among Nassau and Suffolk County, Long Island, high school teams, culminating in the October 16 flagship event, when hundreds of fans showed up to cheer Hauppauge High's own boys' and girls' teams to victory. **Kicks for Cancer** was organized by Alexis Gonzalez and her family along with Jesseca Kulesa, coach of the Hauppauge High Lady Eagles. While the week yielded many winners, the luckiest among them is Making Headway, which now has \$22,300 more to put towards its mission.

A Funny Thing Happened On the Way to This Fundraiser

When the Tumminello family brought their toddler, Matteo, to the Hassenfeld Children's Center for treatment, they learned first-hand how the playroom team can make everyone smile. So when they were deciding on a fundraiser, they opted to keep the smiles coming, organizing a night out at the Brokerage Comedy Club in Bellmore, New York. **Making Laughs with Making Headway**, which featured emcee Joey Kola and a roster of other side-splitting comedians, had the audience rolling in the aisles. The smiles continued as one hundred percent of proceeds—\$15,780—went to Making Headway.



Top Left: Golfers at the Brian McCabe Drive for a Cure event.

Middle Left: Brian McCabe and his mom Eileen, with their friends at the Brian McCabe Drive for a Cure event.

Top Right: Dr. Jeffrey Allen speaking to the Girls Varsity Soccer Team from Hauppauge High School.

Above: Matteo Tumminello.

Bottom: Tom Tumminello with MC Joey Kola at the Making Laughs with Making Headway fundraiser.

Baubles and Bubbly

Jewelry shopping can be fun, but rarely does it include champagne, sushi, and the unique satisfaction of giving back. The dozens of people who turned up at ICD Contemporary Jewelry's **Shopping for a Cause** event last December had the added pleasure of knowing that 20 percent of proceeds would go to Making Headway. Varda Singer, a friend of the Foundation, organized the event at her Chappaqua store for the second consecutive year, raising \$1,735.



They Walk the Walk

The second annual **Horace Greeley All-Athlete Walkathon** was held at the Chappaqua high school's competition field on November 8. Hundreds of student athletes of all stripes teamed up to walk the field for two hours on a beautiful fall day. Music was piped in from the broadcast booth and deli food was served up by local shop, Villarina's. Other local merchants, including Elder's Auto Spa, Chappaqua Mobil and Old Stone Trattoria, chipped in with gift cards and other treats for the



thoughtful young participants. The event raised \$16,000, which was split between Making Headway and Team G: The Gardner Marks Foundation.

Tapping Into a Really Fun Day

Manhattan's New Victory Theater was filled to capacity one February afternoon when nearly 500 people showed up for **Untapped!**, a rousing, rhythmic, funny—and just plain fun—dance spectacle. The show featured five men and women, members of the Australian troupe, Raw Dance Company, whirling and tapping in an energetic hip-hop style. Their shoes tattooed a lively beat, adding to the rhythm of the on-stage guitar-and-drum combo—except for the occasions when they traded in their taps for flip flops or even bright blue swim flippers. Over half the audience were Making Headway families and they attended free, courtesy of our generous donors. A highlight came when one such lucky boy, Aaron Caceres, was invited to the stage, where the emcee taught him the basics of beatbox. In addition to providing a fun outing for patients and their families, **Untapped!** brought in over \$440,000 for the Foundation.



Above: Horace Greeley High School students participating in the Horace Greeley All-Athlete Walkathon.

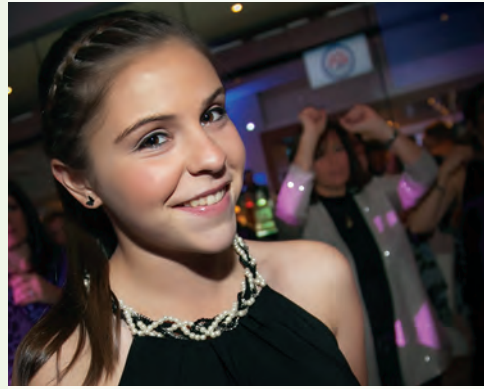
Left: Varda Singer (right) with Edward and Maya Manley at the Shopping for a Cause event at ICD Contemporary Jewelry.

Left Below: Horace Greeley High School students presenting a check to the Making Headway and Gardner Marks Foundations after the Horace Greeley All-Athlete Walkathon.

Below: Audience members at the Untapped! fundraiser in New York City.

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:

By the time **Barbara Roach** sat down to her turkey last Thanksgiving, she'd definitely earned it! Roach spent the morning running the five-mile Garden City Turkey Trot, completing the race in an impressive 71 minutes. She also gave *Making Headway* something extra to be thankful for, when she donated the \$2,230 she raised in sponsorships.



Rebecca Landau ensured that her sixteenth birthday was the occasion for sweetness all around when she directed guests at her milestone party to donate to *Making Headway*. The event was a joint celebration with three of her peers, each of whom chose a cause to support in lieu of gifts. Rebecca's kindness raised \$636 in memory of her cousin Jamie Levy.

It must have been a hot day: 12-year-old **Chloe Talbot** and her friend **Amanda Rosenzweig** did a brisk business in lemonade, bringing in \$201. Proceeds from the entrepreneurial enterprise went to *Making Headway's* Talbot Family Research Fund in honor of Chloe's twin sister, Alexandra.

In December, a **group of old friends** joined together to carry on a new tradition, the fourth annual "Look Bad & Do Good" ugly sweater party in memory of their friend, Andrew Ecker. Each year, they tell us, the crowds get bigger, and the sweaters get uglier. But ugly is as ugly does, and what this group did was beautiful, raising \$1,927 for *Making Headway*.

For more than a month during the holiday season, shoppers at **Family Britches**, a Chappaqua boutique, enjoyed a discount on select cashmere sweaters. Their purchases bought them more than the warmth of soft wool—they also got a warm feeling inside, as the store owner donated \$10 from every purchase to *Making Headway*, bringing in \$250. 🌱

Above: Rebecca Landau.

Left: Barbara Roach (left) and a friend at the five-mile Garden City Turkey Trot.

Below: Abdulai Jalloh with his mom. Todd Shapera Photography.



Writing the Chapters of My Life

By Sydney Lilieholm

The gift of life is the greatest thing bestowed upon any human. Naturally, we hope everyone can take their own steps forward towards excellence and growth. What we don't expect are traumatic situations that change everything. Approaching age three, I was diagnosed with a brain tumor in my cerebellum, which ultimately took over my life and shaped me into the person I am today. The tumor grew back on two separate occasions, both times exerting such pressure on my skull that it was jaw-dropping to understand how I was still alive. By the time it was successfully removed, I had lost all basic motor skills and needed to relearn everything from scratch.



A recreational therapist during my hospital stay helped me greatly, showing me a strong and positive way to persevere. Over a nine-year period, I required a long list of therapies to fine-tune my abilities and better my life. I was very fortunate to have exceptional support throughout this process. Not only did my incredibly strong, dedicated and hopeful family give me all the support a kid could ask for, but *Making Headway* opened a whole other avenue. It gave me room to be comfortable with who I am and what I've been through, and also to celebrate myself and other kids just like me. Right before my surgery I met Maya Manley, telling her how much I liked peanut butter. To my amazement, following surgery, Maya was at my side with peanut treats. The fact that she remembered spoke volumes. *Making Headway* became my second support system.

I never wanted to admit that I had to rely on others. I so badly yearned to be independent. I fought so hard for this that one of my physical therapists nicknamed me "the tenacious chainsaw." But writing this now, at age 23, I realize how much I did, in fact, have to rely on others. I cannot express enough how grateful I am to have had all the incredible support that I did.

My two siblings and I relied on my single mom's income and sporadic child support, making finances at home very tight. After high school, *Making Headway* made college a possibility when I received a *Making Headway* scholarship. I started by attending Salem State University, took a year off to work, then resumed my business major at County College of Morris in Randolph, New Jersey. I then began to realize my passion for working with kids who are overcoming disabilities. I want to be a special education teacher, like some of the teachers who have done so much for me.

School fulfills my thirst for knowledge and, though I have had my fair share of struggles due to my unique background, I never let myself get down. When I found myself struggling I enjoyed pushing myself and continuing to move forward, keeping up with peers. I have surpassed levels of excellence through all of my classes. I have spent long hours of studying and, with the help from my grandfather, an electrical engineer/mathematician, have become top of my class in math courses such as statistics. I should graduate from County College by spring 2017, and then will transfer to a four year school to complete my bachelor's degree.

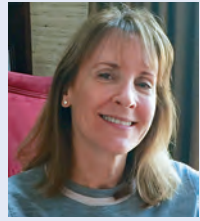
My last MRI, a full body scan, showed no residual tumors. I continue to push myself through any obstacle, working hard and presently paying for my own education. I am thankful to be building my own story through life, moving through chapters with the satisfaction of knowing that I have put in great effort to get to where I am and where I want to go. 🌱



Above: Sydney Lilieholm.

Below: Sydney Lilieholm (center) with her family.

Dr. Susan Leslie: Advocate, Partner and Friend



For children who have undergone treatment for a brain tumor, school can be an overwhelming experience. They may struggle with attention span,

processing speed and memory. Depending on the tumor's location and treatment, other aspects of functioning, such as language, executive and motor skills may also be affected. In addition, children may experience behavioral changes—irritability, unpredictable bouts of fatigue, difficulty regulating emotions, and more. Not surprisingly, issues like these can lead to both academic and social challenges. That's where the educational specialists on the Making Headway Ongoing Care Team come in.

One such specialist is Susan Leslie, PhD, a neuropsychology and educational consultant who supports families in the Connecticut area.

Dr. Leslie serves as an advocate for families, working to ensure each child's academic, social and emotional needs are met. One way she does this is by partnering with staff at the child's school. She reviews cognitive testing and other medical records to establish what type of curriculum, classroom situation, modifications, and accommodations would be most helpful for a given child, and then shares her findings with the family and the school. She is supported in this by her

colleagues: when appropriate, members of the Ongoing Care Team consult with each other, so families benefit from a range of specialties and expertise. It is a long-term commitment.

"The process of returning to school is a journey that unfolds over time, as the child's brain heals and new connections are developed," says Dr. Leslie. "Our team is typically available to families right through college."

Grace came to Making Headway as a 10-year-old. She was being treated for a brain tumor that had first been discovered two years before, and was experiencing significant behavioral and learning issues at school. School personnel welcomed ideas for how best to educate her.

"After meeting her and reading all relevant medical and educational records, I partnered with the public school team to help them create an appropriate educational program," says Dr. Leslie.

She met with school staff to explain the neurology behind Grace's particular challenges. Then she suggested both behavioral and teaching strategies that would help. For example, she recommended that worksheets be made visually less cluttered, that a break room be provided, and that certain activities be instituted to help with social skills.

Today, Grace is in ninth grade and enjoying school. She is motivated to learn, enjoys her relationships with staff and friends, and is progressing academically, behaviorally and socially. Dr. Leslie continues to meet with school staff throughout each academic year to help tweak the program based on her progress, and to address any issues that arise. Grace's mom has come to count on her:

"I can confidently handle the medical aspect of my daughter's care but am not always sure when it comes to Grace's education. Susan always has my daughter's back. I never fear walking into a [school team] meeting with her by my side because I know that she knows Grace and will do everything she can to help her reach her goals. I don't know what we would do without Susan." 🌱

Left: Dr. Susan Leslie.

Below: Naomi Borbon. Todd Shapera Photography.



A Treasure Moves On

Gunilla Asp, beloved massage therapist and Reiki master whose "healing hands" and kind words have helped bring peace and strength to hundreds of children and families at the Hassenfeld Children's Center, has decided it is time to do some relaxing of her own. She has retired to San Diego, where her daughter lives, and is currently enjoying the sunshine while devoting herself to Buddhist study and meditation. It is a temporary hiatus, however: Asp, who is nearly 79, is making plans to move to Poland next year to help run a hospice for orphans.

"There are many children there who are not getting the care they need," Asp explains. She will team up on this project with an old friend, a Polish nurse who spent a lot of time at Hassenfeld when her child was in treatment.

Treating Each Individual Need

Both Reiki, a Japanese technique for stress reduction and relaxation, and massage therapy have been shown to support healing in numerous ways, from reducing pain and stress to speeding recovery. But Asp, who worked as part of the Making Headway team for nearly 10 years, is also a former lay chaplain. She supported children and their family members—and even hospital staff—not just physically but emotionally, listening to their concerns and dispensing sage advice.

Asp's experience with her own serious childhood illness helped her identify deeply with the children and families she met at Hassenfeld. She listened, both literally and metaphorically, to their needs and responded to each as an individual. A child arriving for chemotherapy was particularly stressed. Asp followed her lead, placing a heated pillow on her back and massaging her belly with soothing peppermint lotion. A father was exhausted from travel and sleepless from worry. She encouraged him to lie down, using Reiki to gently lull him into an hour of refreshing sleep. A distraught mother couldn't let herself cry. Asp created a quiet space for her, holding her hand until the tears came. Former patients and family members, reacting to news of her retirement in a recent Facebook post, thanked her for "healing massage and warm conversations" and called her "an angel on earth." For her part, Asp says her years with Making Headway were the best of her life:

"It was such a privilege to be there for ten years. I am so deeply grateful to all those children and parents who gave me the precious gift of letting me help and support them."

And we're grateful to you, Gunilla! We wish you the best of luck and happiness in your future endeavors. 🌱

Left: Gunilla Asp (left) with Maya and Edward Manley at her "Farewell" party.

Below: Sophia Blankenbuehler doing a craft project in the Hassenfeld Children's Center playroom.



Caring For Patients

(continued from cover)

showed that the vaccines are safe and that they work: they are able to stimulate the patient's immune system. I am now developing a second trial to see if we can further enhance the immune response to actually shrink the tumors.

I am so grateful for the opportunity to work with these wonderful children and their families. Every one of them is an inspiration, further motivating me to take my research as far as it can possibly go. 🌱



Above: Elijah Connell with his family, Dr. Allen and Nurse Practitioner Miriam Pudel, celebrating the end of his chemotherapy treatment.

Todd Shapera Photography.

Below: Maya Manley with Katie Hanson at the Hassenfeld Children's Center.

Save the Dates!

June 3, 2016

For a dozen years, friends and family of young Nicky Docu have held an annual golf outing and fundraiser in the boy's memory; the event, which includes food and entertainment, was known for its warmth and camaraderie. With the passing of Nicky's dad, Tom Docu—the outing's lead organizer—Nicky's brother (also named Tom) took over, but now Tom has announced with regret that he can no longer do justice to the event, and that this year's **Nicky and Thomas Docu Memorial Golf Outing** will be the last. Tom announced this decision online, encouraging all to come out to the Split Rock/Pelham Bay golf courses for the final big day: "I will do my best to make this go out with a real bang. We'll tip our hats one last time to the kid and the old man, raise some money for the children of today and tomorrow who must battle this disease, and say our goodbyes with a smile."

June 12, 2016

You don't need cycling gear, just a warm heart. Get yourself to CYC Fitness in Astor Place for the 1st annual **Race for ACE**, a spin-a-thon to honor the memory of Andrew Cooperman Ecker (ACE).

September 11, 2016

Making Headway families are invited to set sail for the annual **Family Yacht Cruise** around Manhattan—come enjoy the annual event, featuring food, entertainment, and one of the most famous skylines in the world.

September 26, 2016

Get your clubs ready and come out to enjoy one of the first days of fall at the fifth annual **Brian McCabe Drive for a Cure**, also at the Split Rock/Pelham Bay golf courses in the Bronx.

Making Headway Foundation

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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.

Making Headway thanks Linda Mudford-Lewis for her generous help with this newsletter. Special thanks to Gunilla Asp, Dr. Sharon Gardner, Dr. Susan Leslie and Sydney Lilieholm for sharing their stories.

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

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