



## Why I Fight the Fight

*A Message from Greg Taubin, Board of Directors, Making Headway Foundation*



*“Three children.” That is my response when anyone asks me how many kids I have.*

*Our oldest child, Lily, was born April 9, 2004. On June 27, 2008, she was diagnosed with an inoperable malignant brain tumor. Her treatment started immediately. For six weeks, Lily received an aggressive combination of radiation and chemotherapy.*

*Except for the last two months of her life, no one would ever have guessed what this beautiful little girl was going through. Even though treatments continued throughout that school year, her strong will did not deter her from attending school and in fact, she only missed the days on which she received treatment. Lily lost her battle on November 4, 2009, but she will be with my wife, Felicia, daughter Lauren, 8, son Andrew, 4, and me forever.*

*To say that our precious Lily was a warrior is an understatement. At the tender age of 5, Lily possessed qualities that one typically attains much later in life. Her strong will, positive attitude, selflessness and sense of humor gave our family the strength and courage to endure this horrible disease.*

*Dr. Jeffrey Allen was Lily’s primary doctor at NYU Langone Medical Center’s Hassenfeld Children’s Center for Cancer and Blood Disorders, and that is where Making Headway began to guide us along this difficult journey. While a center like Hassenfeld is the last place one would ever want to have to go, it became a special place for us, thanks to all the loving staff and the presence of Maya Manley. Maya is as close to an angel as I’ve ever known. Everything that she represents soon gave us the strength and courage in our battle with this awful disease. Even after Lily passed away, Maya would stop by our house on her way home to do an arts and craft project with Lauren, who affectionately referred to Maya as “the art teacher.”*

*A few years after Lily passed away, Ed and Maya had us over for a delicious home-cooked dinner and asked if I wanted to join the board of Making Headway. It was an easy answer. I had been thinking about how to get involved with doing something about this dreaded disease. What better way of fighting the fight than to join a distinguished group of people helping not only patients, but their loved ones? Surely one of the most meaningful things I could do would be to champion Making Headway’s mission of supporting the entire family during this most devastating of times. So I accepted gratefully, and am glad I am able to do what I can in memory of that great warrior, my daughter Lily.* 

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

### Board of Directors

Edward Manley  
*Founder and Chairman*

Maya Manley  
*Founder and Secretary*

Clint Greenbaum  
*Founder and Treasurer*

Elisa Greenbaum  
*Vice Chair*

Sam Schwartz  
*Vice President, Research*

David Almeida

Charlie McMahon

Greg Taubin

### Medical Advisory Board

Jeffrey Allen, MD  
*Director of Clinical Neuro-Oncology, NYU School of Medicine and Otto and Marguerite Manley and Making Headway Foundation Endowed Professor of Pediatric Neuro-Oncology*

Karl Kothbauer, MD  
*Chief of Neurosurgery, Luzerner Kantonsspital, Luzern, Switzerland*

### Administration

Catherine Lepone  
*Executive Director*

Linda Mudford-Lewis  
*Office Administrator*

### Making Headway Foundation

115 King Street  
Chappaqua, NY  
10514-3460  
Tel: (914) 238-8384  
[info@makingheadway.org](mailto:info@makingheadway.org)  
[www.makingheadway.org](http://www.makingheadway.org)

Making Headway Foundation is a 501(c)(3) not-for-profit foundation.

Top: Greg Taubin.



### A Last Taste of Spring Flowers

Unless you own a ski resort, there aren't generally too many advantages to a longer-than-average winter, but guests at this year's **Tulip Festival Casino Night** in Roslyn, Long Island, discovered one—the lovely tulips that fill the grounds of the Swan Club were still in full bloom on May 14. The evening was once again hosted by the Trunz family in memory of their daughter, Allison, and a crowd of 200 showed up to try their luck and savor a delicious dinner at the seventeenth annual event. A highlight of the night was a moving presentation by 17-year-old Bogdan Reza Far. Bogdan, who is currently being treated for a brain tumor, described how he has personally benefited from Making Headway. But Making Headway benefited, as well: the evening brought in \$50,000. 🌷

### Spinning a Bounty

On May 17, some phenomenal high school students pulled off an incredible fundraising feat with their **One L1fe Club Cycle-a-thon**. The One L1fe Club at Scarsdale High School was founded by student Fazl Shaikh in 2012. Fazl wanted to organize fundraising events in memory of his friend and soccer teammate, Jack Reyna. The various activities he put together led to a gift of \$1,000 to Making Headway, but that was just the start. Early in 2014, brain tumor survivor Alexis Zachem, also of Scarsdale High, approached Making Headway about doing

some fundraising herself. Her enthusiasm was infectious, and we soon connected her to Fazl and the One L1fe Club. The result was a massive effort of planning and outreach—with very little adult assistance—culminating in a one-hour, calorie-busting cycle-a-thon at a local spin studio. Forty-nine cyclists and a crowd of supporters showed up, and a whopping \$11,000 was raised. 🌷

### Bringing New Meaning to the Word "Multitasking"

Who says you can't do two things at once? The thirty or so professionals who gathered at The Brazen Fox in White Plains last May were ostensibly there for a quarterly networking event. But that didn't stop them from simultaneously chipping in for a good cause. It was long-time Making Headway volunteer, Laurie Nicoletti, who came up with the idea of combining these two activities, and it was clearly a success. In addition to exchanging business cards and sharing ideas, the group enjoyed a tasty meal and donated \$1,770 to Making Headway. 🌷

### Smooth Sailing

On September 14, about 150 guests of all ages turned out to enjoy another lovely sail on the Hudson during our annual **Family Yacht Cruise**. The sun always shines warmly on this event, and this year was no exception. Once again guests laughed at Looney Lenny, the clown; oohed and aahed to the New York City Fire Department's water cannon display and feasted on a delicious lunch. The delightful floating party for patients and their families is funded each year by Marisa and Richard Stadtmauer; Tom Ryan, a retired firefighter, arranges for the spectacular water show. 🌷

Top left: Bogdan Reza Far with his mother, Oksana Kompaneyets, at the Tulip Festival Casino Night.

Photo: Gleb Kuznetsov/Todd Shapera Photography.



Above: Edward and Maya Manley of Making Headway join Laurie Nicoletti and others at the networking event at The Brazen Fox.



Above: Hildy and Sam Parks on the Family Yacht Cruise.

Bottom left: Alexis Zachem (second from right) with her mother Karen and other participants in the One L1fe Club Cycle-a-thon event.





## The Best of the Old and the New

It was a new venue and another great year for the **Nicky and Thomas Docu Memorial Golf Outing**. This annual event is always an opportunity for golfers from the casual to the obsessed to come together for some friendly competition and camaraderie. Held June 6 at the Pelham Bay & Split Rock Golf Course in the Bronx, the day once again featured barbecue, prizes and some good-natured ribbing aimed at host Tom Docu, son of the event's founder and brother of the late Nicky Docu. Longtime family friend, James O'Reilly, also helped plan the wildly successful day, which brought in nearly \$20,000 for Making Headway. 🌻

## A Night of Sparkling Magic

It all started when Making Headway Executive Director Catherine Lepone met John Crabtree of Crabtree's Kittle House in Chappaqua, New York. John had recently lost his wife, Amy, to a brain tumor and had launched a foundation in her memory. Amy had always loved children, and John felt immediately that he wanted to direct some of the foundation's resources our way. So on September 9, Making Headway Foundation held its second annual **Sparkle for a Cause** night at the Kittle House. Almost 40 people came to enjoy the lovely evening under the stars in the garden that Amy's friends had designed in her memory. Guests enjoyed dinner and sparkling cocktails, and The Amy Crabtree Foundation (aka Team Amy), donated 30 percent of the proceeds to Making Headway. 🌻



## This One's For Holly

Park renovations didn't stop nearly 100 people from attending the third annual **A Day in the Park to Honor Holly Kensicki Lind** on September 20. Thanks to construction, the event's usual picnic pavilion was unavailable, but no one much minded: it was a day filled with blue skies and spectacular views of Long Island Sound. In addition to the now-traditional walk in Holly's memory, kids had their own fun run and there were other activities too, along with coffee, snacks and prizes. There were even options for those who couldn't attend. Donations poured in through an online fundraising drive and many fellow alumni of Susquehanna University (Holly's alma mater) took a "virtual walk," posting selfies with the hashtag "thisonesforholly" as they gave via a dedicated fundraising page. All the live and digital action together brought in \$20,000 for Making Headway. 🌻



## Bewitched

One day in late May, music filled the air of the Hassenfeld Playroom, as the Knickerbocker Chamber Orchestra performed its special condensed version of Engelbert Humperdinck's opera **Hansel and Gretel**. The spirited, interactive performance was part of the group's Youth Outreach Program, funded by Goldman Sachs, which works to make classical music come alive for young people. Children and their parents crowded the room, while medical staff took a break to enjoy the proceedings, as well. The New York-based orchestra is directed by Gary Fagin, a friend of the Manleys' daughter. 🌻

*Do you know someone who has a family foundation? Maybe they'd like to consider providing a grant to Making Headway! Contact Executive Director Catherine Lepone at 914-238-8384, ext. 12, or [catherine@makingheadway.org](mailto:catherine@makingheadway.org) to discuss how our mission might dovetail with theirs, and how best to share our goals with someone you know.*

*Top left: Event organizer Tom Docu (on far left), with T.J. McKenna, Danny Scales, Brendan O'Brien, and Jim O'Reilly at the Nicky and Thomas Docu Memorial Golf Outing.*

*Middle: Rachel Henry, Jamie Brisby, Megan Matthews, Courtney Mello and Carolyn Oldham at the Day in the Park to Honor Holly Kensicki Lind event.*

*Bottom left: Making Headway board member David Almeida with Maryellen Almeida, Bernadette Almeida, Peter Brunelli, Don Almeida, Deborah Almeida, Paula Brunelli at the Sparkle for a Cause fundraiser.*



*Above: Lara Ryan (as the witch) and Victoria Weil (as Hansel) in the Knickerbocker Chamber Orchestra's performance of Hansel and Gretel at the Hassenfeld playroom.*



# fundraising & events



1



2



3



4



5



6

1. Fazl Shaikh (center) with the other officers from the One Life Club holding up Alexis Zachem.

2. Andrew Sussman at the Tulip Festival Casino Night event.

3. Laurie Nicoletti with her family at the Sparkle for a Cause fundraiser.

4. Golfers at the Nicky and Thomas Docu Memorial Golf Outing.

5. The New York City Fire Department giving a water show for the Making Headway families during the Family Yacht Cruise.

6. A fun run for the kids at the Day in the Park to Honor Holly Kensicki Lind event.



## Treating the Whole Child

by Preeti Saigal, PhD

Pediatric Neuropsychologist, Coordinator  
of Psychosocial Services

Stephen D. Hassenfeld Children's Center  
for Cancer and Blood Disorders



I never know what will await me when I arrive at my office at the Stephen D. Hassenfeld Children's Center for Cancer and Blood Disorders. As

Coordinator of Psychosocial Services, I oversee the supportive components of a small team that does everything from therapy to wellness to running child life programs. I consult with doctors, families, and members of my team; provide one-on-one and group therapy; conduct neuropsychological testing; and more.

A child who is in the hospital, and that child's family, often need a tremendous amount of support—and we serve many, many children and loved ones. Fortunately, our team is incredibly strong—bolstered by incredible Hassenfeld Center staff and graduate fellows, but also by staff and volunteers provided by Making Headway Foundation, who have become fixtures in the clinic. We are all able to rely on one another. Our patients benefit from the collaborative efforts of our group. For example, when a young, newly diagnosed teenager suffered a lot of pain as a side effect of his treatment, I was grateful to be able to offer alternative therapies, courtesy of Making Headway. At first, he resisted these therapies. When he reluctantly agreed to try them out, we called in Making Headway's massage

therapist and Reiki master, Gunilla Asp. To the young man's surprise, the therapies offered him great relief. Now, he frequently participates in both bedside and individual treatment sessions to manage his physical symptoms and stress.

Through one-on-one therapy or co-led support groups, I help young patients address both the anxiety of their current situations and the daily stressors common to all children—from concerns about friends to family conflicts. We also have specialized groups, including one for parents and one for teenagers; we sometimes offer groups for siblings or focused on special topics, as well.

The neuropsychological testing I conduct also has a significant impact. Results of these tests provide further diagnostic and treatment information to our medical teams, and they are also very helpful for advising families, teachers, and schools about how to best support a child's education.

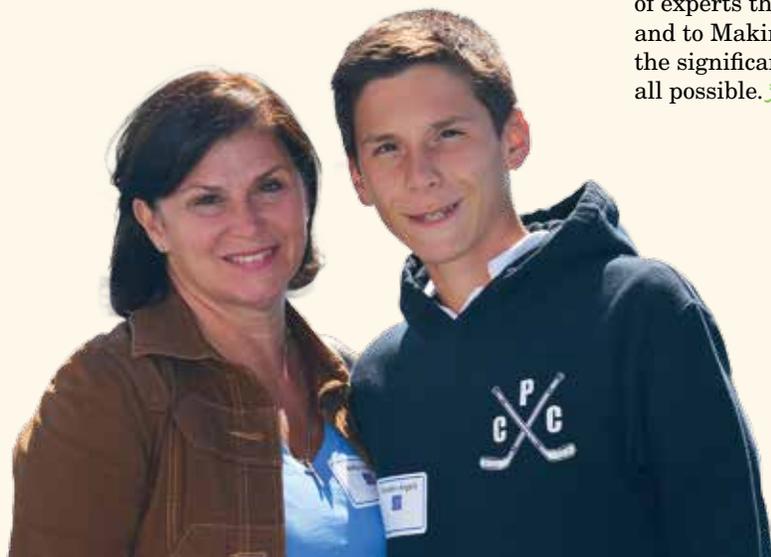
We recently treated a 17-year-old male patient with a complex medical history and associated learning issues. Due to his medical condition, this patient had been home-schooled for an extended period of time—over two years. Our neuropsychology team worked with a Making Headway Foundation-provided educational consultant, who used her expertise as a former teacher to navigate the New York City Department of Education. She was able to identify an appropriate educational placement that could meet this teenager's complex learning needs. We are happy to report that he made a successful return to school this fall, and continues to thrive.

Sometimes I think of the Hassenfeld Center as a sea-worthy ship. No single person could possibly do everything there is to do here. I am so grateful for the team of experts that surround me every day, and to Making Headway Foundation for the significant role they play in making it all possible. 🌱

Top left: Preeti Saigal.

Bottom left: Kelly Angelo  
with her son, Branden,  
on the Family Yacht  
Cruise.

a view from NYU



## Eight Stellar Students Pursue their Dreams

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. This year, Making Headway awarded six scholarships in addition to the two available through the Scott J. Reisser Fund, enabling a total of eight deserving young people to continue their educations with a \$5,000 grant apiece.

This year's winners are:

- **Thomas Golden.** In high school, Thomas was in both the Business & Marketing and the Foreign Language Honor Societies—along with working on the school paper and participating in Model United Nations. This fall, he entered Lehigh University, with the ultimate goal of earning a PhD and become a college professor of English.
- **Jasmine Hall.** In the summer between her two years at Borough of Manhattan Community College, Jasmine interned with the infants and toddlers at a child-care center within a homeless shelter. She's continued to visit the children she came to know and love there, and will now pursue her degree in early childhood education at Brooklyn College. Upon graduation, Jasmine plans to find a job while simultaneously pursuing a master's degree in education.
- **Gene Jerskey.** Gene earned both his high school diploma and an Associate's Degree last June, when he graduated from Bard High School Early College. While in high school, he pursued his interests in photography and film at NYU. He also advocated for pediatric brain tumor survivors' education rights, collaborating on an "Education Toolkit" and serving on panels with the Children's Brain Tumor Foundation. Next step—a bachelor's degree at St. John's College in Annapolis, Maryland.
- **Hannah Klitsberg.** A senior at Marymount Manhattan College, Hannah is majoring in studio art and minoring in art therapy. In her spare time, she volunteers on art projects with the children at Hassenfeld. Her goal is to head to graduate school in order to become an art therapist and work with veterans suffering from PTSD as well as children that have had experiences similar to her own.
- **Juliana LoPiccolo.** Juliana was on the honor roll all four years of high school. A chorister since the age of six, she was a member of the Brooklyn Youth Chorus and has performed with Barbra Streisand, been on the David Letterman Show, and sung at the 9/11 Memorial. She is now pursuing her bachelor's at Bucknell University.
- **Katherine Nelson.** Kate published her first novel at age 13 and had her first play performed at Playwrights Horizons (off-Broadway) at age 14; she also composed original instrumental music for, and acted in, an inter-school production of Romeo and Juliet. This fall, she took her considerable talents to Hollins University in Roanoke, Virginia, which she hopes will be a first step in becoming a lawyer with a specialty in entertainment law.
- **Samantha Ragone.** The first student in the history of her high school to receive two "Silver Awards" for excellence, Samantha was on the Principal's List and Honor Roll in High School. She's now continuing her studies at Camden County College.
- **Joanne Rhee.** In high school Joanne received the AP Scholar with Honor award and President Obama's Award for Educational Excellence. Planning to become a doctor, Joanne is on the next stage of her educational journey at New York University.



Thomas Golden



Jasmine Hall



Gene Jerskey



Hannah Klitsberg



Juliana LoPiccolo



Katherine Nelson

Not pictured:  
Samantha Ragone and  
Joanne Rhee.

## 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:

Adults spend a lot of time debating the state of education and parenting in this country, but if these young people are any indication we're clearly doing something right:

- The **children of Waverly Park Elementary School** proudly marched through the neighborhood in a walk-a-thon to benefit local charities. At the suggestion of one of their teachers, **Jessica Ryan**, they presented Making Headway with a check for \$625 in memory of Elizabeth Ryan, whose family are long-time friends and supporters.
- Members of the **St. Margaret of Cortona School's student council**, in Riverdale, New York, generously continued the school's tradition of remembering third grader Nicky Docu, who succumbed to a brain tumor in 2003. They donated \$377 from an Easter fundraiser to what they termed an "awesome foundation"—aka, Making Headway.
- Each year **students at The Chapin School**, in New York City, are encouraged to donate money to a "Miss Chapin Holiday Fund" in lieu of buying holiday teacher gifts. This year the students, who range from kindergarteners through high school seniors, showed their spirit with a donation of \$1,987 to Making Headway, in memory of classmate Shruti Srinivasan.
- Sixteen-year-old **Donald Wehr** helped out some grateful neighbors with yard work, then donated \$10—fully half of his proceeds—to Making Headway.
- When Dr. Erin Hartnett worked as a nurse practitioner with pediatric oncology at NYU Langone Medical Center, she was a great supporter of Making Headway. Although she left to join the staff of NYU College of Nursing in 2013, her family carries on her legacy. This summer her grandchildren, **Tucker and Teagan McDonough**, 10 and 8 respectively, and **Annie and Zoe Zaumeyer**, 6 and 4, set up a lemonade stand at the Jersey shore. In addition to slaking a lot of thirsts, the enterprising youngsters raised \$35 for Making Headway.



Top: The grandchildren of Dr. Erin Hartnett.

Bottom: Karla DeOliviera with her children Sofia and Sabina, enjoying the breeze and the fine weather on the Family Yacht Cruise.

It was a win/win for employees of Fortistar LLC and Making Headway last July. The employees got to "dress down" in relaxing casual clothes, and Making Headway got paid for the privilege—to the tune of \$166. **Adam Comora**, an employee whose niece, Lily Taubin, passed away from a brain tumor in 2009, suggested that the foundation be targeted in the company's monthly "Dress Down for Charity" event.

Every child (and adult!) knows you can never have too many blankets and warm hats in which to snuggle. Once again, beautiful handmade specimens of each arrived at Hassenfeld Children's Center. The **Linus Blanket Group** of Plainview Reformed Church, led by **Ethel Thomas**, sent another batch of their lovely hand-crocheted blankets, and **Corinne and Bob Jeziorski** sent cuddly handmade blankets and hats of their own.

Each year, the global financial services firm **BTIG** holds a **Commissions for Charity Day**, donating one day's net commissions from around the world in support of non-profit organizations dedicated to child-related causes. Celebrity athletes from Bode Miller to Shaquille O'Neal joined traders on the floor for the 12th annual event this year. Making Headway was delighted to be among the beneficiaries, accepting a check for \$50,000.

making a difference



## Keep in Mind

On **November 2, 2014**, join the athletes of Horace Greeley High School in Chappaqua, New York for a walk-athon in memory of former classmate, Gardner Marks. Proceeds will be shared by Making Headway Foundation and the Pediatric Cancer Research Foundation.

**December 2, 2014** is #GivingTuesday. Following Thanksgiving, Black Friday and Cyber Monday, #GivingTuesday is a day dedicated to giving back. Charities, families, businesses, community centers, and students around the world will come together to celebrate generosity and find ways to give back. Tell your friends about Making Headway and encourage them to give at [MakingHeadway.org](http://MakingHeadway.org).

**March 29, 2015** is the date for Making Headway's annual winter show at the New Victory Theater: *Catch Me!* With awesome acrobatics, astonishing aerial acts and the wherewithal for whatever, this talented troupe from Quebec City has a ball discovering new ways to lift each other up and reach new heights.

### The holidays are coming!

When you shop online through [iGive.com](http://iGive.com), a percentage of your purchase price will automatically be donated to Making Headway. To get started, simply register at [www.iGive.com/makingheadway](http://www.iGive.com/makingheadway). Then follow the instructions and you'll be able to shop directly from the websites of nearly 1,500 stores that have agreed to donate a percentage of each sale.

*For more information about promotions and events listed above, contact Executive Director, Catherine Lepone: [catherine@makingheadway.org](mailto:catherine@makingheadway.org).*



*Top: Michael Abell, with his son Jun and daughter Maya, on the Family Yacht Cruise.*

*Middle: Children enjoying the antics of clown Lenny during the Family Yacht Cruise.*

*Bottom: Yoga instructor Annie Hickman with Sali Konate in the Hassenfeld playground.*

## Making Headway Foundation

115 King Street  
Chappaqua, NY  
10514-3460  
Tel: (914) 238-8384  
[info@makingheadway.org](mailto:info@makingheadway.org)  
[www.makingheadway.org](http://www.makingheadway.org)



[www.facebook.com/makingheadwayfoundation](http://www.facebook.com/makingheadwayfoundation)

*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 Catherine Lepone and Linda Mudford-Lewis for their generous help with this newsletter. Special thanks to Preeti Saigal and Greg Taubin for sharing their stories.

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

*Managing Editors:*  
Robin Hardman  
Audrey Manley

*Photos:*  
Erin Hartnett  
Gleb Kuznetsov/Todd Shapera Photography  
Maya Manley  
Catherine Lepone  
Alison Simko

*Design:*  
Cara Galowitz

*Printing:*  
H & S Graphics

