



Announcing the New NYU Brain Tumor Center

A message from Dr. Howard Fine, Chief, Division of Hematology and Medical Oncology; Director, Brain Tumor Center; Deputy Director, NYU Cancer Institute

With a crucial commitment of \$1 million from Making Headway Foundation, NYU Langone Medical Center recently embarked on an exciting and ambitious new initiative to bring all the components of cancer care and research under a single umbrella—a coordinated effort analogous to a Manhattan Project for brain tumors. The NYU Brain Tumor Center (NYUBTC) will be one of the world’s leading brain and spinal cord centers. It will be dedicated to outstanding patient care; training for the next generation of neuro-oncology-focused clinicians and investigators; and the discovery of improved diagnostic tests and treatments for both children and adults.



I’m thrilled to have been asked to lead this exciting and ambitious venture, joining NYU in the role of Chief of the Division of Hematology and Medical Oncology, Director of the Brain Tumor Center, and Deputy Director of the NYU Cancer Institute. In my new role, I’ll partner closely with Dr. Jeffery Allen, Director of the Pediatric Neuro-Oncology Program, NYU Langone Medical Center and the Otto and Marguerite Manley and Making Headway Foundation Endowed Professor of Pediatric Neuro-Oncology. Other vital leaders of NYUBTC include Dr. John Golfinos, Chair of the Department of Neurosurgery; Dr. Jeffery Wisoff, Director of Pediatric Neurosurgery; Dr. William Carroll, Director of the NYU Cancer Institute and Dr. David Zagzag, Chief, Section of Neuropathology.

NYUBTC will be a multidisciplinary consortium of established clinical and scientific departments, programs and institutes at the NYU Langone Medical Center. It will provide comprehensive evaluation and diagnosis, leading edge treatment and thorough follow-up, including psychosocial support. At the same time, it will push the frontiers of biomedical research, establishing a core group of laboratory-based scientists dedicated to the study of genetic and molecular drivers of brain tumors. These lab-based scientists will be able to share their most promising discoveries directly with researchers working with patients, in order to develop improved diagnostic tests and therapies. In addition, NYUBTC will have a matrix structure that taps into the expertise and resources of the NYU Cancer Institute, the new NYU Medical Center Neuroscience Program and NYU’s Skirball Institute of Molecular Medicine.

With clinicians, lab-based and clinical investigators working together in close proximity, the result will be a more streamlined and efficient flow of patient material (such as tumor tissue,

(Continues on back page)

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

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

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.



A Spring Tradition Takes Its Final Lap

“After years of great success, countless hours of hard work, an outpouring of donations, and a plethora of amazing family and friends helping along the way, it is with bittersweet emotions that we announce this year’s Little Bit of a Walk will be our 15th and final.”

Thus begins a letter from Diane Ryan to the many family members, friends, and Making Headway supporters who have turned out each year for a very special fundraiser. Each April since 1998, the Ryan family has hosted an event celebrating the life of Diane and Pat Ryan’s daughter Elizabeth, who died from a brain tumor in 1997. The **Little Bit of a Walk and Fun Run** features both a run and a leisurely stroll around the lovely Long Island town of Point Lookout. The popular event also includes refreshments, music, and such activities as face-painting and an auction.

Elizabeth Ryan was diagnosed with an inoperable brain tumor in July, 1997. Throughout the summer and fall, the young girl underwent treatment at Beth Israel Hospital, where Dr. Allen (who has since moved to the NYU Langone Medical Center) and his staff did everything they could for her. During her many visits, the shy nine-year-old was embraced by members of the Making Headway team. She accompanied Maya Manley around the floor, passing out candy. She played and enjoyed parties in the playground. Her parents, too, were supported, in part by being put in touch with other parents in similar situations. Then, just three days before Christmas, Elizabeth passed away.

Not surprisingly, when the Ryans began to consider how they could best remember and celebrate Elizabeth’s life, Making Headway came to mind.

“Some families start their own foundations. It took a burden off me to be able to support an organization that was already doing such good work,” Diane explains. She also knew how she wanted the bulk of her fundraising dollars spent: on research.

“Making Headway does wonderful things for families and I support that, but I always figure, if we can find a cure, then they won’t have to do those other things!”

When it came time to decide what sort of fundraiser to hold, the answer was clear: “We wanted to associate happy memories with Elizabeth, not have it be all about doom and gloom.” So, beginning on April 3, 1998, the day Elizabeth would have turned ten, every year the Ryans have hosted their **Little Bit of a Walk**. This year, with the round number of “fifteen” in sight, and with a total of \$318,000 raised so far, Diane decided it was time to bring the tradition to a close.

As it turns out, planning the final event was bittersweet. Point Lookout was hit hard by Superstorm Sandy. Many people suffered losses, and some of the friends who had participated each year were still not back in their homes. Even the hall where the event traditionally begins and ends was so badly damaged that proceedings had to be moved outside. But nothing stopped the activities. The final **Little Bit of a Walk and Fun Run** brought in just over \$30,000. And Diane has made it clear that even though her family will no longer be organizing the event, they’ll continue to fundraise and support Making Headway in other ways.

Making Headway thanks Diane, her family and all the others who worked so hard to plan and host this wonderful event for so many years. 🌻

Cover page:

Top: Dr. Howard Fine.

Bottom: Christian Velez-Guzman with Marjorie Transou, Nurse Coordinator at Hassenfeld Children’s Center.

Photo: Todd Shapera Photography.

Left:

Laura Hall Oweis (on left) and Donna Johanns at the 15th annual Little Bit of a Walk and Fun Run.





Top Left:
Diane Ryan (middle)
with sisters Erica
and Julie.

All other photos are of
participants at the 15th
Annual Little Bit of a
Walk and Fun Run in
Point Lookout,
New York.



giving back



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:

Late last spring **Noelle Sullivan** once again offered her classmates a rare opportunity to flout the dress code of Saints Mary and Elizabeth Academy in Linden, New Jersey. The enterprising middle-schooler organized the dress down event in honor of Brain Tumor Awareness Day, collecting \$143 for Making Headway. Noelle has big plans to continue the tradition at her high school, Benedictine Academy, this year.

Grown-ups appreciate the opportunity to dress down, too—and the Williams Lea company makes good use of that fact. Each month, it selects a cause and offers employees the opportunity to wear jeans every Friday in exchange for a \$1-\$5 donation. In February, employee **Kevin Mepyans** suggested Making Headway, raising \$275 and making a lot of co-workers happy.

Twelve-year-old **Marirose Fischer** elicited the help of her cousin, **Susan Smith**, in the sale of “Cool Caps”—bottle caps that she’d personally transformed into decorative refrigerator magnets. Smith sold the caps to fellow faculty members at the elementary school where she teaches, raising \$200 for Making Headway. It was the second such venture for the enterprising Marirose, whose request that the money be used to purchase new video games for the teen room at Hassenfeld Children’s Center has already been honored.

When **Georgia Gerber** turned thirteen not long ago, the only gift she wanted was a way to honor her friend Jack Reyna. So she thoughtfully asked friends and family to divert their gift-giving to Making Headway, bringing in \$2,977.

Lending new resonance to the phrase, “turning lemons into lemonade,” a civic-minded group of preteens braved a landscape of fallen trees in Bethpage, Long Island, to hand out free lemonade and cookies to their neighbors in the aftermath of Superstorm Sandy. People apparently appreciated the efforts of **Rachael Kessler**, her cousins **Alexandra and Elana Kaminsky**, and their friends **Hope and Ava Feinberg**—they responded by donating a total of \$25, which the girls generously passed on to Making Headway.

Twelve-year-old **Georgie D’Avanzo** researched companies that could produce bracelets for her fundraising efforts, then designed and ordered them. She sold nearly 200 to classmates, friends and family—appropriately designating the \$34 she raised for craft supplies in the Playroom.

As student body president of Irvington High School, **Preyaa Docu** has made generous use of her position, entering the school in Cablevision’s “Power to Learn Charity Champions” initiative. The initiative provides seed money and prizes to participating schools, which compete to raise

money for causes of their choosing. Preyaa signed on Irvington High to fundraise for Making Headway, and has thus far been able to deliver \$1,748 for use in research, in memory of her cousin Nicky Docu and his dad, Tom (see back page). One of the biggest fundraising events so far was “Compete for a Cure,” in which students and faculty alike donated \$5 to compete in athletic events.

Jason Barrie is no stranger to multi-tasking. Even as he biked 40 miles through New York City as part of the annual Five Boro Bike Tour he was raising money in honor of his cousin, Mikey Schwartz, survivor of a childhood brain tumor. Jason put out a call for donations on the Bike Tour event page, setting a goal of \$1,000—but to date he has nearly tripled that goal, benefitting Making Headway to the tune of \$3,127.

Giving was recently on the mind of **Dr. Daniel Meltzer**, too. The former resident and fellow in neuroradiology at NYU made good time in the March 17 New York City half-marathon, but thanks to his generosity Making Headway was the clear winner, coming away with \$2,502.

Winters in the Northeast can be chilly, but thanks to the efforts of **Corinne and Bob Jeziorski** as well as those of **Ethel Thomas** and her **Linus Blanket Group** at Plainview Reformed Church, the children at Hassenfeld have stayed warm and cozy. The Jeziorskis delivered boxes of their beautiful hand-crocheted blankets in December and again in March, while the Plainview crowd sent regular shipments of their own handmade blankets throughout the year.

Children visiting Hassenfeld Children’s Center around the holidays were showered with gifts this year, as Maya Manley handed out heaps of wonderful toys. One shipment came courtesy of **Jeanne Egan**, her mother, **Doris Egan**, and her aunt and uncle, **the Jeziorskis**, while another came from Jeanne’s friend **Irene Wlodarski**.



Above top:
Preyaa Docu.

Above bottom:
Georgia Gerber.

Below:
Dr. Daniel Meltzer.



A Tribute to Dr. Erin Hartnett

by **Jeffrey C. Allen, MD**

Director of the Pediatric Neuro-Oncology Program, NYU Langone Medical Center and Otto and Marguerite Manley and Making Headway Foundation Endowed Professor of Pediatric Neuro-Oncology

Erin Hartnett has served as a pediatric nurse practitioner in partnership with me for a total of eleven years, first with Pediatric Neuro-Oncology Services at the Institute of Neurology and Neurosurgery of Beth Israel Medical Center and then, from 2004–2012, at NYU Langone Medical Center. She has decided to move on this year to assume a job as a Professor of Nursing at the NYU School of Nursing. We wish to acknowledge the long-term commitment she made to the care and comfort of our patients.

Erin partnered with a pediatrician in lower Manhattan for over ten years before joining our team at Beth Israel. She brought us a wealth of experience and knowledge of child health and well-being. After assuming her new role as a pediatric nurse oncologist, she quickly mastered the art of chemotherapy. In partnership with me, she assumed the responsibility for prescribing and administering chemotherapy to our children with primary brain and spinal cord tumors, a challenging and complex undertaking, and she did it with the utmost sense of caution and responsibility. She is largely responsible for the safe passage and ultimate cure of many of our patients, and the children and their parents have expressed their everlasting gratitude over the years.

Since coming to NYU in 2004, Erin has assumed several new responsibilities and developed additional interests. She undertook the training of pediatric nurse practitioner students from the NYU School of Nursing on a regular basis. She developed a liaison with the NYU School of Dentistry, so that many dental students now rotate at Hassenfeld Clinic to learn about and treat the unique dental problems of children with cancer. She started a multi-disciplinary Long Term Follow-up Clinic for the children who were fortunate to survive their brain and spinal cord



*Left: Dr. Erin Hartnett.
Photo: Todd Shapera Photography.*

tumors, for whom she remediates health and cognitive problems that may have developed as a result of cancer therapy. Always striving for self-improvement, Erin went back to nursing school at NYU and attained a Doctorate of Nursing Degree. In her new role, she will continue to train pediatric nurse practitioners.

On a personal level, Erin and I worked as close partners, supporting each other in our complimentary areas of expertise. I always had full confidence in her ability to provide outstanding cancer care to our patients, and the children and their families developed close bonds with her. I am not alone in my respect and praise for her; she has been honored by the NYU Nursing Department and has received the New York Times Nursing Innovation Award and the American Association of Colleges of Nursing Award for her Doctorate in Nursing Practice.

We are fortunate that one of her students, Miriam Pudel, has now assumed her position at Hassenfeld, so Erin's legacy lives on. But Erin has also promised us that she will stay in touch. We wish her every success in her new role. 🌱

good-bye & good luck



Thinking of One, Giving to Many

Following the success of last summer's *Holly's Angels Gala*, nearly a hundred college friends of Holly Lind gathered at the picturesque Sherwood Island State Park in Westport, Connecticut, on September 23. The friends walked, shared memories and outbid each other for items in a silent auction. In all, *A Day in the Park to Honor Holly Lind* raised \$15,542 for Making Headway.



OMG! Bowling for Vegas!

When Barbara Rittner lost her 17-year-old daughter, Chelsea, to a brain tumor six years ago, she and her son, Daniel, pondered what they could do to both give back to Making Headway and help other teen and young adult brain tumor survivors enjoy a "little slice of normal." The idea they came up with was perfect. In late September they held the *Chelsea Cohen Memorial Bowl-a-Thon*, bringing in \$8,692. These funds were then delivered to Making Headway, where staff selected three deserving young people to win scholarships to the *OMG! Cancer Summit for Young Adults* in Las Vegas, Nevada.



In April, as this newsletter was going to press, the teens enjoyed three days of friendship, learning and inspiration—and Making Headway discovered yet another way to provide a special kind of care and support.

Hitting it Home, Again

Once again the balls and bats of summer lingered on into September, as ten teams competed in the annual *Swing for a Cure* whiffle ball tournament. The event was held at the scenic Federal Little League Park in Stamford, Connecticut, on a warm, sunny day. Spectators and participants alike enjoyed the breeze drifting in from Long Island Sound and feasted on grilled delicacies. As always, the event was sponsored by the Conetta family, who hosts it each year in gratitude for the help they received when their son Chris underwent treatment for a brain tumor. This year's tournament brought in \$12,400, bringing the total amount raised since its 2009 launch to \$33,555.



En-Garde!

No true follower of the great Zorro would be deterred by a little snow, so it was no surprise that an enthusiastic crowd of more than 300 found their way to the New Victory Theater on February 8, just days after a devastating blizzard, to cheer on the swashbuckling hero. *The Mark of Zorro*, an entertaining new interpretation in which three actors took on all the roles, enthralled the audience with adventure and magical stagecraft. Zorro is famed for defending the defenseless, but his biggest beneficiary this time around was Making Headway, which raised close to \$360,000 from the event.

Left: Kaelyn Brisby and her cousin Gianna Wallace (on left) at the A Day in the Park to Honor Holly Lind fundraising event.

Below right: Jake Bendler at the Swing for a Cure event.

Below left: Amy Barest and Jessica Lippin (on right) at the Chelsea Cohen Memorial Bowl-a-Thon fundraiser.



Advantage, Lady Eagles!

October also marked the return of **Kicks for Cancer**, the spirited sports event organized each year by the Hauppauge High School Lady Eagles varsity soccer team in memory of former classmate Courtney Tomkin, who died of brain cancer in 2008 during her senior year. The event, now in its fifth year, gets more expansive each time—this year involved numerous other schools and weeks of play, culminating in games featuring not only the undefeated Lady Eagles but their counterparts in boys varsity soccer, the Eagles. For those seeking further thrills, there were also carnival rides, refreshments and special amenities like t-shirts and pink hair extensions. In keeping with another tradition, the day was followed a few weeks later by a visit to the Hassenfeld Children’s Center from the Lady Eagles and their coach, Jessica Kulesa, who presented a \$20,000 check for Making Headway. 🌸

Stepping Out for Carnival

Stand back, Rio! Watch out, New Orleans! Your own celebrations may be better known, but surely none are more anticipated and enjoyed than the Fitzgerald family’s annual **Mardi Gras Bash** at the Colonial Terrace in Cortlandt Manor, New York. This year, the winter event included delicious eats and high energy dancing late into the night, along with the opportunity to bid on some choice auction items. But what most distinguished it from those other Mardi Gras celebrations is the generosity it inspired: all told, Making Headway received \$4,000 from the proceedings. 🌸



Making a Dramatic Difference

In keeping with yet another annual tradition, Jeanne Egan and her family hosted a very special **Night at the Theatre**, selling tickets to a riveting performance of “One Flew Over The Cuckoo’s Nest” at the Merrick Theatre and Center for the Arts in Merrick, New York. Members of the Northshore Kiwanis Club also supported the event, which benefited Making Headway to the tune of \$645. 🌸



Step Back, Masters— A New Tournament is Born

At 16, brain tumor survivor Brian McCabe has been through more than any teenager should have to. But he and his family decided to give their experience a positive spin by hosting **Drive for a Cure**, a golf tournament in support of Making Headway. The event was held on a beautiful October day at American Golf’s Pelham Bay and Split Rock Golf Course in the Bronx. Nearly a hundred golfers spread out on the greens, seeking that ace in the hole and, in the process, raising a total of \$45,343. For the McCabes, it was the start of a new tradition—so dig out your clubs and mark your calendars for October 7, 2013. 🌸

Left: Participants at the Kicks for Cancer event.


Below right: Brian McCabe (far left) with other golfers at the Drive for a Cure fundraiser.

Below left: Dana De Santo and her mom Joy De Santo with Kylie Fitzgerald (far right) at the Mardi Gras Bash fundraiser.



In Memoriam: Tom Docu

Our hearts go out to the wife and family of Tom Docu, a great friend and supporter of Making Headway, who passed away on February 8. After his son Nicky died in 2003, Tom launched an annual golf tournament in his memory. With the help of his family, including his wife, Christine, and children, Tommy and Alexandra, he worked tirelessly on the event, securing all the auction prizes and acting as both master of ceremonies and auctioneer. Each year Tom's loyal friends from the police, fire and security services came to play golf and to subject their M.C. to a great deal of good-natured ribbing, which he took entirely in stride.

Since 2007, the proceeds from the *Friends of Nicky Docu Memorial Golf Outing* have been designated entirely for Making Headway Foundation, bringing in over \$126,000 in all. We are grateful that Tommy and other family members have agreed to continue the tradition: this year's tournament will be held on June 28th at Van Cortlandt Park Golf Course in the Bronx. 



New NYU Brain Tumor Center

(Continued from cover)

serum and imaging data)—making research much more productive. For example, every tumor that is surgically removed at NYUBTC will be extensively evaluated for genomic/epigenomic mutations and grown in the laboratory for purposes such as drug testing. Thus, with the patient's consent, a tumor will not only provide material to feed research for years to come, but may yield biological clues allowing doctors to devise treatments tailored to the unique genomic makeup of that specific tumor.

Finally, NYUBTC will also be dedicated to cross-disciplinary physician and scientist training, providing academic courses, laboratory training opportunities and neuro-oncology clinical fellowships. All of these capabilities will, in turn, become the basis for a vibrant interaction with the pharmaceutical and biotechnology industries, attracting promising new therapies for our patients.

In short, NYUBTC will be the most comprehensive program for brain tumor patient treatment and clinical/translational research in the world, enhancing still further NYU Langone Medical Center's reputation for excellence. We are deeply indebted to Making Headway Foundation for its commitment of \$1 million dollars to help make this program come to life.

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Making Headway thanks Catherine Lepone and Linda Mudford-Lewis for their generous help with this newsletter. Special thanks to Dr. Howard Fine and Dr. Jeffrey Allen for their contributions.

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

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Above right: Volunteer Maya Manley with Amina Moursy working on a craft project at the Hassenfeld Children's Center.

Photo: Todd Shapera Photography.

Top left: Tom Docu.

Bottom left: Golfers at the Friends of Nicky Docu Memorial Golf Outing.

