



Pediatric Brain Tumor Research Continues to Expand

A message from Dr. Matthias Karajannis, Associate Professor of Pediatrics and Otolaryngology, NYU Langone Medical Center



I'm pleased to report that pediatric brain tumor research at NYU Langone Medical Center is expanding in both breadth and depth, thanks in part to the ongoing support of Making Headway Foundation. Our existing faculty, including Drs. Jeffrey Allen, Sharon Gardner, David Zagzag and myself, continue to conduct research both within NYU and in collaboration with other researchers

around the country and around the world. In addition, we've recently been joined by Drs. Matija Snuderl and Hae-Ri Song, two new faculty members and experienced researchers who bring special expertise in pediatric brain tumors.

Our team conducts three overall types of research:

- ***Fine-tuning our ability to make diagnoses, in part by identifying biological markers.** Biological markers are anything that offers a measurable indicator that a certain type of tumor exists, or what the state of a tumor is, in order to both diagnose and treat it. For example, we're currently involved in a project that allows us to see the molecular "fingerprint" of a given tumor, providing us with in-depth information about its origin that we can use to pinpoint the diagnosis and customize treatment. We are already successfully applying this powerful technology with patients at NYU Langone Medical Center—the first hospital in the United States to be using it.*
- ***Exploring new targets for therapy.** One such project involves studying the genetics and biology of a rare but deadly pediatric brain tumor, pineoblastoma, in the hopes of uncovering new approaches to treating it. Another example is a study of a special substance produced by pilomyxoid astrocytoma (PMA) tumor cells. We have preliminary evidence that this substance not only feeds the growth of this tumor and causes resistance to chemotherapy, but that the substance, itself, could be amenable to targeted therapy.*



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Photos: Dr. Matthias Karajannis with patients at the Hassenfeld Children's Center at NYU Langone Medical Center. Todd Shapera Photography.

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Coming Out Swinging

October 6 started out foggy and cool, but eventually the sun came out, replacing the mist with blue skies. Dozens of golfers and their friends showed up at the Split Rock/Pelham Bay Golf Courses to play in the third annual **Brian McCabe Drive for a Cure**. Organized once again by Mike McCabe, proud father of brain tumor survivor, Brian McCabe (see page 6), the event featured breakfast, lunch and a reception, along with some exciting action on the greens! Golfers and non-golfers alike also had the opportunity to bid on an impressive array of auction items, from a giant-screen TV to a George Foreman Grill to all the golf paraphernalia one might ever need. In all, the event raised more than \$45,000 for Making Headway. 🌻

The Boys (and Girls) of October

Is there anything more idyllic than a little league field on a crisp New England day, with players and fans enjoying a summertime game in the first bright days of fall? For some sports enthusiasts October may be all about the World Series, but in Stamford, Connecticut, on October 18 all eyes were on the wiffle ball teams battling it out in the annual **Swing for a Cause** tournament. This year the event, sponsored by the family of brain tumor survivor, Chris Conetta, featured more than a half dozen teams and (once again) the irresistible tang of barbecue. It was a home run for Making Headway, too, which was delighted to receive \$3,830. 🌻



G-o-o-o-a-a-a-a-l!

There was plenty of action for soccer fans in October, as well, with the annual week-long **Kicks for Cancer**, a Long Island fundraiser in memory of Hauppauge High School student, Courtney Tomkin. Schools across two counties participated, but the centerpiece came on October 17, when Hauppauge High’s girls and boys soccer teams, the Lady Eagles and the Eagles, both took to the field. A chill in the air didn’t stop hundreds of supporters of all ages—including long-time Making Headway friends Greg Trunz, Daryl and Theresa Tomkin and Lizette Rivera-Gonzalez—from showing up to cheer on their teams, enjoy other activities and munch on delicious food. All told, the event, organized each year by Alexis Gonzalez and Lady Eagles coach, Jesseca Kulesa, took in thousands of dollars for a variety of causes, including \$20,250 for Making Headway. 🌻



Top left: Golfers Mike Prunty and Mike Hannon at the Brian McCabe Drive for a Cure event.

Right top: The Lady Eagles at the Kicks for Cancer fundraiser.

Right bottom: Hauppauge Lady Eagles team captains presenting a check to Maya and Edward Manley of Making Headway at Hassenfeld Children’s Center.



Bottom Left: The winning team at the Swing for a Cause tournament.

A Promise Fulfilled

Courtney Tomkin was the inspiration for another athletic fundraiser this year, as well. The **Gains for Brains Lacrosse Showcase** was the end result of a commitment journalist Andrew Rappaport made to himself way back in 2008. Working at the time for local station News 12, Andrew interviewed Courtney for a story just months before she died. The experience so moved him that he vowed to do something in her memory as soon as the opportunity arose. This past year, he had that opportunity, and he laid plans for the April 18 tournament. On a hot spring day in Cold Spring Harbor, Long Island, twelve high school girls' lacrosse teams competed in six games. In addition to raising money through ticket sales, each participating team made a contribution; still more funds were raised through the sale of t-shirts and baked goods. (Coincidentally, one of the team members playing her heart out that day was Casey Tucker, sister of a young man currently being treated at Hassenfeld Children's Center.) And before the afternoon was out, about \$8,000 had been raised for Making Headway. 🌱



A Jewel of a Party

Sometime last fall, Varda Singer, owner of ICD Contemporary Jewelry in Chappaqua, New York, had an idea: why not hold a holiday party and fundraiser for her neighbor, Making Headway? The foundation's offices are not far from her store, and the Manley's daughter, Cynthia, had once worked there. In no time, the event was organized. Dozens of people showed up on a cold December night to enjoy sushi and champagne and take care of some

holiday shopping. Twenty percent of the proceeds from the evening's sales went to Making Headway, bringing in a greatly-appreciated \$1,861. 🌱



Catch Me!

On March 29, a sold-out crowd packed the New Victory Theater in Manhattan to witness an astonishing performance by **Flip FabriQue**, the wildly talented acrobatic troupe from Quebec City, Canada. Audience members—consisting of patients and their families as well as donors—held their breaths as they followed the antics of this talented group of performers, who seemed immune to gravity as they swung through the air, leapt to staggering heights from a trampoline, twirled balls and hula hoops and more—all accompanied by gasps, giggles and shout-outs from the delighted audience. The troupe stayed after the show to greet the crowd and sign autographs. Attendees young and old even got to try their hands at hula hoops and juggling! In addition to being a much-needed day out for many, the event brought in over \$450,000 for Making Headway. 🌱



Top right: Virginia Shasha, Laura McKillop, Maya Manley, Jan Johnsen and Vivian Shasha at the holiday party and fundraiser held at ICD Contemporary Jewelry.

Bottom left: Participants in the Gains for Brains Lacrosse Showcase.

Bottom right: Mary Church with her daughter Shanna at the Catch Me! fundraiser.

Below: Jasmine Hall and her cousin enjoy Catch Me! 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:

Another frigid and very snowy winter was made that much warmer when Maya distributed soft, hand-crocheted blankets and hats from **Corinne and Bob Jeziorski**, then piled on still more cuddly, hand-crafted blankets courtesy of the Plainview Reformed Church **Linus Blanket Group**, which was organized by **Ethel Thomas**.

Two sets of newlyweds are starting their lives together in a spirit of giving that's bound to ensure a bright future:

- **Kathryn Weiss** and **Adam Segall**, married at the Swan Club in Long Island in October 2014, donated \$350 to Making Headway in lieu of wedding favors. The gift was in memory of Allison Trunz.
- Longtime Making Headway supporter **Jensy Luka** and her fiancé, **Lance Antony**, have set the big date for June 2015, but have already redirected their \$500 favor budget to Making Headway.

Proving that the fruit doesn't fall far from the tree, **Esmé Fritton**, granddaughter of Maya and Edward Manley, presented her **6th grade homeroom classmates at Grace Church School** in New York City with a moving slide show about Making Headway. Her activism inspired an enthusiastic response: the students decided to hold a bake sale, raising \$351 for their new-found cause.



For more than a hundred years, teachers at **The Chapin School** in Manhattan have generously encouraged students and families to forgo teacher gifts and instead donate to a special "Miss Chapin Holiday Fund." Making Headway was once again one of the lucky beneficiaries of this thoughtful tradition, receiving \$511 from young philanthropists in grades 8-12.

Clearly, **Ally Landau** doesn't believe in half-measures. The young teen took a double-pronged approach to her Bat Mitzvah project, both selling tasty baked goods and collecting donations—all in memory of her cousin, Jamie Levy. Her efforts brought in not only \$1,570 in cash, but hundreds of dollars' worth of Dunkin Donuts and Starbucks gift cards, which were handed out to grateful parents and children at the Hassenfeld Children's Center.

Numerous runners—and walkers—have been racing to make a difference lately:

- Last June, the **Children's Future Fund** held its fifth annual 5K race in memory of Christian Brito. Christian had been a patient at the Hassenfeld Children's Center, and his family generously directed \$800 of proceeds from the run toward Making Headway.



- When the Ridge Runners' running club was looking around for an organization to benefit from its first annual Super Ridge 5K Run, new members **Lourdes and Alan Steffen** had the answer. The Steffen's son, Alan Paul Steffen, had died from a pediatric brain tumor in 2013, and the couple immediately thought of Making Headway. Fellow club members agreed it was a great idea; the race brought in \$554.
- Making Headway Foundation recently joined forces with the Pediatric Cancer Research Foundation and the **Horace Greeley High School Sports Teams** to hold a collaborative fundraiser benefitting both foundations. All the young athletes joined together for a walk-a-thon, raising \$7,400 for Making Headway.

Save the Dates!

June 5, 2015
Pack up those putters and irons, dig out your golf shoes and get ready for some fun at the annual **Nicky and Tom Docu Memorial Golf Outing** at Split Rock/Pelham Bay Golf Courses, Bronx, New York.

September 8, 2015
Savor the last days of summer as you enjoy sparkling cocktails, delicious food and a stroll around the lovely garden at the third annual **Sparkle for a Cause** event, held once again at Crabtree's Kittle House in Chappaqua, New York.

October 5, 2015
And don't put away those clubs just yet—join us at the fourth annual **Brian McCabe Drive for a Cure**, also at the Split Rock/Pelham Bay golf courses in the Bronx.

Upwards and Onwards: A Look to the Future of Making Headway



For most of us, Maya and Edward Manley are the faces of Making Headway Foundation. Nearly twenty years ago, after coming to understand firsthand the trauma of having

a child with a brain tumor, they made the momentous decision—along with co-founder, Clint Greenbaum—to devote the rest of their lives to helping other families in similar situations. Making Headway has been an act of love, every step of the way.

Most people who know them know the Manleys are ideally suited for this mission. Edward, with his background in finance and planning, has the requisite skills to manage the foundation, taking care of the books, overseeing budgeting and the distribution of funds and ensuring everything is done with as much efficiency and as little waste as possible. Maya, with her sensitivity, warmth, and boundless energy, is a natural for reaching out to families, counseling parents and making every child she meets feel special and cared for.

“From the beginning, we had two distinct roles, which matched our strengths very well. We didn’t plan it that way—it was just a natural way for things to go. It has worked beautifully,” says Edward.

But the Manleys never set out to have Making Headway be about themselves. Their goal was to put something in place that would continue to deliver services to families living through a uniquely devastating experience—and continue to grow and expand research.



Nineteen years later, Making Headway is doing just that. Since its inception, the foundation has raised over \$19 million, provided services to thousands of family members, and supported research being conducted both locally and around the world. But that’s only part of the impact Making Headway has had. When Maya and Edward co-founded Making Headway, it was in part because they found something lacking in the medical system.

“While our own daughter received excellent medical care, the hospital had almost no systems in place to support any of us emotionally, or to help us on the long journey that was to follow, getting her back on track with her peers and her schooling,” Edward explains.

Today, while Making Headway continues to support families with an array of in-hospital and ongoing care services, the organization is no longer completely alone in this. The work Making Headway undertook nearly two decades ago has created a paradigm shift; many hospitals now see their role much more holistically, providing services that go far beyond the medical side of things.

Stepping Back...Just a Bit

Making Headway has always looked not just to the present but to the future, and over the years it has deliberately built up a strong infrastructure. The staff now includes Executive Director, Catherine Lepone, who has taken over some of Edward’s duties. Catherine has a hands-on approach to not just maintaining the organization but growing it: developing partnerships with other public and private organizations; supporting community- and family-based fundraisers; building a powerful presence on social media and more. Linda Mudford-Lewis, longtime Office Administrator, aided by new accounting software, is ready to take over the daily bookkeeping duties. The foundation has also been gradually expanding its Board of Directors and Medical Advisory Board—see page 7 for the latest additions.

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Top left: Maya Manley with a participant on the annual Family Yacht Cruise.

Top right: Maya Manley with a patient at the Hassenfeld Children’s Center at NYU Langone Medical Center.

Todd Shapera Photography.

Bottom: Edward and Maya Manley at the annual Family Fun Day.

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Top: Runners at the first annual Super Ridge 5K Run.

Middle: Participants at the Horace Greeley High School Sports Teams Walk-a-Thon.

Bottom Left: Students at Grace Church School including Esmé Fritton, Greer Goergen, Vaughn Nalley, Cadence Plenge, Liya Yaniv, Henry Epstein, Peter Madoff, Henry Houston, Christian Tan, Jonah Feinberg, Mila Piasecki, Susanna Langan, Evelyn Ward, Alexandra Blum, Emily Williams, Bryanna Antigua, Houldin Marcovitz, Ian Rotheroe, Benny Mander, Noah Kates, Summer Green and Theo Attanasio.

One Family's Story

When Brian McCabe was just seven, doctors discovered he had a medullablastoma—a highly malignant brain tumor. His shocked parents were told he had only a 20-30 percent chance of surviving, and they had 36 hours to get him into surgery. His mother, Eileen, who is a nurse, got to work. She called everyone she could think of that might give them a lead on where to take him, and by next morning they were pulling up to Manhattan's Beth Israel Hospital.

Making Headway made its presence known before they even set foot in the door. Crossing the street toward the main entrance, filled with worry and trepidation, Eileen remembers noticing a woman waiting for them on the other side. "I think you're coming to see us," was the woman's surprising comment. As Eileen started to object that there must be a misunderstanding, the bystander continued, looking kindly toward young Brian. "But I have something for you." She offered him a piece of candy.

The woman was Maya Manley, and to this day Eileen McCabe has no idea how she knew that they were headed for treatment at the hospital's Institute for Neurology and Neurosurgery, Making Headway's headquarters at the time. Later that morning, Maya found the family waiting in a conference room, introduced herself more formally and invited them to visit the playroom.

Brian was to spend a lot of time in that playroom. He was in the hospital for ten days following the surgery that successfully removed the tumor. For a few months after that, the family commuted to Boston for specialized radiation treatment. Then they returned to Beth Israel for

chemotherapy, which required Brian to stay at the hospital for four days every third week, and come by for day-treatment every second. It wouldn't have been a pleasant regimen for anyone, let alone a lively seven-year-old boy, but the playroom made a world of difference.

Although Brian remembers very little about this time, his parents haven't forgotten. "There was a clown, a woman who gave massages. Video games and wonderful snacks," recalls his father, Mike. Eileen can't say enough about the artist who visited weekly, doing drawing and painting with Brian one-on-one, for an hour at a time. Later, the family was grateful for the help of Patty Weiner, one of Making Headway's education specialists, who helped them make decisions about Brian's schooling. When he was ready to enter high school, at Iona Preparatory Academy, she joined them in meeting with teachers to share his Individual Education Plan (IEP) and ensure he got the few services he needed.

Brian beat the odds. Today, he has gone from a child who had trouble walking a straight line—the tumor was pressing against his brainstem—to avid snowboarder. He's finished his fall semester at Iona College with a 4.0 and is polishing off a full load of five courses to end the year.

Brian is planning on a degree from the business department—but beyond that, he's keeping his options open.

"I'm taking lots of different classes right now. I'll figure out in a year or so exactly what I'm going to major in."

A Chance to Give Back

Not surprisingly, the McCabes feel very, very lucky.

"It's been better than we ever hoped," says Mike. "But we've seen so many kids who haven't done as well and we wanted to do something for them. We wanted to give back."

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Brian McCabe and Maya Manley.

Bottom: Eileen, Brian and Mike McCabe.



Welcome to Our Two Newest Making Headway Foundation Board Members!



David Almeida is a retired executive from the global investment company, BNY Mellon. A resident of Briarcliff, New York, he has known and admired both Dr. Jeffrey Allen

and the Manleys for over thirty years, and loves the unique approach Making Headway takes to supporting children and their families during a terrible time. While he is devoting a good portion of his retirement to several organizations and causes, Making Headway Foundation holds a special place in his heart and it is the only one that has been lucky enough to have him on the Board. When he's not volunteering, David enjoys working out and spending time with his family, which now extends to four generations.



Charles (Charlie) McMahon is an associate director at SSA & Company, a New York-based organizational consulting firm.

His previous position was as a financial analyst for the global investment firm, Jefferies, Inc. A graduate of Claremont McKenna College, in Claremont, California, Charlie will be heading west again in the fall to start working on his MBA. (He'll participate in board meetings and any related activities remotely.) Charlie, who survived a brain tumor as a teenager, enjoys travelling and a range of sports, from snowboarding to lacrosse. When he reached his tenth year cancer-free, he felt a strong desire to give back in some way and asked his oncologist, Dr. Allen, if he could recommend any organizations for him to work with. Dr. Allen immediately put him in touch with Making Headway.

And Joining Our Medical Advisory Board...



We are pleased to announce that **Dr. Oren J. Becher** has joined our Medical Advisory Board. Dr. Becher is an assistant professor in the division of pediatric

hematology-oncology at Duke University. A graduate of Johns Hopkins Medical School, he has published dozens of papers and research reviews in the field of pediatric brain cancer. His numerous awards and recognitions include a Vision of Hope Award from the Cristian Rivera Foundation, a Damon Runyon Clinical Investigator Award, an AACR Team Science Award and a Basic Science Award from the 13th International Symposium on Pediatric Neuro-Oncology—among many others. Dr. Becher is active in numerous professional organizations including the Children's Oncology Group, the Pediatric Brain Tumor Consortium and the Society of Neuro-Oncology. 

Photos: David Almeida, Charlie McMahon and Dr. Oren J. Becher.

In Memoriam: Thomas Fitzgerald

It is with great sadness that we announce the passing of Thomas Fitzgerald, longtime friend and supporter of Making Headway. Thomas's young son, also named Thomas, passed away from a brain tumor in 2003, and the family created the Thomas D. Fitzgerald III Memorial Fund in his memory. Over the years the Fund has sponsored numerous events, including an annual **Mardi Gras Bash**, raising more than \$176,000. Proceeds were often split between Making Headway and Friends of Karen—except when they were handed out directly to families in need.

Fitzgerald retired from his work with the New York State Department of Corrections a few years ago and started a second career as a foodie, selling "Fitzzy's Famous Franks" from a stylish truck in Peekskill, New York. He is survived by his wife, Lisa, and two daughters, Tauri and Kylie. He will be greatly missed.

Editor's Note: As we were going to press, the Thomas D. Fitzgerald III Memorial Fund announced it would once again hold the Mardi Gras Bash this year, on April 25. While it's too late to report on it in this issue, we'll tell you all about it in the Fall / Winter newsletter.

Pediatric Brain Tumor Research

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- **Conducting clinical trials.** Clinical trials provide us with the opportunity to put the other two kinds of research to the test. We are involved in clinical trials at all levels: smaller ones within NYU or in collaboration with one or more research partners at other centers; and large trials that we conduct as members of the Children's Oncology Group (COG), an international network of cancer researchers. For example, recent research included a multi-center clinical trial exploring the effectiveness of a drug called sorafenib in treating low-grade gliomas—a slow-growing form of one of the most common kinds of brain tumors. Another example is a recently completed immunotherapy (i.e. vaccine) study for children with brain tumors led by Dr. Gardner. As the chair of an upcoming COG study, I will be taking the lead on a large clinical trial testing novel therapies for children with newly diagnosed high-grade (malignant) gliomas.

Not only does Making Headway directly support a great deal of research, but the Foundation has made global contributions to research through its long-standing funding of a biorepository center and (more recently) of a full-time position for a pediatric neuro-oncology data manager. The biorepository makes adult and pediatric tumor samples collected at NYU available to collaborating researchers anywhere in the world. The new data management position magnifies the biorepository's value, by making it possible to create and manage a database that includes salient details about every sample it contains.

Finally, all of this activity has been supported by an expanding research infrastructure. We're thrilled to have a new, state-of-the-art Genome Technology Center and a new Molecular Pathology Laboratory here at NYU.

Research—finding a cure—is the all-important third pillar of Making Headway's mission: *care, comfort, and a cure*. It is an honor to be able to play a role in bringing this mission to life. 

Upwards and Onwards

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With all this new structure in place, the Manleys feel confident enough to begin stepping back—just a little. It's time to spend a bit more time with the family and grandchildren. Instead of coming to the office all day, every day, Edward will come in a few days each week. He'll continue to discuss issues and programs with Catherine, do a limited amount of financial analysis and participate in budgeting.

As for Maya—although she, too, says she is stepping back “just a little,” most would be hard pressed to see the difference. She'll continue working at Hassenfeld two days a week as she has long done, doing arts and crafts with the children and greeting new families, and she'll continue acting as consultant and guide to many who need it. She wouldn't have it any other way:

“All these years it has been so much my privilege to go to the hospital and work with the children and their parents. This has meant the world to me and I cannot think of not doing that. Every time I come home from the clinic at Hassenfeld I feel so very thankful to have been there. These families have given me so much more than I have given them.”

In short, the Manleys are confident that whatever transitions are afoot will happen seamlessly, and that Making Headway Foundation will continue to fulfill its mission for many long years to come. 

One Family's Story

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For many years, the McCabes were active participants in a number of fundraisers for Making Headway, most notably an annual golf tournament organized by Stephen and Tracey Casale. But when that event took up permanent residence in southern New Jersey, it became increasingly difficult for Mike to get his New York-based friends and co-workers to attend. So he decided to start his own.

Three years ago, the family launched the **Brian McCabe Drive for a Cure**, a daylong golfing event that brings in thousands of dollars for Making Headway each year (see page 2). Mike proudly points out that it was Brian who came up with the name. His parents just hope that it will make a difference in the lives of other families—most especially in finding a cure for the devastating illness that tried, but failed, to conquer the McCabes. 

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 Catherine Lepone and Linda Mudford-Lewis for their generous help with this newsletter. Special thanks to Dr. Karajannis, Edward and Maya Manley and the McCabe family for sharing their stories.

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

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