



**making headway**  
**foundation**

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

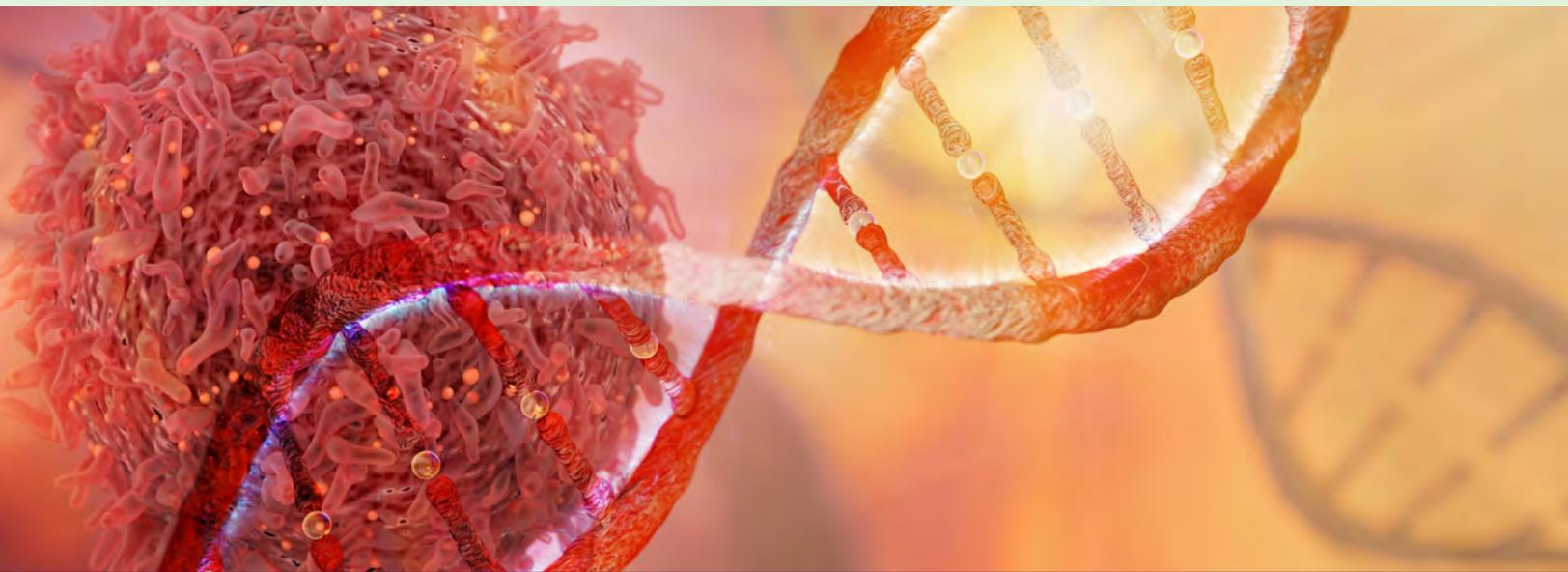
# makingnews

Spring/Summer 2019

**PAGE 02** **MAKING HEADWAY ONGOING CARE TEAM**  
Partnering with more hospitals

**PAGE 04** **MAKING HEADWAY EVENT HIGHLIGHT**  
Family Fun Day was amazing

**PAGE 08** **REAL FAMILIES, REAL IMPACT**  
Invaluable help for Kaitlyn Nivins



**06** THE MAKING HEADWAY RESEARCH LABORATORY



**03** VIDEO: IT CAN HAPPEN TO ANYONE



**07** HEAD TO THE HILL



## LETTER FROM OUR CHAIRMAN & FOUNDER

On April 14 Making Headway held its 24th annual fundraising event, *SNAP*, a show at the New Victory Theater in New York. Throughout the years, I have always been both touched and gratified by seeing the many patients, their parents and siblings that we invite to the show free of charge. I am touched by their excitement at spending a day away from home and the hospital and the gratitude that each family expresses when they see us in the lobby of the theater. And I am gratified that thanks to our generous donors, we have been able to invite these families, year after year. I am confident that the Foundation will continue to do so for many years to come, bringing joy and excitement to those who need it most.

*Edward P. Manley*

## ANNOUNCING MAKING HEADWAY'S EXPANDED ONGOING CARE TEAM

This spring, Making Headway began working with numerous new hospitals in the region to identify and provide services to children with a brain or spinal cord tumor. Our partnerships will now include four hospitals in New York City (NYU Langone Medical Center, Mount Sinai Kravis Children's Hospital, New York Presbyterian's Morgan Stanley Children's Hospital, and Memorial Sloan Kettering), two in Westchester (Maria Fareri Children's Hospital and Blythedale Children's Hospital), and one each on Long Island (Cohen Children's Center), in New Jersey (Joseph M. Sanzari Children's Hospital), and in Connecticut (Yale New Haven Children's Hospital).

In preparation for this significant expansion, Making Headway spent substantial time recruiting new members for our Ongoing Care Team. We identified highly-trained and experienced psychologists, psychiatrists, and educational advocates who will be able to support families in each location. Families served through our partner hospitals will have free access to these professionals, who work with, and advocate for, children and their families as they navigate life during and following treatment.

### Making Headway is proud to announce our newly expanded Ongoing Care Team:

- Dr. Mitchell Banks, MD  
Psychiatrist, Long Island
- Ms. Vicki Beckerman, LCSW  
Psychotherapist, New Jersey
- Mr. Carmine Depalma, BS  
Educational Advocate, Hudson Valley
- Dr. Jean Donnelly, PhD  
Psychologist, New York City
- Dr. Megan Eliot, PhD  
Neuropsychologist, New York City
- Dr. Charles Goodstein, MD  
Psychiatrist, New Jersey
- Ms. Carol Greenberg, MA  
Educational Advocate, New York City
- Dr. Marcia Greenleaf, PhD  
Psychologist, New York City
- Dr. Amy Gross, PhD  
Psychologist, Hudson Valley
- Dr. Lincoln Hess, MD  
Psychiatrist, New York City
- Dr. Ruth Lax, PhD  
Psychologist, Long Island
- Dr. Susan Leslie-Greisman, PhD  
Educational Advocate, Neuropsychologist, Connecticut
- Dr. Daniel Mason, MD  
Neuropsychologist, Connecticut
- Dr. Katelyn McGee, Psy.D.  
Neuropsychologist, New York City
- Dr. Jessica Nowillo, DO  
Psychiatrist, Hudson Valley
- Dr. Mark Owens, DO  
Psychiatrist, New York City
- Dr. Lisa Parsonnet, LCSW, PhD  
Psychologist, New Jersey
- Ms. Katie Passman, MSED  
Educational Advocate, New Jersey
- Dr. Marian Rissenberg, PhD  
Neuropsychologist, Hudson Valley
- Ms. Jennifer Kahn Ruoff, LMSW, MSED  
Educational Advocate, Hudson Valley
- Ms. Sallie Sanborn, MS  
Psychotherapist, New York City
- Ms. Patty Weiner, MS  
Educational Advocate, New York City
- Long Island Advocacy Center  
Educational Advocates, Long Island

## IT CAN HAPPEN TO **ANYONE**



It opens with the voice of Vanessa Williams: “Did you know that brain and spinal cord tumors are the deadliest form of pediatric cancer?” The first-ever Making Headway public service announcement, *It Can Happen to Anyone*, is the culmination of months of work by a host of supportive and talented individuals, many of whom volunteered their time.

It all began last winter, when Making Headway approached acclaimed documentary producer Dan Wilson, owner of ORG® Media. Our idea was to create a brief, captivating video that would illustrate dramatically how any

family might discover that their child has a brain tumor—and how Making Headway can help. We wanted it to take viewers through a year in the life of a family...in just 90 seconds. ORG Media added the novel idea of filming through the eyes of the dad.

After an exhaustive creative process, we agreed on a script and cast professional actors to play the main roles. A large crew spent one ten-hour day filming at the Maria Fareri Children’s Hospital. A second full day of filming, both at a private home and at Life The Place To Be event center, was followed by weeks of editing and review. Then our expert production team handled the task of cutting the video down for Instagram- and Facebook-friendly versions (30 and 60 seconds, respectively). Yet it wasn’t quite done. Everything we wanted to say could not be explained with visuals alone—we needed a voice-over. We were honored when critically acclaimed

actress and singer Vanessa Williams agreed to volunteer her time for this role.

Making Headway wants to thank all the many individuals and organizations that made this whole process possible. We are especially grateful to the folks at ORG Media, who produced a professional, high-quality video within a tight budget. We’re confident *It Can Happen To Anyone* will play a significant part in raising awareness about pediatric brain tumors and the work we do.

 See it for yourself—along with a bonus mini-documentary—at [MakingHeadway.org/video](http://MakingHeadway.org/video).



## A LETTER FROM OUR **EXECUTIVE DIRECTOR**



When a child is diagnosed with a serious illness, they need a great doctor; but when the illness is a brain or spinal cord tumor, the entire family needs a dynamic, diverse, and long-term set of services and support systems. Making Headway Foundation is dedicated to helping these families, providing a lifetime of meaningful assistance and a multitude of needed programs.

Like many organizations, Making Headway uses data and advanced quantitative analysis to evaluate programs and measure success. However, we really understand our

impact the old-fashioned way; we listen, understand, and react. Over the years, I have talked with hundreds of families about their experiences with pediatric brain tumors and with Making Headway. It is through their words that we know Making Headway is achieving its mission. Parents and children alike tell stories sharing the same theme; that during the worst crisis of their lives, Making Headway helped them overcome, gave them strength, and created a supportive community. Even when a child passes away, Making Headway works and grieves with each and every family.

Making Headway Foundation provides necessary services and support that are

just not available anywhere else. Our investments in research are specifically targeted to find better treatments, in a field that is often ignored. Last year, Making Headway spent 85% of all donations on direct services. However, there is so much more we can do to help even more families. If you haven’t donated, it only takes a minute at MakingHeadway.org. If you have already donated this year, please tell your friends, family, and colleagues about our cause. Thank you.

Daniel Lipka  
Executive Director

# FAMILY FUN DAY



This year's **Family Fun Day** took on an aquatic theme as several hundred kids and their families descended on the New York Aquarium at Coney Island. The 26th annual Making Headway event was held, once again, on Father's Day, and it proved a great way to celebrate. We're so pleased to be able to provide this day of joy and respite for our families, past and present.

Photos by Todd Shapera Photography



**IT WAS MAGIC!**

On April 14, Making Headway welcomed over 450 supporters and friends to our annual spring Broadway show. We filled the entire New Victory Theater, and for one lovely afternoon everyone entered a world of mystery and magic. **SNAP!** featured Korea's seven greatest illusion artists, who conjured silver hoops out of glittering sand,

transformed playing cards into fluttering butterflies, and juggled bricks that appeared out of thin air. Events like these—which provide entertainment and respite to so many families impacted by a pediatric brain or spinal cord tumor—are a key component of Making Headway's mission to provide Care, Comfort, and a Cure. We are so grateful to the many donors that make unique opportunities like this possible.



**ATHLETES WITH HEART**

On April 27, some of the best girls' high school teams in the country competed in the fifth annual **Gains for Brains** lacrosse showcase. The spirited event, founded and organized by devoted Making Headway supporter Andrew Rappaport, was

held at Cold Spring Harbor High School on Long Island. In addition to exhibiting some of the best girls' lacrosse in the country, the event succeeded in its goal of raising significant funds to support Making Headway programs and vital research. We're grateful to Andrew and his family for continuing this wonderful tradition.



**REMEMBERING**

The fourth annual **Race for ACE** was held on May 19, honoring Andy Cooperman Ecker (nicknamed "ACE"), who passed away from a brain tumor four years ago. Friends, family, and supporters took a long spin on the stationary

bikes at Cyc Fitness Center in Manhattan, before heading over to Patrick's oyster bar to toast their memories of ACE, a talented and courageous young man. The money raised will go a long way to support Making Headway's many programs and services.



**MARDI GRAS IN APRIL**

For the past thirteen years, spring has heralded the arrival of the annual **Thomas D. Fitzgerald III Memorial Fund Mardi Gras Bash**, and this year was no different. Music was courtesy of DJ Big Al and the dance floor was filled with movement, color, and laughter. Held in memory of Thomas Fitzgerald III and his son, Thomas Jr., it came together, as it always does,

thanks to the hard work of Lisa Fitzgerald and her daughters, Kylie and Tauri. Proceeds from this year's event, which was held once again at Colonial Terrace in Cortland, New York, have been divided two ways. A portion will benefit young Brody Canestro, a 9-month-old who is battling a Stage 4 neuroblastoma, and the other portion will go toward Making Headway Foundation programs, such as our in-hospital services for families.

# THE MAKING HEADWAY RESEARCH LABORATORY

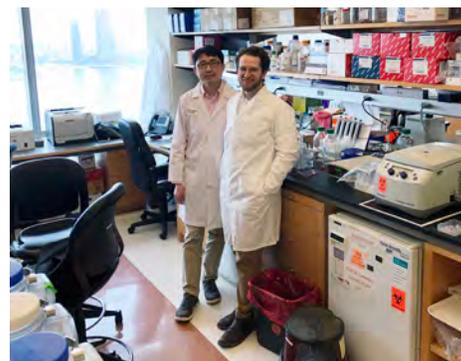
We're extremely proud to announce the new **Making Headway Foundation Brain Tumor Preclinical Core** at the NYU Langone Medical Center.

The last ten years have seen an explosion in our knowledge of how genetics drives both adult and pediatric brain tumors, resulting in a wealth of novel approaches to treatment. However, until now, the initial testing of such treatment has required tumors grown in animal models. Low-grade gliomas—the most common brain tumors to develop in children—are historically especially difficult to grow on traditional animal models. And the models that do exist are spread throughout dozens of institutions around the world, severely limiting access.

The Making Headway Foundation Brain Tumor Preclinical Core solves this

problem with the creation of a dedicated laboratory that uses state-of-the-art technology to create a fundamentally new type of model for testing new treatments. The models will all be available in a single location, and applicable to all types (and sub-types) of pediatric brain tumors. The Core will revolutionize researchers' ability to test out new treatments.

Over the next three years, models of more than thirty distinct pediatric CNS tumor subtypes will be created, including some of the rarest and most deadly brain tumors. At the end of this time, Making Headway's initial investments are expected to have created a financially self-sustaining facility. Six months into the project, things are going extremely well. Expert professional staff have been hired, the infrastructure has been established, and some new models have already been developed.



The Making Headway Foundation Preclinical Core will be particularly groundbreaking for research into pediatric low-grade gliomas. *No institution in the world has a library of tumor models that includes all the subsets of this most common pediatric tumor—until now.*



## MAKING HEADWAY SPONSORS A KEY LEARNING OPPORTUNITY FOR AREA MEDICAL PROFESSIONALS

This spring, Making Headway Foundation sponsored "Pediatric CNS Tumors in the Molecular Era," a unique half-day event highlighting state-of-the-art methodologies and treatment techniques for tumors of the central nervous system (CNS). More than one hundred medical professionals from around the tri-state area attended the course to learn how molecular and genetic insights are dramatically changing treatment for children with CNS tumors. The program included first-rate presentations in the fields of pathology,

radiology, surgery, precision medicine, and liquid biopsy. The event was held at the NYU Langone Medical Center and organized by Director of Pediatric Neuro-Oncology, Dr. Theo Nicolaidis.

The New York City area is home to the greatest concentration of pediatric CNS tumor expertise and research in the country. Through events like this, doctors from a variety of disciplines can learn new techniques, share information, network, and develop partnerships. All of this will lead to an increased level of proficiency, more efficient research projects, and better treatments for children with brain or spinal cord tumors.



## HEAD TO THE HILL

*This year, Making Headway brought four childhood brain tumor survivors and their families to “Head to the Hill,” an annual advocacy event that has become a powerful vehicle to ensure the brain tumor community is being heard on Capitol Hill. Our group was joined by 300 other individuals from all around the country. After an initial training session, everyone met with their Senators and Representatives to advocate for more government investment in research and other support for those diagnosed with brain and spinal cord tumors. We asked some of the families to share their experiences. Read what they had to say below.*

### Licciardi Family

“We had an inspiring and thrilling experience at the Capitol. The National Brain Tumor Society and their many advocates welcomed us and educated us...and then we shared our story on Capitol Hill—what could be more gratifying? We are so appreciative of Making Headway’s generosity in funding our trip. We were honored to attend and look forward to helping you advocate for pediatric brain tumor patients and their families moving forward. It is clear to me after attending Head to the Hill that there is a need for increased awareness of pediatric brain tumors as well as advocacy for increased pediatric research. I look forward to getting more involved in these efforts.”

### Hanson Family

“What an amazing experience! I can’t begin to express how much we

appreciated our few days in Washington, D.C. Making Headway once again reminded us of how much they will always be there to support us and guide us as we advocate for children everywhere battling brain tumors. Spending time with so many other families and sharing our story about Katie not only gave us a sense of empowerment but also helped us to feel a connection that not many others could understand.

Kevin and Katie now see that no matter how young you are ... you will always have a voice no matter how small you think it is!”

### Cappello Family

“Josh and I had the honor of attending Head to the Hill in both 2018 and 2019. Both experiences were powerful and gave us a strong sense of community. This year, there was another impactful

event that I’d like to share. It didn’t occur while on Capitol Hill when we thanked our Senators for passing the Childhood Star Act. It didn’t happen while attending our training and learning that this year, in our state of Connecticut, over 1,000 people will be diagnosed with a brain tumor. It happened at dinner with our group from Making Headway. As Josh and I sat down to eat with three other Making Headway families, we began to share our stories. I’m sure a parent that has not lived through this awful diagnosis would assume that the evening quickly turned grim. They’d be wrong. And they’d be wrong for one reason: The Making Headway Foundation. As we spoke, we learned we had different surgeons; our children were diagnosed at different ages, and with tumors in different locations. But one factor was the same, and the main topic of our conversation was Making Headway.

### WHAT IS PALLIATIVE CARE?

One of the goals of 2019’s “Head to the Hill” event was to advocate for the passage of the Palliative Care and Hospice Education and Training Act (H.R. 647). Palliative care is a critically important form of medical care that Making Headway has promoted and funded since our inception. The term refers to specialized medical care for people living with a serious illness, focusing on the quality of life for both

the patient and the family. The care is provided by a specially-trained team of doctors, nurses and other professionals who work together with the patient’s other doctors to provide an extra layer of support. More than that, palliative care staff help each family understand its unique options and explore personal goals, working to ensure patients have a meaningful level of control over the care they receive.

While we were on the Hill, asking that the Palliative Care Act be passed, I realized how very lucky we were to have had Making Headway, which was ahead of its time and provided our family with the care and comfort we needed. Thank you, Making Headway, for everything! Thank you for the opportunity to be an advocate in this community of survivors, for the positive memories (that could have otherwise been negative), the research funding to find a cure, and for always being there for your families.”

Dear Making Headway,

My name is Lynn Nivins, and I am the mom of Kaitlyn Nivins. Kait was diagnosed with a brain tumor at age two, along with hydrocephalus and epilepsy. She is now 31, and has had 96 operations. The majority of them have been due to severe complications from her hydrocephalus.

Kait was a patient at the Institute of Neurology and Neurosurgery (known as the INN) with Dr. Epstein, Dr. Abbott, Dr. Allen, and others back in 2003-2004. During our long visits there, my daughter and I developed a relationship with psychologist Dr. Jean Donnelly [Dr. Donnelly is part of Making Headway's Ongoing Care Team]. Kait confided things to her that she was afraid to tell me, but with Jean's help was able to let me know. Kaitlyn has continued to talk with Jean over the years, and it has been invaluable for her.

Kait has been very, very sick since 2015. She has had over 30 operations in the past four years, and experienced some very serious, life-threatening complications.

I had continued to talk with Jean over the years. Since 2015, I can't express how fragile, frightened, overwhelmed, and isolated I have been. Talking with Jean these past four years has kept me on an even keel. She has helped me communicate with Kait's doctors when I felt they weren't hearing anything I said. She has supported us in going for second opinions when I had no one else to do so. I do believe I would have lost my cool with numerous doctors and would be afraid of the negative effect that would have on Kait's care, but Jean has continually kept me focused on Kait's health.

I don't know how to thank Making Headway for supporting Dr. Jean Donnelly's continued, long-term therapy for my family. I want you to know it is not taken for granted. It is not a casual relationship. Dr. Jean Donnelly is literally a lifeline for me. And I have such gratitude and thanks to Making Headway for making this happen.

*With gratitude,  
Lynn and Kaitlyn Nivins*



Making Headway has worked with over 1,500 families since our founding. Some families required extensive service, often for many years. For example, the Nivins family received over 125 hours of service from 2004 to 2019. With the support of donors, Making Headway has been able to help them, with whatever they need, for as long as it takes.



**making headway  
foundation**

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

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

#### Board of Directors

**Edward Manley**, Founder & Chairman  
**Clint Greenbaum**, Founder & Treasurer  
**Sam Schwartz**, Vice President, Research  
**Elisa Greenbaum**, Vice Chair  
**Audrey Manley**, Secretary  
**Maya Manley**, Founder  
**David Almeida**  
**Charles McMahon**  
**Susan Rubin**  
**Greg Taubin**

#### Staff

**Daniel Lipka**, Executive Director  
**Jennifer Samuels**, Office Manager

#### Medical Advisory Board

**Dr. Jeffrey Allen**, Director of Clinical Neuro-Oncology, NYU School of Medicine, New York  
**Dr. Karl Kothbauer**, Chief of Neurosurgery, Luzerner Kantonsspital, Switzerland  
**Dr. Oren Becher**, Attending Physician, Hematology/Oncology, Ann & Robert H. Lurie Children's Hospital of Chicago

#### Contact

**Making Headway Foundation**  
115 King Street, Chappaqua, NY 10514  
(914) 238-8384  
info@makingheadway.org  
www.makingheadway.org

**f** MakingHeadwayFoundation  
**t** @makingheadwayfd  
**i** @makingheadwayfd

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

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

**Managing Editor**  
**Robin Hardman**

Making Headway is a 501(c)(3) non-profit organization. EIN# 13-3906297.