



**making headway
foundation**

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

makingnews

Summer 2021

HIGHLIGHTS

BRAIN TUMOR FACTS • 25TH ANNIVERSARY • PROGRAMS • NYU HASSENFELD UPDATE • IN LOVING MEMORY • SCHOLARSHIP FUND • PHOTO PROJECT • IN THE COMMUNITY • YOUNG ADULTS • REAL FAMILIES REAL IMPACT



Photo by Petra Romano Photography

The Muthana Family



Photo by Justine Cooper Photography

The Clark Family



Photo by Gotham Family Photos

The Wagner Family



LETTER FROM OUR CHAIRMAN & FOUNDER: COMING UP ON 25 YEARS!

Dear Friends and Supporters,

On September 4th, 1996 the Making Headway Foundation was officially incorporated, with no assets but with a fervent desire to help families of children diagnosed with a brain or spinal cord tumor. The three members of the Board of Directors were the founders: Clint Greenbaum, Maya and me.

I served as Chairman and Clint served as Treasurer and Maya served as Family Liaison.

Our first fundraising event that fall raised \$450,000 and we were off and running, establishing services for the families and funding grants at the hospital. From the outset we worked closely with Dr. Jeffrey Allen, who became our Medical Advisor, and we used his vast experience to guide our efforts. Over the years, our reach has expanded to thousands of families, while funding research that we hope will result in improved treatments and eventually a cure.

I am very proud of what we have accomplished since our founding, and am honored to have served as Chairman. Now, after 25 years, it

is time for me to step down. I have decided to retire as of our 25th anniversary, but will still be an active member of the Board of Directors and will consult with Dan Lipka, our Executive Director. Maya will remain on the Board as well and will enthusiastically continue her work for the families. The Foundation's nominating committee will be identifying my successor and I will work closely with that person to ensure a smooth transition. I want to thank all our friends who over the years have steadfastly supported our efforts to provide care and comfort to the families of the children we serve.

Edward Manley

PEDIATRIC BRAIN TUMOR FACTS

Brain tumors are the **most common type of cancer and the leading cause of cancer deaths** in infants, children, and young adults under age 20.

In 2021, an estimated **4,630** new cases of pediatric brain tumors will be diagnosed in the U.S.

The five-year relative survival rate for all primary pediatric brain tumors is **76.7%**.

Spotlight: Medulloblastoma

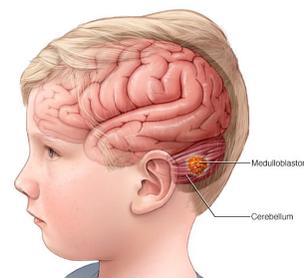
Many types of brain and spinal cord tumors are diagnosed almost exclusively in children. The largest categories of such pediatric tumors are medulloblastomas, ependymomas, and brainstem gliomas.

Among those, medulloblastoma is the most common. Medulloblastoma is a cancerous (malignant) brain tumor that starts in the lower back part of the brain, called the cerebellum. The relative five-year survival rate for medulloblastoma is 72%, but many factors can affect prognosis, including the tumor grade and type, traits of the cancer, the child's age and health when diagnosed, and the child's response to treatment.

The first choice for treating medulloblastoma is surgery, when possible. The goal is to obtain tissue to determine the type of tumor and remove as much of it as possible without causing more symptoms. Most children with medulloblastomas receive further treatments, including radiation, chemotherapy, or novel medications being tested in clinical trials.

Families of a child diagnosed with medulloblastoma, or any type of brain or spinal cord tumor, need expert medical care, access to clinical trials and novel treatments, emotional care, and a variety of long-term support systems to meet the ever-changing demands of this disease. Making Headway is there to help families through every part of the journey.

 **Learn more at [makingheadway.org/facts](https://www.makingheadway.org/facts)**





MAKING HEADWAY SILVER ANNIVERSARY

25 years ago, Making Headway Foundation was established to provide “Care, Comfort, and a Cure,” with an ambitious mission to provide compassionate care for children and families impacted by a pediatric brain or spinal cord tumor, while funding medical research geared to better treatments and a cure. Founders Edward Manley, Maya Manley, and Clint Greenbaum have each devoted 25 years of their lives—so far!—to nurture our growth. What started as help for just a few families has grown into assistance for thousands, through a wide range of programs, services, and research investments.

Over the past 25 years, Making Headway Foundation has raised and allocated over \$26.6 million to support medical research, quality-of-life programs, college scholarships, hospital care services, clinical trials, neuro-oncology fellowships, family events, emergency care, educational advocacy, bereavement services, public education, playroom improvements, family and individual therapy, health and wellness, tissue banking, and research equipment. None of this would have been possible without our supporters. We are so grateful to each of the more than 24,000 people who have donated to Making Headway, allowing us to provide every one of our programs at no cost to families.

We are tremendously proud of all our achievements since inception, highlighted by:

- **Psychological and Educational Support** Our Ongoing Care Team has provided over 11,500 hours of free, expert, psychological therapy to help families throughout their journey, as well as over 8,000 hours of free professional educational advocacy services, ensuring that all children receive the school-based services and assistance they need to reach their academic potential.
- **Medical Research Advances** Our investments in medical research have led to critical discoveries in the areas of hypoxia proliferation of neuroblastoma, immunotherapy, medulloblastoma, sonic hedgehog pathway mutations, novel medications, epigenetic signatures in DIPG, pilocytic astrocytomas, and vulnerabilities of pediatric high-grade gliomas.
- **Family Events** We have hosted almost 100 events for children and their families, including events at the Bronx Zoo and New York Aquarium, the annual Broadway show and cruise around Manhattan, Riley’s Walk, the Tulip Festival, countless Family Fun Days at the Manleys, and much more.
- **College Scholarships** We have awarded over 100 college scholarships to survivors of a brain or spinal cord tumor.

Winners attended the University of Pennsylvania, University of Chicago, Rochester Institute of Technology, and many other local and national schools. Many graduates have pursued careers in public health, including nursing, special education, neuroscience, and social work.

- **Long-Term Research Investments** We established the Making Headway Preclinical Core at the NYU Langone Medical Center, the country’s first laboratory where novel therapies can be tested on any subtype of pediatric brain tumor sample.

Over the next 25 years—and beyond—Making Headway Foundation will remain passionately dedicated to helping as many families as we can. With your continued support, we will provide an even deeper level of care and develop new programs and grants to improve the quality of life for every child with a brain or spinal cord tumor.

Has your life been impacted by Making Headway Foundation? Help us celebrate our 25th anniversary by telling us how in a brief video. Just use your smartphone (or any device with a camera) and visit www.MakingHeadway.org/25 to upload your message.

COMING SOON

Our 2021 Winter Newsletter will be dedicated to our 25 years of service. We would love to have you contribute to this special issue. If you are interested in writing an article, contact Dan Lipka at 914-238-8384.

A LETTER FROM OUR EXECUTIVE DIRECTOR



25 years ago, Making Headway Foundation was built on the enduring principals of Care, Comfort, and a Cure

for children with a brain or spinal cord tumor. Today, that mission still guides all of our programs, services, grants, and activities. Over the years, Making Headway, and the families we work with, have faced many challenges, but the COVID-19 epidemic pushed everyone to their limits. Beyond the all-too-real risk of contracting COVID-19, there were also hospital restrictions (like only one parent allowed in with a child), school closures, special education services cancelled, clinical trials

delayed, research facilities closed, economic uncertainty and high unemployment, rising rents, physical isolation for peers, and increased cases of depression. This is what parents faced on top of the already overwhelming circumstance of having a child with a tumor. At Making Headway, we have worked to adjust our programs and services to help families where they are, including providing new emergency support services. As families struggle to cope, referrals to our Ongoing Care Team of psychologists have never been higher; we have responded by expanding the team and helping every single family that is referred to us. Thankfully, after a year of lockdown, our communities are opening up and our families are

able to focus more fully again on caring for their children.

Having a child with a brain or spinal cord tumor will always be devastating. Every family develops its own resilience to the pain and the work needed to move forward each day. This year, we honor our 25th year of helping families throughout their entire journey. We have done so much, and come so far, but there is still so much to do. With your continued support, Making Headway will always be there to help those most in need.

Daniel Lipka, Executive Director

MAKING HEADWAY FAMILY SURVEY

Making Headway has created a short online survey to better understand each family's experiences and needs, so that our programs, services, and advocacy can better meet those needs. If someone in your family (or you) was diagnosed with a brain or spinal cord tumor, please visit www.MakingHeadway.org/survey and answer a few questions as honestly as possible. It is only through your input that we can better understand the changing needs of families and adjust our programs to help. Your experiences and opinions are so important and can help other families and children with a brain or spinal cord tumor. As a bonus, Making Headway is offering the first 50 families that complete the survey a free, professional family photoshoot at a location of your choice.



By Georgie D'Avanzo



This past May, Georgie, Making Headway Foundation staff, and hundreds of other brain tumor survivors participated in Head to the Hill, a national advocacy event organized by the National Brain Tumor Society. Head to the Hill aims to increase funding for medical research at the National Institute of Health and National Cancer Institute, pass the Telehealth Modernization Act, increase funding for the Peer Reviewed Cancer Research Program, and raise awareness of this terrible disease among our U.S. Congressmembers and Senators.

Participating in my first Head to the Hill event was extremely inspiring and I couldn't be more happy to have been a part of such an amazing day. I have never had a sense of community when it comes to being a survivor of a brain tumor. Being able to hear people's stories and relate was extremely powerful; I only hope it had the same effect on the Members of Congress.

I felt so beyond lucky to be able to share my story and advocate for more research, funding, and awareness. Also, having my Making Headway family by my side during this event only made my experience more special. Despite it being virtual, the Head to the Hill event was so impactful and I would encourage anyone who can to participate in the future!

Georgie D'Avanzo was awarded a Making Headway college scholarship in 2018 and is currently attending Syracuse University.



MAKING HEADWAY PEDIATRIC NEURO-ONCOLOGY FELLOWSHIP



For the eighth time, Making Headway has funded a pediatric neuro-oncology fellowship at the NYU Langone Hassenfeld

Center. The field of pediatric neuro-oncology is a dynamic and complex discipline. It takes a special kind of doctor to succeed in this field—one who can manage the multifaceted technical elements as well as the emotional aspects of helping families and children through overwhelmingly difficult situations. The Making Headway Pediatric Neuro-Oncology Fellowship was designed to recruit the brightest and most compassionate doctors, and focus their careers on a lifetime of helping those most in need. After an extensive nationwide search, Dr. Robyn

Borsuk was identified and selected for this unique career-building opportunity. Dr. Borsuk is a graduate of the Ross University School of Medicine and is dedicated to the study of pediatric hematology-oncology.

The Making Headway Pediatric Neuro-Oncology Fellowship emphasizes clinical management skills and knowledge,

familiarity with radiation therapy and chemotherapy administration, and exposure to the rigors of following—and eventually designing—clinical trials. Dr. Borsuk will participate in all aspects of care for pediatric neuro-oncology patients, from their initial diagnoses through their evaluation, and the formulation and execution of a treatment plan.

“I’m grateful that over the course of my training I’ve been able to focus my research efforts on the field of neuro-oncology. Recently, I’ve been pursuing a translational research project focused on combinational drug testing in pediatric diffuse midline glioma. The findings are promising, and have led to presentations at several international symposiums and conferences. I am excited to be joining the NYU team and am grateful for Making Headway Foundation’s support in pursuing my career ambition of specializing in pediatric neuro-oncology. While I have treated patients with a variety of disease processes, it is the connections made with the families that keep me motivated.” —Dr. Robyn Borsuk

MAKING HEADWAY CARE COORDINATOR: SARA COUGHLIN



Last winter, Making Headway announced a grant to fund the new position of Pediatric Neuro-Oncology Care

Coordinator at NYU’s Stephen D. Hassenfeld Children’s Center for Cancer and Blood Disorders. We are pleased to report that they have hired Sara Coughlin to fill this important role. Sara is a registered nurse who comes to us from Yale New Haven Hospital, where she worked in the pediatric hematology and oncology inpatient unit.

“The meaningful connections that I made in my previous role and continue to make in my new role at NYU inspire me to serve those affected by pediatric cancer, particularly neuro-oncology. My new role at Hassenfeld is devoted to working alongside the multidisciplinary team to coordinate care for the children and families that receive care here. I am also a resource for children and families regarding care coordination concerns and connections to Making Headway Foundation.

I am proud to join the team at Hassenfeld because it is an exceptional resource for children and families. It is especially unique in that it offers care from many disciplines in one common place. I am excited to make a purposeful contribution to the care that Hassenfeld provides. I am very grateful to Making Headway Foundation for making the role of Clinical Care Coordinator a reality.” —Sara Coughlin, RN

IN LOVING MEMORY



Patty Weiner

On January 26, 2021, Patty Weiner, longtime Making Headway Educational Advocate, passed away. For over 20 years, Patty was one of the most knowledgeable, hard-working, and dedicated members of Making Headway's Ongoing Care

Team. As our Senior Educational Advocate, Patty provided over 3,000 hours of expert support to ensure children received all the educational services they needed. Her knowledge and passionate advocacy on behalf of families earned her the respect of school administrators and special educators throughout the region. She was recognized throughout her career with multiple awards, including Making Headway's first ever Lifetime Care Award, in 2020.

Patty was the bedrock on which our entire educational advocacy program was built. Her dedication to children and their families, her expertise, and her compassion were evident in her work every day, year after year. More than that, she inspired everyone around her to be the best that they could be. Patty Weiner exemplified Making Headway's vision of helping families through compassionate and comprehensive service. We will miss her greatly.



Dr. Karl Kothbauer

This past winter, Making Headway Medical Advisory Board Member Karl Kothbauer passed away at the age of 58. The Making Headway team first came to know Dr. Kothbauer during his training with Drs. Fred Epstein and Rick Abbott at the Institute

of Neurology and Neurosurgery in New York City. Upon his return to Europe in 2004 he was appointed chief, and associate professor of neurosurgery at the Kantonsspital in Luzern, Switzerland. There, over the past 16 years, he built a renowned academic neurosurgery referral center, but in his heart, Dr. Kothbauer was always a pediatric neurosurgeon.

"Dr. Kothbauer was known for his immense medical expertise and his sincere compassion when working with families. Yet as his colleague Dr. Francesco Sala put it, "Whoever had the fortune and privilege to know him well, knows that Karl was much more than that. He was a humble colleague and a loyal friend, with a genuinely generous heart."

In the words of one of his mentors, Rick Abbott, "behind his quiet, reflective personality, Karl was the model for an empathic surgeon whose patients and trainees loved and treasured him."

SPECIAL THANKS: CHARLES A. FRUEAUFF FOUNDATION



When Making Headway was just starting out, nearly 25 years ago, it was a struggle to gain momentum and build sustainable programs. Our budget was very tight and it was difficult to make the necessary long-term investments. That all changed when we were awarded our first large grant, courtesy of the Charles A. Frueauff Foundation. This award was the catalyst that not only launched our Ongoing Care Team of psychologists

and educational advocates, but also gave Making Headway the confidence to boldly move forward, dedicated to achieving our mission. In those early years, Making Headway staff worked tirelessly to prove that we were worthy of this grant, applying year after year. Twenty-four years and 24 approved grants later, Making Headway wants to recognize the extraordinary generosity of the Frueauff Foundation.

The Charles A. Frueauff Foundation (CAFF) was founded in 1950 as a legacy of Charles A. Frueauff, a successful New York attorney who gave his time and resources to many New York charitable organizations. CAFF is dedicated to

supporting organizations that address directly some of the most pressing issues facing America today—especially those that provide services for those in greatest need. It gives generously to front-line organizations and institutions in the areas of education, health, and human services, funding programs that improve access and raise the quality of health care, provide housing and shelter, expand educational opportunities, and much, much more. Since 1950, the Frueauff Foundation has awarded over \$164 million to over 1,185 mostly local and community-based agencies and organizations. Making Headway is thrilled and humbled to be among them.

WHERE TO FIND MEDICAL RESEARCH UPDATES

Did you know that in Atlanta, Georgia, a research team has figured out a way to use ultrasound and RNA-loaded nanoparticles to get through the protective blood-brain barrier and deliver potent medicine to brain tumors? Or that in London, scientists

have demonstrated that a naturally-occurring compound present in plants and animals, inositol hexaphosphate (IP6), inhibits medulloblastoma and can be combined with chemotherapy to kill brain tumor cells? Perhaps you didn't get to read about the fascinating

study from the University of Alabama, in which researchers discovered that a modified herpes virus, both alone and in combination with radiation, has been shown to be well tolerated, with early signs of clinical effectiveness in pediatric patients with high-grade brain tumors?

Researchers from around the world are constantly looking to better understand and develop treatments for pediatric brain and spinal cord tumors. For families, finding updates on this research can be a difficult, and often overwhelming, task. Let Making Headway help. "Like" our Facebook page and you will receive curated articles on pediatric brain and spinal cord clinical trials, research, and advocacy:

[facebook.com/MakingHeadwayFoundation](https://www.facebook.com/MakingHeadwayFoundation)

EDUCATIONAL ADVOCACY: OUR TEAM AT WORK

Arianna was 8 years old when she was diagnosed with medulloblastoma. During a post-treatment follow-up visit, she was seen by the Making Headway-funded Educational Coordinator at NYU, Julia Gomez. Julia swiftly coordinated meetings between Arianna's parents and her school team to get home instruction set up. This allowed Arianna, a strong student who was upset by the idea of missing school, to continue her studies with a program designed specifically to work around her medical appointments and the side effects she was experiencing.

At age 10, Arianna began to notice some negative effects of her treatment, including a slower processing speed, trouble completing tasks independently,

and difficulty keeping up with her workload (all common issues facing brain tumor survivors). With Julia's help, she received a full neuropsychological re-evaluation from Dr. Sara Powell, whose position is also partially funded by Making Headway. The results indicated that, although she had generally tolerated her treatment quite well, subtle difficulties in her learning capabilities had, indeed, arisen that would make school a bit more challenging. Recommendations were made to the school, but their staff were reluctant to implement them. This is why it is so important to have someone like Julia, an expert in brain-behavior relationships and the effects of medical treatments, who can make the case for academic and emotional support. Effects of radiation treatment can emerge over the years, becoming more pronounced as time goes on, and thus quick intervention is critical in order to identify the related areas of decline as they appear.

After obtaining the re-evaluation results, Julia went to work to help

advocate for Arianna and her need for additional services. She met repeatedly with the school social worker in order to explain how Arianna's difficulties perfectly aligned with expected treatment effects of radiation. While Julia was able to get many supports in place (specialized instruction, occupational therapy, etc.), the school remained hesitant about implementing other services. So Julia brought in Dr. Powell to help, and together they explained, from both the medical and educational perspectives, the critical need for these services. Ultimately, the school team agreed to provide them.

Arianna was recently seen by Dr. Powell for a follow-up, and she is doing quite well. She has made excellent use of the various educational supports and no longer feels stressed and upset by school. Thanks to her own hard work, the efforts of her parents, and the dedication of two members of the Making Headway Ongoing Care Team, Arianna is managing her workload and her sunny mood has returned.

MAKING HEADWAY COLLEGE SCHOLARSHIP PROGRAM

The Making Headway College Scholarship class of 2021 is made up of 16 amazing and inspiring survivors of a brain or spinal cord tumor. Winners have been awarded \$5,000 each, to help fund their dreams of obtaining a college degree. Two of these awards were funded by the Scott J. Reisser Memorial Scholarship Fund established by the Reisser Family in memory of their 22-year-old son, who succumbed to a brain tumor just short of achieving his dream of college graduation. The remainder of the awards were funded through the generosity of Making Headway's donors. Since 2008, Making Headway has awarded 112 college scholarships.

NAME	SCHOOL	CAREER	DIAGNOSIS
Marcella Borgenicht	University of British Columbia	Forest Bioeconomy & Science Technology	DLGNT at age 18
Giancarlo Cusimano	Emory University	Neuroscience	Medulloblastoma at age 14
Karem Fermin	William Paterson University	Public Health - Education	Grade 3 Anaplastic Astrocytoma at age 19
Douglas Gonzalez	Manhattanville College	Environmental Sciences	Medulloblastoma at age 12
Julia Grosek	Columbia University	Urban Sociology	Brainstem Glioma at age 17
Rachael Kessler	New York University	Biology/Medicine	Ependymoma at age 1
Rhea Kochhar	Penn State University	Business	Pineoblastoma at age 11
Tara Lockwood	Farmingdale State College	Early Childhood Education	Astrocytoma at age 13
Kathryn Murdoch	St. John's University	Finance	Neurofibromatosis and optic glioma at 3 months old
Shaul Niyazov	Lander College for Men	Computer science	Medulloblastoma at age 13
Adrianna Oliva	University of Connecticut	Social Work	Ependymoma at age 3
Bryan Paredes	Manhattan College	Economics and Finance	Pilocytic astrocytoma at age 12
Hubert Skwara	NJ Institute of Technology	Architecture	Pilocytic astrocytoma at age 3
Andrew Sussman	Farmingdale State College	Science, Technology & Society	Craniopharyngioma at age 4
Isabella Vallaro	Villanova University	Nursing	Pilomyxoid astrocytoma at age 11
Keyonu Williams	University at Albany	Communications	Medulloblastoma at age 20

Marcella Borgenicht and Douglas Gonzalez are the second and third recipients of the Michael Schwartz Making Headway College Scholarship. This \$15,000 scholarship is funded from donations raised by the Schwartz family and is named in honor of their son, Michael, who is a 25-year-old survivor of brain cancer.



“The Michael Schwartz Scholarship & Making Headway Foundation have made my dream of a college degree a reality while helping ease the financial stress on my Mom. I know my Dad in Heaven is also beyond grateful for your help! I am so thankful!”
—Douglas Gonzalez



“The Michael Schwartz Scholarship from Making Headway means that I can go to college to focus on learning, healing, and rebuilding my independence that was taken away from me when I was diagnosed.”
—Marcella Borgenicht

CREATING JOYFUL MOMENTS

This spring and summer, with support from the David Justus Joyful Moments Fund, Making Headway has continued our free Front Door Photo Project, where we send a professional photographer to take family portraits.



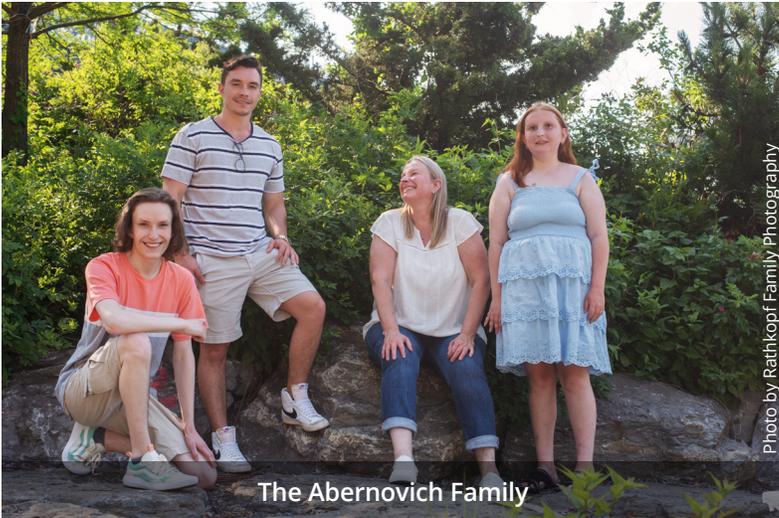
The Mancia Family

Photo by Steve Waskovsky



The Diptee Family

Photo by Petra Romano Photography



The Abernovich Family

Photo by Rathkopf Family Photography



The Kristoph Family

Photo by Alessandra DeStefano



The Montera Family

Photo by BJA Garbelotti Photography



The Houli Family

Photo by Rathkopf Family Photography

MAKING HEADWAY [VIRTUAL] DANCE CLASSES



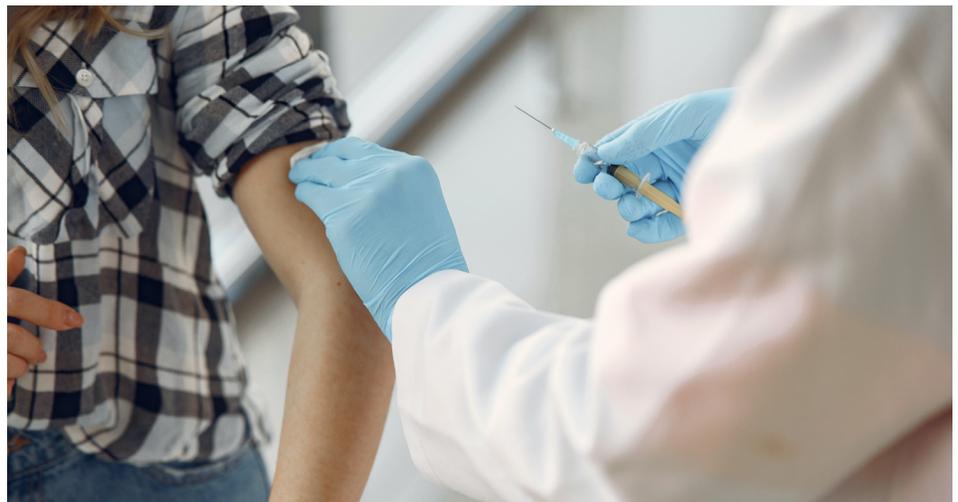
“Hi! My name is Chloe and I am a junior at Byram Hills High School. At 3 years old, I began to dance and have danced competitively ever since. Back when I was 10 months old, my twin sister Alexandra was diagnosed with an inoperable brain tumor. Since then, my family has been highly involved with Making Headway Foundation. I have witnessed first-hand how difficult it has been for Alex to attend social outings and get in some physical activity, as I am sure it is for many other children just like her. So, I want to use my passion for dance to host quick and simple dance lessons for the Making Headway community.”

That was how it started, with Chloe telling Making Headway Executive Director, Dan Lipka, about her idea to use dance to help children diagnosed with a brain or spinal cord tumor. Families then signed up to participate in a pilot program. They met through Zoom every Monday and celebrated dance together, learning technical skills and having lots of fun. Chloe and Making Headway want to continue these free classes with more students this summer and fall. If you are interested, please contact Making Headway at 914-238-8384 or family@makingheadway.org.

“We would like to be part of the big “thank you” shout-out to Chloe for what she is doing. Her ballet dance class became a big part of our kids’ weekly routine and they can’t wait till Monday to do it again. It is amazing how much they love the class and demonstrate the dance moves they learn weekly. Chloe, thank you so much for teaching and motivating our children to be their best selves and to push themselves into something unknown that, obviously, is becoming something they are really enjoying. Once again, thank you so much. Sincerely, the Shvartsman family.”

COVID VACCINE

As of July 6, 2021, 60.6% of eligible Americans have received at least one dose of the COVID-19 vaccine (according to the CDC). If you are one of the unvaccinated, we hope to inspire you to make a different choice, if not for yourself, then for kids like Billy. Billy was diagnosed with a brain tumor at the age of four. All he wants to do is go back to camp, visit his friends, and see a movie. Although things have improved over the past few months, the risk of COVID-19 is still a serious concern. For children like Billy, who are immunocompromised due to their cancer treatments, COVID-19 could cause very serious reactions and lead to more time in the hospital, or worse. And even once vaccines are approved for children Billy’s age, they may not be as effective for those undergoing chemotherapy.



Every year in the U.S. another 15,000 children are diagnosed with cancer. These kids are in almost every county in the country, including yours. Because of the life-saving treatments they receive for childhood cancer, including chemotherapy, radiation, and bone marrow transplants, many survivors are

at higher risk than the healthy population for the most severe effects of COVID-19 infection. Even as COVID-19 cases remain low, the pandemic is far from over. There are still thousands of new cases every single day. When you get vaccinated, you are doing your part for yourself, your country, and for kids like Billy.

draw for paws

By Robin Chwatko

The Draw for Paws concept was created in 2018 by my daughter 8-year-old Scarlett Chwatko, an animal lover and a Society for the Prevention of Cruelty to Animals (SPCA) volunteer who often said she would “adopt every animal in the world” and that she “would like to be dipped in a bucket of puppies.” Combining her passion for animals and art, the idea for Draw for Paws was born, with a simple

concept: donate \$20 or more to the local SPCA and Scarlett would draw a portrait of your pet or favorite animal.

Shortly after she drew what became the Draw for Paws logo, Scarlett lost her courageous 3-year battle with medulloblastoma. Her friends immediately took over, dubbing themselves the “scarlysquad” and promising to fulfill her vision. The scarlysquad invites anyone, of any age

and skill level, to become a Draw for Paws artist. In the less than two years since the organization’s inception, over 100 artists from all over the world have helped raise over \$65,000 in food and funds to rescue animals in need. In fact, they just celebrated the drawing of their 500th portrait! Now an official 501(c)3 nonprofit organization, Draw for Paws is expanding both geographically and with new initiatives. There are so many ways to get involved! Visit drawforpaws.org or follow @scarlysquad on Instagram.

Since Scarlett passed away, Making Headway Foundation has worked with the Chwatko family to provide care and comfort through our Ongoing Care Team.



MAKING HEADWAY TEEN AND YOUNG ADULT ACTIVITIES

Making Headway Foundation is working to develop a safe place for teen and young adult pediatric brain tumor survivors, where they can create a community among their peers. We are hoping to bring together these survivors for a series of fun social activities as well as collaborative therapy. The survivor program helps teens and young adults: build and maintain connections with peers who have similar medical histories and experiences; share physical and emotional concerns; and develop lasting friendships. Social events

might include picnics in Central Park, Yankee games, museum trips, or just hanging out together. Members of this group will also have the opportunity to be trained as advocates to raise awareness of pediatric brain tumors and fight for more government funding to identify better treatments. Furthermore, participants can help Making Headway design our own programs in order to best meet the needs of survivors of all ages. Every other meeting will be more therapeutic, and will be led by an expertly trained and experienced therapist. COVID-19

precautions will be in place as needed, and as recommended by our medical advisory board.

If you are a pediatric brain or spinal cord tumor survivor, and are age 16-29, please let us know if you are interested in this type of group. There is no cost to participate and Making Headway can even arrange for transportation to and from the activities. If you want to be part of this community, please contact Making Headway Family Liaison, Jenn Cabarcas, at family@makingheadway.org or 914-238-8384.



WHAT COMES NEXT?

By Renée Leva

I'm writing to tell you what having access to a psychologist who understands what it's like to have a medically complicated child means to me. The Making Headway Ongoing Care Team has been a life saver. Not many people realize how challenging it is to have a child with a brain tumor, with all it entails. My son, Zach, was diagnosed with a juvenile pilocytic

astrocytoma in 2009, and has had such a difficult time since his surgery. It's been difficult finding him the correct care and services. There have been medical scares along the way. It falls on the parent to make all the decisions you never expected to make. But there really wasn't anywhere for us to go. No place to just talk about our child. About how afraid you are. About what comes next. Making Headway was there and is there for us throughout this journey. Making Headway has become an important part of life for me. I so appreciate the opportunity to consult with their team to help keep me sane. Thanks for all you do.

LIFE SAVER

"I have always appreciated the support that Making Headway provides to our family and to so many others as well. I wanted to let you know, however, that I have been especially grateful in the past year for the long-term programs and support that have been made available, particularly through Making Headway psychologist Dr. Jean Donnelly, who has been a life saver for me in many ways. Jean has supported me both in the hours she has spent on the phone with me, and also the connections she has helped me make. She encouraged me to call [Making Headway Family Liaison] Jenn



Cabarcas, who was able to give me helpful advice about resources for my daughter who was struggling with the challenges of a college education, and also helped me find much-needed mental health support for the family. I truly don't know what I would have done without her assistance.

I am extremely grateful to Jean and all she has done for our family, but I am also very aware that it is only through the generosity of Making Headway that she has been able to do so much—to provide us with the support, the resources, and the connections that she has. My thanks to Jean, Jenn, the Manleys, and Making Headway Foundation." —F.Z.



**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.

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Managing Editor
Robin Hardman

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