



making headway
foundation

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

makingnews

Winter 2020

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LETTER FROM OUR CHAIRMAN & FOUNDER

Dear Friends and Supporters,

Even in this difficult time we are facing—COVID-19—one thing remains constant. Every single day, 13 children in the United States are diagnosed with a brain tumor. For those in the tri-state area, as well as the many others who come to New York for treatment, our mission is to provide the resources needed to make their journey through a devastating disease less stressful. We do so by funding programs at the NYU Langone Hospital and providing a multitude of services for the family once the child leaves the hospital.

But to do so, we need your continued support. You have been such faithful donors over the past years, and without your help we could never have achieved as much as we have. Your generosity will carry us through this difficult time, and you can be proud to be a part of the work we do for the children.

Please be careful, follow the recommended guidelines, and stay safe and healthy.

Edward Manley

**THE MOST DIFFICULT WORDS FOR A PARENT TO WRITE:
IN MEMORY OF OUR SON, JAKE**

A Message from Clint & Elisa Greenbaum

Ever since our Jake survived a rare malignant brain tumor, as an infant, 30 years ago, he was the picture of health. We even joked that Jake didn't get the common cold, just the uncommon brain tumor. It was only last year, in this very Making Headway newsletter, that we wrote about how thankful we were to be able to celebrate Jake's milestone 30th birthday!

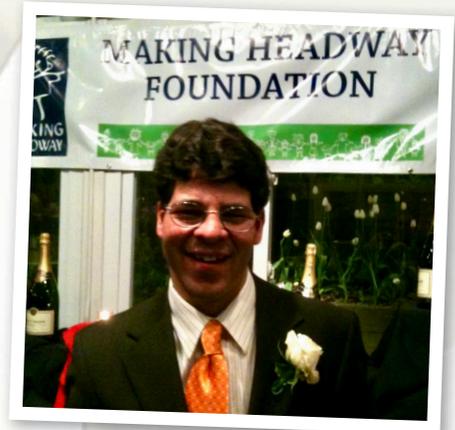
But then out of nowhere, one month after his first minor symptoms started, Jake died on August 23rd from a rare, aggressive cancer. It was not a reoccurrence of brain cancer, and we were told it was likely not caused by the treatments that he received many decades ago.

We were heartbroken 30 years ago when we first discovered that our perfect, newborn baby Jake was far from perfect. Alongside Jake, we fought for his survival, and we worked hard for Jake to be able to walk. We accepted his inability to speak and his learning disabilities, although we tried to minimize their effects. Jake's special needs changed the course of our lives, but we were able to make it work beautifully.

Everyone who met Jake saw that he was ALWALYS happy, 24/7/365. Jake was also empathetic. When his younger sister Augusta was a baby and cried, Jake would give us his boo-boo face in sympathy.

But what do we do now that Jake is gone? We are devastated and heartbroken—but we will not lose Jake's happiness and concern for others.

Being back in the world of parents of a sick child with a rare cancer, took us back in time. There is good news and bad news. We rediscovered, firsthand,



that everyone at NYU Langone Medical Center is caring, hardworking, and passionate about achieving a positive outcome. The bad news is that even with the passage of three decades, and even though the type of cancer this time was different—the recommended chemotherapy was the same! Imagine what the world would be like if we were using the same computers as in 1990! We know that there have been improvements in treatments, but not enough. We know that there is no lack of brain power and passion to win the war against cancer. We know that the war must continue and the Greenbaums will continue to be a part of Making Headway. (We hope that all other parents who have been impacted by pediatric brain tumors will join us.)

From the date of Jake's death on, all the money that is donated to Making Headway through the efforts of the Greenbaum Family will be part of the Jake Greenbaum Memorial Fund. To all our friends and relatives who have contributed to Making Headway since 1990 in honor of Jake (a sum of about \$2 million), please, continue to donate, but now, very sadly, in memory of Jake.

Clint Greenbaum is a Co-Founder of Making Headway and Elisa Greenbaum is the Vice Chair of the Board of Directors.

A SECOND CHANCE AT A FUTURE

By Susan Kenny

After my child, Eve, was diagnosed and treated for medulloblastoma, we struggled with the New York City school system on many levels for nearly five years. The stress, anxiety, and heartache were profound. Over the past year, especially, I watched Eve deteriorate psychologically, emotionally, academically, and socially. Her doctors and I recognized she was in a state of true crisis, and I felt demoralized.

Then I reached out to the Making Headway Foundation. I talked with their staff and they told me about their amazing, free educational advocacy program. In no time, I was connected to a team of advocates from Susan Luger & Associates. I was immediately taken by their urgency and concern for Eve's case, and impressed by their professionalism. The compassion they showed was incomparably meaningful and validating. It was striking how quickly and profoundly they enlightened me about the rights and possibilities for children with disabilities within our education system.

I was assigned a personal Educational Advocate, Rita Ashdale, who took over our case. She was an absolute godsend—I have no better way to state this. I am humbled by the amount of time

she spent, painstakingly absorbing Eve's medical and educational information, then dedicating unparalleled efforts to creating dense and concise documentation on Eve's behalf. In addition to this, Rita spent countless hours with me on the phone, educating me about Eve's rights, specific educational needs (as interpreted by her neurocognitive and psychological evaluations), and the numerous ways in which Eve's academics had been gravely neglected.

Rita prepared meticulously for the Independent Education Plan (IEP) meeting at Eve's school, and by the end, the school had agreed that Eve should be placed in an appropriate, nurturing private school setting. When Eve learned that she would not have to continue at the school, and would instead attend a place that would give her the support she needs, a heavy weight was visibly lifted—she was radiant. Eve has been elated ever since and resembles much more the carefree and happy child I used to see.



I struggle to fully express how grateful I am to Rita and Making Headway Foundation, who have continually offered such beautiful programs and support to children that have suffered so much. Eve feels like she has been given a second chance at a future, and beams when I tell her that she is supported by a team of people that revere her and all the children who have likewise battled brain and spinal tumors.

Update October 2020: Despite all that is affecting our children and their school experience during COVID, Eve is truly the happiest I've seen her in several years. In just a few weeks, her confidence has grown exponentially and she feels valued and understood. Her innate capabilities are blossoming, with absolute credit to her nurturing school environment. Thank you all at Making Headway so much! Your support has changed everything.



Winter 2020 Newsletter

EDUCATIONAL COORDINATOR



As a result of their cancer diagnoses and associated treatments, patients are often deprived of the consistent teaching, enrichment, and social experiences that school offers. In addition, both tumors and their treatment can lead to common and lasting neuropsychological effects

that can affect learning over time. Many young patients need an array of educational services, supports, and therapies to ensure their continued progress both during and after treatment. To meet this need, Making Headway is once again funding an exceptional Educational Coordinator at NYU Hassenfeld, Julia Gomez.



NEW SUPPORT FOR FAMILIES: CARE COORDINATOR

We're pleased to announce that Making Headway has agreed 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.

Scientific discoveries and technological advancements have improved the survival rates and quality of life for patients with central nervous system (CNS) tumors. Yet these new diagnostic testing and treatments have made the logistics of caring for the children increasingly complex. Families who are already over-stressed are told to schedule evaluations with a range of specialists: neuro-psychologists, occupational therapists, ophthalmologists, and more, and are on their own to keep track of all these activities. It can be overwhelming.

The new Care Coordinator, an experienced registered nurse, will coordinate with the Neuro-Oncology team to create and maintain treatment plans for families, keeping track of appointment dates, and managing routines to ensure the children are scheduled for and complete all their evaluations. He or she will also work

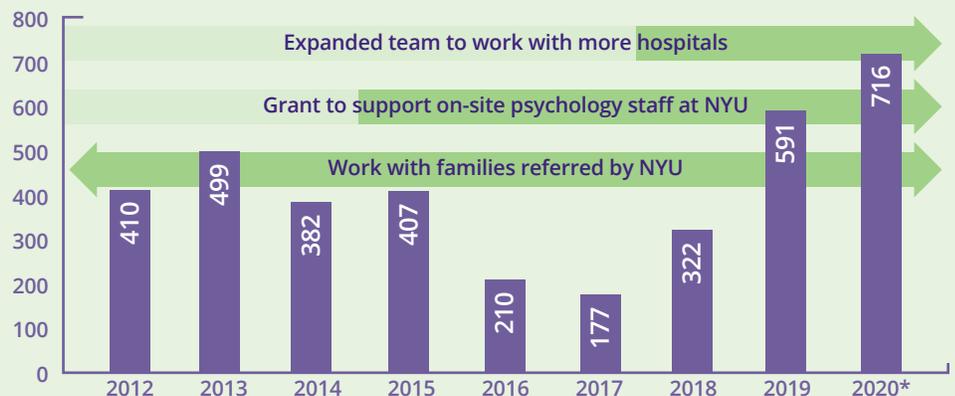
with families to coordinate second opinion appointments, including ensuring that tissue, imaging, medical records, and pathology results are sent to the other providers. The Care Coordinator's other major role will be to coordinate processes for the Making Headway Pediatric Brain and Nervous System Tumor Tissue Bank, including coordinating all the outside testing of Hassenfeld patients' samples that are required for accurate diagnosis and identification of therapeutic targets.

Because the Care Coordinator, who will work for NYU Langone, will have access to many families that might benefit from Making Headway's programs and services, he or she will also meet regularly with our own Family Liaison, Jennifer Cabarcas, and Making Headway Co-Founder Maya Manley. In this way, Making Headway can ensure we are reaching all the families we possibly can.

EXPANDED PSYCHOLOGICAL SERVICES

In addition to our expert educational advocates (see page 3) Making Headway's Ongoing Care Team includes professional psychologists and psychiatrists. Many children's hospitals provide very limited psychological support for patients and almost no such services for parents or siblings. Making Headway has helped fill this gap with our own team and in 2015 we began providing funding so that NYU Hassenfeld Center could maintain a dedicated neuropsychologist on its staff. With this professional helping so many families at the hospital, our own team was needed less on-site, and we could begin expanding our services deeper into the community.

MAKING HEADWAY ONGOING CARE TEAM
Free Psychological and Psychiatric Services Provided (Hours)



* 2020 final data is a projection based on the first 11 months of the year.

In late 2018, Making Headway embarked on a robust and dedicated effort to bring access to free psychological services to any local family that has a child diagnosed with a brain or spinal cord tumor. Since that time, we have revitalized and expanded our Ongoing Care Team through increased outreach partnerships

with other children's hospitals. We still work with many families seen at NYU, but now we are also able to help families treated at the Morgan Stanley Children's Hospital (NY Presbyterian/Columbia), Cohen's Children's Hospital (Northwell), Memorial Sloan Kettering, and Kravis Children's Hospital (Mt. Sinai).

2020–2021 FUNDED GRANTS

Each year, Making Headway Foundation awards numerous grants to provide much needed support for families at the hospital, as well as critical research infrastructure and staff. Below is a partial list of the many grants that we have funded in 2020-2021:

Clinical Trials Manager



Clinical Trials are the most effective way to bring new treatments to children with brain or spinal cord tumors. They can also be a last resort for children who do not respond to traditional treatments. In order for the NYU Hassenfeld Center to be part of as many clinical trials as possible, Making Headway has funded Anna Yaffe, Clinical Trials Manager, for over a decade. During this time, hundreds of clinical trials have been conducted, with thousands of children receiving critically important, and novel treatments.

Clinical Trials Research Nurse



Due to the overwhelmingly positive response from families, Making Headway is continuing to fund Kara Donovan, NYU Hassenfeld Clinical Trials Research Nurse. First funded two years ago, Kara helps families manage the vast array of responsibilities they face during a clinical trial. The role has become especially indispensable this year, with the pandemic: the clinical trials nurse works with families to set up telehealth visits, oversees complex procedures for mailing out vital medications, and works with families to ensure their proper administration, monitoring, and documentation.

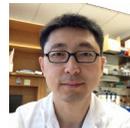
NYU Pediatric Neurosurgeon



Two years ago, Making Headway contributed funding to NYU Medical Center for an exceptional

young neurosurgeon, Dr. Teresa Hidalgo. Dr. Hidalgo, who is emerging as a leader in her field, has become a vital part of the Pediatric Neurosurgery Division's clinical and research efforts. She has performed hundreds of pediatric brain surgeries, including extremely complicated, lifesaving procedures, while she is also conducting research into molecular subgroups in low-grade pediatric brain tumors and the molecular pathology of optic pathway gliomas. Dr. Hidalgo is a compassionate, caring person who relishes mentoring medical students—especially women and underrepresented minorities—and treats every family as if it were her own.

Making Headway Pre-Clinical Core



Making Headway's Preclinical Core has revolutionized researchers' abilities to test new treatments for pediatric brain tumors. Led by Dr. Guisheng Zhao, the lab uses technology to create models of more than 30 distinct pediatric CNS tumor subtypes—previously extremely difficult to come by. The Core is providing the materials needed for regional, national, and international hospitals, as well as pharmaceutical companies and universities, to test potential new drugs and treatments. Making Headway has committed to funding this vital project for three years; at the end of 2021 it will become financially self-sustainable.

Neuropsychological Testing



Ensuring continued developmental and educational progress is essential to help children adjust and maintain a normal lifestyle as they contend with medical illness. Throughout the evolving COVID-19 pandemic, NYU Hassenfeld Neuropsychologist Sarah Powell has used telemedicine to maintain services, allowing children and their families to continue accessing psychological

support and neuropsychological testing services from the safety of their homes. Making Headway funds the expert neuropsychologist on the team, making it one of the most comprehensive of any such pediatric teams in the country.

Neuroanatomical, Cognitive & Family Aspects to Recovery



Today, when two-thirds of children with brain tumors survive, it is critical to understand how their quality of life might be affected going forward. This grant supports a longitudinal research project led by Memorial Sloan Kettering neuropsychologist, Dr. Stephen Sands. The project has partnered with over 50 children's hospitals around the country to evaluate the impact of socioeconomic status, home environment, parenting, and parental distress on pediatric brain and spinal cord tumor patients. It is possible the study will lead to the ability to identify the specific subgroups of pediatric brain tumor patients who are at increased risk for neuropsychological decline and warrant early, proactive remedial interventions and support.

Bio Repository Center/ Brain Tumor Bank



For the past 13 years, Making Headway has funded the NYU Bio Repository Center/Brain Tumor Bank, enabling NYU to collect rare and valuable specimens and clinical data for distribution to leading researchers around the world. In the past year, NYU has begun using expanded molecular pathology capabilities to analyze collected tissues, such as performing DNA sequencing and methylation profiling on most pediatric brain tumors. In 2021, the Tumor Bank, led by Dr. Theo Nicolaides, will join the Children's Brain Tumor Tissue Consortium, exponentially increasing the Bio Repository Center's ability to share rare tissues and data with leading researchers.

OUR MEMORIES



Arunaraje Patil

By Aruna Patil

I first met Cynthia Manley at the Memorial Sloan Kettering Hospital in New York in 1982. My daughter, Gaagi, who was diagnosed with bone cancer, shared a room with her. It was a

difficult time for us—we had come all the way from India to save our daughter. We were filled with hope, but it was also our first visit to the United States and we were taking things slowly, one step at a time. Cynthia was just a child, but she opened her heart out to Gaagi and us just as her parents, Maya and Edward, did.

It is not easy for any child to deal with cancer and all it entails—the pain, the chemotherapy, the medications, the taking away of a part of one's childhood. But Cynthia was a true warrior in that sense. She took the game on—the game of survival.

Even in that situation, I knew Cynthia as a mischievous little spirit, a live wire, always playing pranks. She never sat still. After Gaagi passed away, it was like Cynthia became my friend. She could spend hours chatting, joking, acting, always putting up some kind of a performance, ever ready with a new idea. She had a wacky sense of humor, and could exchange stories limitlessly. She even wore a sari on one of my trips. There was no role she could not play. She became friends with my son Hith, too.

Cynthia had found a way to deal with what is almost impossible to deal with. I don't know if she had that spirit before the tumor showed up, or she developed it later. She was so alive—she lived like every moment was precious and needed to be celebrated. I kept visiting Cynthia's family for many years and not once did I see her down—she was always fighting for her space on the planet. In time, I attended her wedding; she made such a beautiful bride. I know she was on medication, but she took it all so sportingly. She understood that life is for living, not merely existing.

Cynthia's indomitable spirit saw her through all the way until now, actually celebrating fifty years! My best wishes to Cynthia to continue being who she is, celebrating, and leading a happy, peaceful life.

By Maya Manley

The adjacent story was written by Arunaraje Patil, a beautiful soul and dear friend, in celebration of our daughter Cynthia's 50th birthday. I first met Aruna, her husband, Vikas, and their daughter, Gaagi, at Sloan Kettering, where Cynthia was being treated by Dr. Jeffrey Allen following surgery to remove a brain tumor.

One night, there was a bustle and a new patient—a smiling 6-year-old girl—was brought in to share the room. At the time, Aruna and Vikas were well-known filmmakers in India. Vikas was a tall, handsome man; Aruna was petite and stunningly beautiful. Their child Gaagi was full of smiles, even after her surgery, which left her with a plaster cast from waist to toe.

Sharing a hospital room breaks down all boundaries. We shared the radio, the hair dryer, toiletries, food, and more. We also shared stories, kindness, and tears. The Patils were so far from their home and family in Mumbai.



Aruna and Maya

In between Gaagi's and Cynthia's ongoing chemo treatments, we invited the family to our home in Chappaqua. Gaagi stayed in bed, but all the children sat next to her and they played together, happy as can be. Aruna and I cooked meals—one day Indian, the next day Swiss—and so it went for weeks. We even had a cheese fondue night! It was a joyful, beautiful time.

After the Patils returned to India, we remained in touch by phone, but Gaagi's condition deteriorated rapidly. The cancer came back, and Aruna took over the round-the-clock nursing she needed. She was also keenly aware of how Gaagi's younger brother Hith suffered during that time. A year later, Gaagi passed away. The next morning, Vikas asked for a divorce.

It was a very difficult time. Edward and I worried about how Aruna would make a living and take care of Hith. She told us she planned to work on her own, making films that dealt with a range of socially relevant topics—women, children, and mental health. This was radical for India: a single woman working in a male-dominated world, focusing on difficult, but important, themes.

During those first 10 years of struggling and remaking her life, Aruna visited Chappaqua almost every year. For her, America *Continued on page 7*

Continued from page 6

was a land where she could refocus and recharge, as well as remember the happy times that Gaagi experienced. One year, she brought some of Gaagi’s ashes and together we spread them in our garden, holding hands.

A few years later, Edward’s mother called and told me to open the Sunday New York Times. There, in a double-page spread about the Indian film industry, one of Aruna’s works was prominently highlighted. Rihaee, a daring film about male promiscuity and female sexuality, had shocked India’s filmgoing public. It had a tremendous impact, exposing uncomfortable double-standards about men and society. I had not seen the film, as it wasn’t available here, but I knew the screenplay! Aruna had written it during one of her trips to Chappaqua, and I remember one harrowing moment when she fell asleep while working on it by the pool. A sudden breeze swept all her handwritten pages into the water. Edward and I worked quickly to help rescue the pages and spread them across every available surface to dry.

Since then, Aruna has made many award-winning narrative films and documentaries, including: A New Paradigm, about

mentally-challenged children, and Behind the Glass Wall, about autistic children. She herself was honored with the “First Lady Award,” presented to her by India’s last president for her heroic work in raising awareness about socially relevant topics.

It has been almost 40 years since I first met Aruna. We are still in touch, but Aruna travels and visits less now, as she is busy with her work and with mentoring young women in the film industry. Her life has been one of unconditional love and sacrifice—of finding inner strength to overcome terrible tragedy.

If you are intrigued, and would like to know more about Arunaraje Patil, this profile in The Hindu is a great place to start. Read the article at <https://bit.ly/34oyswQ>.



Left: Gaagi. Right: Maya and Cynthia 37 years ago

DR. JEFFREY ALLEN JOINS THE MAKING HEADWAY BOARD



Making Headway Foundation is proud to announce that Dr. Jeffrey Allen has agreed to join our Board of Directors.

Dr. Allen’s contributions to the field of pediatric neuro-oncology are immense and his status among colleagues is almost legendary. Dr. Allen received his MD from Harvard Medical College. He became one of the principal pioneers in the treatment of children with central nervous system tumors. Over the years, he has tended to thousands of children, providing the highest quality treatments and the deepest level of personal care. Thirty years ago, it was his commitment to care for each family that drew the attention of one particular child, Cynthia Manley, and her parents, Edward and

Maya. Their relationship would blossom and create the philosophy at the core of Making Headway Foundation. Since that time, Dr. Allen has led Making Headway’s Medical Advisory Board, providing expertise and a partnership that would create some of our most impactful programs, including the NYU Brain Tissue BioRepository Center. Dr. Allen was also the primary teacher and mentor for the first ten Making Headway Neuro-oncology Fellows.

After 16 years as the leader and director of the pediatric neuro-oncology and neurology team at the NYU Langone Hassenfeld Center, Dr. Allen is now working closely with the next generation of doctors to ensure his legacy of comprehensive patient care will continue. As a member of Making Headway’s Board of Directors, Dr. Allen will bring his lifetime of experience and expertise to our organization. He will help guide our programs and services, ensuring that they are both technically sound, as well as have a meaningful,

positive effect on families impacted by pediatric brain or spinal cord tumors.

The children and families, who have been under Dr. Allen’s care, always remember their first visit with him and truly appreciate his personal commitment to healing, his genuine compassion, and his love for every child. Dr. Jeffrey Allen represents the best of Making Headway and we are honored he agreed to join our board.

“Helping families who have a child diagnosed with a brain or spinal cord tumor is not a complicated or controversial idea. We are dedicated to every child, sibling, and parent who is affected by this illness, each of whom becomes part of the Making Headway Family. We are there to help them in the hospital, at home, at school, with special events, and during times of celebration or sadness.”

—Dr. Jeffrey Allen

MAKING HEADWAY COLLEGE SCHOLARSHIP PROGRAM

In 2020, Making Headway awarded \$5,000 college scholarships to each of 15 inspiring survivors of brain or spinal cord tumors. Two of these 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. 2020 also marks the first year of the Michael Schwartz Making Headway College Scholarship. This \$16,000 scholarship is funded from donations raised by the Schwartz family and is named in honor of their son, Michael, who is a 24-year-old survivor of brain cancer. The 2020 Michael Schwartz Scholarship is dedicated to the memory of Jake Greenbaum, whose spirit will live on forever.

NAME	SCHOOL	CAREER	DIAGNOSIS
Riley Antalek	Pace University	Nursing	Juvenile Pilocytic Astrocytoma, age 15
Emily Calabro	Auburn College of Architecture	Construction & Design	Suprasellar Mass/ Brain Tumor, age 10
Taylor Cole	University of NC at Pembroke	Psychology, Child Life Specialist	Medulloblastoma, age 9
Douglas Gonzalez	Manhattanville College	Environmental Sciences	Medulloblastoma, age 12
Michael Holtz	Stonehill College	Business/ Marketing	Glioblastoma Multiforme, age 3
Rhea Kochar	Lafayette College	Business	Pineoblastoma, age 11
Gregory Licciardi	Fordham University	Healthcare	Brain tumor, age 10
Alex Long	Rider University	Physical Therapy	Ependymoma, age 8
Mary Nelson	Ramapo College of New Jersey	Special education	NF and Optic Pathway Glioma, age 3
Shaul Niyazov	Touro College	Computer Science	Medulloblastoma, age 15
Anny Safier	Binghamton University	Social Work	Multiple Ganglioma, age 11
Logan Sands	Pennsylvania College of Technology	Engineering Technologies	Brain cancer, age 2
Alexander Storey	Pace University	Cinema/literature	Medulloblastoma, age 9
Ryan Tucker	Champlain College	Game Programing	Large brain tumor, age 3
Hina Zahid	Boston University	Biology	Astrocytoma, age 2
Undisclosed	Undisclosed	Political Science & Neuroscience	Medulloblastoma, age 13



"Making Headway Foundation Scholarship has helped me continue to NEVER GIVE UP!

The road has been bumpy...but the future is bright!"

—Douglas Gonzalez



"So many of us have been living in the shadow of a brain tumor diagnosis for such a long time.

Pursuing a college education lets us emerge out of that darkness. This scholarship is such a meaningful gesture that honors everything survivors have accomplished and encourages everything we still want to accomplish. Thank you for lighting the way and helping us shine."

—Michael Holtz



"When I was 11, I was diagnosed with multiple brain tumors (ganglioglioma). I did not know if I would live a normal life again after receiving a craniotomy and chemotherapy. I soon learned that yes, I would be able to; except the one thing that would not return to normal would be my vision. I was born with low vision, but now I am blind. Cancer has shown me how important the things we love to do are in one's life. The two lessons I have learned from my journey are to always be prepared for bad news and that life is not worth living without a passion."

—Anne Safier, inaugural winner of the Michael Schwartz College Scholarship

—Anne Safier, inaugural winner of the Michael Schwartz College Scholarship

CREATING JOYFUL MOMENTS

During a year when most of the traditional in-person Making Headway events have not been possible, we've sought out new ways to bring some joy to families and remind them we are here for them. We thought that the Front Steps Project, a movement which sends a professional photographer to people's homes (or another public space) for a 30-minute

outdoor photo shoot might be the perfect thing. This fall, we located and vetted talented professional photographers throughout the tri-state area to participate. There was no cost to the families; Making Headway and the David Justus Joyful Moments Fund picked up all costs. So far 18 families have participated, posing for fun, relaxed, and memorable portraits.



Photo by Luisa Martalucci

The Shvartsman Family

"I want to say a huge Thank you!!! to you and your team for letting us be part of this project! Luisa Wall Photography was absolutely terrific: so patient, accommodating and positive. We had a wonderful time making those memories."
—Shvartsman Family



Photo by Justine Cooper

The Mansaray Family

"This was our first time taking family photos together and it was especially nice to photograph mostly in our backyard and color coordinate our family's outfits. We met Maya many years ago after taking our son to NYU for yearly visits with Dr Allen for NF1. We feel very fortunate to be a part of this organization and to be granted such lovely experiences like the family portrait series."
—Steiner Family



Photo by Elena Goodridge

The Steiner Family



Photo by Jessica Madero

The Reger Family



Photo by Carolyn Angelli

The Sturm Family

"Such a great project, thank you Making Headway for the beautiful pictures of our family! We are so sad to have missed being part of the Making Headway programs this year however, the photos were a beautiful way to remind us what is most important during this difficult time... family." —Sturm Family



Photo by Todd Shapera Photography

The Talbot Family

"Making Headway has been a constant by my family's side over the past sixteen years. We can't thank the entire organization enough; especially, Maya and Edward for all of their support." — Talbot Family

GRACIOUS GIVING

Over the past year, wonderful supporters, just like you, have used social media fundraising to raise over \$25,000. Whether as a fundraiser for your birthday or as a way to honor somebody you love, this is an easy and effective way to support Making Headway's mission. It only takes a minute— just visit www.facebook.com/fund/MakingHeadwayFoundation to set up your fundraiser. Making Headway is honored and grateful to be the beneficiary of online donation campaigns from the following supporters. We can't thank you enough.

Limor Aberman Weinstein	Mary Lynn Martin
Cassie Avirom	Mike McCabe
Deanna Nicole Carey	Karen O'Callahan-Stokes
Erin Celletti	Laura Hall Oweis
Esta Algava Czic	Donna Peacock
Nina Froriep	Roxy Polara
Lene Gray	Janaki Rao
Clint and Elisa Greenbaum	Licda Raynelda
Pam Halayko	Serenity Rose
Dan Hallak	Susan Rubin
Hillel High School Class of '77	Mindy and Sam Schwartz
Heather Hudson Kummer	Mike Scozzari
JR Clothing	Angela Severiano
Linda Justus	Andrew Sussman
Rachel Justus	Caren Carder Tucker
Hannah Klitsberg	Alexandra Valentine
Jeffrey Laikind	Kimberly Voigt-Blum
Dan Lipka	Alexa Wilding and Ian Sullivan
Emma Lipnicky	Sara Zaloom Lipinski
Audrey Manley	

“ Making Headway Foundation had made so much possible for our family. I first met Maya when we had our long, four-month stay at NYU. She would often be our only visitor and I began to look forward to the days she would visit. Financially, Making Headway also has paid for our stay at the Ronald McDonald House and provided other support to help keep me on my feet when I felt I was just about to crash. This is a foundation that offers more than I could have imagined, they offer love and support. —Lene Gray

“ I just want to say how thankful I am for the foundation and I'm very proud to see how far it has come! It had only been established for two years prior to my surgery! Maya coming around with her smiling face to give candy brightened my day. My surgery was on January 25 1999 which was 5 days before my 7th birthday. Once I was able to walk around and strong enough, Maya threw a surprise party for me where my grandparents, parents, and brother attended. It was Maya's kind nature and selflessness that made my 7th birthday such a special event in the most difficult of times! The events and support for my family members meant more than anyone will ever know! —Deanna Nicole Carey

“ For my birthday this year, I'm asking for donations to the Making Headway Foundation. I've chosen this nonprofit because it means so much to me. This fundraiser is to honor the legacy of David Justus, who recently passed away after a two-year battle with glioblastoma. After his diagnosis, he did everything he could to fight his cancer and create joyful moments with his beautiful wife, Rachel and their children Oliver and Emma. I feel so fortunate that I got to share some of these joyful moments with the Justus family, and those memories will stay close to me always. —Angela Severiano

IN MEMORY OF THOSE WHO PASSED

Every year, generous individuals donate their own money or fundraise on Making Headway's behalf. And every year, these donations include a heartbreaking number that are made in memory of a child who has passed away. These individuals represent an especially big-hearted sort of kindness, as they have found a way to turn personal tragedy into hope for others. Here are some of the children remembered by such gifts this year:

ERIN BENTIVEGNA	THOMAS DOCU	CALLIE HACKER	ILANA SCHWARTZ
MICHAEL BURKHARDT	RACHAEL DON	PRESLEY KLEIN	MAX SCOTTI
RAYNERO CALDERON VICENTE	ANDY ECKER	JAMIE KOCHER	PIERCE SLUTZKY
SHANNON CELESTINE	STEFANIE GARWIN	JAMES LANE	LILY TAUBIN
LAUREN CUMMINS	CAROLINE GILES	OLIVIA LIPNICKY	COURTNEY TOMKIN
PETER DECAPRIO	JAKE GREENBAUM	JACK REYNA	ALLISON TRUNZ

A LETTER FROM OUR EXECUTIVE DIRECTOR



This fall marked my fourth year as the Executive Director of the Making Headway Foundation.

During this time, I have come to understand and truly appreciate the impact that Making Headway has had on families with a child that was diagnosed with a brain or spinal cord tumor. From Making Headway's humble, yet inspiring origins, to their authentic dedication to those in need, this organization exemplifies the very best of what we all hope to be. Over the years, I have gotten to know our Board of Directors and hundreds of families and, through their experiences, I have gained a deeper understanding of core, life-concepts such as perseverance, flexibility, love, and sorrow.

Every day, Making Headway continues to be inspired by the families we encounter and it reminds me to always

be diligent in our work, think creatively, and focus on our mission. More than that, we want to adjust our programs to effectively meet the changing needs of families and children. And we want to keep pushing the boundaries of what the "highest level of care" means both to our staff and our hospital partners.

Over the past several years, I am particularly proud of Making Headway's efforts to work with new hospitals, connect with more families, and invest in cutting-edge medical research. From a direct-care perspective, Making Headway has increased our commitment at the NYU Hassenfeld Children's Center. We have funded multiyear grants for neuropsychologists, educational coordinators, a clinical trials manager, a research nurse, a pediatric neurosurgeon, and several neuro-oncology fellowships. Most recently, we approved funding for 100% of a critical new position at Hassenfeld

of Family Care Coordinator. Making Headway has also increased our focus on pediatric brain tumor research, funding projects that empower researchers from around the world to access rare brain tissue samples and to effectively test novel treatments.

At the core of Making Headway Foundation are families who have first-hand experience taking care of a child with a brain or spinal cord tumor. They understand what it takes to move forward. They set the tone for the organization to inspire staff to take this work seriously and with steadfast fortitude. I am proud to be part of this team and I am fully devoted to pursuing Making Headway's mission with enthusiasm, resourcefulness, empathy, and hope.

Daniel Lipka, Executive Director

DNA METHYLATION IS MAKING A DIFFERENCE

Last year, Making Headway funded a pilot program to analyze 25 pediatric brain tumors using state-of-the-art "DNA methylation testing." This new process has increased diagnostic accuracy, enabling NYU to provide patients with more effective treatment plans, and it costs less than traditional diagnostic techniques. In an age of targeted medicine, having the correct diagnosis reduces the potential toxic side effects of treatment, and increases chances for survival. The test has already prevented at least one serious misdiagnosis, in which a



child who was originally diagnosed with medulloblastoma was found to actually have glioblastoma. Treatments for these two diagnoses vary significantly, so having the correct diagnosis has very likely

both increased the treatment effectiveness for this child and reduced negative side effects.

After just one year, in response to the noticeable diagnostic value of this tool, the NYU Neurosurgery Department has agreed to pay for all future pediatric brain and spine tumor cases to be worked up genetically (including with methylation testing). Seeing the importance of this test, Making Headway is also currently looking to partner with other hospitals to bring this remarkable tool to their clinics.



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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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.



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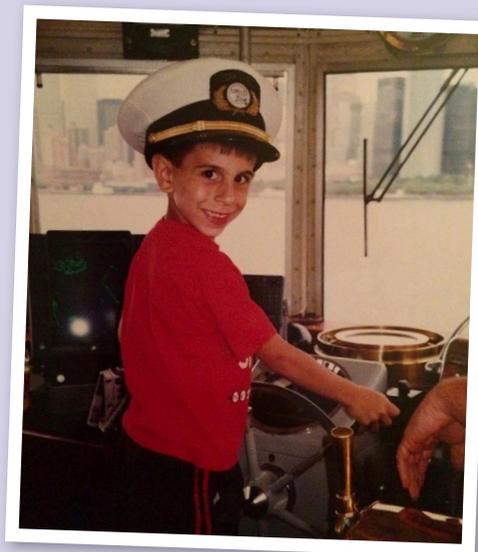
By Danielle Casimir

That was the exact date and time I received the call from Dr. Forem. My daughter, Kadence, was diagnosed with multiple brain tumors. We discussed next steps as we had to move aggressively given that Kadence's right side and overall motor functions were beginning to be affected. My family and I had a hard time trying to cope and grasp it all. Kadence began chemo shortly thereafter; however, her body wasn't reacting well to her initial treatment plan and that saddened

me a great deal. During my third visit to Hassenfeld, I met Maya. She simply touched my shoulder and said "hello, how are you?" and I began to weep. We spoke at length and without her knowing, she restored my faith that day. After our conversation, I had a different outlook and approach to our new normal and Maya continued to be a light with each visit. Kadence began to look forward to our trips to Hassenfeld because she knew Maya would have treats and Looney Lenny would give her a million dollars or a coin after performing one of his tricks. Our journey is far from over but Making Headway has definitely helped make things easier to deal with and my family and I are beyond appreciative.

**REMEMBERING
 NICKY DOCU**

Our brother was diagnosed with a glioblastoma on April 11, 2003 and passed away on October 21, 2003. During that time and all these years later, Making Headway Foundation has always been there to support us. We are so happy to be supporting them with Nicky's Memorial Golf Outing every year since his diagnosis. There are not enough words to describe the outpouring of love, understanding, and support this group of people gives to the families going through these difficult times.



*Love, Nicky's siblings,
 Alexandra and Tom Docu*