

SPECIAL EDITION
Celebrating
25 years of
Making
Headway
Foundation
WINTER 2021

making news

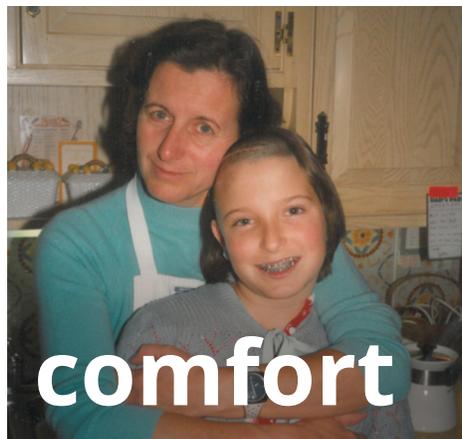


Photos by Todd Shepera Photography

www.makingheadway.org



care



comfort



cure



**MESSAGE FROM MAKING HEADWAY'S
NEW CHAIR, ELISA GREENBAUM**

**Why Would I Want to be the
Chair of Making Headway?
(And why I hope you will support
me and the Foundation.)**

At the beginning of its 25th anniversary year, Making Headway Foundation elected me as its new Chair. I take the reins from Edward Manley, who was our wonderful Chair from the inception of the foundation, and for the next quarter of a century. I have the responsibility of filling his big shoes.

But given all that has happened to me in the past year and a half, I've been asked, why would I take this job?

Since our first-born son Jake was diagnosed at three months old with a rare, malignant brain tumor in February of 1990, there was hardly a moment that pediatric brain tumors have not been a part of my life. For almost 32 years, I have been actively raising money to help children with brain and spinal cord tumors. It was also our way of giving thanks for the gift of Jake's life. For the past 25

years, I have been an active board member of Making Headway. All this time, I was caring for our survivor—our special needs son, Jake (and later, also his sister, Augusta).

But tragically, at the end of August 2020, our delightful Jake died at age thirty from an aggressive (non-brain) cancer. Then, this past July, I badly broke my leg in a bike accident that required two complex surgeries and hospitalizations, kept me off my feet for three months, and will require extensive rehabilitation.

So wasn't it time, and fair, for me to step away from this stressful affliction, to live my own, unencumbered life?

I couldn't. My husband Clint couldn't either (Clint is a Making Headway Founder and board member). We learned this philosophy by example from Ed and Maya Manley. They couldn't walk away 35+ years ago, after their daughter Cynthia survived a brain tumor. (Cynthia graduated college, got married, and lives upstate.)

Brain tumors are the #1 cancer killer of children. Brain surgery is acknowledged as the pinnacle of difficulty. For survivors, follow-up chemotherapy and radiation cause their own side effects and collateral damage. Currently, we can't prevent pediatric brain tumors from happening. But it is my pledge to lead Making Headway to live up to its name: To "make headway" in caring for children who have brain and spinal cord tumors (particularly in the hospital); to "make headway" in comforting these children, their parents and their families; to "make headway" in the fight to cure pediatric brain tumors.

To do all of this costs money. Since our inception, Making Headway has spent over \$26 million towards fulfilling our mission of Care, Comfort, and Cure. We have a current annual budget of \$1.5 million. We have three full-time employees, and pay for 28 outside specialists (Neuropsychologists, Educational Coordinator, Pediatric Neuro-Oncology Fellow, Clinical Trials Research Nurse, Care Coordinator, etc.). The point of this is, while the Making Headway Foundation has the warmth and passion of a family charity, we are highly professional, and an important presence in the world of pediatric brain tumors. Your donations will be well-spent, supporting our very important mission to help the most desperate of situations. Together, we can make headway!

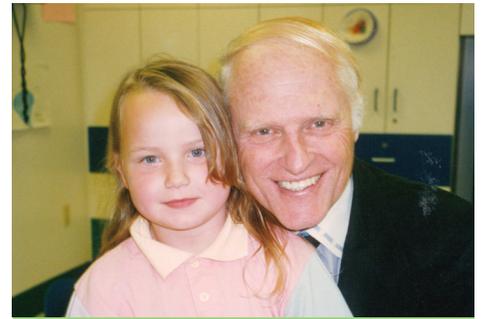
Elisa Greenbaum

Superkids, Then and Now

In Making Headway's 2004 fall newsletter, we shared the story of "superkid" Lina Orfanos. Lina was a gifted child who found out she had a pediatric brain tumor, the size of an orange, deep within her brain. After surgery, Lina was left with learning difficulties and impaired peripheral vision, but she never let anything get her down. Back in 2004, we learned that she had graduated from high school and college, interned as a music therapist at the INN (where she had been treated years earlier), and was pursuing a career in music.

21 years later, Lina is now living her best life. She lives in New York City with her husband and three-year-old son Alexander, who just "lights up her world." Lina achieved her goal of becoming a singer and just completed her 9th album with

the late, great Greek composer Mikis Theodorakis. Lina is really happy with the way her life turned out. She attributes her success to strong supporters in her life such as Making Headway. Lina was specifically grateful for Maya and Edward Manley and the Brain Tumor "Community" they have created. Lina stated that throughout the years she has felt the support for her and her Brain Tumor community at all our events and in our newsletters. Lina said she was forever grateful to be a part of this community and part of Making Headway.



Our association with Making Headway not only unites kindred spirits in terms of motives, goals, and long-term aspirations, it enables us to translate so many concepts into reality. These include psychosocial support and funding for quality-of-life projects which are beyond the budgetary scope of the hospital program. The caring support that Making Headway makes possible is a valued part of the care we provide.

—Dr. Fred Epstein, 1997 newsletter

Dr. Epstein was inspirational in helping to create Making Headway. In 2006, he passed away from complications of a malignant melanoma.

Commemorating Making Headway's 25th Anniversary

Making Headway's 25 years of serving children and families has been recognized beyond our own community of brain tumor survivors. This fall, Making Headway received official proclamations describing the needs of children with brain or spinal cord tumors, and distinguishing our mission to provide Care, Comfort, and a Cure. Each proclamation commends Making Headway on our unceasing dedication to helping children and our tangible impact on families, medical research, hospital care, and much more. As one elected official said, "Organizations like Making Headway don't happen every day, and

lasting for 25 years is an incredible achievement." Additionally, Westchester County named October 17th "Making Headway Foundation Day" in honor of our silver anniversary. We would like to thank the following officials for their ongoing support and for ensuring the passage of proclamations that acknowledge the seriousness of pediatric brain tumors and Making Headway's role in helping those impacted by this terrible disease.

- US Congressman Mondaire Jones
- NYS Senator Pete Harckham
- NYS Assemblyman Chris Burdick
- Westchester Legislator Vedat Gashi



LOOKING BACK AT THE LAST 25 YEARS



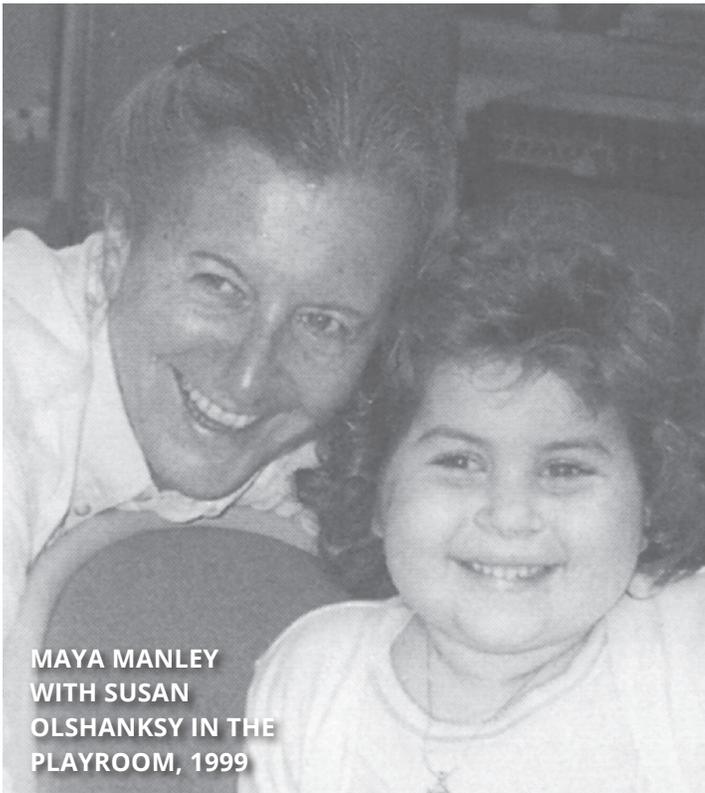
LAUREN ELLE RICHMOND (1993-2008) WITH DR. ALLEN AND THE MANLEYS

“ Maya and the entire Making Headway team made Lauren Elle’s treatments at Hassenfeld easier and at times even enjoyable. Although Lauren Elle’s journey ended in her returning home to heaven—we know how loved she was and always will be by Maya, Edward and the entire team.
—Laurie Richmond, President of ELLE Foundation and Elle’s Mom ”

“ This picture on the right represents all that we love and appreciate about Making Headway. Dr. Allen’s leadership and guidance, Maya’s attention to the children, all inspired by Cynthia. All that is missing is Edward, and as I remember, that day, he was there behind the scenes making it all happen, taking care of innumerable details and welcoming the families. We have been profoundly touched by the commitment of Making Headway and the whole Board of Directors who have done so much for our son and so many children in need.
—Clare and Patrick Robert ”



NATHANAEL ROBERT (1984-2008) WITH DR. ALLEN AND MAYA MANLEY, BIG APPLE CIRCUS FUNDRAISER IN 1993



MAYA MANLEY WITH SUSAN OLSHANKSY IN THE PLAYROOM, 1999

“ An island. That’s how I always think of the playroom. A friendly place for children to undergo their therapies while having fun. The staff and volunteers work hard to furnish an environment that encourages the children’s self-esteem and sparks their creativity. For the parents, the playroom has also become a special spot. It provides them with an opportunity to meet other parents, to share information, and to gain hope. I have always felt very strongly that one of Making Headway’s main goals should be to provide these “islands” of comfort and support. Based on my own personal experiences, I know this is not a journey any family should have to undergo alone...One of the best parts of the day in the playroom comes at about six o’clock. The children have been poked and prodded and have endured procedure after procedure, yet they still wish to linger. “Just a few more minutes” is like music to my ears. It makes me believe that this island truly has become a sanctuary.
—Maya Manley, 1999 newsletter ”

The Making Headway Story • by Edward Manley

After our daughter Cynthia underwent surgery, chemotherapy, and radiation for her malignant brain tumor, Maya and I struggled to find the help we needed to try and return to a more “normal” life. We didn’t know where to turn for advice on how to address the stresses that our family faced, or where to find the help Cynthia needed to succeed in school. Little by little, here and there, we found resources to help, but it was a haphazard, difficult, and often frustrating endeavor.

After Cynthia went away to college, Maya started working as a volunteer art therapist in the NYU playroom. There she met many other families that were going through the same stressful journey we had gone through. They needed help in the hospital and navigating the system; they needed help at home, learning to cope with new dynamics, responsibilities and emotions; they needed help in their communities, addressing the challenges of school and life. Maya and I knew—from our own experiences—that we wanted to provide support and resources to families facing these sorts of challenges. Thus, our vision for

Making Headway, and its mission of “care, comfort, and cure,” was born.

In 1996, Clint Greenbaum (a fellow parent), Maya, and I established Making Headway Foundation. Beth Israel Hospital had just opened its new Institute for Neurology and Neurosurgery (INN) and recruited many faculty members from NYU, including Dr. Jeffrey Allen. Knowing of our mission, he welcomed us there. Maya went right to work again in the playroom to meet the families, and we engaged our first psychologist, Dr. Marcia Greenleaf, and an educational consultant so they could provide their services free-of-charge to the families.

To raise funds, we bought tickets for a performance of “Toy Story on Ice” at



Madison Square Garden. We asked the families we were helping to solicit their family members and friends to either buy tickets or make a donation to the Foundation. The results went beyond our wildest dreams: we raised \$450,000! We have successfully continued this approach to this day. With funds in hand, we were able to engage additional therapists to offer more services and begin the first family event tradition, with our yearly “Family Fun Day” in our Chappaqua Garden.

When the INN closed its doors in 2004, we joined Dr. Allen and his staff back at NYU, where we have been active ever since. It has been a journey of love. Although there have been deeply sad moments, we have also been able to see the joy and help our services have brought to families. We are touched by every family who has been part of the Making Headway journey.

After serving as Making Headway’s Chairman for 25 years, Edward stepped down from that position in 2021. Both he and Maya remain very active members of the Board of Directors.

HONORING OUR 25TH ANNIVERSARY WITH AN EXTRA 25%

Nearly everything Making Headway does is made possible by the support of individuals like you—individuals who together fund 95% of our programs and services. Over the past 25 years, we have received more than 75,000 donations. Every one of them has been critical to our short- and long-term ability to help children with a brain or spinal cord tumor. As we look to the future, Making Headway has realized

how many more programs and services we could offer to families, if we could only fund them. Keeping in mind that 85% of every donation we receive goes to direct services, it comes down to a simple fact: If we receive more or larger donations, we can help more people.

For the past 25 years, we have demonstrated our track record for developing effective programs and minimizing administrative costs. To celebrate our 25th anniversary, we humbly ask that you consider a one-time increase in your yearly or monthly

donation. Add an extra 25% onto your gift and Making Headway will ensure that it will be used to help a family in need. If you have never donated, start with a \$25 donation, and join our family of supporters.

And to all of those who have helped support Making Headway over the past years, please accept our deepest and most sincere thank you. Everything we have done is only thanks to your generosity. To make a contribution online, visit MakingHeadway.org/donate.



Reflections on a Longstanding Collaboration

by Jeffrey C. Allen, MD

The primary goals of a hospital-based pediatric neuro-oncology program are to deliver a high standard of neurosurgical and medical care while fostering basic and clinical research and the training of future medical leaders in the field. Few institutions have the resources to address the extended needs of patients with diseases such as brain or spinal cord tumors. Making Headway Foundation, founded in 1996 by families whose children I cared for at NYU and Beth Israel Medical Center, demonstrates the formative role that patients, families, and friends can play in broadening the scope of services delivered to their loved ones. Many of the achievements of the NYU Pediatric Neuro-Oncology Program I have directed over the past 25 years have been enabled in large measure by the inspiration and generosity of this foundation. Here is a brief history of Making Headway's accomplishments:

In 1996, my colleague and close personal friend, Dr. Fred Epstein, who was NYU's Director of Pediatric Neurosurgery at the time, was offered a unique opportunity by Beth Israel Medical Center to create a freestanding, clinical neuroscience center for adults and children dedicated to the principles of humanism and

outstanding comprehensive care. The Institute of Neurology and Neurosurgery of Beth Israel North (INN) opened its doors soon after. Dr. Epstein recruited 110 medical personnel from NYU, including me, to join him in this novel venture. We sought advice from the parents associated with MHF regarding the design of patients' rooms and the provision of family services. For over eight years, patients, their families, and clinicians alike valued the opportunity to ameliorate the impact of critical illnesses on children at the INN. Unfortunately, in September 2001 Dr. Epstein suffered a career-ending head injury, and Beth Israel closed the INN in 2004.

I returned to NYU to lead the Pediatric Neuro-Oncology Program, partnering with a former pediatric neurosurgical colleague and associate of Dr. Epstein's, Dr. Jeffrey Wisoff, and other colleagues. Dr. William Carroll, the newly recruited Director of Pediatric Oncology at NYU, welcomed Making Headway and me to the Hassenfeld Clinic on East 32nd Street. Over the ensuing 16 years, a close partnership evolved as the missions and visions of Making Headway, Hassenfeld Clinic, and the NYU Langone Pediatric Neuro-Oncology Program became unified.

Making Headway agreed to fund several new services at the Hassenfeld outpatient clinic, including enhancements to child life, neuropsychology services, a librarian, and a masseuse. They also funded expansion of our clinical research team to include a research coordinator, several basic research grants, a brain tissue biorepository, and an annual fellowship in pediatric neuro-oncology.

Maya Manley started volunteering her child life services at the Hassenfeld Clinic in 2004 several days a week. She met and welcomed new patients, informing them of the many unique services Making Headway Foundation offers both inside and outside the hospital. In 2008 the Manleys established the Otto and Marguerite Manley Endowed Chair in Pediatric Neuro-Oncology at NYU, enabled by funds provided in the will of Edward's mother. The endowment ensured recruitment of outstanding programmatic leadership in perpetuity, and I was the Chair's first appointment. Making Headway also hired a team of caretakers to evaluate and counsel patients and families outside NYU. They made funds available to support college education, patient transportation, and burial expenses to families in need. With the help of their extensive network of supporters and multiple fundraising events, Making Headway supports these and other important causes annually.

Making Headway has made every effort to give each child and their family the love and safety net they need. I remain extremely grateful to Making Headway Foundation, including its Executive Director, Dan Lipka, and its hardworking, dedicated board, for enabling and enhancing a shared vision for the advancement of compassionate care, training, and medical advances in pediatric neuro-oncology.

CURRENT PROGRAM HIGHLIGHTS



In 2021, Making Headway has continued to expand our Ongoing Care Team in response to the new reality of COVID-19 and its psychological impact on children, siblings, and parents. We've also increased direct support for NYU Hassenfeld families trying to navigate the complex and often overwhelming number of doctors and treatment visits they need. The situation is especially complex for families taking part in clinical trials, which may happen when their child's illness has not responded well enough to standard treatments. Overall, Making Headway has been moving resources from family events—postponed by the pandemic—to services that offer families immediate help.

ONGOING CARE TEAM

The Making Headway Ongoing Care Team was a revolutionary concept 25 years ago, and has proven to be one of the most impactful aspects of our work. A child's serious illness is an intensely personal experience for the whole family. The value of free-of-charge individual or family counseling sessions with licensed psychologists, specializing in dealing with the unique issues that these families face, can hardly be measured. Nor can the value of expert educational advocacy to ensure these children have the best school experience they can possibly have. What started as a team of four has grown to encompass 28 highly qualified professionals—many bilingual—including community-based specialists in areas such as neuropsychology and bereavement.

NEUROPSYCHOLOGY TEAM AT NYU HASSENFELD

Although Making Headway provides psychological support to families through our Ongoing Care Team, we understand that comprehensive support starts in the hospital, immediately after a child is diagnosed with a brain tumor. Through one of our grants, Making Headway Foundation has enabled NYU Hassenfeld to maintain a full-time licensed clinical neuropsychologist, allowing for increased and enhanced neuropsychological interventions including screening, testing/assessment, and treatment. In addition, Making Headway's support of NYU's educational coordinator enables her to partner with the neuropsychologist, helping to advance children's educational and developmental progress throughout the course of treatment.

In 2021, the Making Headway-funded neuropsychologist significantly increased the number of assessments and testing hours for patients. This was vitally important, as pediatric brain tumor survivors may experience cognitive decline post-treatment, and neuropsychology assessments are critically important to assessing short and long-term needs. The combination of neuropsychological testing, specialized mental health services, and educational support, gives each child the best chance to overcome current and future challenges and achieve their individual potential.

MAKING HEADWAY CARE COORDINATOR

Sarah Coughlin, the Making Headway Care Coordinator, supports the NYU pediatric Neuro-Oncology program by organizing schedules and serving as the first point of contact for all patients and their families. Sarah addresses their questions, concerns, or care coordination needs, and places check-in calls after care to ensure everyone is doing well. Her work leads to safer, more efficient, more timely care for patients, and removes the burden of effective care coordination from families—especially valuable for patients who have complicated care and follow-up needs. This, in turn, improves long-term outcomes.

"Sarah has been an asset to the team, and a wonderful liaison between our patients and families and our multidisciplinary team of providers. Her attention to detail has been instrumental in ensuring a patient-centered approach to care, and she's worked diligently with the Making Headway Family Liaison to connect interested families to the foundation's available services."

—*Dr. Theo Nicolaidis, Program Supervisor*

OTHER PROGRAMS

Beyond these highlighted programs, Making Headway has invested in and continued a number of other grants, including ones supporting: a clinical trials manager and clinical trials research nurse, the Center for Biospecimen Research and Development (tissue bank), the Making Headway Preclinical Core, bereavement support, pediatric Neuro-Oncology fellowships, Ronald McDonald housing, college scholarships, DNA methylation profiling, the Making Headway family liaison, COVID-19 emergency support, the Justus Special Moments Fund, various continuing medical research projects, and many other direct and indirect programs and services.

REFLECTIONS FROM OUR ONGOING CARE TEAM



I have had the privilege of being a member of the Making Headway Ongoing Care Team almost from the beginning, when the program was based at Doctors Hospital, with Dr. Fred Epstein at the helm.

I had been a Child Life Specialist at Bellevue Hospital for 10 years and had recently started a private practice when I met the Manleys...an unforgettable experience that has only grown more magical with time!

The children and families I've worked with have given me great joy and have trusted me in their most vulnerable times. They are always in my heart. Thank you to all of the team I've worked with over the years, and my deepest love and appreciation to Edward and Maya for the great gift of Making Headway.

—Sallie Sanborn

The years I have spent with Making Headway have been one of the greatest privileges of my life. My gratitude to this wonderful foundation is immense. Most of the conversations I have had with children and family members over the years end in their thanking me. I sometimes wonder if they could ever imagine how thankful we, who work with Making Headway, are for them. The patients and survivors, the parents, and the siblings we meet are living a battle between their hopes and fears, often in pain and exhaustion. Yet, so many are models of strength, patience, self-sacrifice, total dedication, and pure love. So, to our families, deepest thanks for being an unending source of hope and inspiration. May you and Making Headway flourish in the years to come.

—Dr. Jean Donnelly



My memories start in 1982. Cynthia Manley was the first child with a brain tumor I had ever worked with. The struggles and solutions for the entire Manley family—live and “hands-on”—

taught me more than all my training and textbook references. As we learned from each other, Cynthia and I met in my office; Maya would come speak with me at my kitchen table; Edward came to learn imagery to help Cynthia through chemotherapy and MRIs.

Years later, I sat with Maya, Edward, Jeff Allen, and their minister, Jack Miller, in discussions about whether they should start a foundation dedicated to supportive care and the science to help find cures for children. It was clear there was a need; it was also clear that the Manleys had the courage, the vision, and the skills to create Making Headway Foundation. And so, they did! Little by little, our tiny team expanded to become the Ongoing Care Team. I cherish the memories of working with our original team to provide concrete services and arrange school accommodations for the children. We shared a perspective that the families were our teachers and a source of inspiration as we forged pathways to deliver support and find solutions to meet their needs.

I am forever grateful to the Manleys and the Board of Making Headway Foundation for the services they provide.

—Dr. Marcia Greenleaf

I am honored to have been part of the Making Headway Team since 2014. The Foundation works tirelessly to ensure the evolving needs of the children and families we serve are being met. This has never been more true than in the past 19 months as the organization found creative and adaptive ways to continue our work during the most trying of times. I will always be indebted to the Making Headway Foundation for making it possible for me to pursue my calling in supporting these extraordinary children. It has brought a sense of purpose and meaning to my life. I can't wait to see what's in store for the next 25.

—Dr. Kate McGee

1996 MISSION STATEMENT:
“While the medical treatment we render must be as good as, or better than, that which is available anywhere else in the world, we believe it is also critical that patients and their families be cared for in a warm, friendly, comfortable and comforting environment. This ‘marriage’ of technology to humanity is seen where the most sophisticated equipment and medical treatments are combined with state-of-the-‘heart’ caring.”



Over the past several months, in preparing for this special newsletter, I have had the opportunity to look back at the

amazing 25-year history of Making Headway. Making Headway’s long-lasting, steadfast dedication is demonstrated by our commitment to effective core programs and services. For 25 years, our Ongoing Care Team of psychologists, psychiatrists, and educational advocates has helped thousands of families. Our family events, investments in hospital playrooms, and medical research have been going strong for over 20 years. However, what makes us unique is our ability to create new programs and adjust to the changing needs of families and hospitals. Innovative programs like family wellness, college scholarships, massage therapy, and neuropsychological testing have come about as a direct result of learning the needs of families and reacting decisively to meet those needs.

On a personal note, it is almost overwhelming to look back at Making Headway’s impact and imagine the awesome responsibility of continuing these efforts for the next 25 years. We are working with families who have a child with a brain or spinal cord tumor. I write that often, but I think about it all the time. I’m going to ask that you take a moment right now, close your eyes, and really try to put yourself in their shoes—really think about having to make life-altering medical choices for your child, and having to trust their mortality to the hands of strangers.

Imagine what it is like to have the lives of everyone in your family altered forever in a single moment, knowing there was nothing anyone could have done to prevent it.

If you couldn’t image this scenario, or just didn’t want to, you are not alone. Most people don’t even want to think about or acknowledge that childhood cancer exists in this world. But it does, and these families need help—all of them, even the strongest ones out there. They need help from doctors, nurses, and child life specialists. They need help from their own families and their own communities. They need help from expert psychologists, therapists, and educators. No family should have to do this alone, and at Making Headway, it is our proud mission to make sure they never have to. Yet it is only through the support of our donors that we can continue our work.

Some of our supporters have been here since we started in 1996, and some may make their first donation today, but wherever you stand on this continuum, know that your contribution makes an important impact. Making Headway has the vision to have a real impact, the stability to make both short and long-term decisions in the best interest of families, and the track record to show it works. Over the next 25 years, we will continue to focus on our mission and always do what is right for children with brain and spinal cord tumors.

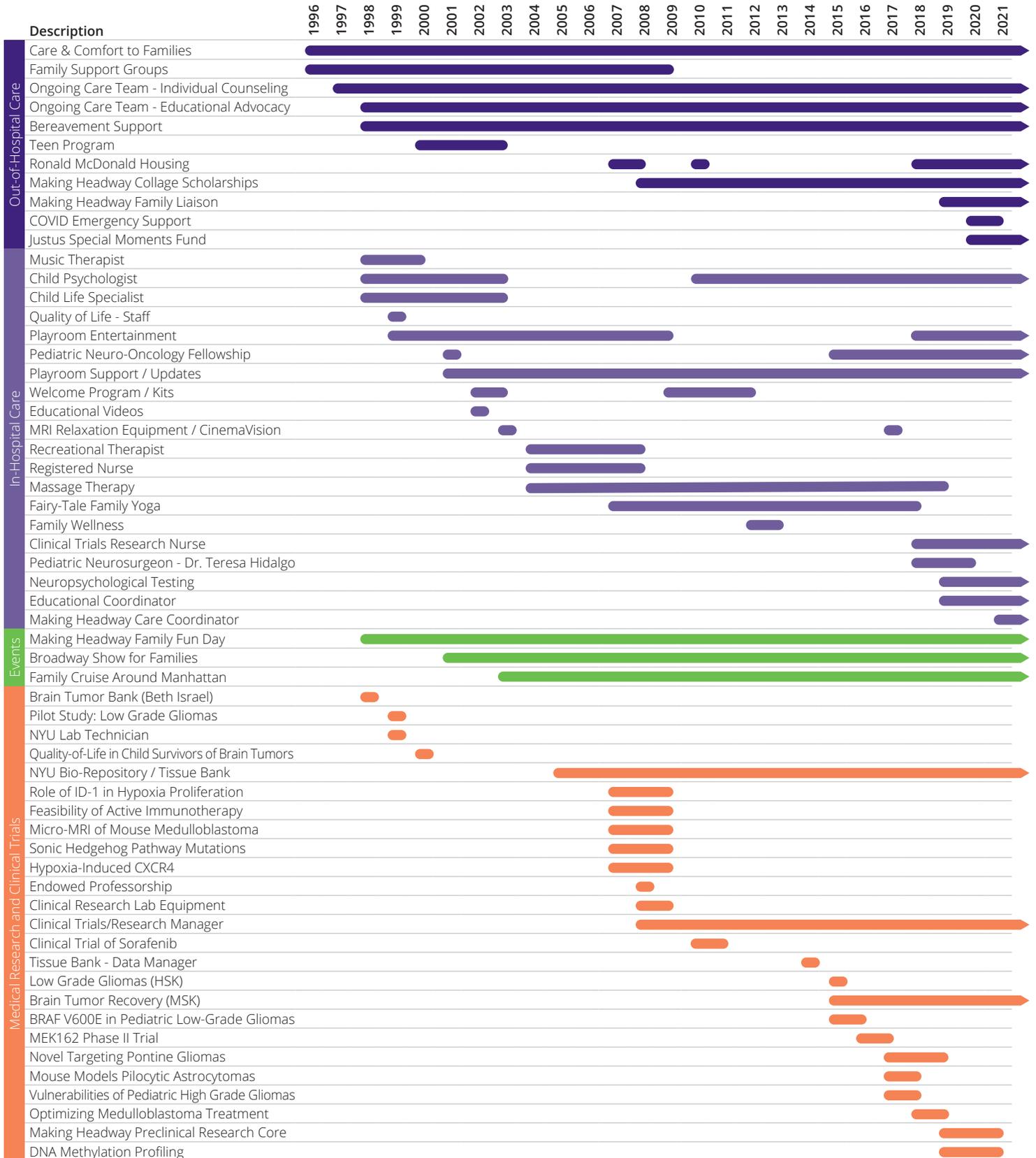
Daniel Lipka, Executive Director

LOOKING BACK

It was a great privilege to serve as Office Manager at Making Headway Foundation for close to 15 years. It goes without saying that Edward and Maya were, hands down, the best bosses! Their devotion to helping all the children and their families was amazing and it was so rewarding to help with the many fundraisers and family events, and to get to know many of the families. I continue to follow Making Headway’s progress and am thrilled to read about the expansion of many of their programs and the growth of their many research initiatives. I wish the Foundation the very best in the years ahead. On a more personal note, I wish Maya and Edward the very best in their retirement from the day-to-day operations of the Foundation and many, many thanks for their years of work for Making Headway and the families they have served.”

—Linda Lewis, Making Headway
Office Manager, 2002–2016

TIMELINE OF MAKING HEADWAY



MAKING HEADWAY BY THE NUMBERS

MAKING HEADWAY ACCOMPLISHMENTS: BY THE NUMBERS

Over the past 25 years, Making Headway has had an impact on thousands of families. We try to measure this impact through surveys, but it is not always easy to quantify. There are some things we can measure in data and numbers, however. Here are just some of the quantitative accomplishments of our work.

Direct or indirect support to over
2,000
families

8,000+
hours of educational advocacy services

12,000+
hours of individual and family counseling

114
college scholarships

More than
65
events for families

Invested over
\$26m
in grants, services, programs, and events for families impacted by a childhood brain or spinal cord tumor

Over
60
published research papers as a direct result of our grants

75,000+
donations, from more than
25,000
unique households

8
pediatric Neuro-Oncology fellowships fully funded

Funded over
150
supporting research and quality-of-life programs at local hospitals

Assisted families from
9
major children's hospitals

85%
of all donations have gone directly to programs and services

Financial support for over
150
funerals

Superkids, Then and Now



SOPHIA AND HER BABY SISTER IN 2005



SOPHIA 2021

In Making Headway's 2005 newsletter, we shared the story of "superkid" Sophia. How when she was 18 months old, Sophia was diagnosed with optic chiasmatic glioma. When the story was written, she was eight-years old and was finally off chemotherapy. She was learning braille, but "what she lacks in sight, she more than makes up for in sound. The joyous, lyrical sound of Sophia's laughter is like to music to everyone's ears." Today, Sophia is thriving as a student and a survivor.

"Hi, my name is Sophia Casale, and Making Headway has been a part of my life for roughly 22.5 years. I am grateful for every hug, smile, and warm heart I have encountered over these decades. I try to

implement these traits into my work as a memory care activity assistant each day as well. When I am not at work, I can be seen buried in graduate school assignments. I am proud to attend UMass-Boston's Gerontology and Management of Aging Services master's degree program. I strive to understand older adulthood and one day contribute to the field of aging in some way. Here I plan always to remember how powerful a meaningful hug, big smile, and generous heart can truly be. I have Making Headway to thank for that."

Back in our 1999 newsletter, there was a story about "superkid" Megan Marchica. Megan was 12-years-old and had been diagnosed with an inoperable brain tumor. She endured 17 months of chemotherapy, losing her hair, and facing many difficult personal and medical challenges. Throughout it all she spoke about how, with the help of Making Headway, her time at the hospital could be pretty fun, especially the playroom with Maya.

22 years later, Megan looks back at her time in the hospital as she looks forward to the future. She recently wrote, "Well, life has not always been easy, but given the challenges that have come up along the way, I'd say things have turned out pretty good. I am now 35 years old, married, and I obtained a bachelor's degree in bioscience at age 32 and just began a master's program. I currently work as a biology tutor at the college I got my BS from (SUNY Farmingdale) and am hoping to pursue a career in plant ecology."



MEGAN 1999



MEGAN 2021



Photo by Todd Shapera Photography

PRESIDENT BILL CLINTON SPEAKS AT THE HOLLY'S ANGELS GALA FOR MAKING HEADWAY FOUNDATION.

"Twenty-five years ago Edward and Maya Manley's daughter, then just fourteen, developed a brain tumor. Surgery and chemotherapy proved effective, and she went on to lead a full life. But their struggle left the Manleys with a desire to do something to help families in the same situation. At first they tried raising funds to support more brain tumor research, but after a few years they decided what they really wanted to do was to create a support network for the families. In September 1996, along with Clint Greenbaum, another parent of a survivor, they founded the Making Headway Foundation, to help children with brain and spinal cord tumors. Starting small and growing to meet the demand for its work, Making Headway now provides support for children and their families before, during, and after hospital care, including free counseling, support groups, and, when surgery, radiation, and chemotherapy have caused learning disabilities, education remediation services...Making Headway is an excellent model for putting a good idea into action by asking for help from friends, family, neighbors, and those who share a passion for the cause. It's something you can do"

—As written by President Bill Clinton in his book "Giving"



There are so many ways you can help a child with a brain or spinal cord tumor. You can volunteer at a local nonprofit, participate in fundraising events, or donate to Making Headway. But there is another thing you can do that you might not have thought of: advocate for important state and federal legislation that increases investments in research, directly helps families, or helps create a platform for future medical discoveries. Here are some examples:

THE CREDIT FOR CARING ACT (H.R. 3321 / S. 1670) would provide family caregivers with financial relief, and help offset some of the expenses they incur when taking care of a sick child or other family member. Caregivers play a critical role in helping brain tumor patients navigate their health care journey, but often incur significant financial costs as a result. Family caregivers spend, on

average, nearly 20% of their total income on caregiving activities. For families whose child is diagnosed with a brain tumor the costs are even more extreme, given that one parent usually has to quit their job to manage their child's constant doctor and hospital visits, as well as being a full-time caregiver. Through this legislation, families would receive a credit of up to \$5,000 to help cover all these costs.

THE GIVE KIDS A CHANCE ACT (H.R. 5416) will give children with cancer the opportunity to receive trials of two or more drugs at the same time. The legislation will authorize the FDA, at its discretion, to require companies undertaking regulatorily-directed pediatric cancer trials to plan combination trials instead of single drug trials, giving kids with relapsed cancer a better chance of success. The Give Kids a Chance Act will also require biotech

firms and pharmaceutical companies to pay for their pediatric cancer trials.

THE GABRIELLA MILLER KIDS FIRST RESEARCH ACT 2.0 (H.R. 623 / S.1523) redirects penalties collected from law-breaking pharmaceutical, cosmetic, supplement, and medical device companies to pediatric and childhood cancer research. The Kids First program supports critical research into pediatric cancer and structural birth defects, and has focused on building a pediatric data resource combining genetic sequencing data with clinical data from multiple pediatric cohorts.



To get involved or learn more about each of these acts and find quick links to support them, visit www.MakingHeadway.org/advocacy.

Making Headway Joined CBTN Executive Council



This fall, Making Headway was pleased to join the Executive Council of the Children's Brain Tumor Network (CBTN). CBTN is dedicated to driving innovative discovery, pioneering new treatments, and accelerating open science to improve health for all children diagnosed with a brain tumor. "Innovation through collaboration" is made possible by CBTN's biorepository and shared data portals, as well as the expertise of leaders in the field of biomedicine. This collaborative research effort has 26 primary member institutions; and has enrolled more than 4,361 subjects and collected more than 50,000 specimens.

Through CBTN, researchers share expertise, specimens, and data to accelerate the finding of less toxic, more effective treatments and cures for children with brain tumors around the world. What sets CBTN apart from other biorepositories is the immediate and free availability of data for any researcher in the world, with the caveat that all information resulting from its use be shared back for everyone's use.

Just recently, CBTN received some extremely exciting news. The National Institutes of Health (NIH) has approved

its request for support in sequencing a considerable portion of the remaining CBTN bank. CBTN's entire cohort of 4,594 specimens will undergo whole genome sequencing, and 1,531 subjects will also get RNA sequencing. The sequencing will provide researchers with unprecedented access to extraordinary data, which will provide fundamental insights into the causes of pediatric brain tumors, how they grow, and how patients can be effectively treated. At a cost equivalent to about \$45 million, this is one of the largest projects of its type NIH has ever funded.

MAKING HEADWAY AND NYU LANGONE: A SPECIAL PARTNERSHIP

Making Headway Foundation's two-decade long partnership with the Hassenfeld Children's Hospital at NYU Langone has had an immeasurable impact on patients with pediatric brain and spinal cord tumors and their families. The Making Headway's unwavering commitment to NYU Langone's research initiatives, quality patient care, and family well-being during these most difficult times aligns powerfully with that NYU Langone's values of patient care, education, and research.



“The diagnosis of cancer is a life changing event. Making Headway Foundation is devoted to minimizing the impact this diagnosis has on patients and their families. I have been amazed at how many resources they are able to deploy to help families in every way imaginable in their time of need. Our patients are so fortunate that this wonderful foundation continues to grow and provide its services after 25 incredible years.

—Dr. Theo Nicolaides, Director, Pediatric Neuro-Oncology, Hassenfeld Children's Hospital

“We are so grateful to the Making Headway Foundation for your unwavering support and love for children and families at NYU over the past 25 years. The programs and services supported by the foundation have touched the lives of so many children and families, making their journeys easier. Due to your support, we have been able to offer expanded psychosocial and educational services, develop and open innovative clinical trials, launch new research programs, and embrace every child and family in a holistic, compassionate, and personalized way. We are so very thankful for your partnership.

—Dr. Elizabeth Raetz, Director of Pediatric Hematology-Oncology, Hassenfeld Children's Hospital

“There aren't enough words to describe the tremendous contributions Making Headway Foundation has made to the patients, families, and staff at the Hassenfeld Children's Hospital. I have had the honor of seeing firsthand the difference Making Headway has made. Through the Making Headway Foundation, not only our patients but also their families have had the opportunity to have fun and take their minds off their medical issues: going on boat rides, visiting the aquarium, and enjoying live theater. And Maya and Edward know firsthand that when a child is diagnosed with a brain or spinal cord tumor, one of the child's biggest wishes is to get back with their friends and do the things other children their age are doing. Making Headway supports education specialists who work with the children's schools to enable them to keep up with school work as much as possible and to help transition back into the classroom when possible. They also support psychologists to help the patients, their siblings, and their parents deal with emotional and psychological issues associated with their illness.

More recently, Making Headway has expanded its support to include our research efforts. These include our study of a new drug to treat children with a very aggressive type of brain tumor, which we hope will soon be approved by the FDA, and numerous additional clinical trials for children with central nervous system tumors.

Caring for children with a central nervous system tumor takes a village. The Making Headway Foundation is an extremely valuable part of our village. I would like to say a huge THANK YOU to Making Headway from the bottom of my heart!

—Dr. Sharon Gardner, Pediatric Neuro-Oncologist, Hassenfeld Children's Hospital



Super Power. by the Trush Family

Over the years, our family has been blessed by the generosity of many. It has allowed us to move forward and stay positive. Our paths have crossed with many special individuals and organizations alike, who have had a meaningful impact on our lives—and Maya Manley and Making Headway have left an indelible imprint on us. When one of five brain aneurysms unexpectedly exploded inside Daniel's head, at the age of 12, we were a family in crisis. Through the care of the exceptional doctors and staff at Beth Israel North, Daniel was given life. And Maya was one of a select few who gave us hope. Speaking in her calm and warm voice, along with her ever-present smile and of course, sharing her own life experiences, Maya and Making Headway became an important part of our family. And of course, we would be remiss not to mention the basket of candy! We can still hear her voice after Daniel woke up from his 30-day coma—"Daniel, would you like some candy?"

After Daniel was discharged from Beth Israel and subsequently Rusk, we understood that not only was Daniel different, but so was our family. We started a journey together that was focused on love, acceptance, the setting of achievable goals, and looking for that one spark that would provide meaning

to Daniel's life. After 8 long years, Daniel found that one thing, his "super power"—music.

As we researched the power of music and programs that were available for individuals with disabilities, we found there was a void. There were conservatories that focused on music performance and excellence, and music therapy that focused on achieving goals, but there wasn't anything in between. And there were no programs available for individuals with disabilities in a group setting. So, in 2005, we decided to start Daniel's Music Foundation, a non-profit organization that empowers individuals with disabilities through music. All of our programs would be based on acceptance, respect, and socialization, wrapped around the one universal language in the world—music. We wanted to celebrate diversity and provide a community for individuals with developmental and physical disabilities from ages three to adult.

Today we serve thousands of individuals and organizations, both within NYC and nationally, through our in-person and online programs. As a family and an organization, we are also committed to helping create a mindset of understanding and mutual respect through our Disability Awareness

Programs. Our state-of-the-art, custom built music center in NYC is where we call home. This modern, 8,700 square foot barrier-free facility houses 5 music studios, a recording studio and sound booth, a video production studio and a fun cafe appropriately named Snackappella. Our music center is the foundation of the foundation—a place where individuals of all abilities can celebrate the joy of music together and most importantly, families can feel like they belong. However, during the pandemic, we realized that music can be shared virtually by offering private lessons and events, like our Open Mic and dance parties and we are now serving hundreds of children and adults throughout the United States.

All those years ago, when we attended the Making Headway events in Chappaqua, we always felt like we were part of something special. We are forever grateful to the Manley family for the opportunity to experience such a sense of community. As Daniel's Music continues to grow, we remain passionately committed to cultivating that same sense of community and belonging—a feeling that we learned 20+ years ago through a chance encounter with a wonderful woman, family and organization! Thank you Making Headway—keep it going!



Medical research into pediatric brain tumors is extraordinarily complex to conduct and often very difficult to evaluate. The image of an individual doctor experiencing some masterful insight that leads directly to a new treatment is the stuff of Hollywood, not real life. For something as complicated as childhood brain tumors, it takes teams of researchers, from many hospitals and companies, decades to make breakthroughs, with every small bit of understanding working together to gradually build new knowledge. And even with that knowledge, it may be another decade before actionable treatments can be developed, tested, and approved for safe use. Over the past 25 years, Making Headway has done our part in this process, because we know that if we don't try, there will never be any breakthroughs, new treatments, or a cure. As we celebrate our 25th anniversary, we look back at a few of our research grants to see their short and long-term impact.

**DR. DANIEL TURNBULL, 2007
MICRO-MRI OF MOUSE
MEDULLOBLASTOMA PROGRESSION
AND RESPONSE TO THERAPY**



The original goals of this grant were to use micro-MRIs to better understand medulloblastomas (a malignant central nervous system tumor) in mice, and to analyze the effects of cyclopamine, a naturally-occurring chemical, on the progression of these tumors.

Unfortunately, the researchers were not able to achieve their primary goals, but the techniques they used to image the medulloblastoma progression had a lasting impact, allowing the team to investigate a number of approaches to detecting early stage medulloblastomas using MRIs. This led them to form collaborations in which Manganese Enhanced MRI (MEMRI) was employed to study tumor progression; MEMRI turned out to be a very useful tool for studying medulloblastoma biology and for use in preclinical drug studies. Even today, this research has continued. In a fruitful collaboration with the Joyner lab at Memorial Sloan Kettering Cancer Center, researchers applied MEMRI to two mouse models of a common form of medulloblastoma, pinpointing mutations that lead to medulloblastomas forming in the cerebellum. At least four publications have come from this research, most recently just this year.

**DR. MATTHIAS KARAJANNIS, 2010-11
CLINICAL TRIALS: THE MULTI-
INSTITUTIONAL PHASE II STUDY OF
SORAFENIB**



As we know, most clinical trials fail, but even when that happens, scientists can glean valuable information from them. This was the case with Making Headway's Phase II research study into the drug sorafenib. We learned from the clinical trial and accompanying laboratory research that sorafenib is not effective in treating BRAF fusion

positive and NF1 related low-grade gliomas, and identified the underlying molecular mechanisms that explain why these treatments fail. Based on this knowledge, a different class of drugs, called MEK inhibitors were studied in subsequent trials and shown to be effective.

**DR. RICHARD POSSEMATO, 2017-2018
VULNERABILITIES OF PEDIATRIC
HIGH GRADE GLIOMAS**



Funding provided by the Making Headway Foundation enabled this research team to generate metabolic profiles of a precious set of pediatric brain tumors, including diffuse intrinsic pontine gliomas (DIPG) and pilocytic astrocytomas. The team was then able to compare these profiles to metabolic profiles that had previously been generated from adult brain tumors. In addition, they used patient samples to generate additional DIPG cell line models for future testing. Specifically, the team was able to take the first look at how pediatric brain tumors make use of nutrients from the environment; this knowledge will help researchers explore how to target metabolic pathways and nutrient acquisition in future work, and may provide critical insights into future discoveries. The study's principal investigator is also collaborating with an investigator at another institution to consider the impact of metabolism on a novel anti-cancer agent on pediatric gliomas.

INVESTING IN PEOPLE



I am a Victim, Fighter, and Survivor

by **Cristino Chavez**

Every morning I wake up and see myself: I see my scar on my head, and I see a survivor. It's been 15 years since I was diagnosed with a brain tumor (ganglioglioma) and undergone surgery and treatment, and not a day goes by that I don't embrace my resilience and motivation to strive for success. When I first started my academic career, I felt that it was going to be a challenge post-surgery and financially, but with the support of my family and the Making Headway Foundation, I was able to keep my head up high and move forward. As a recipient of the Making Headway Foundation scholarship and the support it provided, I was able to graduate with my bachelor's degree in psychology from SUNY College at Old Westbury. Today, I currently have my master's in social work, hold a license in the state of New York (LMSW), and am in my first year as a doctoral student, pursuing my Ph.D. at Adelphi University School of Social Work. In addition, I hold the positions of Program Coordinator & Director of Immigrant Outreach, Psychotherapist, and Research Assistant through several universities in the tri-state area.

When I first discovered that I had a brain tumor I felt like my life was over, and the hardships my parents faced having to cope with this news were not easy. But I knew I wasn't going to let any of this stop me from accomplishing my goals! I am a victim, fighter, and survivor of a brain tumor and despite all the odds, I continue to fight and advocate for youth and families who face similar struggles and hardships!

Cristino was the 8th winner of a Making Headway College Scholarship. Since that time, we have awarded scholarships to over 100 childhood brain tumor survivors.

Global Impact

by **Dr. Diana Osorio**

Following my 2013 Making Headway Fellowship at NYU, I started practicing as a pediatric neuro-oncologist at Nationwide Children's Hospital, where I have worked for the last seven years. I have continued my international work providing real-time Neuro-Oncology consultative services to oncologists and other pediatric subspecialists throughout 20 countries in Latin America. An average of 50 participants log in to our weekly meetings; some institutions have made it part of their educational tumor board for trainees. We have published several articles on this work, and have provided second pathology reviews for numerous patients. Our most recent numbers show that we reviewed 104 samples from 14 countries between 2015-2021. Sixty-six percent of these reviews resulted in a diagnostic change, and of those 47% had either a major change in histopathologic diagnosis and/or an impact on patient treatment and/or outcome (publication forthcoming). For the past year, I have been the site Principal Investigator for the Pacific Pediatric Neuro-Oncology Consortium, and have collaborated in other early phase clinical trials such as the HSV-Oncolytic viral trial with supratentorial high grade gliomas. My interest in clinical trial work is growing and I hope to continue to move in this direction.

My work would not have been possible without the training I received as part of the Making Headway Fellowship. They are an inspiring and generous foundation with a vision to improve the lives of those afflicted by pediatric brain tumors.

Dr. Diana Osorio is currently a Neuro-Oncologist and Director of the Global Health Neuro-Oncology Program at Nationwide Children's Hospital. She has been cited on at least 24 peer reviewed research publications. Dr. Osorio has also supervised six of her own pediatric Neuro-Oncology fellows, exponentially increasing the impact of Making Headway's original grant.

Helping Families Access Critical Services

Hundreds of high-quality, community- and state-based services are available to support Making Headway families. These services include early intervention, medical and dental care, early childhood mental health consultation, parent education programs, public housing assistance, transportation, education support, and job assistance programs, among many others. But accessing many of these programs can be complicated and frustrating. Making Headway is here to help. If you or your child has been diagnosed with a brain or spinal cord tumor and need assistance accessing government or community services, please feel free to contact Making Headway's Family Liaison, Jenn Cabarcas, at (914) 238-8384 or family@makingheadway.org.

Among the programs Making Headway can assist you in accessing, are these two:

Office for People with Developmental Disabilities

New York State's Office for People with Developmental Disabilities (OPWDD) is responsible for coordinating services

for children or adults with developmental disabilities. A majority of children with brain or spinal cord tumors develop mental or physical disabilities, making them eligible for OPWDD services. OPWDD relies on over 500 nonprofit service providers who specialize in direct services related to independent housing, employment, transportation, day programs, and social supports. OPWDD also provides access to respite, assistive technology, environmental modification, and crisis services.

Children and Youth with Special Health Care Needs

The federal government's Children and Youth with Special Health Care Needs (CYSHCN) program is aimed at improving the system of care for children and youth from birth to age 21. Children with a brain or spinal cord tumor who develop physical, developmental, or behavior problems are eligible for their services. A related program, Children and Youth with Special Health Care Needs Support Services (CYSHCNSS), assists families in paying medical bills for children with severe chronic illnesses and/or physical disabilities.

Empowering Families

by Jenn Cabarcas, Making Headway Family Liaison

It is always nice to put a face with a name, a voice, and an email. I recently had the honor of meeting the Diptee Family, whom I have been working with for quite some time. During my in-person conversation with the mom, I learned that after her daughter, Lily, was diagnosed with optic pathway glioma as a baby, their entire family had to adapt instantly to a complex and overwhelming new world. Like most families, after Lily left the hospital her parents did not know where to go and what to do. They applied for services through OPWDD, but did not hear anything back, and years later still didn't know if their daughter was eligible or approved for services. During our talk, I walked Lily's mom through the process of applying for specific procedures to ensure her daughter got the services she was entitled to. A few days later, she wrote to say she had spoken with the OPWDD program coordinator and learned that Lily was approved for services, and the process began moving rapidly forward.

Many Making Headway families are so overwhelmed with meeting the medical needs of their child, that they never have time to explore available public and community services. If I can use my experience and make life easier for them, it is my honor to do so. I am grateful to have the means to assist families in achieving their goals and getting the best and most appropriate services for them. It is important that we empower families to take control of their lives and secure the help they need. It is a joy to work with Making Headway families and support them in any way possible.



IN MEMORY OF THOSE WHO HAVE PASSED

In this newsletter, we share many inspiring stories of children whose treatment has been successful, and who have gone on to overcome countless challenges and achieve their own success. However, this isn't always how the story goes. Since the Making Headway

Foundation was launched in 1996, approximately 13,000 children in the U.S. alone have died from a brain or spinal cord tumor. This is a reality that we at Making Headway face every day, and it should not be ignored. Over 300 children whom we have personally known, and deeply loved, are no longer with us due to this terrible disease. As much as we celebrate those who survive, we must always remember those we have lost. With our deepest condolences, we remember and honor those who have passed.*

Aaliyah	Brian	Elizabeth	Iyana	Julianna	Maxwell	Pierce	Steve
Aaliyah	Brian	Elizabeth	J'amir	Julianna	Meghan	Presley	Steven
Aaron	Brian	Elliott	Jack	Kamiyah	Menachem	Rachael	Suhad
Adam	Brooke	Emma	Jackie	Kenneth	Micahel	Rachel	Susan
Adam	Callie	Eric	Jacob	Khloe	Michael	Rameen	Susan
Adrian	Callie	Eric	Jacob	Khloe	Michael	Randy	Talia
Akila	Carley	Eric	Jacqueline	Kohl	Miguel	Randy	Tania
Akila	Carol Ann	Erica	Jake	Kyle	Miguel	Raymond	Taylor
Alex	Caroline	Erica	James	Kyle	Miguel	Raynero	Taylor
Alex	Casey	Erin	James	Kyra	Mike	Richard	Teddy
Alexander	Catherine	Erion	Jamie	Lara	Mike	Richard	Teresa
Alexander	Charles	Esmeralda	Jamie	Lastiny	Mikey	Robert	Tess
Ali	Chase	Ethan	Jasmina	Lauren	Milina	Robyn	Than
Aliza	Chris	Ethan	Jason	Lauren	Misha	Ryan	Thomas
Allan	Christian	Evangeline	Jason	Legacie	Moses	Ryan	Tom
Allison	Christian	Evelyn	Jason	Leslie	Moshe	Salimatou	Torrey
Alyse	Christian	Faith	Jason	Libi	Naomi	Sami	Trish
Andres	Christian	Fallon	Jayden	Lila	Nathalie	Sammy	Tru
Andrew	Christine	Francesca	Jeffrey	Liliana	Nathanael	Sara	Tru
Anika	Christine	Ana	Jenna	Liliana	Nicholas	Sara	Tyler
Anne	Christine	Gabrielle	Jennifer	Lily	Nicholas	Sara Mae	Valentine
Anthony	Christine	Gabrielle	Jennifer	Lindsey	Nicholas	Sarah	Vanessa
Anthony	Christopher	Gamery	Jeremy	Lori	Nicky	Scarlet	Vanessa
Anthony	Chun Lok	Gary	Jessica	Lori	Nicole	Scott	Victoria
Anthony	Cindy	Gianna	Jimmy	Lucas	Odette	Scott	Vincent
Anthony	Connor	Gianna	Joaquin	Luis	Oliva	Scottie	Vincent
Antonella	Daniel	Gordo	Joey	Luis	Olivia	Selina	Violeta
April	Daniel	Hailey	John	Luis	Olivia	Serenity	Vivar
April	David	Hanna	John	Luis	Owais	Seth	Wiley
Araminta	Debbie	Hannah	Jordan	Magdalena	Pamala	Shaindy	Xavier
Arnoldo	Devan	Heather	Jordan	Malik	Paris	Shane	Xiao Xian
Arvin	Devon	Holly	Joseph	Malik	Paul	Shane	Zachary
Avital	Dina	Holly	Joseph	Marcel	Paul	Shannon	Zachary
Bobby	Dominik	Ilana	Joshua	Mark	Penelope	Shruti	Zoefia
Brandon	Drew	Isabella	Josiah	Marlenie	Peter	Simon	Zyasia
Brandon	Edwin	Isabella	Josnell	Mason	Peter	Simone	
Brandon	Elijah	Isabella	Juan Antonio	Mason	Peter	Sojairis	
Brendan	Elijah	Issiah	Julia	Matthew	Philip	Stephanie	

*We apologize for any names we may have inadvertently left off this list.



The Future

If the past is any indicator, Making Headway's next 25 years may be very similar to our first quarter century. Too many children are still being diagnosed with brain and spinal cord tumors, leading to serious, lifelong challenges for them and their entire family. In fact, if, as we hope, technology leads to more children surviving, the need for ongoing care support will be greater than ever. Most of our programs are not standard at most local hospitals, and the need for Making Headway's services will continue to grow.

We still hope that treatment for children with a brain or spinal cord tumor will fundamentally change over the next 25 years. Through new technologies, like artificial intelligence and advanced DNA sequencing, combined with truly collaborative worldwide research efforts, scientists will be able to detect tumors earlier and treat them with non-toxic therapies. We dream of a day when craniotomies, radiation, and chemotherapy have been replaced with new treatments that do not cause any long-term damage. Perhaps treatments will be custom-designed for each child and each tumor, maximizing their effectiveness while minimizing their side effects.

Reaching these goals will not be easy. It will take a massive investment from government agencies, pharmaceutical companies, hospitals, and philanthropic foundations. It will take new levels

of advocacy, and long-lasting partnerships among those in this field. New treatments are likely to come only from new and extraordinary collaborations that will involve hundreds of researchers, dozens of institutions, terabytes of shared data, and a single, shared goal.

In the meantime, Making Headway will continue to be on the ground floor, helping every family we can. We will benefit from the lessons learned over the past 25 years, while continuing valuable programs as well as developing new services that directly meet the needs of children and their families. We will continue our mission to provide Care, Comfort, and Cure through strategies that are effective and efficient and, with your support, provide new and deeper levels of individual and family care. We will keep an open mind, always with an eye to new solutions, moving forward hand-in-hand with the families we serve.

In our very first flyer, we wrote that our mission was to "Enhance medical care by providing humanistic and psychosocial services, research, education, and training." For 25 years we have been steadfast in our dedication to that cause, and will remain so for the foreseeable future. Together, we can directly help children with brain and spinal cord tumors. We are so grateful for your past support and know that you will be with us in the years ahead.



**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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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.

