



making headway
foundation

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



2022-23 ANNUAL REPORT

Making Headway Foundation, Inc.
115 King Street
Chappaqua, NY 10514-3460

Telephone: (914) 238-8384
Fax: (914) 238-1693

makingheadway.org
info@makingheadway.org



Over the past 26 years, Making Headway has consistently improved, diversified, and expanded our services to best meet our mission. Our motto of Care, Comfort, and Cure guides our programs to ensure that we address the complex needs of

families throughout the entire process. This includes **Caring** for the family on their long journey that begins at the time of diagnosis of a child's brain or spinal cord tumor. We strive to create a sense of family and **Comfort** at the hospital or

outpatient clinics where families may spend countless days or months. Finally, it includes our unrelenting passion to learn more about pediatric brain and spinal cord tumors, develop better treatments, and find a **Cure**.

MAKING HEADWAY: WHAT WE DO

Our Mission: 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.

All Making Headway programs, services, activities, and events are always provided at free-of-charge.



CARE

Fully Funded RN/Care Coordinator to Help Families at the Hospital

Individual & Family Counseling

Educational Assistance

College Scholarship Fund

Bereavement Support

Housing & Emergency Assistance

Connect Families to Needed Services



COMFORT

Expert Psychological Support and Educational Advocacy for Families

Making Headway Family Liaison

Justus Joyful Moments Fund

Family Events and Activities

Looney Lenny the Clown and Entertainment at Hassenfeld



CURE

Clinical Trials Research Manager

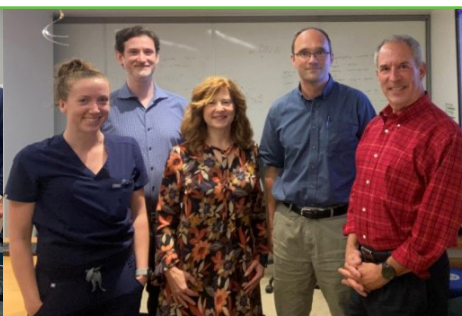
Tissue Biorepository Center

Children's Brain Tumor Network

Neuro-oncology Fellowship Program

Local and Federal Advocacy

Brain Tumor Recovery Research at MSK



[Left image] Left to right: Dan Lipka, Clint Greenbaum, Elisa Greenbaum, Sarah Coughlin, Dr. Devorah Segal, Dr. Jessica Clymer, Maya Manley, Edward Manley. [Right image] Left to right: Dr. Kristyn Galbraith, Dan Lipka, Elisa Greenbaum, Matija Dr. Snuderl, Clint Greenbaum.

LETTER FROM OUR CHAIR

Making My Rounds in 2022

I am not a doctor (and I don't play one on TV), but I am happy to report that over a year since my two leg surgeries after my bike accident, I am so much more mobile, and I've been making the rounds. Here are some recent things I've gone to:

I was privileged to attend a presentation by Dr. Matija Snuderl, a brilliant neuropathologist at NYU Langone Health. Dr. Snuderl updated our Making Headway team on his current work diagnosing pediatric brain tumors. Dr. Snuderl's goal is for every patient to receive a rapid and accurate diagnosis, that would result in better treatments and outcomes. Making Headway funds the NYU tissue bank that provided

the samples needed for Dr. Snuderl's breakthrough research into DNA methylation profiling.

I attended Making Headway's Family Fun Day at the Bronx Zoo. It was our first Family Fun Day in two years (because of COVID-19). It was wonderful to see the smiles on the faces of the children, who got to just be regular kids for the day.

Along with other Making Headway Board Members, I met with senior physicians at NYU Langone Health to get an update on their pediatric neuro-oncology program and to discuss the partnership with Making Headway. Again because of COVID-19, we had not had any in-person meetings since I became Board Chair. It was great to hear from and speak with doctors Elizabeth Raetz, Catherine Manno, and William Carroll and to know that we are all on the same page.

I met two professionals whom Making Headway funds: Dr. Jess Clymer, the new Marguerite and Otto Manley Director of Pediatric Neurosurgery at NYU Langone Health, and Sarah Coughlin, RN, the Pediatric Neuro-Oncology Clinical Family Coordinator at NYU Langone Health. Great things to come.

Finally, we all had a blast at the Eat, Drink, & Karaoke fundraiser in memory of our son, Jake Greenbaum, and Board member Susan Rubin's son, Andy Ecker. Thanks to the generosity of our friend and longtime Making Headway supporter Joe Sprung and his Bear Givers, who underwrote the event, everything we made that evening went directly to Making Headway.

I am not a doctor, but I prescribe a donation to Making Headway to help you feel as best as possible!

Stay well,
Elisa Greenbaum

Elisa Greenbaum



FROM OUR FOUNDERS

Maya and I love the title of "Emeritus," but we want our friends to know that we're certainly not retired from the exciting developments at Making Headway. On the contrary, both of us are still deeply involved in age-appropriate ways! There is still so much to be done to help the children and their families. Besides that, many parents whom Maya has counseled through the years still want the calming presence of her gentle voice and understanding spirit. And of course, because we want the foundation to continue providing all the services so

critical to the children, we are actively seeking contributions for special programs. To that end, we will be sending out over 600 invitations for the upcoming winter event. So yes, we plan to stay actively involved as long as we are able. Rest assured that the children of Making Headway, together with their families, will always be first in our hearts.

Maya and Edward

Maya Edward P. Manley

MY MAKING HEADWAY PEDIATRIC NEURO-ONCOLOGY FELLOWSHIP

By Dr. Robyn Borsuk



My work completing the Making Headway Pediatric Neuro-Oncology Fellowship at the NYU Stephen D. Hassenfeld

Children's Center has been an invaluable educational experience that has prepared me for a career dedicated to helping children with brain and spinal cord tumors. The technical and interpersonal skills I've learned throughout my fellowship have allowed me to provide superior care and treatment to my patients and their families.

During my 2021-22 fellowship, I have had the opportunity to play a critical role in the diagnosis and treatment of pediatric patients with CNS (central nervous system) tumors, and have also been an instrumental part in managing relapses and helping families

to anticipate long-term complications of their treatment regimens. Through the advanced molecular testing available to the patients of NYU Langone, I have garnered an in-depth understanding of the contributions of genetic mutations to the development of tumors as well as to the targeted approach to their treatment.

The Making Headway Fellowship also gave me the opportunity to rotate with the adult neuro-oncology, neuroradiology, and neuropathology teams. Each of these rotations provided the chance to expand my knowledge base in these very distinct areas, further improving my neurology examination skills, understanding of various tumor types, ability to interpret patient MRIs, and recognition of histological patterns. Additionally, being able to practice within the nation's largest neurofibromatosis

center has provided me with experience working with a unique population unavailable at any other facility.

Throughout my time at NYU, I have been able to appreciate and draw from the experience and different approaches of my mentors, Dr. Segal, Dr. Nicolaides, and Dr. Gardner. Through their leadership, I am now much more comfortable in leading my patients and their families through the process of diagnosis and management of CNS tumors.

This fellowship has inspired me to pursue a career dedicated to helping children with CNS tumors. To continue this work, I have joined the faculty of SUNY Upstate Golisano Children's Hospital as a pediatric neuro-oncologist.

Overall, I am incredibly grateful for the opportunity and support Making Headway Foundation has given me. It has made me a stronger and more well-rounded pediatric neuro-oncologist.

Dr. Borsuk was the 11th Making Headway Pediatric Neuro-Oncology Fellow. Previous Fellows continue to help children all around the world.

ONGOING CARE TEAM

One of the very first services ever offered by Making Headway Foundation was psychological and educational support for families impacted by a childhood brain or spinal cord tumor. The trauma families face in the wake of a diagnosis like this isn't just limited to children. Parents and siblings are often overwhelmed, in need of help from highly experienced, extremely knowledgeable and compassionate therapists, psychologists, and psychiatrists. Our Ongoing Care Team was created to address these pressing needs.

Furthermore, young survivors of these tumors can often develop mental or physical disabilities as a result of surgery, radiation, and chemotherapy. When they return to school, they almost always need extra support designed around their individual needs. Yet getting services from a school district is often challenging, and the bureaucracy can stun even the most educated parent. So years ago, Making Headway added professional Education

Advocates to the Ongoing Care team, ensuring all children get what they need to reach their academic potential. Over the last quarter century, this service has blossomed into one of our most essential and valued programs.

In recent years, as Making Headway has expanded to work with new hospitals and new families, we have grown our Ongoing Care Team, with the goal of ensuring we can meet the needs of every family with the highest quality care. We now have 30 team members, who collectively provide thousands of hours of care to hundreds of families. And just as with all our programs, families will never receive a bill for any of these services, no matter how long they need them.



Ongoing Care Team from our most recent Zoom meeting

To learn more visit www.makingheadway.org/care

TICKETS FOR KIDS

Since the summer of 2022, Making Headway has received donations of over 592 seats from Tickets for Kids. Through our partnership with this unique organization, on whose board our co-founder and Vice Chair, Clint Greenbaum, serves, Making Headway was able to send our families to Mets, Yankees, and New Jersey Devils games, five Broadway shows (including “Aladdin”), and Cirque du Soleil. These are amazing opportunities for our kids, most of whom have never had the opportunity for this type of experience before.

All tickets received by Making Headway are free, courtesy of Tickets for Kids.



Seeing “Wicked” with my dad was extra special! I’ve loved the show’s soundtrack for a couple of years now, so this opportunity made it full circle. —*Marcella Borgenicht*

I brought my kids last night and they LOVED it. First baseball game for both of them. And they immediately begged to go back every day! —*Parisa Sahay*

Did you know that the home team is 7-0 in games that Making Headway families attended?

- **Aug. 26: The Mets win 7-6 on a game winning, 9th inning hit by Pete Alonso.**
- **Sept. 21: The Yankees crush the Pirates 14-2**
- **Sept. 28: The Mets win 5-4 thanks to an extra-inning, game-winning hit.**
- **Oct. 5: The Mets win 9-2 in their regular season finale.**
- **Oct. 17: The Yankees beat the Guardians to advance to the next round of the playoffs.**
- **Oct. 22: The Devils win 2-1 as Dawson Mercer scores the game-winning goal.**
- **Nov. 10: The Devils win 4-3, scoring with 33 seconds left in overtime.**

KARAOKE IN MEMORY OF ANDY AND JAKE



[Top image] Making Headway Board Member Susan Rubin (left) with a group of her son Andy Ecker’s Michigan friends singing the Michigan fight song.
[Bottom image] Left to right: Dan Lipka; Michele Mirman (Bear Givers President); Joe Sprung (Bear Givers Founder); Elisa, Clint, and Augusta Greenbaum.

It was an offer too good to refuse! Thank you, Bear Givers, and to its president Michel Mirman, and its founder Joe Sprung, for underwriting the Eat, Drink, & Karaoke Fundraiser at Sid Gold’s Request Room in New York City on November 3. What a night it was! The food was delicious and plentiful, the open bar drinks flowed, and the singing was—well, enthusiastic.

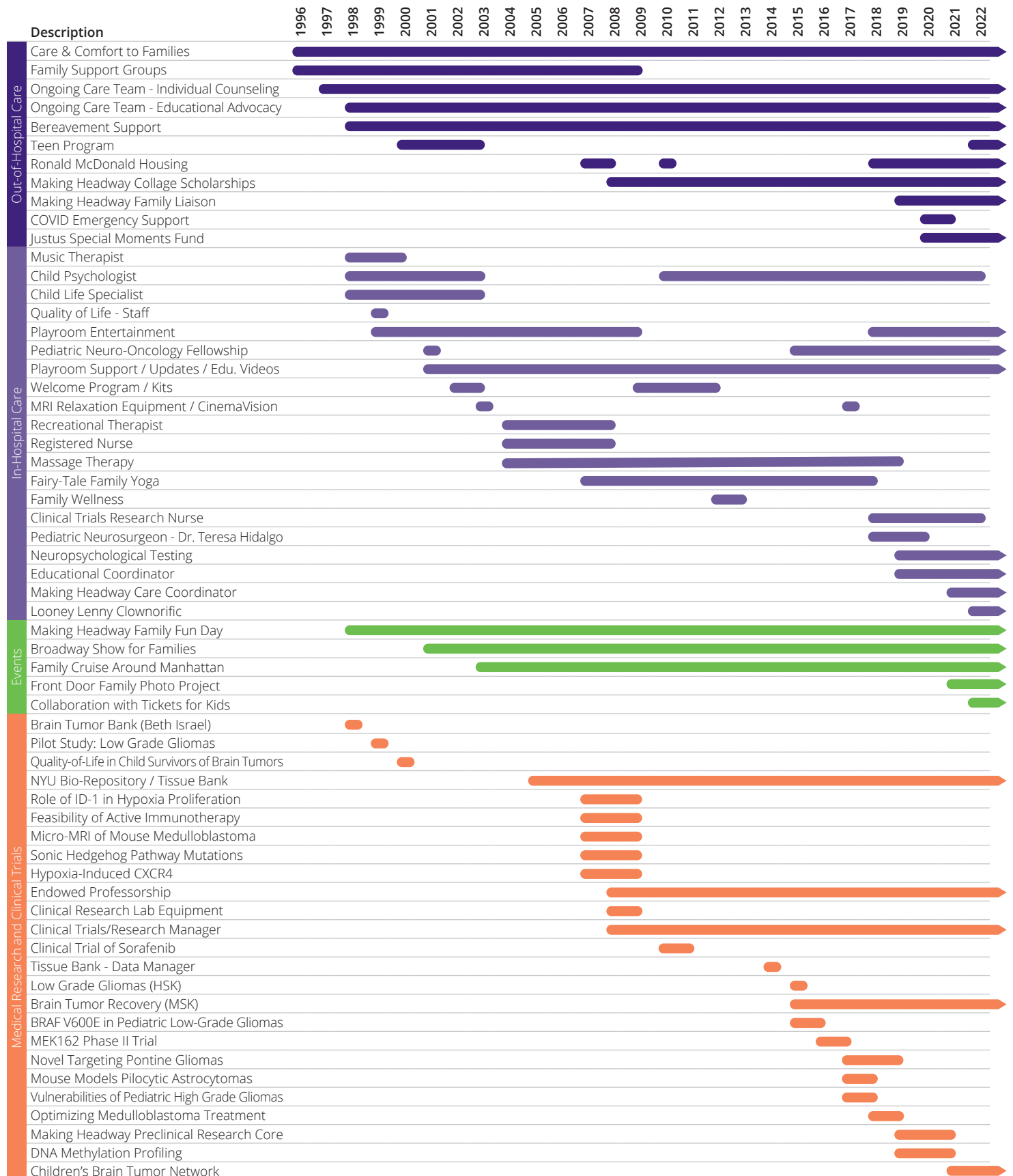
The event was in celebration and in memory of the lives of Andy Ecker and Jake Greenbaum.

Andy would be beaming knowing his friends were proudly singing the Michigan fight song in his honor. Andy sadly lost his brave fight against brain cancer in July 2015. Besides being a Michigan fan, he was a mathematical genius, a board game champion, a welcoming and loyal friend, a loving big brother, an amazing son, and an all-around remarkable man. Appropriately, given the event, Andy knew all the words to every song in the “Pitch Perfect” movie.

Although Jake literally couldn’t sing (or talk), because of a brain tumor diagnosed at 3 months old, he, too, would have loved to have been at the event. He would have given all the karaoke singers his trademark standing ovations and shrieks of joy! Jake was a brain tumor survivor for 30 years, but another aggressive cancer took his life in August 2020.

Thank you to everyone who bought tickets, those who sang, and those who couldn’t attend but still donated. Overall, the evening raised \$57,000, with 100% of proceeds supporting Making Headway Foundation and its mission to help children with brain or spinal cord tumors. The event proved that despite the horrific nature of the disease of pediatric brain and spinal cord tumors, those touched by it can still find solace by celebrating those who have survived, those who have passed, and those who are currently fighting the battle by singing “I Will Survive.”

26 YEAR TIMELINE OF MAKING HEADWAY



MAKING HEADWAY ACCOMPLISHMENTS: BY THE NUMBERS

Over the past 26 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
2,100
families

8,150+
hours of educational
advocacy services

13,000+
hours of individual
and family counseling

134
college scholarships

More than
67
events for families

Invested over
\$27m
in grants, services, programs,
and events for families impacted
by a childhood brain or spinal
cord tumor

Over
63
published research papers as a
direct result of our grants

81,000+
donations, from more than
25,500
unique households

9
pediatric Neuro-Oncology
fellowships fully funded

Funded over
155
supporting research and
quality-of-life programs
at local hospitals

Assisted families from
10
major children's
hospitals

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

Financial support for over
165
funerals

A LETTER FROM OUR **EXECUTIVE DIRECTOR**



The mission of Making Headway Foundation can only truly be achieved when we work in partnership with the children and


families we serve. For the vast majority of our history, this was done face-to-face, at NYU Hassenfeld, or at one of our many events. After more than two years away, due to the pandemic, I was so relieved to finally see everyone again at Family Fun Day 2022. This was our first in-person event since 2019, and it renewed the commitment that Making Headway makes to every family we work with. Other recent events, including our teen and young adult activities and professional baseball games, also served to provide our families with a greater sense of community and support. There is nothing like talking to someone face-to-face to truly understand their unique needs, circumstances, and perspective.

Making Headway certainly learned from the challenges families faced during COVID-19, but we are all so grateful to return to the in-person programs and services that are critical to so many. Time with these families is not only precious but completely necessary for our work.

Since I joined Making Headway Foundation in 2016, I have had to redefine my perceptions of time. It is only through the experiences families have shared with me, about the short period of time after a family learns their child has a brain or spinal cord tumor, that I understand how a single day can change your life and can seem to last forever. The questions each family faces, the trauma they endure, and the life-changing decisions they have to make—often within 24 hours—are overwhelming. Then there are the inevitable and unbearably vague timeframes, such as “6-12 months to live,” “18-24 months of rehabilitation,” or perhaps “a lifetime of challenges.”

Within this world, there are also single moments of time, occasionally joyous, but often profoundly tragic. At Making Headway, I have learned to treasure any positive and beautiful moments the world gives us and use them to remain strong when things look their darkest. We can all learn from our experiences, and I have learned to treat time as the world's most precious commodity. Like anything else, it can be treasured or it can be wasted. At Making Headway, we revere time, appreciate and understand it, and aim to help our families cherish every moment like it was their last—because, sadly, sometimes it is. Making Headway Foundation is dedicated to providing every child with individualized care and love. With your continued support, we will make every year, month, day, and minute count.

Daniel Lipka, Executive Director



TEEN AND YOUNG ADULT SURVIVOR PROGRAM

“I don’t know any other survivors,” was the poignant comment of one former Making Headway college scholarship winner. She first came to know Making Headway 15 years ago, when she was five years old and newly diagnosed with an Oligodendroglioma tumor. Now she is a college senior and, like most pediatric

brain tumor survivors, still experiences ongoing stress relating to her childhood illness. Her story confirmed what Making Headway found in a recent family survey: teenage and young adult brain tumor survivors often feel isolated and are eager to connect with others who have had similar experiences.

Based on this need, Making Headway worked with several young adult volunteers to design a social program for this upcoming summer. We’re pleased to announce that the first Making Headway teen and young adult event will be this summer at the Manhattan Dave & Buster’s (Times Square). This event is

limited to survivors of a brain or spinal cord tumor, ages 17-25. Siblings within the same age group are also invited, and parents can come too, but are not required to be there. We will have a private room to get to know each other for a few hours, there will be plenty of snacks, and then anyone who wishes can enjoy playing arcade games, at no cost.

If you are interested in learning about future survivor events for teens and young adults, please contact Making Headway at 914-238-8384 or family@makingheadway.org.

CONGRATULATIONS TO MAKING HEADWAY'S SECOND ANNUAL **CARE AWARD WINNER,** DR. MARCIA GREENLEAF

Families whose child is diagnosed with a brain or spinal cord tumor often face significant stress and psychological trauma. Parents, siblings, and the diagnosed child often need professional help understanding or working through difficult and painful feelings. Experienced, expert psychological care may be just as important as medical care. Making Headway understands this, and funds free programs both in and out of the hospital for anyone in need.

Twenty-five years ago, Dr. Marcia Greenleaf became the first member of Making Headway's Ongoing Care Team. When Making Headway was just starting, Dr. Greenleaf developed our first parent support groups at a NYC synagogue, and soon after she created and led our siblings support groups. From these humble beginnings, Dr. Greenleaf was also responsible for identifying the amazing professionals who would make up the core of our Ongoing

Care Team. Dr. Greenleaf, as a very experienced professional psychologist, directly provided over 300 families with comprehensive support, helping them to manage some of the most difficult and complicated situations anyone could imagine. Dr. Greenleaf's trailblazing work created the groundwork for an expanded Ongoing Care Team that has, to date, provided over 20,000 hours of services.

Dr. Greenleaf started her career as a dancer, studying relaxation techniques & ideokinesis. In the mid-1970s, she began intensive training in the hypnotic modality which includes formal hypnosis, guided imagery, relaxation techniques, and visualization. In 1986, she was appointed Assistant Professor in the Department of Psychiatry at the Albert Einstein College of Medicine. In the medical field, she is trained to help patients and their families activate healing, improve recovery, and

find practical solutions to cope with every phase of treatment, recovery or loss. In private practice since 1988, she's developed psycho-physiological techniques and strategies to help people take control over their lives, manage severe medical conditions, resolve interpersonal conflicts, and optimize their lives. As a pioneering psychologist, working with patients that face enormous challenges, Dr. Greenleaf is a teacher and guide who offers emotional support as well as world class psychotherapy.



Dr. Greenleaf has provided over 4,000 hours of care to hundreds of Making Headway families.

Her compassionate demeanor and proactive approach have had a lifelong positive impact on every individual with whom she's worked. In sincere recognition of her four decades of helping others, and quarter century working with Making Headway, we are honored and proud to present Dr. Marcia Greenleaf with the Making Headway Care Award.

INAUGURAL MAKING HEADWAY FAMILY CARE AWARD WINNER: TRUNZ FAMILY

Making Headway is awarding our first ever Family Care Award to Greg and Jeannie Trunz and their family for their enduring commitment to helping children who have been diagnosed with a brain or spinal cord tumor.

The Trunz family has been part of our Making Headway family since 1996 when their beautiful daughter, Allison, was diagnosed, at age 3, with a large supratentorial primitive neuroectodermal tumor. After a year of treatments, the tumor metastasized

to her spine. Her family searched for answers, but came to understand that even the best treatments, ones that showed so much promise, were just not working. It was time to begin focusing on how to spend the rest of her days. On August 12, 1997, after naming in a clear voice all the people and pets she loved and singing "You Are My Sunshine" to her parents, Allison died quietly at home.

As they mourned their daughter, Greg and Jeannie considered what they could do to honor her memory. Their family chose to raise money so that other children could be helped by Making Headway, and increase awareness of this terrible disease. With the support of their family and the community, they launched the ALL-IS-ONE Tulip Festival Dinner, which they generously hosted at The Swan Club for the next 17 years. The event included not just dinner but

a silent auction, raffles, and a printed journal that took a tremendous effort to organize, year after year. Ultimately, the Trunz family raised over \$1,500,000 from over 3,000 donations; and personally and generously donated more than 100 times.

Those of us lucky enough to have known Allison will always remember her, and we thank Greg and Jeannie for being such wonderful parents and role models.



Greg and Jeannie Trunz.

INVESTING IN THE FUTURE:

MAKING HEADWAY COLLEGE SCHOLARSHIPS

The Making Headway College Scholarship class of 2022 is made up of 12 hardworking and extremely inspiring survivors of a brain or spinal cord tumor. Winners have been awarded at least \$5,000 each, to help fund their dreams of obtaining a college degree. Two awards were funded by the Scott J. Reisser Memorial Scholarship Fund established by the Reisser Family in memory of their 22-year-old son, who succumbed to a brain tumor just short of achieving his dream of college graduation. The remainder of the awards were funded through the generosity of Making Headway's donors. Since 2008, Making Headway has awarded 124 college scholarships.

NAME	SCHOOL	CAREER/MAJOR	DIAGNOSIS
Kyla Coughlin	Sacred Heart University	Undecided	Anaplastic Ependymoma at age 2
Carly DeMartino	Belmont University	Public Relations	CNS Tumor at age 10
Douglas Gonzalez	Manhattanville College	Environmental Sciences	Medulloblastoma at age 12
Rachael Kessler	New York University	Biology/Medicine	Ependymoma at age 1
Hunter Kline	Undecided	Civil Engineering	Brain tumor at age 10
Gregory Licciardi	Fordham University	Healthcare	Brain tumor at age 10
Edward McCarthy	Mount Saint Mary College	Education	Anaplastic Ependymoma at age 14
Shaelyn Ray	Coastal Carolina University	Psychology	Brain Tumor at age 17
Andrew Sussman	Farmingdale State College	Science, Technology & Society	Craniopharyngioma at age 4
Justin Tarigan	NYC College of Technology	Communications Technology	Neurofibromatosis-2 at age 13
Julia Ventura	Molloy College	Early Childhood Education	Germinoma at age 4
Matthew Yautz	Fairleigh Dickinson University	Fine Arts	Juvenile Pilocytic Astrocytoma at age 9

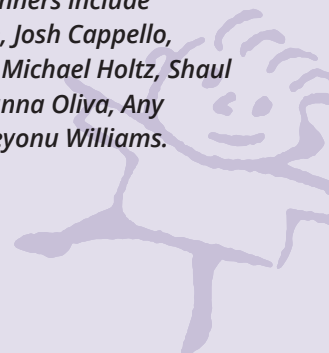


Carly DeMartino and Rachael Kessler are the fourth and fifth recipients of the annual Michael Schwartz Making Headway College Scholarship. These scholarships, \$15,000 and \$10,000 respectively, were funded from donations raised by the Schwartz family and are named in honor of their son, Michael, who is a 26-year-old survivor of brain cancer.

"I am so honored to be a recipient of the Michael Schwartz Making Headway College Scholarship. I worked very hard in High School to keep up with my education despite my diagnosis and I feel so proud that my perseverance has been acknowledged." —Carly DeMartino

"As a recipient of the Michael Schwartz College Scholarship, I feel supported by my community as I continue on in my collegiate journey. Higher education is a gift, and I am so excited to utilize this gift in order to push the boundaries of what I think is possible for myself. I am truly honored!" —Rachael Kessler

In 2022, Making Headway awarded eight additional \$1,000 college scholarships to very worthy applicants. Winners include Armani Brown, Josh Cappello, Robert Fisher, Michael Holtz, Shaul Niyazov, Adrianna Oliva, Any Saffier, and Keyonu Williams.

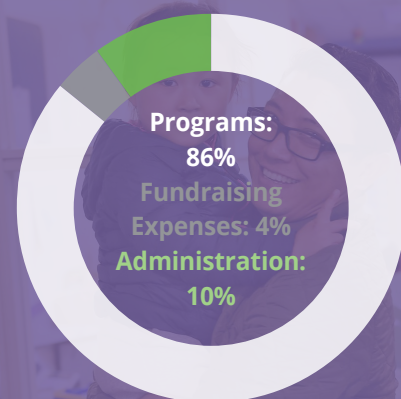


FINANCIAL SUMMARY 2022

Revenue	\$1,196,520
Winter Show	\$651,216
General Contributions	\$344,983
Trusts and Bequests	\$35,705
Grants Received	\$60,000
Other Events	\$100,277
Interest/Dividends/Other	\$4,339

Expenses	\$1,238,061
Making Headway Program and Support Staff	\$312,735
Research Grants	
Clinical Trials Manager	\$69,992
Aspects to Recovery from a Brain Tumor	\$46,637
Research Labs, CBTN, & Biorepository	\$15,000
Patient Support Programs	
Individual Counseling/Therapy	\$205,637
Making Headway Care Coordinator	\$139,546
Educational Coordinator/School Advocacy	\$96,928
Playroom / Entertainment	\$25,271
Housing / Advocacy / Joyful Moments Fund/ Other	\$7,596
Events and Other Programs	
College Scholarships	\$88,000
Family Events	\$37,925
Funeral Expenses	\$72,814
Other Expenses	
Supplies / Printing / Copying / Postage	\$27,128
Outside Services / Technology / Outreach	\$17,128
Office Rent / Insurance / Professional Fees	\$37,798
Fundraising Events & Expenses	\$37,925

Notes: Unaudited financial data as of February 1, 2023 (accrued basis).
Making Headway uses a fund balance savings account to cover any yearly deficits.



86%
of our total budget
goes directly to
programs, services, or
research.

In 2022, Making Headway had our first post-COVID public event and plan to bring them all back in 2023.

Making Headway continues to focus on critical programs and services that are overlooked by hospitals and other institutions.



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Contact

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

f MakingHeadwayFoundation
t @makingheadwayfd
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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.