



making headway
foundation

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

2018–19 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



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

About Making Headway

Since 1996, the Making Headway Foundation has been supporting families of children diagnosed with brain or spinal cord tumors. During this time, we have helped thousands of families through an unimaginably difficult time, providing a wide range of holistic programs and services. Our investments in medical research and training have been equally important, leading to new advancements in treatment and training the next generation of pediatric neuro-oncologists. In 2018-2019, Making Headway is embarking on an exciting and ambitious expansion of services and grants. We have already funded new research grants, including a cutting-edge facility called the Making Headway Preclinical Core. We are also expanding access to services to families at many additional hospitals. Making Headway will carry on with our unique work, covering a continuum of services that focus on both research and quality of life for children and their families. We will always be there for families impacted by pediatric brain and spinal cord tumors, whatever they need, for as long as it takes.

2018 Highlights

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Letter from our Chairman & Founder

Looking back 22 years ago, when Maya, Clint, and I established the Making Headway Foundation, we did not have a great deal of experience as to how to make it a success. But with hard work, the support of friends, and some good advice from Dr. Jeffrey Allen, we were able to raise enough funds to begin implementation of our mission of Care, Comfort, and Cure. At first, we focused on the care and comfort aspect, which was not a core focus of medical facilities at the time. Making Headway engaged expert professionals to provide much needed psychological help for parents and educational guidance for surviving children. Over the years, we have expanded the quantity and quality of our services and have made them available to thousands of families going through what may be the most difficult journey of their lives.

More recently, we have devoted significant resources to the third aspect of our mission: Cure. While progress in the area of research comes in small incremental steps, they form the basis for further progress toward new treatments and eventually a viable cure.

To all our friends and families, I give my heartfelt thanks. Without your gifts, we would never have made the progress we have achieved so far. I am confident that with your ongoing support, our dedicated Board and office staff will continue to lead the Foundation to provide more services to families and children and fund promising research initiatives.

A handwritten signature in black ink that reads "Edward P. Manley".





Making Headway Services

CARE	COMFORT	CURE
Educational Assistance	In-hospital Programs	Preclinical Core Research Center
Individual Counseling	Family Events	Clinical Trials Manager and Nurse
Ongoing Care Team & Family Liaison	Therapeutic Massage	Tissue Biorepository Center
College Scholarship Fund	Respite Program	Neuro-oncology Fellowship Program
Bereavement	Hassenfeld Playroom Improvements	Psychological Protocol Research

Making Headway was founded more than two decades ago on the conviction that when a child is diagnosed with a brain or spinal cord tumor, the best medical care can only do so much. Making Headway Foundation's unique approach funds

stress-reducing programs and services for children and family members at local hospitals, and psycho-social, educational, and caregiving services to help families address the numerous struggles that almost inevitably follow. Constantly re-evaluating and expanding

our work, we have also become more involved in advocacy, invested in innovative research, and expanded our Ongoing Care Programs to hospitals across the region.

Childhood Brain Tumor Facts

In 2019, nearly 4,000 children under the age of 15 are expected to be diagnosed with brain or spinal cord tumors, collectively known as Central Nervous System (CNS) tumors. Tumors may be benign (non-cancerous) or malignant (cancerous). Benign tumors grow and press on nearby areas of the brain or spine, but rarely spread into other tissue. Malignant tumors, on the other hand, are likely to grow quickly and spread. Either way, tumors directly affect a child's physical, psychological, emotional, and cognitive health. Unfortunately, the best current treatments often have side effects that make things even worse.

Pediatric brain tumors are fundamentally different from those found in adults. In adults, the majority of brain tumors are secondary to other types of cancer, such as cancers which originally arose in the lung, colon, breast or skin. Childhood brain tumors also arise in different areas of the brain than adult brain tumors, such as the posterior fossa, which contains the brain stem and cerebellum.

While many children diagnosed with a CNS tumor will live, the fatality rate from malignant CNS tumors has remained steady in recent years, and 1 in 4 of these children will die. In fact, more children die from CNS cancer than any other disease or condition, including many that are much more well-known and researched, such as leukemia and asthma.

Those that do survive face numerous challenges. As a result of both the tumor itself, and its treatment, most children experience one or more forms of physical, mental, behavioral or psychological impairment. They may have physical disabilities such as diminished motor control or

hearing loss. They may have cognitive difficulties affecting their attention, working memory, executive functioning, processing speed and more. Their social and emotional health may also be negatively affected.

In recent years, scientists have identified over 100 different types of pediatric brain and spinal cord tumors. Researchers are using this data, combined with breakthroughs in DNA analysis, to better understand the causes of these tumors. The complexity of developing new treatments and finding cures is greater than we ever expected. Although progress is very slow, there have been some advances in recent years. Researchers have found some changes in genes, chromosomes, and proteins inside brain tumor cells that can be used to help predict a child's outlook (prognosis) or help guide treatment. Recent advances have made surgery for brain tumors much safer and more successful, including magnetic resonance spectroscopy (MRS), diffusion tensor imaging (DTI), and fluorescence guided surgery. Other treatment strategies are also promising, including adjuvant chemotherapy, stem cell transplants, targeted drugs, angiogenesis inhibitors, and immunotherapy.

Making Headway was founded to provide diverse and needed assistance to families impacted by pediatric CNS tumors. We address the real-life ongoing needs of the child, while investing in collaborative research projects designed to find new treatments. Each child diagnosed with a brain or spinal cord tumor is a reminder of our mission, and inspires us to develop and expand our work every day.

More children will die from brain and spinal cord tumors than from any other disease.

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**This is why Making
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"Susan was able to advocate for Gracie, and help build a program that allowed her to stay in the school system that she was accustomed to. She has been such a wonderful advocate for us; she's made it possible for Grace to be the best that she can be."
— Cindy Sturm



Credit: Todd Shopera Photography

"[Making Headway] provided us support before we even realized we needed it...we're forever grateful."
— Renee Ravello



"Making Headway fills a void in brain tumor care that would otherwise go unfilled."
— Michael Katz

Care

Families of children who have experienced brain or spinal cord tumors face many challenges. With nowhere to turn for help, they are often left to cope for themselves. Making Headway Foundation funds caring professionals who provide free-of-charge services to support families from the start of their ordeal, often until long after the hospital stay has ended.

Educational Assistance

Most children who undergo surgery, chemotherapy, or radiation experience learning and other related disabilities. To compound matters, they are likely to have fallen behind in school during treatment, and may have difficulty adjusting socially. While families often expect their child will return to school and all will be the way it was, this is almost never the case. Many children are unable to keep up with their peers, struggle academically, and may experience rejection and social isolation. Teachers and administrators are often unprepared to address the child's cognitive and social deficits. Parents may not be fully aware of their child's rights under federal law, or understand how best to advocate for their child.

Making Headway Foundation offers families the services of trained, experienced educational specialists. These specialists work side by side with families, often for years, to:

- Advocate for the child
- Assist the family and school in identifying appropriate support and accommodations
- Ensure the school provides these services, as required by law

Since our founding, Making Headway education specialists have provided hundreds of children with thousands of hours of educational counseling and advocacy—often lasting throughout the child's educational career—to help them succeed in school.

Individual Counseling

A child's serious illness is an intensely personal experience for every member of the family. Both children and parents need help understanding or working through overwhelming and painful feelings. Some have a hard time finding the language to articulate their feelings or concerns. Different reactions and ways of coping may strain family and marital relations. Often, experienced, expert psychological care becomes just as important as medical care.

Making Headway Foundation offers free-of-charge individual counseling sessions for anyone in need, including the sick child, parents, and siblings. Sessions are conducted in person or by phone, with licensed psychologists and psychiatrists who are specialists in dealing with the unique issues families in this situation face.

College Scholarship Program

Making Headway provides funding for a scholarship program that helps brain tumor survivors achieve their college dreams. This program, which started with two scholarships in 2008, has grown over the years, providing over 70 scholarships—totaling more than \$350,000—to date. In 2018, the program was expanded, and 14 deserving young brain tumor survivors received scholarships. This program provides much needed financial assistance and winners have expressed the positive impact it has had on their lives and careers.

Ongoing Care Team & Family Liaison

Making Headway's team of psychiatrists, psychologists, education specialists and other professionals are experts in the specific sorts of challenges faced by children with brain and spinal cord tumors and their families. Along with our family liaison, they provide ongoing, often long-term support for families for whom the hospital experience is just the beginning.



Comfort

While Making Headway provides care and services to children throughout the New York tri-state area, we have a long-standing relationship with the Hassenfeld Children's Center at NYU Langone Medical Center. Most children treated at Hassenfeld have an initial stay at the hospital, then return dozens of times for treatments, procedures, therapy, and evaluations. We make these visits more comfortable, and allay anxiety, by funding enhanced staffing, supplies, and special services in the Playroom. Beyond the hospital, we offer a trio of beloved, free-of-charge annual events for families we've worked with—many of whom continue to attend, year after year.

Family Events

For children with a brain or spinal cord tumor—and for their parents and siblings—everyday life can be stressful, scary, and painful. Each year, Making Headway hosts a round of special events just so these children and their families can take some time off from their day-to-day trials, have fun like any other family, and meet others who share their experience. Our three biggest annual events generally include:

- **Family Fun Day** A summer party featuring games, activities, music and delicious food. In 2018, families were delighted with our newest venue, the Bronx Zoo.
- **Yacht Cruise** Each fall, Making Headway invites all the families we have worked with to enjoy a free yacht cruise around Manhattan. Guests are treated to lunch, games, and entertainment as they sail around New York City's iconic harbor.
- **Winter/Spring Show** Each year, children and their families join us for a special theatrical event on Broadway. In 2018, we featured *Air Play*, an exhilarating acrobatic performance that left the audience of nearly 500 on the edge of their seats.

Therapeutic Massage

Massage therapy promotes healing, reducing muscle tension, stimulating circulation, lessening joint pain, and increasing mobility. It can also reduce anxiety and stress, provide an improved sense of well-being, and even enhance self-esteem. Making Headway is proud to fund this innovative and proven approach to wellness. Children and their family members can enjoy the benefits of a relaxing, therapeutic massage while visiting the Hassenfeld Children's Center.

Respite

For the long-term well-being of a family, parents need to be able to relax and spend time with each other. But the parents of a seriously ill child are often left with little or no time to care for themselves. To complicate matters, many families served by Making Headway can't afford additional child care, or can't find care that meets their child's medical needs. Our new respite program coordinates and pays for highly trained and vetted nurses, home health aides, or babysitters to provide in-home care several times a year, so parents can take the time to meet their own needs or those of their family.

Hassenfeld Playroom

A hospital can be a scary place for a child, but the playroom at Hassenfeld Children's Center goes a long way toward making children, their parents, and siblings feel safe and comfortable. On any given day, children of all ages and backgrounds can be found there, happily absorbed in arts and crafts activities or play, munching on delicious, healthy snacks. Professional entertainers and child therapists are on hand, as well—all supported by funding from Making Headway.

Cure

Making Headway is dedicated to improving long-term treatments for children diagnosed with a brain or spinal cord tumor. Due to the overwhelming complexity of this

disease, we have taken a multi-pronged approach to achieving this goal. We're funding cutting edge research facilities and world-class research projects, maintaining a unique biorepository for brain tumor tissue, providing the means for staffing more clinical trials,

funding pediatric neuro-oncology fellowships and more. From developing expertise to facilitating research to promoting clinical trials, Making Headway is focused on improving the lives of young patients today and in the future.



Developing Expertise and Supporting Core Research

The next new treatment, or even cure, for children with pediatric brain or spinal cord tumors will be developed by talented doctors who are completely committed to this cause. For seven straight years the Making Headway Neuro-oncology Fellowship

program has helped develop the next generation of talented young doctors and scientists. In addition, Making Headway is currently funding several technically ambitious and creative projects at NYU Langone Medical Center, Memorial Sloan

Kettering, and Harvard School of Public Health. It might take one year or it might take twenty, but Making Headway is dedicated to creating the infrastructure and programs that are essential for finding a cure.



Facilitating Research: The Making Headway Preclinical Core

This newly created research lab will address one of the fundamental challenges that researchers face. The most common brain tumors to develop in children are low-grade gliomas. However, historically this type of tumor has been difficult to grow on animal models, a process which is essential for some of the initial testing

of new drugs and treatments. The new lab will use state-of-the-art techniques to develop a fundamentally new type of model, patient-derived xenografts (PDX), in which the tissue or cells from a patient's tumor are implanted into specialized mice. The lab will endeavor to develop viable PDX models for every type of pediatric CNS tumor,

with a particular focus on low-grade gliomas. Researchers from around the world could then access these models to test new drugs in a way that is currently impossible. Making Headway's initial investments are expected to create a financially self-sustainable facility within three years.



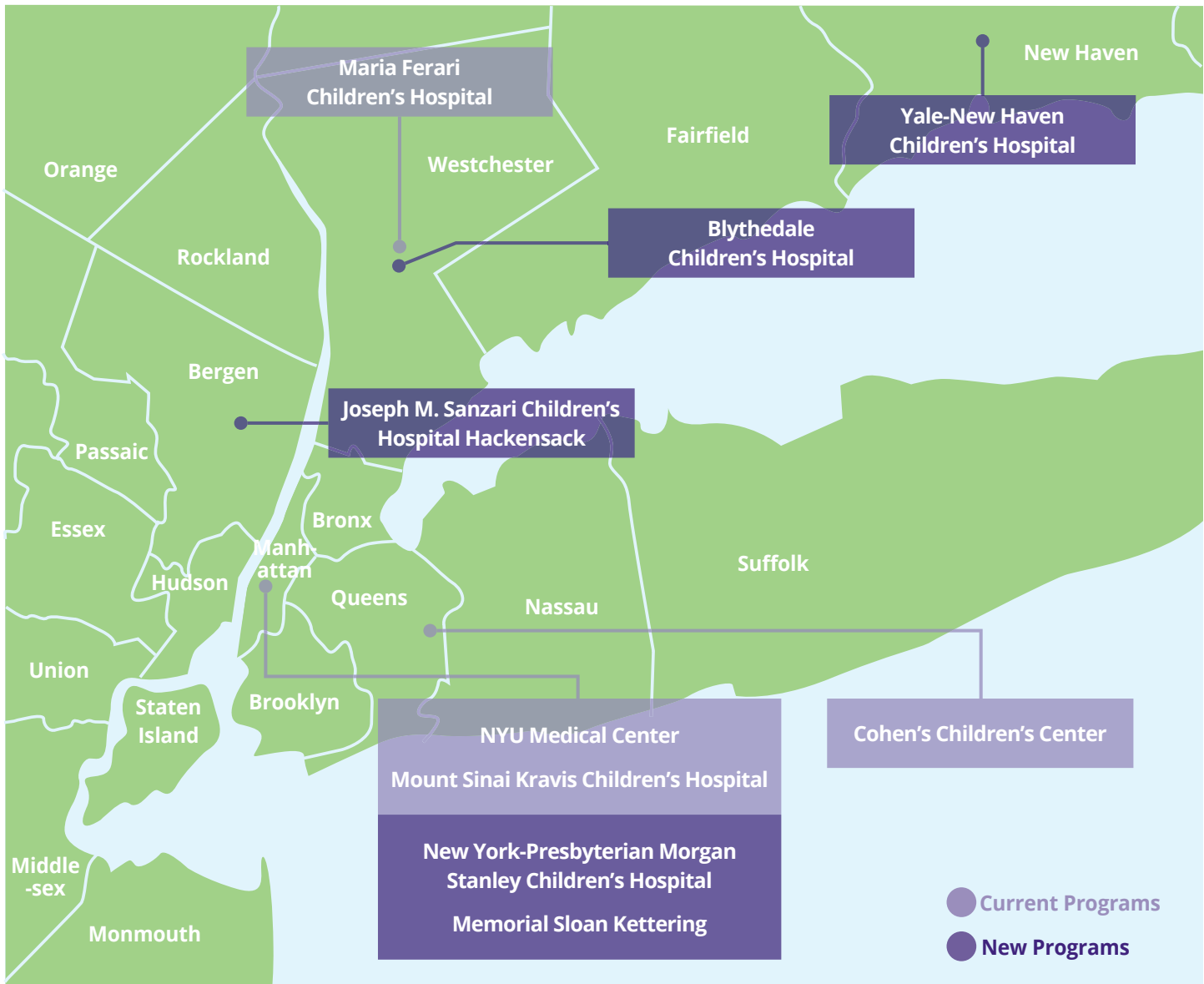
Promoting Translational Clinical Trials

Every year, hundreds of potentially effective new treatments for pediatric brain and spinal cord tumors are ready to be tested on children. Due to the relative rarity of childhood cancer in any one location, clinical trials are often conducted simultaneously by dozens of medical institutions around

the country. At the NYU Langone Medical Center, children have the potential to be enrolled in dozens of different clinical trials, depending on their specific type of tumor. With the help of grants from Making Headway, NYU will retain a clinical trials manager and create the much-needed position

of clinical trials nurse. This will enable children in need to participate in over 40 different clinical trials. Each has the potential to save a child's life, improve quality-of-life, and contribute substantially to the worldwide search for a cure.

Plans for Expansion



In 2018, Making Headway embarked on a pilot program to expand some of our programs to three new hospitals. Based on the success of the pilot, we are now undertaking a bold and ambitious plan to provide services to every children's hospital in the New York metropolitan area. Our goal is simple: we want to help more families. Over the past year, Making Headway has visited each of these hospitals and has developed partnerships to provide access to new services. Each hospital has its own unique style and structure, but we all share the same desire to help families as much as possible.

Through this expansion, children and their families across the New York City region will gain access to our Ongoing Care Team of psychologists, psychiatrists, educational advocates, and family liaisons. Additionally, families in these hospitals can attend Making Headway events, apply for our college scholarship program, and receive bereavement services. These programs were specifically chosen because they address a significant need and have a proven success helping families. Our Ongoing Care Team understands the various and complex physical, psychological, and

educational needs of children with cancer, and provides the highest quality of personalized care.

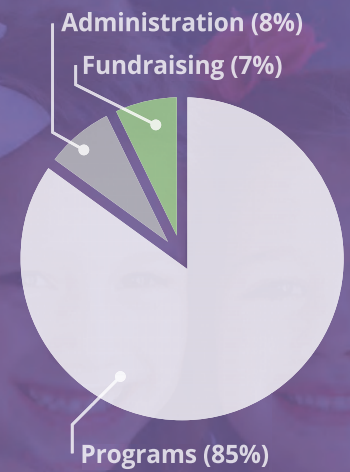
Any local child with a brain or spinal cord tumor is eligible for these services, as are their parents and siblings. There is no limit to how many services families can use or how long they use them. And they will never receive a bill; Making Headway pays for everything. In short, Making Headway will be there for these families, as we have always been for the families we now serve—whatever they need, for as long as it takes.

Financial Summary

Revenue	\$1,352,884
Winter Show	\$531,188
General Contributions	\$263,644
Trusts and Bequests	\$256,215
Other Events	\$116,790
Race for Ace	\$90,872
Grants Received	\$71,500
Interest/Dividends/Other	\$22,675

Expenses	\$1,670,911
Staff and Taxes	\$251,752
Research Grants	
Pediatric Neurosurgeon	\$218,400
Research Labs and Biorepository	\$192,689
Clinical Trials Manager and Nurse	\$148,308
Research Projects	\$124,010
Pediatric Neuro-oncology Fellowship	\$113,295
Patient Support	
Neuro-Psychology Testing	\$138,606
Massage Therapy / Playroom	\$78,278
Housing / Advocacy / Other	\$12,882
Out-of-Hospital Programs	
Individual Counseling/Therapy	\$53,357
Educational Counseling/Advocacy	\$27,326
Events and Other Programs	
College Scholarships	\$70,000
Family Events	\$60,005
Funeral Expenses	\$22,516
Other Expenses	
Rent / Insurance / Professional Fees	\$50,374
Outside Services / Technology / Outreach	\$45,956
Supplies / Printing / Copying / Postage	\$34,516
Fundraising Events	\$28,641

Notes: Unaudited financial data as of February 1, 2019 (accrued basis).
Making Headway uses a fund balance savings account to cover any yearly deficits.



85%

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

Revenue and spending increased in 2018, making it our most productive year yet.

Making Headway received the highest level awards, from both Guidestar.org and GreatNonProfits.org, for six consecutive years.

Over 90%

of our revenue comes from individual donors.

Credit: Todd Shapera Photography





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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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Contact

Making Headway Foundation
115 King Street, Chappaqua, NY 10514
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info@makingheadway.org
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Making Headway services are available to all pediatric brain and spinal cord tumor patients and their families throughout the NY/NJ/CT tri-state area.

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

