

SPECIAL POINTS OF INTEREST

- Care & Comfort at the Hospital
- Ongoing Care
- Advance to a Cure
- Benefits of Our Services

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

A MESSAGE FROM OUR CHAIRMAN & FOUNDER

Dear Friends and Supporters,

Making Headway is proud to share this annual report with you.

Nearly twenty years ago, after each of us had come to understand firsthand the trauma of having a child with a brain tumor, my wife, Maya, Clint Greenbaum and I made the momentous decision to establish the Making Headway Foundation and devote the rest of our lives to helping other families in similar situations. Our goal was to put something in place that would deliver services to families living through a uniquely devastating experience, as well as to grow and expand research.

For over nineteen years, Making Headway has been doing just that. It has been an act of love, every step of the way.

Making Headway Foundation has raised over 19 million dollars since its inception. It has provided services to thousands of family members and supported research being conducted both locally and around the world. But that's only part of the impact it has had.

When we founded Making Headway, it was in part because we found something lacking in the medical system. Today, while the foundation continues to support families with an array of in-hospital and ongoing care services, the organization is no longer completely alone in this. The work Making Headway undertook nearly two decades ago has created a paradigm shift; many hospitals now see their role much more holistically, providing services that go far beyond medical treatments.

Making Headway has always looked not only to the present but to the future, as well. Over the years it has deliberately built up a strong infrastructure. The staff now includes Executive Director Catherine Lepone, who has taken over some of my duties in running the day-to-day operations. Catherine has a hands-on approach to not just maintaining the organization but growing it: developing partnerships with other public and private organizations; supporting community- and family-based fundraisers; building a powerful presence on social media and more. Linda Mudford-Lewis, long-time Office Administrator, aided by a new accounting software, is taking over the daily bookkeeping duties. The Foundation has also been gradually expanding its Board of Directors and Medical Advisory Board.

In short, I am confident that we are positioning ourselves to have a strong future, and that Making Headway Foundation will continue to fulfill its mission for many long years to come.

Edward P. Manley

Edward P. Manley Chairman & Founder



"Inspiring work.
Way to go and keep it up! It certainly is life-changing."



"My brother was diagnosed with brain cancer 11 years ago and Making Headway Foundation has been there to support us through the good times and bad. Making Headway does a great job lifting the spirits of those families going through such difficult times."





"Camp friends encouraged us to contact Making **Headway Foundation** and we are so glad we did! My son was given the opportunity to cruise around the Statue of Liberty while socializing with peers and making new friends. His journey has taken us on a rocky road but Making Headway provided one of those remarkable rest areas along this path that helps put everything else into perspective. We are so thankful."



MISSION, HISTORY, PROGRAMS AND SERVICES

When a child is diagnosed with a brain or spinal cord tumor, the whole family needs a special kind of care and support. Making Headway Foundation was created in response to this compelling need. Our humanistic programs support children and their families from diagnosis through treatment and beyond.

Making Headway Foundation was established in 1996 by a small group of parents— Maya and Edward Manley and Clint Greenbaum—whose own children had undergone treatment for brain tumors. They found that traditional hospital-based medical programs failed to provide essential humanistic services that enabled a child to reintegrate physically and emotionally with his or her family, school and peer groups. The founders of Making Headway wished to provide other families with what they had found wanting—even with the finest medical care.

Care and Comfort at the Hospital

While in treatment at the Stephen D. Hassenfeld Children's Center for Cancer and Blood Disorders at NYU Langone Medical Center, children from infancy through adolescence, as well as their siblings, parents and other family members, benefit from entertainment, support, snacks, and services that help alleviate pain, fear and anxiety. These services are provided, in part, by Making Headway, and incorporate several clinic staff positions—including a massage therapist and yoga instructor—funded entirely by the foundation.

Ongoing Care

An illness in the family is an intensely personal experience for all involved. Some people need help understanding or working through difficult and painful feelings. Others have a hard time even finding the language to articulate their emotions and concerns. A child's illness can lead to family or marital stress, as roles shift and expand. Children returning from the hospital may face whole new questions around next steps for education and care.

Making Headway provides free-of-charge individual and family counseling, educational consultants who help patients return to school, scholarships, bereavement counseling and assistance with funeral expenses.

With this unique combination of program services, families can get the help they need to move forward.



LONG TERM BENEFITS OF HOSPITAL-BASED AND ONGOING CARE PROGRAMS



Now that Making Headway has been in existence for 19 years, the potential long-term effects of our services have become increasingly apparent:

- Children receiving treatment have more positive experiences that may increase their morale and fortify their will to live—thereby potentially increasing survival rates.
- The positive atmosphere of the Playroom supports all family members who must wait at the hospital during doctor visits and treatment, making it more likely that appointments are kept and treatments can be successful.
- Support for siblings and parents as well as extended family members can help make family life more cohesive and stable, thereby potentially reducing divorce rates for parents and behavioral problems for other children in the family.
- Making Headway's educational consultation services ensure that children have the best possible chance to complete their education and become responsible adults who have the ability to work and hold a job, making them less likely to need public assistance and other support going forward.
- Survivors of a brain or spinal cord tumor have the opportunity to apply for one of four scholarships offered each year by Making Headway and the Scott J. Reisser Memorial Scholarship Fund. These scholarships have enabled survivors to earn college degrees, often in fields that involve the care and treatment of patients just like them, thus perpetuating the cycle of care.
- Many patient families describe the services received from Making Headway Foundation as "life changing".

Advance to a Cure

About 3,000 children are diagnosed with a brain tumor each year. Current conventional treatments such as surgery, chemotherapy and radiation therapy do not always have favorable outcomes: brain tumors are the leading cause of solid tumor-related deaths in children. In order to have a significant impact on this devastating disease, additional research is necessary.

Making Headway has committed \$1,000,000 to a new Neuro-Oncology Laboratory at NYU, and we are continuing to consider funding for new pediatric cancer research projects proposed for this and other labs.



"I hope this nonprofit is around for many, many years to come. Dedication like this is rare, but the big hearts on board are even harder to find."



"Our 3 year old daughter looked forward to her weekly treatment visits because of all the activities that Making Headway supports at her oncology clinic. Their arms stretch out not only to the patient by the entire family...knowing that cancer affects the patient, siblings and family as a whole."



"Making Headway funds the most wonderful programs at our clinic, which make my son's visits to his oncologist a treat to look forward to, rather than a chore to endure. Making Headway, the people who run it and the programs it funds are warm, friendly and supportive during a time of great need for pediatric cancer patients and their families."



2014 PROGRAM AND RESEARCH EXPENDITURES

2014 Expenditures on In-Hospital Programs

Making Headway funded \$194,701 to support our hospital-based programs. The programs, which provide positive experiences for children and their families visiting NYU Langone Medical Center on clinic days, include massage, yoga, arts and crafts, healthy snacks and entertainment. Some young patients have been overheard to say that they don't want to go home after treatment because they are enjoying their activities so much.



2014 Expenditures on Ongoing Care Services

Our ongoing care services reach patients in the tri-state area regardless of where they are treated. Making Headway provides individual and family counseling to all members of the patient's family. Educational consulting services ensure smooth transitions back to school--the enthusiastic college scholarship applications we receive from our older patients demonstrate how successful

these services are. Family outings such as the annual yacht cruise and New York City theatrical performance have proved to be among the highlights of our activities, giving patients and their families a break from the rigors of treatment.

The following expenditures, totaling \$244,466, provided services to hundreds of patient family members:

Individual Counseling — \$79,464
Educational Consulting — \$90,970
Family Outings — \$16,529
Funeral and Bereavement Support — \$17,747
College or Vocational Scholarships — \$39,756





2014 PROGRAM AND RESEARCH EXPENDITURES

2014 Research Grants

In 2014, Making Headway made grants totaling \$315,518 to NYU Langone Medical Center. Each award was made for a one-year period and required specific reporting on results at the conclusion of that period. In addition, Making Headway staff and board members made frequent visits to NYU in order to monitor progress and results:

GRANT #1 — Funded a one-year fellowship in Pediatric Neuro-Oncology for Dr. Harini Rao under Dr. Jeffrey Allen (NYU School of Medicine). Dr. Rao evaluated and treated a broad range of CNS tumors in children, managed neurologic complications of systemic cancer in children, participated in the conducting of clinical trials and prepared for an academic leadership career in pediatric neuro-oncology.

GRANT #2 — Provided partial funding for a full-time Clinical Trials Manager at NYU's Stephen D. Hassenfeld Children's Center for Cancer and Blood Disorders.

Grant #3 — Provided partial funding for human brain tissue banking at a Bio Repository Center at the NYU School of Medicine. The Center obtains and archives tissue samples from adult and pediatric brain tumor patients at the NYU Langone Medical Center. These samples are made available for cancer research at the medical center and other institutions at no cost or for a nominal charge.

Grant #4 — Provided partial funding of a Data Manager who established a clinical database of pediatric brain tumor samples at the Bio Repository Center funded by the above grant.



"Making Headway Foundation has been an incredible source of inspiration and strength for me over the past ten years as a cancer survivor. With an amazing staff, and vast amounts of programming, they have given my life meaning and valuesomething I thought I had lost after being diagnosed in 2003. I can't thank them enough for all they have done, and don't know where I'd be today without them."





FUNDRAISING EVENTS



Recurring Activities

Grateful families frequently want to find a way to give back to Making Headway for the support they have received. Some have created fundraising traditions that go back to the beginning of the foundation. For example, the "All-is-onE" Tulip Dinner had its 17th successful year in May, 2014. This festive evening has raised more than \$1.7 million since its inception.

Other ongoing fundraisers held in 2014 included: the Friends of Nicky Docu Memorial Golf Outing, Night at the Theater, Kicks for Cancer, A Day in the Park to Honor Holly Kensicki Lind, Sparkle for a Cause, the Brian McCabe Drive for a Cure, the Swing for a Cause Wiffle Ball Tournament and the Thomas D. Fitzgerald III Memorial Mardi Gras Night.



New in 2014

We were lucky to have several new events that added to our fundraising success in 2014. The One Life Club of Scarsdale High School was founded by Fazl Shaikh to honor his best friend, Jack Reyna, who passed away from a brain tumor in 2012. Together with classmate and brain tumor survivor, Alexis Zachem, Shaikh's club hosted a Spin-A-Thon at a local spin studio, raising more than \$11,000. This feat won them the Youth in Philanthropy Award from the Association of Fundraising Professionals' Westchester chapter.

Other events that were new last year included a young professionals' networking event; a concert featuring soprano, Lina Orfanos; a holiday party at ICD Contemporary Jewelry in Chappaqua; and the Horace Greeley Sports Teams' Walkathon (co-organized with the Pediatric Cancer Foundation).

"In 2004, when my son was diagnosed with a malignant brain tumor, my life changed forever. What also changed my life was when my doctor walked into the room saying, "I want you to meet someone" and introduced me to Maya Manley. Ten years later Making Headway is in my heart, an inspiration, a friend and a shoulder to lean on. The resources they offer are wonderful. As they try to strive to eliminate this terrible disease, I

support them and

thank God for them."

BOARD OF DIRECTORS AND GOVERNANCE

BOARD OF DIRECTORS

Edward Manley, Founder & Chairman

Maya Manley, Founder & Secretary

Clint Greenbaum, Founder & Treasurer

Elisa Greenbaum, Vice Chair

Sam Schwartz, Vice President - Research

Greg Taubin, Member at Large

David Almeida, Member at Large

Charlie McMahon, Member at Large

Governance

During the course of 2014, Making Headway Foundation's board continued to implement policies and procedures recommended and required by the federal government and charity watchdog organizations. This process began in 2012 with the retention of a nonprofit attorney who conducted a legal audit. It continues with our adherence to current "best practice" recommendations for nonprofits.

In 2014, the board created a finance and audit committee tasked with reviewing the financial policies and procedures of the foundation, meeting with auditors during the annual preparation of our financial statements and reviewing Form 990 before its distribution to the full board.

The foundation also moved from manual bookkeeping to a new software designed for nonprofit accounting.

Making Headway Foundation is now registered in 11 states, which are represented by our extensive donor database.

For the fourth straight year, we were awarded both a Top Rated Nonprofit designation as well as a Silver Participant Seal on the Guidestar Exchange.

The first pediatric brain tumor survivor to serve on our board, Charles McMahon, joined us in 2014. Mr. McMahon is a management consultant in New York City.







"Thank you for being there in our time of need. Although our son will always have residual effects from his illness (epilepsy and learning differences) we are proud to say he finished H.S and will be doing a gap year in Israel and then attending **University of Hart**ford!"



STAFF & CONTACT INFORMATION

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FIND US ONLINE

On the Web Website

http://www.makingheadway.org/

Facebook

http://www.facebook.com/makingheadwayfoundation

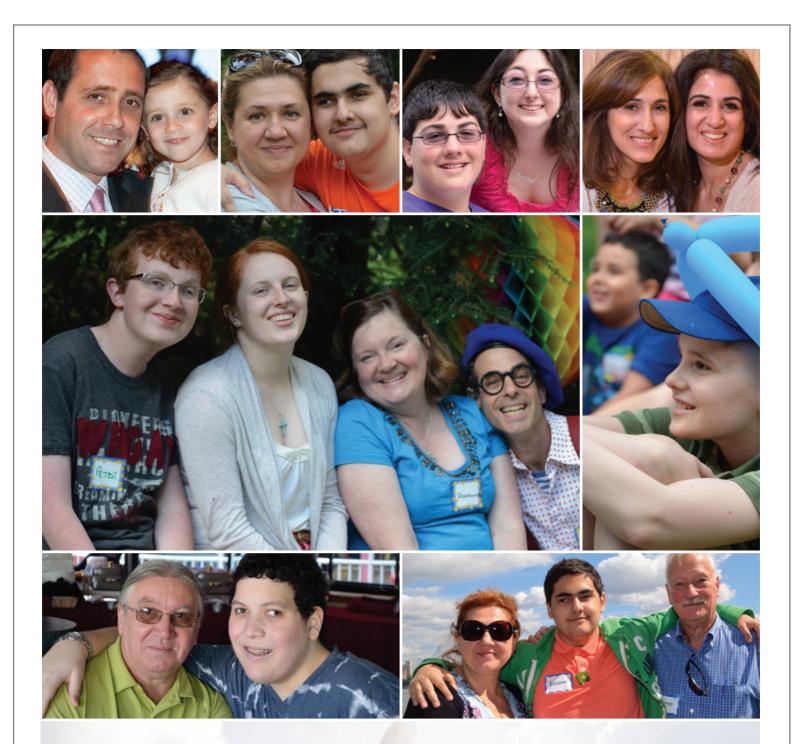
Guidestar

http://www.guidestar.org/organizations/13-3906297/making-headway-foundation.aspx

LinkedIn

https://www.linkedin.com/company/making-headway-foundation







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