



2012 Annual Report

Making Headway Foundation

President's Letter

March 1, 2013

Dear Friends and Supporters,

2012 was an exciting year for Making Headway Foundation. With the addition of a full time Director of Development, we successfully increased awareness of our Foundation across many new platforms. These included: new special events, social media, online support groups and collaboration with allied organizations. These new vehicles are allowing us to reach more patients as well as potential donors. Also, in 2012, we added a member to our Board of Directors and created a Presidential Advisory Board.

While Making Headway has traditionally focused its energies on the first two aspects of our mission: care and comfort, by funding many different programs and services to assist patient families during treatment and beyond, we have started to devote more effort to the third aspect: cure. We have found that current treatments for the children have reached their limits of effectiveness and few new treatments are forthcoming.

To this end, we made a \$1 million commitment for a new neuro-oncology laboratory at the NYU Langone Medical Center and in 2012, we made the first payment toward that pledge following the September 5th hiring of Howard A. Fine, MD, the Anne Murnick Cogan and David H. Cogan Professor of Oncology, chief of the Division of Hematology and Medical Oncology, director of the Brain Tumor Center, and deputy director of the NYU Cancer Institute. These are very exciting developments and we look forward to new and innovative findings from these new research efforts.

We are overwhelmed by the continuing generosity of all of our donors, and are most appreciative of their unwavering support and commitment.

Sincerely,

Edward P. Manley
President

Special points of interest:

- History of the Organization
- Ongoing Care Program
- Benefits of our Services
- Research
- Grants Given
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- Governance & Staff
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History of the Organization



Maya Manley visits patient child.

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 wish to provide other families with what they had found wanting—even with the finest medical care.

Ongoing Care

“Making Headway was wonderful to my son and my family when he was hospitalized for a brain tumor. They also gave us support after we went home. They still continue to provide great activities for our son - 11 years later!”

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 finding the language to articulate their feelings or concerns. A child’s illness can lead to family or marital stress as roles shift and expand.

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

With this unique combination of program services, families can get the help they need so that they can look forward to a positive future.

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, families are in need of entertainment, support, snacks, and services that alleviate the fear and pain of the children and their siblings while undergoing treatment. These children can range in age from several months old to teen-aged.

Making Headway funds several staff positions right in the Clinic setting such as a Massage Therapist, Wellness Coordinator and Yoga Instructor.

Long Term Benefits of Programs

Now that Making Headway has been in existence for 17 years, the long term effects of our services are becoming more and more apparent as we keep in touch with the families we serve on a regular basis.

- Children receiving treatment will have positive experiences that increase their morale and fortify their will to live thereby increasing survival rates;
- The positive atmosphere of the Playroom supports all family members who must wait at the hospital during doctor visits and treatment. Therefore, it is more likely that appointments are kept and treatments are more successful.
- Support for siblings and parents as well as extended family members makes family life more cohesive and stable, thereby reducing divorce rates and behavioral problems with other children in the family.
- Making Headway's Educational Consultation services ensure that the children will have the best possible chance to complete their education and become responsible adults who have the ability to work and hold a job in the future. They will be less likely to need public assistance and 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 the best chance of success to earn college degrees, often in fields that involve the care and treatment of patients just like them, thereby creating the future generation of caregivers for patients who are faced with the same illness that affected them.
- Many patient families describe the services received from Making Headway Foundation as "life changing".

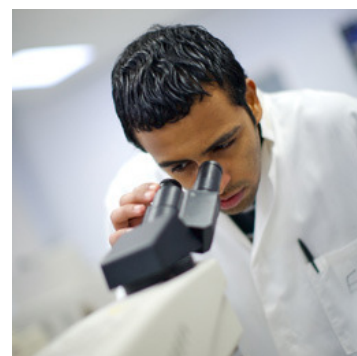


"I don't know any other organization that would go that far to make sure their clients were doing OK. In college my daughter did an internship with Making Headway, she is now a licensed Master of Social Work and Child Life Specialist due to their influence."

Advance to a Cure

About 3,000 children are diagnosed with a brain tumor each year. Brain tumors are the second leading cause of cancer-related deaths in children under age 20. In order to have a significant impact on this devastating disease in children, additional basic research into the fundamental aspects of brain tumors is necessary. Conventional treatments such as surgery, chemotherapy and radiation therapy currently used to treat brain tumors do not always have favorable prognoses.

In 2012, Making Headway made the first payment of \$250,000 toward a new neuro oncology laboratory at NYU Langone Medical Center. In addition grants were awarded for a pediatric neuro oncology fellowship, brain tissue repository and a clinical trials manager.



Grants Given



"This is not a charity - it's a family. Going through the worst time of my life, my son's tumor treatment, would have been unbearable without Making Headway... And so much is going on behind this. The fundraising for research and treatment is phenomenal. Created by and run by a beautiful and humble couple, who have gone through this with their own daughter, they have poured their lives into this very needed cause. Thank you Making Headway!"

In 2012 four grants totaling more than \$325,000 were made to NYU Langone Medical Center. Each award is made for a one year period and requires specific reports on results at the conclusion of each grant period. In addition, frequent visits to NYU are made by Making Headway Board and Staff in order to monitor progress and results.

\$75,000 — For the support of human brain tissue banking at the New York University School of Medicine. The Bio Repository Center will obtain and archive tissue samples from adult and pediatric brain tumor patients at the NYU Langone Medical Center (NYULMC). The samples will be made available for cancer research at NYULMC and other institutions at nominal or no cost.

\$97,985 — For a full time Wellness Coordinator at the Hassenfeld Children's Center. Under the direction of the Director, Dr. Linda Granowetter, he/she will oversee the recreation program, assist in coordinating all aspects of the Wellness Program and take a lead in continuing to grow the latter. The grant funds include \$4,000 for supplies and \$1,000 for professional development.

\$50,015 — The grant is for partial funding of a full time Clinical Trials Manager at the Hassenfeld Children's Center, under the supervision of Dr. Linda Granowetter, Director.

\$102,897 — The grant is for a third one-year fellowship for Genevieve Legault, MD. Under the direction of Dr. Jeffrey Allen, she evaluates and treats a broad range of CNS tumors in children, manages neurologic complications of systemic cancer in children, participates in the conduct of clinical trials and prepares for an academic leadership career in pediatric neuro-oncology.

The foundation also funded \$185,231 to support several programs that provide positive experiences for children on clinic days. This includes massage, yoga, arts and crafts, healthy snacks and entertainment. Some patient children have been overheard to say that they don't want to go home after treatment because they are enjoying their activities so much.

Program Expenditures



Aside from grants given to NYU, our programs of Ongoing Care reach patients in the tri-state area regardless of where they are treated. The following expenditures totaling \$283,152 provided services to hundreds of patient family members.

Individual Counseling — **\$107,595**

Educational Consulting — **\$73,917**

Family Outings — **\$54,142**

Funeral and Bereavement Support — **\$27,497**

College or Vocational Scholarships — **\$20,000**

Long Standing Fundraising Events

Grateful families frequently want to find a way to give back to the Foundation for the support they have received. Some of these traditions go back to the beginning of the Foundation such as the “All-is-onE” Tulip Dinner having completed its 15th year in May of 2012. This evening of festivities has raised more than \$1.7 million since its inception.

Other on-going fundraisers include the Little Bit of a Walk and Fun Run, Friends of Nicky Docu Golf Tournament, Kicks for Cancer, and the Thomas D. Fitzgerald III Memorial Mardi Gras Night.

Making Headway is so grateful for the continued support of these families who strive so hard to re-pay the kindnesses they have received by helping families who follow them in treatment and in need. It truly exemplifies how patients desire to “pay it forward” when they have benefitted from our services.

These fundraisers are the lifeblood of our program budget.



Greg and Jeannie Trunz.

Holly's Angels Gala

A highlight of 2012 was the inaugural Holly's Angels Gala which was held on June 26 at Cipriani 42nd Street in NYC. With 750 attendees, the Gala raised \$1.4 million. This dinner represented the vision of Keith Lind, whose wife passed away from a pediatric spinal cord tumor in 2011.

Moving presentations by Edward Manley, Dr. Jeffrey Allen and Keith Lind informed the audience of the Making Headway Foundation mission and moved them to donate generously throughout the evening.

Flowers and décor were provided by Louis Vellios and specialized lighting washed the walls of the main ballroom. With a keynote speech by President Bill Clinton, comedy by Seth Meyers and emcee duties performed by ESPN's Erin Andrews, the gala was a roaring success in a stunning venue.

From the attendees:

“So glad such a wonderful cause got so much support.”

“Wow! Inspirational!”

“Over the moon and over a million dollars.”

“Amazing. Truly amazing.”

Additional New Events in 2012

Several families decided to help Making Headway Foundation in 2012 with new events designed to “give back” in appreciation for services they had received.

Friends of Holly Lind (see above) conducted a Walkathon entitled, A Day in the Park to Honor Holly Lind.

Barbara Rittner and her son, Daniel Cohen, sponsored a Bowlathon to benefit programs for young adult patients.

Mike McCabe and his son, Brian, pulled out all the stops for their first golf tournament appropriately named Drive for a Cure.

These events raised tens of thousands of dollars for programs helping patient families.



MAKING HEADWAY FOUNDATION, INC.
STATEMENTS OF FINANCIAL POSITION
DECEMBER 31,

	<u>2012</u>	<u>2011</u>
<u>ASSETS</u>		
Cash and Cash Equivalents	\$ 2,876,506	\$ 2,264,202
Investments	682,803	563,172
Equipment and Software, net	2,191	3,139
Security Deposits	1,000	1,000
Promises To Give	22,842	10,733
Prepaid Expenses	<u>16,532</u>	<u>16,418</u>
TOTAL ASSETS	<u>\$ 3,601,874</u>	<u>\$ 2,858,664</u>
<u>LIABILITIES</u>		
Accounts Payable	\$ 51,448	\$ 46,182
Grants Payable	927,791	175,300
Accrued Expenses	12,224	1,096
Deferred Revenue	<u>4,975</u>	<u>5,875</u>
TOTAL LIABILITIES	<u>996,438</u>	<u>228,453</u>
<u>NET ASSETS</u>		
Unrestricted:		
Board Restricted	106,602	63,649
Other	1,426,321	1,192,332
Temporarily Restricted	<u>1,072,513</u>	<u>1,374,230</u>
TOTAL NET ASSETS	<u>2,605,436</u>	<u>2,630,211</u>
TOTAL LIABILITIES AND NET ASSETS	<u>\$ 3,601,874</u>	<u>\$ 2,858,664</u>

MAKING HEADWAY FOUNDATION, INC.
STATEMENTS OF ACTIVITIES
FOR THE YEARS ENDED DECEMBER 31,

	2012			2011				
	UNRESTRICTED	TEMPORARILY RESTRICTED	PERMANENTLY RESTRICTED	TOTAL	UNRESTRICTED	TEMPORARILY RESTRICTED	PERMANENTLY RESTRICTED	TOTAL
SUPPORT AND OTHER INCOME:								
Public Support								
Special Events	\$ 2,070,494	\$ 83,241	\$ -	\$ 2,153,735	\$ 640,349	\$ 221,215	-	\$ 861,564
Direct Benefit Costs	(388,240)	(4,309)	-	(392,549)	(34,180)	(21,022)	-	(55,202)
	1,682,254	78,932	-	1,761,186	606,169	200,193	-	806,362
Contributions	250,069	31,610	-	281,679	213,121	42,183	-	255,304
Grants	20,000	-	-	20,000	30,000	-	-	30,000
Total Support	1,952,323	110,542	-	2,062,865	849,290	242,376	-	1,091,666
Interest and Dividend Income	9,118	3,070	-	12,188	8,098	3,758	-	11,856
Unrealized Gains (Losses) on Investments	88,315	-	-	88,315	(41,383)	-	-	(41,383)
TOTAL SUPPORT AND OTHER INCOME	2,049,756	113,612	-	2,163,368	816,005	246,134	-	1,062,139
EXPENSES:								
Program	1,905,522	-	-	1,905,522	714,350	-	-	714,350
Management and General	114,374	-	-	114,374	145,926	-	-	145,926
Fund-Raising	168,247	-	-	168,247	79,893	-	-	79,893
TOTAL EXPENSES	2,188,143	-	-	2,188,143	940,169	-	-	940,169
CHANGE IN NET ASSETS BEFORE NET ASSETS RELEASED/RECLASSIFIED FROM RESTRICTIONS	(138,387)	113,612	-	(24,775)	(124,164)	246,134	-	121,970
NET ASSETS RELEASED FROM RESTRICTIONS	415,329	(415,329)	-	-	61,330	(61,330)	-	-
NET ASSETS RECLASSIFIED FROM RESTRICTIONS	-	-	-	-	-	125,612	(125,612)	-
CHANGE IN NET ASSETS	276,942	(301,717)	-	(24,775)	(62,834)	310,416	(125,612)	121,970
NET ASSETS - BEGINNING OF YEAR	1,255,981	1,374,230	-	2,630,211	1,318,815	1,063,814	125,612	2,508,241
NET ASSETS - END OF YEAR	\$ 1,532,923	\$ 1,072,513	\$ -	\$ 2,605,436	\$ 1,255,981	\$ 1,374,230	\$ -	\$ 2,630,211



Board of Directors and Governance

The Board of Directors undertook many initiatives in 2012 all designed to ensure that the Foundation was adopting all of the appropriate industry standard practices for nonprofit management.

Policies were adopted that covered such subjects as Conflicts of Interest, Whistleblower, Investment of Foundation Funds, Financial Management and Executive Compensation.

Guided by an expert non-profit attorney, the efforts of the Foundation were rewarded with a designation of the 2012 GreatNonprofits (sic) Top-Rated Award .

This Top-Rated Award also led to the receipt of the GuideStar Exchange Seal, which demonstrates our commitment to transparency.

Mr. Greg Taubin, Executive Managing Director of Studley, Inc., joined the Board in the summer of 2012. His daughter, Lily, passed away from a brain tumor when she was 5 1/2 years old. He has two other children and lives with his wife, Felicia, in Rye, NY.

Additionally, a President's Advisory Council was created in order to provide expert advice and counsel to the Foundation President.

Staff

Gunilla Asp:
"My experience with a serious illness as a child allows me to identify deeply with the children and families I meet at Hassenfeld; my training allows me to help them."

In keeping with the Board's desire to expand and prepare for future growth, it created the new full time staff position of Director of Development and hired Catherine Lepone to fill the role. Ms. Lepone had served in that capacity as a part time consultant beginning in June of 2011 and accepted the expanded responsibilities in January of 2012.

Additionally, the staff grew in the Program Department with the retention of Gunilla Asp as a full time massage therapist working directly with patients who are in treatment at the Stephen D. Hassenfeld Center for Blood and Cancer Disorders in NYC. Ms. Asp worked for ten years as a lay chaplain at Memorial Sloan-Kettering Cancer Center and became a massage therapist in 1986.

Long time staff member Linda Mudford-Lewis continues to expertly run the administrative side of the office operations. Ms. Lewis has been with the Foundation for nine years.

Contact Information



Making Headway Foundation

115 King Street
 Chappaqua, NY 10514
 914-238-8384

Edward Manley
emanley@makingheadway.org

Catherine Lepone
catherine@makingheadway.org

Linda Mudford-Lewis
linda@makingheadway.org

On the web

Website
www.makingheadway.org

Facebook
www.facebook.com/makingheadwayfoundation

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

LinkedIn
<http://www.linkedin.com/company/2325349?trk=tyah>



making headway foundation

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

