



2013 Annual Report

Making Headway Foundation

Special points of interest:

- History of the Organization
- Ongoing Care Program
- Benefits of our Services
- Research
- Grants Given
- Special Events
- Governance & Staff
- Financial Statements
- Contact information

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President's Letter

August 1, 2014

Dear Friends and Supporters,

We are delighted to share our 2013 Annual Report with you. We are sure you will enjoy reading it and seeing what a productive and rewarding time it has been for Making Headway and the families we support. All of this in spite of the trauma – the diagnosis of a brain or spinal cord tumor, and in some cases, the loss of a child – that has brought us together in the first place.

It is because of contributions from our dedicated friends and supporters that we have been able to continue our programs of assistance to these very special children and their families.

I am particularly proud of our Board of Directors which continues to grow. All Board Members are engaged, devoted and contribute generously of their time and money to our never ending work. Making Headway is in excellent hands with this dedicated governing body.

Since bringing on a full time Executive Director one year ago, we have taken our operations to the next level of efficiency and we have now received a Top Ranked Nonprofit designation from Great Nonprofits as well as a Silver Level participant seal with Guidestar. We also won a certificate of merit from the NY State Assembly and a Westchester County Certificate of Distinguished Service as the Chappaqua Millwood Chamber of Commerce's "Nonprofit of the Year".

On behalf of all the children and their families we would like to thank you for making the journey through a devastating illness and its aftermath less lonely and more bearable.

Sincerely,

Edward P. Manley
President and Board Chairman

History of the Organization



Photo by Todd Shapera

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



Photo by Todd Shapera

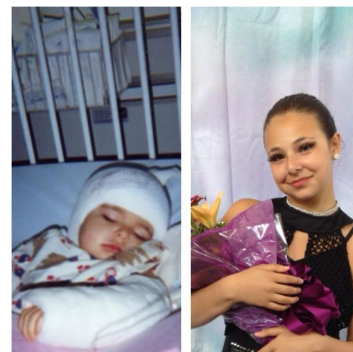
While in treatment at the Stephen D. Hassenfeld Children's Center for Cancer and Blood Disorders at NYU Langone Medical Center, families are in need of entertainment, support, snacks, and services that alleviate the fear and pain of the children and their siblings while undergoing treatment. These children 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".



"The Making Headway Foundation changes lives every day. The volunteers and professionals involved with this non-profit are caring, committed, and tops in their respective fields - seeking constantly to improve the quality of life for children with brain tumors and their families and caregivers."

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.

Making Headway has committed \$1,000,000 to a new Neuro Oncology Laboratory at NYU and continues to monitor the progress of the Lab while considering new research projects that are identified within the parameters of our funding guidelines.



Photo by Todd Shapera

Grants Given



Photo by Todd Shapera

"Making Headway is a top notch organization run by truly caring professionals. What they are able to provide to families with children with brain tumors and related cancers is remarkable. It is a unique model of care and support for families and patients. The funding they provide for research goes to the top doctors in the field that are making incredible strides."

In 2013 four grants totaling \$231,354 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.

Grant #1 — The grant is for a one-year fellowship for Diana Osoria, MD. Under the direction of Dr. Jeffrey Allen, she will evaluate and treat a broad range of CNS tumors in children, manage neurologic complications of systemic cancer in children, participate in the conduct of clinical trials and prepare for an academic leadership career in pediatric neuro-oncology.

Grant #2 — For a full time Wellness Coordinator at the Hassenfeld Children's Center. The Wellness Coordinator oversees the recreation program, assists in coordinating all aspects of the Wellness Program and takes a lead in continuing to grow the latter.

Grant #3 — The grant is for partial funding of a full time Clinical Trials Manager at the Hassenfeld Children's Center, under the supervision of Dr. William Carroll, Director.

Grant #4 — 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.

The foundation also funded \$217,027 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. Making Headway provides individual and family counseling to all members of the patient's family. Educational consulting services ensure smooth transitions back to school. Receipt of scholarship applications from our older patients lets us know how successful the educational consulting services are. Family outings such as the annual picnic, yacht cruise and theater outing prove to be the highlight of our activities giving patients and their families a break from the rigors of treatment.

The following expenditures totaling \$258,523 provided services to hundreds of patient family members.

Individual Counseling — **\$109,234**

Educational Consulting — **\$57,091**

Family Outings — **\$54,222**

Funeral and Bereavement Support — **\$17,760**

College or Vocational Scholarships — **\$20,216**

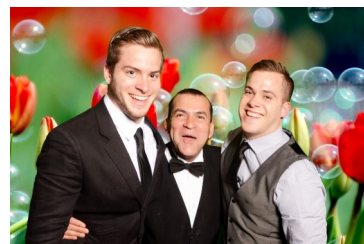
Fundraising Events

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 16th year in May of 2013. This evening of festivities has raised more than \$1.7 million since its inception.

The Friends of Nicky Docu Golf Outing continued despite the sudden passing of the event founder, Nicky’s father, Tom. To our delight, Nicky’s brother, Tommy, stepped up to the tee box and organized the tournament with the help of James O’Reilly and other long standing committee members. The legacy continues.

Other on-going fundraisers included the Little Bit of a Walk and Fun Run, Night at the Theater, Kicks for Cancer, Swing for a Cause Wiffle Ball Tournament and the Thomas D. Fitzgerald III Memorial Mardi Gras Night.

Photo by Todd Shapera



A Day in the Park to Honor Holly Kensicki Lind

Started in 2012, this walk doubled in income during 2013, raising more than \$30,000 for Making Headway Foundation. The attendees enjoyed picture perfect weather with a growing committee who participated in a 3 mile walk in honor of Holly Kensicki Lind. Holly passed away the age of 31 from a pediatric type Anaplastic Astrocytoma tumor on her spinal cord. Her friends and family wanted to find a fitting way to honor her memory and a “walk along the beach” with friends seemed ideal.

From a volunteer:

“It means so much to us to be able to honor and celebrate Holly and at the same time support an amazing cause. Thank you for all you do.”

Brian McCabe Drive for a Cure Golf Outing

The 2nd Annual Brian McCabe Drive for a Cure Golf Outing, put on by brain tumor survivor Brian McCabe and his parents Mike and Eileen, was another huge success in 2013 raising \$50,000. Brian’s family availed themselves of Making Headway’s many services during and following Brian’s treatment. This was the best way they knew to thank the organization while helping other families.



Other Fundraising Activities

2013 was a record year for new events. We were approached by a number of people who wanted to find a way to donate.

Individual fundraisers were a new addition to the fundraising mix with several people participating in endurance events who wanted to gather charity sponsors to support their efforts. One person, pictured to the right, climbed to Mount Everest base camp. Bikers, runners and walkers all joined in to help the children of Making Headway Foundation.

Other new fundraisers included Sparkle for a Cause at Crabtree’s Kittle House in Chappaqua, MTK Tavern Evening featuring a Mount Kisco based local cover band, Pre-school walkathon in New Jersey and a boutique grand opening in Chappaqua.

There are many individuals and donors who contribute during the year in honor of weddings, bar mitzvahs, bat mitzvahs, births, passings, graduations and countless other celebrations. Each is very special to those who organize it and no matter how small, Making Headway is grateful to them all.



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

	<u>2013</u>	<u>2012</u>
<u>ASSETS</u>		
Cash and Cash Equivalents	\$ 2,546,428	\$ 2,876,506
Investments	874,806	682,803
Equipment and Software, net	1,468	2,191
Security Deposits	1,000	1,000
Promises To Give	506	22,842
Prepaid Expenses	<u>15,873</u>	<u>16,532</u>
 TOTAL ASSETS	 \$ <u>3,440,081</u>	 \$ <u>3,601,874</u>
 <u>LIABILITIES</u>		
Accounts Payable	\$ 21,431	\$ 51,448
Grants Payable	697,101	927,791
Accrued Expenses	13,014	12,224
Deferred Revenue	<u>900</u>	<u>4,975</u>
 TOTAL LIABILITIES	 <u>732,446</u>	 <u>996,438</u>
 <u>NET ASSETS</u>		
Unrestricted:		
Board Restricted	186,063	106,602
Other	1,629,393	1,426,321
Temporarily Restricted	<u>892,179</u>	<u>1,072,513</u>
 TOTAL NET ASSETS	 <u>2,707,635</u>	 <u>2,605,436</u>
 TOTAL LIABILITIES AND NET ASSETS	 \$ <u>3,440,081</u>	 \$ <u>3,601,874</u>

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

	2013				2012			
	UNRESTRICTED	TEMPORARILY RESTRICTED	PERMANENTLY RESTRICTED	TOTAL	UNRESTRICTED	TEMPORARILY RESTRICTED	PERMANENTLY RESTRICTED	TOTAL
<u>SUPPORT AND OTHER INCOME:</u>								
Public Support								
Special Events	\$ 604,482	\$ 117,150	\$ -	\$ 721,632	\$ 2,070,494	\$ 83,241	-	\$ 2,153,735
Direct Benefit Costs	(30,848)	(4,244)	-	(35,092)	(388,240)	(4,309)	-	(392,549)
	573,634	112,906	-	686,540	1,682,254	78,932	-	1,761,186
Contributions	128,397	16,656	-	145,053	250,069	31,610	-	281,679
Grants	30,000	-	-	30,000	20,000	-	-	20,000
Total Support	732,031	129,562	-	861,593	1,952,323	110,542	-	2,062,865
Interest and Dividend Income	8,151	1,388	-	9,539	9,118	3,070	-	12,188
Realized Gains on Investments	11,400	-	-	11,400	-	-	-	-
Unrealized Gains on Investments	202,847	-	-	202,847	88,315	-	-	88,315
TOTAL SUPPORT AND OTHER INCOME	954,429	130,950	-	1,085,379	2,049,756	113,612	-	2,163,368
<u>EXPENSES:</u>								
Program	742,640	-	-	742,640	1,905,522	-	-	1,905,522
Management and General	125,387	-	-	125,387	114,374	-	-	114,374
Fund-Raising	115,153	-	-	115,153	168,247	-	-	168,247
TOTAL EXPENSES	983,180	-	-	983,180	2,188,143	-	-	2,188,143
CHANGE IN NET ASSETS BEFORE NET ASSETS RELEASED FROM RESTRICTIONS	(28,751)	130,950	-	102,199	(138,387)	113,612	-	(24,775)
NET ASSETS RELEASED FROM RESTRICTIONS	311,284	(311,284)	-	-	415,329	(415,329)	-	-
CHANGE IN NET ASSETS	282,533	(180,334)	-	102,199	276,942	(301,717)	-	(24,775)
NET ASSETS - BEGINNING OF YEAR	1,532,923	1,072,513	-	2,605,436	1,255,981	1,374,230	-	2,630,211
NET ASSETS - END OF YEAR	\$ 1,815,456	\$ 892,179	\$ -	\$ 2,707,635	\$ 1,532,923	\$ 1,072,513	\$ -	\$ 2,605,436

SEE INDEPENDENT AUDITORS' REPORT
AND ACCOMPANYING NOTES TO



Making Headway is a wonderful Nonprofit organization that helps children and their families deal with brain and spinal tumors. They also support cancer research and fun activities. Making Headway Foundation helped make the long hospital stays bearable. To this day, my son still looks forward to the Making Headway activities!



Board of Directors and Governance

During the course of 2013, the Foundation's Board carefully implemented policies and procedures as recommended and required by the federal government as well as charity watchdog organizations. This process began in 2012 with the retention of a nonprofit attorney who conducted a legal audit and it continues with our adherence to the nonprofit "best practices" recommended to date.

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

We have our IRS Form 990 reviewed by the Board prior to filing and we also have formed an Audit/Finance Committee of the Board.

In addition, we now have our Privacy Statement, Annual Report, Form 990, Audited Financial Statements and Website Terms of Use listed on the Contact Us page of our website.

We were once again (for the third straight year) awarded with a Top Rated Nonprofit designation as well as a Silver Participate Seal on the Guidestar Exchange.

Mr. David Almeida joined the Board during the year and his business acumen and dedication to our mission are welcome additions to the Board's skill set. Board expansion continues to be a priority of the Foundation.

Staff & Contact Information

Making Headway Foundation

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www.makingheadway.org

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www.facebook.com/makingheadwayfoundation

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making headway foundation

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



