



**making
headway
foundation**

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

2011 ANNUAL REPORT MAKING HEADWAY FOUNDATION





LETTER FROM THE PRESIDENT

January 31, 2012

Dear Friends and Supporters,

2011 has proven to be a very exciting year. Making Headway's Board of Directors has been most active, diligently working to ensure that our structure, staff and financial strength are in line with the objectives set forth in our Foundation's long range plans.

Over the years Making Headway has focused primarily on the first two aspects of our mission: care and comfort, by funding staff positions and wellness programs at the Hassenfeld Children's Center, and offering free-of charge psychological and educational counseling to the children and their families. While we have no intention of reducing our commitment to this area, 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 really reach the point where we can effectively achieve a cure, we need to take a step backwards to basic medical research, which will investigate the molecular and genetic aspects of these tumors, and translate those results into new, more effective treatments. To this end, Making Headway and another foundation whose mission is similar to ours have each committed \$1 million for a new neuro-oncology laboratory at the NYU Langone Medical Center. A search is currently ongoing to recruit an established scientist with proven outcomes in neuro-oncology to lead the laboratory. 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



HISTORY OF THE ORGANIZATION

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.

Children, siblings, parents and doctors rely on Making Headway to counter fear and discomfort with laughter and love; to replace confusion and bewilderment with understanding; and to make headway through each impasse to a place where the joy of being a child and the joy of being a parent are nurtured and shared.



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.



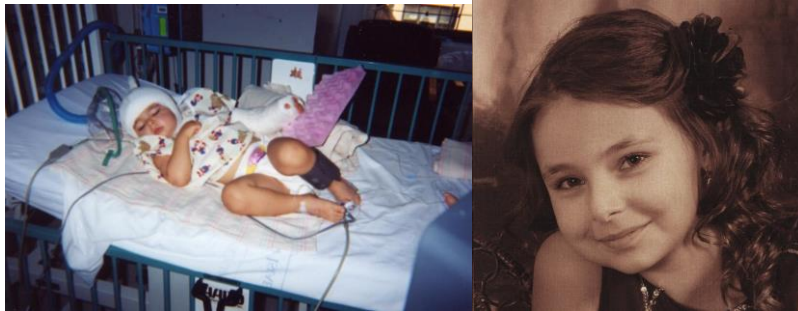
CURRENT PROGRAMS

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.

Following treatments, children and families need ongoing counseling, educational remediation, social and support services so that their life after treatment can return to normal as much as possible. On occasion, when a child passes away, the family needs help with funeral expenses as this can be a large and unplanned burden on the family following massive medical bills.

In response to these needs, Making Headway sponsors the following:

- A Wellness Coordinator who works closely with clinicians, nutritionists, and physical therapists to help carry out the mission of comprehensive and family-centered care and who can bridge wellness and child life programs with clinical treatments.
- A Clinical Research Manager who coordinates the clinical research trials for pediatric neuro-oncology patients.
- A Senior Psychologist who provides psychological services to patients, including neuro-psychological testing, comprehensive assessments of abilities and needs, crisis interventions and support groups.
- A Massage Therapist who helps families with stress reduction and relaxation techniques which also promote healing. These services have been embraced as a way to complement medical treatment in many hospitals. They reduce pain and stress while also speeding recovery.
- A Yoga Instructor who provides relaxation and respite for both children and parents by turning the wellness room into a magical yoga studio with mats, pillows, soft music and twinkle lights. Yoga helps to strengthen the bones, ligaments, tendons and immune system. Practiced regularly, it has a rejuvenating effect on the entire body.
- Making Headway Foundation also provides snacks, such as fruit, cheese, pastries and drinks, to relieve children's hunger pangs while they wait to see the doctor or receive treatment.



After treatment ends...

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 Foundation offers free-of-charge individual counseling sessions, conducted in person or by phone, with licensed psychologists who are specialists in dealing with the unique issues families in this situation face.
- When needed, we also provide bereavement support groups led by counselors and/or assistance with funeral expenses for families who need it.
- One of the most serious problems facing the survivor of a brain or spinal cord tumor is returning to school. Most children experience learning disabilities as a result of their surgery, chemotherapy and radiation treatments. Well-intentioned teachers can be unequipped to understand the specific learning issues that recovering children have and the types of assistance they are entitled to receive under federal law. School districts often decide on eligibility for services and accommodations based on incorrect criteria.

Making Headway Foundation offers the services of trained, experienced educational specialists who work with parents and children to identify and address the educational difficulties stemming from the tumor, treatment and missed school. After assessing a child's educational needs, these specialists advocate for the child and assist the family and the school in identifying the appropriate support and ensuring that the school provides it, as required by law.

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



LONG TERM BENEFITS OF OUR PROGRAMS

The programs funded by Making Headway have long term sustained effects in several ways:

- 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 play room supports all family members who must wait at the hospital during doctor visits and treatment. Therefore, appointments are kept and successful treatment is more likely.
- 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.
- MH'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.

COMMITMENT TO RESEARCH

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. While the medical community has learned to apply conventional treatments such as surgery, chemotherapy and radiation therapy to treat brain tumors in optimal ways, not all cases have favorable prognoses.

As the number of pediatric brain tumors is small, scientific research tends to focus on illnesses with significantly more frequency, such as breast cancer, leukemia and AIDS. Research is needed to discover the underlying biological pathways that drive brain tumor initiation and progression. This knowledge will help improve treatment outcomes for children by developing novel, tumor-specific therapeutic approaches that can be validated for safety and efficiency through clinical trials.

The Dean of the NYU Langone Medical Center has expressed strong support for the establishment of a new dedicated Translational Neuro-oncology Research Laboratory, estimated to cost \$10 million over a 5-year period. A Search Committee has been formed to identify the Senior Laboratory Scientist to lead the laboratory, and the Dean has committed laboratory space and institutional resources.

Making Headway has made a \$1 million commitment toward the cost of the laboratory and has facilitated a \$1 million matching grant from another foundation.





SPECIAL EVENTS

Making Headway's activities are very much driven by our Special Events. Many of our funds come from these events in addition to our individual donations, tributes and memorial gifts.

Each year we host more than 20 special events. Among them are:

- Golf Tournaments
- Walkathons
- Tulip Festival Dinner
- Wiffleball Tournament
- School and Sports Team Fundraisers benefitting Making Headway
- A Night at the Theatre
- Winter Show in New York City*
- Family Fun Day Picnic*
- Manhattan Luncheon Yacht Cruise*

The last two of the above events are not designed to raise funds. Rather, they are program specific events dedicated to giving patient families a brief respite from the daily struggles that they face.

*Admission to each of these is free to patient families.

With the June, 2011 hiring of our new Director of Development, Catherine Lepone, we hope to grow all of our existing special events while adding new events to expand our reach and scope. We plan to add more events in 2012.



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STAFF AND BOARD OF DIRECTORS

BOARD OF DIRECTORS

Edward Manley, President

Previously Director of Planning, Polymers Division, Ciba-Geigy Corporation (retired in 1992)

Maya Manley, Secretary

Volunteer art therapist at Hassenfeld Children's Center
NYU Medical Center, New York, NY 10016

Clint Greenbaum, Treasurer

Financial Planner & Consultant

Elisa Greenbaum

Sam Schwartz, Vice President – Research

Attorney at Law

STAFF

Catherine M. Lepone, Director of Development

Linda Mudford-Lewis, Office Administrator



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ADDRESS

Making Headway Foundation
115 King Street
Chappaqua, NY 10514
914-238-8384

www.makingheadway.org

info@makingheadway.org

Federal Tax ID 13-3906297



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