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Making Headway Foundation
A 501c3 non-profit organization
Founded in 1996
EIN# 13-3906297

Care, Comfort & Cure
2016 Annual Report
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.

**MISSION**

Making Headway Foundation has supported families of children diagnosed with brain or spinal cord tumors 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. Today, Making Headway carries on with its unique work, offering a continuum of services that focus on both research and quality of life for children and their families. In 2016, Making Headway increased our capacity to provide more programs, services and grants than ever before.

**LETTER FROM OUR CHAIRMAN**

As Making Headway enters its 21st year of providing care and comfort to the families, I am proud to look back at our early beginnings and see how far the organization has come. We began our efforts in September of 1996 with no staff, limited fundraising know-how and just three Board members. However, based on our personal experience with our daughter’s brain tumor, my wife Maya and I were determined to make a difference in the lives of families going through the same journey. Making Headway was able to raise approximately $300,000 in the first year, which enabled us to begin providing free-of-charge services to families and fund patient-friendly improvements at the hospital.

Since inception, Making Headway has raised over $22 million for research and programs. However, money alone does not tell the story. With our increasing array of services, Making Headway has guided thousands of families through their journeys and made their hospital experiences less stressful. In more recent years, we have gradually expanded our focus into research aimed at finding improved treatments and, eventually, a cure.

Maya and I are indebted to all of the donors who have made this progress possible, and thank our Board of Directors for their support and guidance.

Edward Manley, Chairman and Founder
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Making Headway Foundation
Hospital Services

Fairytale Yoga

Fairytale Yoga is a one-of-a-kind program designed specifically for children impacted by chemotherapy. Through this program, our instructor, Annie Hickman is able to bring a special joy to children and their families (as well as the doctors and nurses).

Annie Hickman created the daily fairytale yoga program at the Hassenfeld Children's Center, which has been funded by Making Headway for over a decade. In fairy tale yoga, the children use yoga to tell a story. However, at the hospital, the yoga program is unique. The issues are complex and helping the families feel relaxed and content is the primary goal. Annie discovered that children in the hospital do not want her to teach them yoga in the traditional way. They respond best when they can take on the role of teacher. The children have so much fun showing their poses, and Annie follows their lead.

Yoga works wonderfully with children. They love to explore playful movements with their bodies. Children run in circles, dance with silk butterfly wings, play yoga games, and make music with Tibetan singing bowls. Annie fills her special space with magical props and supplies, and then follows the children in creating a playful and rewarding yoga experience, one that often includes parents, siblings and friends. Fairytale yoga helps transform an environment that is often filled with fear and uncertainty, into a place of hope and love.

In their own words...

"Going through the worst time of my life, my son's tumor treatment, would have been unbearable without Making Headway. Healthy kid-friendly snacks, art, parties, massages for the adults, and a shoulder always available. Have you ever heard a child say ‘I can't wait to go to chemo'? I did."

"Making Headway helped us through the most difficult time in our life, when our daughter Elizabeth was sick with a brain tumor. They helped make her happy and comfortable in the hospital where she already was getting the best medical care."

Wellness

Massage Therapy is one of the most unique emotional and spiritual wellness programs supported by Making Headway. By reducing muscle tension, stimulating circulation, reducing joint pain and increasing mobility, massage therapy promotes relaxation and healing. Family members also benefit from massage therapy, as it has been shown to reduce stress and provide an overall improved sense of well-being. Other benefits for both patients and family members include stronger feelings of safety, comfort and support; enhanced self-esteem; and reduced anxiety and depression.

Playroom

A hospital can be a scary place for a child, especially for pediatric cancer patients. Recent studies have proven what Making Headway has known for decades: the hospital's physical environment affects the patients’ experiences, emotional needs, and health outcomes. The physical environment includes how the hospital looks and is organized, as well as the inclusion of age-appropriate activities, games and food for the children, their siblings and their parents.

Every child at the Hassenfeld Children's Center is able to benefit from the enhanced playroom and activities supported by Making Headway. Through our programs, Making Headway has transformed the halls and the playroom into a fun, healthy place for children and families. On any given day, children of all ages and backgrounds can be found happily absorbed in arts and crafts activities, games, or munching on healthy, delicious snacks. Professional entertainers and child therapists are also part of the playroom team, helping the whole family feel comfortable, relaxed and welcome.

Over the past 10 years, Making Headway has assisted over 10,000 children who were diagnosed with cancer.

In 2016, 1,853 children were treated for tumors at the Hassenfeld Children's Center. Most of these children will return to Hassenfeld dozens of times for treatments, therapy, evaluations or procedures. Every child who passes through those doors will benefit from the hospital services that are supported by Making Headway.
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**FAMILY SUPPORT**

**Psychological Counseling**

An illness in the family is an intensely personal experience for all involved. A child’s illness, especially cancer, can lead to family or marital stress on a variety of different levels. Some families need help understanding and working through difficult and painful emotions and situations. Others have a hard time finding the language to articulate their feelings or concerns. The need for experienced, expert psychological care may be just as important as medical care. Making Headway understands this need and funds free programs both in and out of the hospital for anyone in need, including the sick children, their siblings and their parents.

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. This type of counseling provides an important opportunity for children and parents to find ways to cope with their experiences.

**Neuropsychology Testing Program**

Research confirms that children with oncological and neuro-oncological diseases frequently face a host of neurocognitive, academic, and socio-emotional challenges both during and after treatment. Funded by Making Headway, the Hassenfeld Neuropsychology Testing Program was created to evaluate and monitor children newly diagnosed with pediatric brain tumors and cancers at The Stephen D. Hassenfeld Children’s Center for Cancer and Blood Disorders. The aim of the program is to understand, identify and document the effects of both the disease and its treatment. Funds free programs both in and out of the hospital for anyone in need, including the sick children, their siblings and their parents.

In 2016, 43 families received a total of 329 hours of psychological counseling through Making Headway.

**Educational Counseling**

As a result of chemotherapy and radiation, children often develop learning disabilities. When these young survivors return to school, parents and school personnel may be unprepared for the child’s cognitive and social deficits. The children may not be able to keep up with their peers, fall behind academically, and may experience rejection and social isolation. Making Headway offers free-of-charge educational counseling to address the adjustment issues related to the children’s learning disabilities and difficulties in returning to school, as well as their rights under Federal law. Our therapists work with the children’s schools to develop an Individual Education Plan (IEP) for each child. The IEP may include modifications in curriculum and testing, and other services that the child is entitled to by law in order to optimize his or her educational program. In 2016, we provided 38 children with 482 hours of educational counseling to help them succeed in school.

**Molly’s Story**

Molly was a bright young elementary school student who excelled academically and was well-liked by her teachers and other students. One day she began feeling very sick and her family rushed her to the doctor. Molly had a brain tumor and required complex neurosurgery. She survived and recovered after several rounds of chemotherapy and radiation. Unfortunately, the tumor and the radiation had permanent side-effects that impacted her speech, hearing and cognitive abilities. Molly’s school was not equipped with the programs and services for children with these types of special health care needs. The family was referred to Making Headway’s expert Educational Specialist, Patricia Weiner.

Finding the right school in a huge city, attending school meetings and advocating for their child are daunting experiences for any parent. After spending time learning about Molly’s issues and the family’s preferences, Ms. Weiner began researching schools and programs. As Molly grew up, Ms. Weiner continued to ensure that Molly received all the complex services, accommodations and equipment she needed. In Molly’s case, this included a 1-on-1 health paraprofessional; hearing and vision education services; physical, occupational, and language therapies; and transportation. For the last 11 years, Ms. Weiner has continued to work with Molly and her family.

Molly’s family, Ms. Weiner, and Making Headway are so proud that Molly recently earned her high school Regents diploma and is now looking forward to college. With help from Making Headway, Molly was placed in the right environment and given the tools she needed to succeed.

“The Individuals with Disabilities Education Act (IDEA) ensures students with disabilities have access to a free and appropriate public education, just like all other children. Schools are required to provide special education to children returning to school after medical treatment in the least restrictive environment.”
Family Support

Psychological Counseling

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In 2016, 43 families received a total of 329 hours of psychological counseling through Making Headway.
Making Headway Foundation understands that in order for children to receive the highest quality medical services, doctors must be specially trained to understand the unique issues of pediatric brain and spinal cord tumor patients. Making Headway is helping to meet this need through the funding of our annual Pediatric Neuro-oncology Fellowship Program at The Stephen D. Hassenfeld Children’s Center for Cancer and Blood Disorders at NYU Langone Medical Center. Chosen from among the best doctors in the country, fellows evaluate and treat children with a broad range of brain or spinal cord tumors. They manage neurological complications of systemic cancer in children, assist in conducting clinical trials and prepare for an academic leadership career in pediatric neuro-oncology. Now in its sixth year, the Making Headway Fellowship Program has been a great success; each fellow has moved forward with a robust career in pediatric neuro-oncology.

WORLDWIDE IMPACT

2013 Making Headway Fellow, Dr. Diana Osorio is developing an international neuro-oncology program, which provides real-time consultative services to brain tumor patients and their physicians, particularly within Central and South America. Currently Dr. Osorio is a staff member of the Neuro-Oncology Department at the Nationwide Children’s Hospital in Columbus, Ohio.

In their own words...

“My husband and I are so grateful for Making Headway’s guidance and help working our way through the school system. We appreciate you being there for us and your expertise in always finding the right school for our daughter.”

“The support Making Headway offered by way of free psychotherapy and peer support were invaluable to helping me back on my feet and ready to address the ‘what’s next’ and how to get busy living. I will forever be indebted to their services.”

Making Headway Foundation was founded with a unique mission that emphasizes the importance of helping children via holistic, wide-ranging services. We provide a true continuum of care, in which our programs are able to effectively assist patients, families and doctors. The needs of a child with a brain or spinal cord tumor are complex and diverse. Making Headway meets these needs through a variety of individual care, family care and medical care. We invest in both long-term and short-term solutions to the medical and emotional needs of the families we serve. Our flexibility and pro-active philosophy have led to a growth in services, allowing Making Headway to provide Care, Comfort and Cure to more families than ever before.
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**Pediatric Brain and Spinal Cord Tumors**

**Facts and Figures**

Today, there are more than 28,000 children (ages 0-19) living with brain or spinal cord tumors, commonly referred to as Central Nervous System (CNS) tumors. Over 2,500 children are diagnosed every year (seven every day). Their lives are changed forever. In 2016, pediatric CNS tumors caused more deaths than any other type of pediatric cancer.

**Investments Save Lives**

Recently released data from the National Center for Health Statistics revealed that brain cancer is now the leading cause of cancer deaths in children. For many years, leukemia held this unfortunate title, but decades of significant federal and local investments to fight leukemia have resulted in a steady decrease in the number of childhood deaths from this disease. From 1999 to 2013 the number of childhood deaths from leukemia decreased by 24%, despite the fact that the number of children diagnosed with leukemia actually increased during this period. The increase in survival rates for childhood leukemia can be attributed to over $1,000,000,000 in research grants from the National Institutes of Health (NIH) since 2005. Childhood leukemia has been the only specific childhood cancer that has its own line item in the NIH budget, which guarantees significant funding. Unfortunately, the other most common forms of pediatric cancer, including CNS tumors, have not received nearly this level of funding and have not shown any significant advancement in survival rates. Making Headway is planning to team up with other organizations to advocate that pediatric brain and spinal cord tumor research receives the same level of funding as leukemia research. Through collaborative advocacy and increased investments, Making Headway is looking forward to new discoveries, new treatments and cures.

**Types of Tumors**

There are dozens of different types of pediatric CNS tumors, each affecting a different part of the brain or spinal cord. CNS tumors can vary significantly in terms of treatments and survival rates. For example, pilocytic astrocytoma (one of the most common types) has a 5-year survival rate of 95%. Sadly, other types, like anaplastic astrocytoma or glioblastoma, have survival rates of under 30%

Treatments for each type of tumor vary, but they usually include surgery to remove the tumor, as well as chemotherapy and/or radiation therapy. Tumors in the brain or spinal cord directly impact the health (physical, psychological, emotional and cognitive) of the child.

**Funeral Expenses**

Despite significant advances in medical treatment, many children will eventually succumb to the extensive damage caused by brain or spinal cord tumors. Over 500 children die each year from this devastating disease. The stress and financial burden of a sick child can be overwhelming. For local families in need, Making Headway covers up to $5,000 for the cost of a proper funeral service.
**Pediatric Brain and Spinal Cord Tumors**

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**What is a Pediatric CNS Tumor?**

Together, the brain and spinal cord make up the central nervous system (CNS). A childhood CNS tumor is a disease in which abnormal cells form in the tissues of the brain or spinal cord. There are dozens of different childhood brain tumor types and classifications, each based upon a tumor’s cell structure, composition, rate of growth and other characteristics.

CNS tumors may be benign (non-cancerous) or malignant (cancerous). Benign brain tumors grow and press on nearby areas of the brain. They rarely spread into other tissues. Malignant brain tumors are likely to grow quickly and spread into other brain tissue. When a tumor grows into or presses on an area of the brain, it may stop that part of the brain from functioning the way it should.

The cause of most childhood brain and spinal cord tumors is unknown.

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MEDICAL RESEARCH

Bio-Repository Center

Making Headway funds life-saving medical research through a variety of strategies. We fund many specific research projects, but we also support innovative laboratories that enable dozens of other such studies. One of the most successful is the NYU Pediatric Brain and Nervous System Tumor Research Registry and Tissue Bank. This center catalogs and stores thousands of invaluable medical samples from children with brain or spinal cord tumors. Doctors from around the world can request samples for their research. Making Headway covers the cost to prepare and transport the samples, as well as supports the Data Manager position at the center. Our funding of this vital initiative encourages research and collaboration that will lead to practical improvements in the treatment and prevention of pediatric brain and spinal cord tumors.

CLINICAL TRIALS

Manager

Clinical trials are important research studies that explore whether a medical strategy, treatment or device is safe and effective for humans. New treatments and therapies must go through the increasingly complex clinical trials process before being approved, which can take many years. Making Headway understands the critical role that clinical trials play in new discoveries, and currently funds a Research Manager to organize and manage these trials at the Stephen D. Hassenfeld Children’s Center for Cancer and Blood Disorders. In 2016, the Clinical Research Manager oversaw 35 active research projects that are devoted specifically to pediatric brain or spinal cord tumors. Each trial has the potential to discover a new treatment or possibly a cure for these pediatric tumors.

RESEARCH STUDIES

Making Headway Foundation continues to fund several long-term studies that focus on treatments and causes of brain and spinal cord tumors. One such continuing study evaluates the impact of socio-economic status, home environment, parenting and parental distress on pediatric brain and spinal cord tumor patients. This project, led by Dr. Stephen Sands at the Memorial Sloan Kettering Cancer Center, aims to create a more accurate early-intervention protocol, so doctors can help children before neuropsychological problems develop. From a technical standpoint, this study uses brain imaging techniques and demographic factors to assess CNS myelin load, grey and white matter volumes and structural integrity among children who received treatment with Head Start 4 clinical trial protocol. By understanding this information, doctors and families may be able to increase the quality of life for patients.

Did you know?
The Alliance for Childhood Cancer and the American Cancer Society recently reported that “unique scientific, economic, ethical, and regulatory challenges discourage investment in pediatric cancer R&D from the biopharmaceutical industry. Thus, government and philanthropic sources have to carry a heavier load in terms of providing resources for pediatric cancer research.” Organizations like Making Headway fill this gap by funding important research projects that simply would not happen without our support. We are proud to do our part to find a cure for pediatric brain and spinal cord tumors.

For the Experts...
The Bio-Repository Center makes available the germline DNA in which researchers characterize tumors on a molecular basis, with the goals of exploiting novel differences that may increase the understanding of the pathogenesis of these diseases, and aiding the development of therapeutic agents.

For Lay People...
The Bio-Repository Center is a place where researchers can receive samples of pediatric brain tumor tissue. New technology allows researchers to use DNA analysis to better understand how and why these tumors were created. One of the main goals of this type of research is to develop innovative treatments for patients.

Visit MakingHeadway.org for downloads and links.
Medical Research

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Did you know?

The Alliance for Childhood Cancer and the American Cancer Society recently reported that “unique scientific, economic, ethical, and regulatory challenges discourage investment in pediatric cancer R&D from the biopharmaceutical industry. Thus, government and philanthropic sources have to carry a heavier load in terms of providing resources for pediatric cancer research.” Organizations like Making Headway fill this gap by funding important research projects that simply would not happen without our support. We are proud to do our part to find a cure for pediatric brain and spinal cord tumors.
### Making Headway 2016

#### Financial Data

**Revenue**

- **Fund Raising Events**: 74%
- **Contributions**: 18%
- **Grants**: 5%
- **Other**: 3%

**Revenue Receipts**

- Winter Events: $491,520
- Other Events: $203,458
- Contributions and Bequests: $184,231
- Grants: $47,000
- Investment Income: $8,291
- **Total**: $934,500

**Expenses**

- **Programs**:
  - Grants - NYU Medical Center: $411,348
  - Grants - Other Institutions: $39,760
  - Grants - NYU Medical Center - Patient Support: $58,749
  - Individual Counseling: $67,714
  - Educational Counseling: $80,217
  - Family Events: $23,310
  - Funeral, Hospital & Bereavement Expense: $68,455
  - Scholarships: $47,000
  - Allocated Operating Expenses: $41,247
  - Administrative Expenses: $130,809
  - Fund Raising Expenses: $58,457
  - **Total**: $1,027,066

**Note**: Unaudited financial data as of January 1st, 2017.

Making Headway uses a fund balance savings account to cover any yearly deficits.
**Making Headway 2016**

**Financial Report**

**Revenue**
- 74% Fund Raising Events
- 18% Contributions
- 5% Grants
- 3% Other

**Expenses**
- 81%
  - 44% Grants - Research & Medical
  - 14% Counseling Services
  - 7% Funeral & Bereavement
  - 6% Grants - Patient Services
  - 5% Scholarships
  - 6% Other
- 13% Administration
- 6% Fundraising

**Financial Data**

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Scholarship Fund

Making Headway is delighted to support and administer the Scott J. Reisser Memorial Scholarship Fund. Established in 2007, the fund is the culmination of the Reisser family’s efforts to create a fitting memorial to their beloved son, brother, grandson and nephew. Scott’s most cherished dream was to graduate from college, a milestone he fell just short of achieving. After his death in 2006 from a brain tumor, it was clear that the most appropriate way to honor his memory would be by helping young brain tumor survivors to achieve their educational goals. In 2016, The Scott J. Reisser Memorial Scholarship Fund supported two scholarships and Making Headway funded seven additional scholarships. Here are the 2016 winners.

- Lionel Chen, Bergen County Community College
- Logan Ippoliti, Fashion Institute of Technology
- Emily Ousouljoglou, Misericordia University
- Joshua Watabe, Bowling Green State University
- Logan Ippoliti, Fashion Institute of Technology
- Chantelle Lovett, Suffolk County Community College
- Sarah Baumgarten, University of Pennsylvania

In as far back as middle school, Noelle Sollivan demonstrated her big heart by selling gray ribbons to benefit Making Headway during Brain Tumor Awareness Month. In high school, Noelle served as President of the Make-A-Wish Club, organizing a volleyball marathon which raised $4,000 for that organization. She also served as Student Council Treasurer, and was honored with a Students in Action Jefferson Award for Service. The 2016 graduate is now attending Kean University, with plans to become a physical therapist.

When Lucas Sundwall graduated high school, he left a trail of honors including four years on the honor roll, membership in the National Honor Society, and Scholastic Achievement Awards in English, history and Arabic. Lucas, who hopes to make a difference in how people with disabilities are treated in our society, is now attending Quinnipiac University as a legal studies major. His goal is to attend law school and focus on disability rights and advocacy.

During her senior year of high school, Lauren Lam served as president of the Key Club and won the Prudential Spirit of Community Award, which recognizes students for outstanding service to others at the local, state and national levels. After graduating last June, she is attending Campbell University. Lauren hasn’t yet decided on a major, but one thing she knows for sure is that her career will involve helping others.

Carolyn is a hard-working young woman who is currently a sophomore in high school. She is also a brain tumor survivor and lost her father when she was a young girl. Many brain tumor survivors face difficult challenges as a result of surgeries, treatments, and missed time at school. Carolyn was experiencing difficulties after she finally returned to school, including problems with her schoolwork and anxiety about her social life. To help Carolyn, she was referred to Making Headway Education Specialist, Sabina Bragg.

Ms. Bragg worked with the family and realized that at the heart of Carolyn’s struggles there was a common theme: school instruction simply did not meet her unique needs. Ms. Bragg went to the school, conducted staff interviews and observed Carolyn in several learning environments. Using this information, as well as a previous neuro-psychological evaluation, Ms. Bragg put together a comprehensive presentation for Carolyn’s instructional team at school. She worked with them to develop creative instructional approaches, such as the use of an iPhone to take audio notes instead of written notes, as note-taking was difficult for Carolyn. Ms. Bragg demonstrated how small group instructional tables would provide the special education support that would help not only Carolyn, but also the entire class. Ms. Bragg helped change the mindset in the school, enabling staff to understand that Carolyn’s problems were due to behavioral issues caused by her treatment, and were typical of a child with her complex medical background.

Carolyn continues to show how strong she is despite all that she has been through. Her mother is extremely happy with the progress that she has made and is grateful for Ms. Bragg’s assistance, passion and expertise.

Making Headway 2016: Winter Show - Untapped

For 20 years, Making Headway has invited the families with whom they work to an annual winter show. In 2016, hundreds of family members attended a special production of Untapped at the New Victory Theater. The show was a high-octane dance, music and comic experience for the whole family. The dancers leapt across the stage in jeans and singlets, creating amazingly intricate rhythms to complement the live band rocking out on stage. The children in attendance loved every minute and are eagerly looking forward to the next winter show.
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Carolyn’s Story

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Fundraising Events

Every year, families, community organizations, schools and others help support Making Headway Foundation by raising funds. Some of the most effective are those organized by families who have had a loved one diagnosed with a pediatric brain or spinal cord tumor.

10th Annual Nicky and Thomas Docu Memorial Golf Outing
2nd Annual Gains for Brains Lax Showcase

In 2016, friends of Making Headway helped raise over $200,000 by hosting local and regional events. We are so grateful for their support, which helps fund many programs at Making Headway.

1st Annual Race for Ace
10th Annual Thomas Fitzgerald Memorial Fund Mardi Gras Bash
3rd Annual Greeley Walkathon “One Team, One Dream”

5th Annual Brian McCabe Drive for a Cure
8th Annual Kicks for Cancer
Westlake Dinner Dance and Show

Events for Families

For a child with a brain or spinal cord tumor, life can be stressful, scary and often painful. Making Headway hosts several special events just so these children and their families can have fun and meet other families who share their experience. Our three biggest recent events were: Family Fun Day, the annual Yacht Cruise and the winter show Untapped. There is nothing quite like seeing a child’s face fill with joy, especially when you know the challenges they have had to endure. Through fun events like these, hundreds of sick children have been able to simply be children again, enjoying a wonderful, stress-free day with their family and friends.

Photo Credits: Making Headway, Todd Shapera and Kleb Kuznetsov
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