



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

Board of Directors

Edward Manley
Founder and President

Maya Manley
Founder and Secretary

Clint Greenbaum
Founder and Treasurer

Elisa Greenbaum

Sam Schwartz
Vice President, Research

Medical Advisor

Jeffrey Allen, MD
*Director of Clinical Neuro-Oncology,
NYU School of Medicine and Otto and Marguerite Manley and Making Headway Foundation Endowed Professor of Pediatric Neuro-Oncology*

Administration

Linda Mudford-Lewis
Office Administrator

Making Headway Foundation, Inc.
115 King Street
Chappaqua, NY
10514-3460
Tel: (914) 238-8384
Fax: (914) 238-1693
www.makingheadway.org

Making Headway is a 501(c)(3) not-for-profit foundation.

Making Headway Foundation works closely with the Stephen D. Hassenfeld Children's Center for Cancer and Blood Disorders at NYU Langone Medical Center.



Translating Science Into Healing

A Message from Matthias Karajannis, MD, MS, Assistant Professor of Pediatrics, Division of Pediatric Hematology / Oncology, NYU School of Medicine

Since joining the NYU Langone Medical Center (NYU LMC) Division of Hematology/Oncology in 2007, I have focused on expanding our translational research activities for children and young adults with tumors of the brain and central nervous system (CNS). Translational research is medical research that applies information gleaned from basic scientific research to the treatment or prevention of disease. It is an attempt to link the laboratory to the bedside.

We are working on using translational research and clinical trials to develop novel, molecular targeted therapies for pediatric CNS tumors. Molecular targeted therapy is an approach to killing cancer cells that involves targeting the key molecules involved in their growth. In our current work, we are identifying relevant molecular pathways to target, developing therapies to target them and validating our new approaches using clinical trials.

I work closely in my research with Drs. Jeffrey Allen and Sharon Gardner, my colleagues in Pediatric Neuro-Oncology at NYU LMC, as well as with other members of the Division of Hematology/Oncology. I have taken a special interest in children with hereditary syndromes associated with various CNS tumors, such as neurofibromatosis, as well as children with progressive low-grade gliomas.

We are making some exciting progress. We recently published

laboratory findings identifying lapatinib, a molecular targeted drug, as a promising treatment for tumors associated with Neurofibromatosis Type 2 (NF2). Based on these results, we have opened two clinical-translational trials of lapatinib for children and adults with NF2-related tumors. We are about to launch a trial of sorafenib, another molecular targeted drug, across multiple pediatric brain tumor centers. Sorafenib is being tested for children with low-grade astrocytomas, including those with Neurofibromatosis Type 1 (NF1), and we are continuing to prepare for other clinical and translational trials.

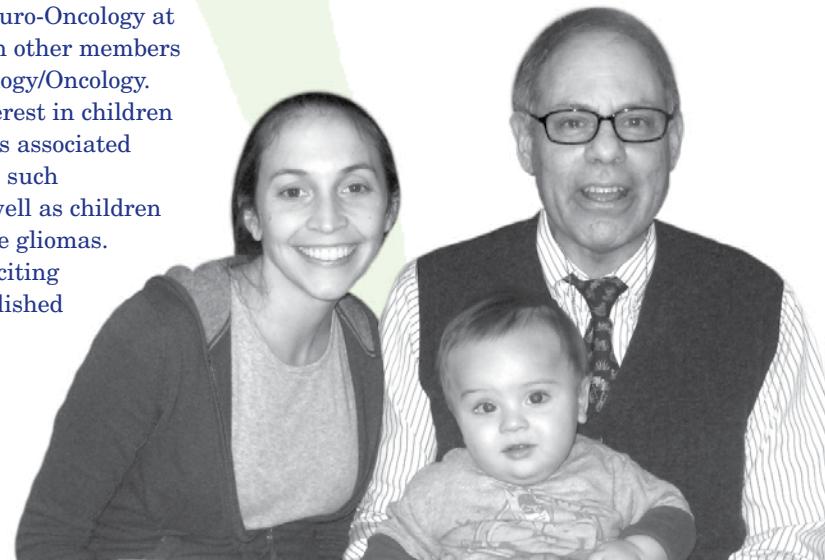
In order to advance our understanding of pediatric brain tumor biology and identify new treatment approaches, we are collaborating with a number of laboratories at NYU LMC, as well as outside institutions including Johns Hopkins University, Memorial Sloan-Kettering Cancer Center and the University of Heidelberg in Germany. Our research efforts are supported by grants from a number of private foundations, including generous funding from the Making Headway Foundation, as well as the National Institutes of Health.

Working together across institutional and national borders, and with the help of our generous funders, we look forward to ultimately discovering new treatments that not only improve health outcomes but make the treatment for CNS tumors less toxic to children and young adults.



Top: Dr. Matthias Karajannis with Eliyahu Soltan.

Below: Dr. Jeffrey Allen with Daniel Cheatham and his mom, Mary Beth.



Gracious Giving

Throughout the year, Making Headway receives numerous gifts from individuals, families and friends, organizations and companies. These gifts help us fulfill our mission. No matter how great or small, we are honored by each contribution and sincerely thank you. Some examples of gracious giving include the following:

In another touchdown for Chappaqua's **Greeley Gridiron Club**, the high school varsity, junior varsity and freshmen members raised \$10,538 for Making Headway during their 3rd Annual Walk-A-Thon. Not to be outdone, members of the **Hauppauge High School Girls Soccer Team** scored another goal with this year's "Kicks for Cancer" fundraiser in memory of fellow student, **Courtney Tomkin**, bringing in \$20,100.

Youngsters once again set an example for us all with their generosity:

- On her 7th birthday, **Casey Tichy** passed up the opportunity for birthday presents, asking that her friends donate to Making Headway, instead. Her thoughtful request brought in \$245.
- **Esmé Fritton** chose to simply pack up half her birthday gifts, bring them to the Hassenfeld Children's Center and distribute them to the delighted children there. The seven-year-old granddaughter of **Maya Manley** later donated \$21.50 she had saved from her allowance.
- **Alexandra Diamond and her cousin** were inspired to donate the contents of their tzedakah (charity) boxes—totaling \$61.29—while sisters **Julia and Barrie Miller** gave \$24 from their tzedakah boxes, too. Both gifts were in memory of **Lily Taubin**.

Glitter and elegance were the order of the day when **Maria Barbieri** hosted a jewelry party, but the most valuable gem was the \$682 raised for Making Headway.

Joseph Grgas and his son, Joseph, Jr. found the key to alchemy, turning their old cars into care and comfort by donating them to the Cars 4 Causes vehicle donation program. The gift, which was in honor of **Khalil Smith**, made Making Headway beneficiary of \$2,183.

NFL Head Linesman, **Wayne Mackie**, and his officiating crew donated \$500 to Making Headway. Mackie's nephew, **Brandon**, is a longtime brain tumor survivor.



Gracious Giving (continued)

Rob Mathes and his superb band held a beautiful Christmas concert, donating the \$4,515 raised through sales of their latest CD to Making Headway in memory of **Max Scotti**, who had been a first-grader in his wife's class. Both concert and CD featured *Everywhere*, a song Mathes had composed for Max.

The children of Hassenfeld Children's Center were kept doubly cozy this winter when they received teddy bear blankets designed and knit by **Nikki Batsford** as well as blankets crocheted by **Ethel Thomas and her fellow parishioners** in the Plainview Reformed Church Project Linus Group.

Children at the Hassenfeld Children's Center were delighted to receive holiday gifts this winter, thanks to boxfuls of toys donated by **Jeanne Egan and her family**. And once again **Anthony Caputo and his co-workers** at Central National-Gottesman filled a car with the proceeds from their toy drive; **Maria Barbieri** assisted them in delivering the playthings to their new home in the Hassenfeld Children's Center playroom.

Jeanne Egan organized a 2nd annual "Night at the Theatre" with the **North Shore Kiwanis Club of Long Island** on March 13. More than two dozen guests braved stormy weather to enjoy the swinging sounds of Duke Ellington and the Gershwin's in "All Night Strut!"; Making Headway benefitted to the tune of \$800.

Angela's House, a program in support of medically-fragile children, held its second annual "A Night for a Cure." Three hundred guests attended the pleasant and informative event, which served the dual purpose of raising awareness about rare diseases and raising funds toward their cures. The organization donated \$875 of proceeds to Making Headway, in memory of **Courtney Tomkin** and **Allison Trunz**.

The party that **Anita Sweeney**, longtime friend of the Trunz Family and supporter of their annual Tulip Festival Dinner Dance, hosted on Dec 5th was "truly magical," according to her daughter, **Ellen Renjifo**. Sweeney was terminally ill, yet her guests at the Swan Club enjoyed a wonderful night of music and dancing, and she, herself, even danced to Frank Sinatra's "My Way" before the evening was out. Sweeney died ten days later, but the donations she had asked for in lieu of gifts, as well as gifts made in her memory, enriched Making Headway by \$2,920.

Send in the Clowns

The *Kaye Playhouse* was the scene of old-fashioned hijinks on January 24, when the **Hey-Ya Brothers** took the stage for two antic performances of classic physical comedy. Performing in the tradition of great clowns like **Charlie Chaplin and Laurel and Hardy**, the trio of "brothers" traded silly banter, juggled and unicycled, made hilarious attempts at music and took a lot of pratfalls. Audience members of all ages joined in the fun, coming to the stage to twirl plates and even throw—or receive—the occasional pie in the face. The mayhem that created so much laughter for one afternoon also had a more lasting benefit, bringing in \$450,000 for Making Headway.



Top: Esmé Fritton with Jonathan Larriu.

Bottom: Michael Uyaguari with his mother, Rosa.



Educational Consultation: How Does Making Headway's Ongoing Care Model Work?

by Patricia Weiner, MS, Special Educator,
IEP and Child Life Specialist, Making
Headway Ongoing Care Team

The education of every child is so important that many people, including the child, family, school and healthcare team need to communicate, collaborate and coordinate care in order to ensure each child's needs are met. And since children's educational needs change as they grow, ongoing care is extremely important. It takes everyone involved to help a child reach his or her full academic, psychological and social potential.

Making Headway's Ongoing Care Program is based on health psychology. It has grown over the years from basic telephone and group support services to a comprehensive program of specialty counseling and resources. The first member of the team was health psychologist, Marcia Greenleaf, PhD. Today, Dr. Greenleaf continues to play a major role by providing ongoing assessments, counseling and care to families.

As the program grew, other critical specialty services were added. A child life/developmental specialist, Sallie Sanborn, MS, became part of the program to help children develop coping skills and build self-esteem and to help their parents. I joined the team as a child life specialist/special educator to help families navigate the complex educational maze,

provide advocacy, review Individual Education Plans (IEPs) and other documents, and coordinate educational services. Most recently, a neuropsychologist, Susan Leslie, PhD, came on board, ensuring that children receive appropriate services and providing advocacy for families.

Most referrals to the Ongoing Care Team come from the Hassenfeld Children's Center at NYU Langone Medical Center. David Salsberg, PsyD, DABPS, Supervisor of Pediatric Psychology and Neuropsychology, and his extraordinary team work with us, collaborating and communicating each child's unique needs to families and schools.

Dr. Greenleaf, who is also Clinical Director for the Ongoing Care Team, assigns consultants to help families as needed. We call the family; meet the child; assess his or her educational needs; review all recent evaluations, reports and IEPs; attend various school meetings and have the parents sign a comprehensive consent so that each of us can be in touch with each other. We also stay in touch with neuropsychologists, physicians, nurses and other healthcare providers.

(Continues on following page)

Left: Patricia Weiner.

Bottom: Dr. David Salsberg with Mohamed Lemrabott and Dr. Laura Tagliareni.

Tips for families:

- 1. Keep expectations of your child's abilities realistic.*
- 2. There is a lot to remember. Bring a notebook to meetings. Take notes and write down your questions.*
- 3. Be persistent. Ask the school about the Individual Education Plan (IEP). It is the school district's responsibility to explain everything to you.*
- 4. Ask questions of all providers. Ask what roles they each play and about their evaluations.*
- 5. Know that the Making Headway Ongoing Care Team is here for you!*



(Continued from previous page)

Educational laws to help children with special needs have existed since 1975 and are constantly being amended. As educational consultants, we must stay abreast of the law so we can inform parents of changes and help them become better advocates for their children. We can also serve as another voice for the children: while all children with special needs have a federal right to a free, appropriate, public education in the least restrictive environment, the level of advocacy and persistence required to make this happen can be exhausting and families can't always manage it alone.

Throughout all of this educational planning, parents remain the most important people. After all, they know their own child best while we are merely interim providers, floating in and out of a child's life as needed.



One Child's Story

Mother

"My daughter was diagnosed with a brain tumor at age four. She attended a private parochial school for many years. With the help of Making Headway and the NYU Langone Medical Center we realized that my child was inappropriately placed...we all worked on finding a new, free, appropriate placement for her. This process took us many months, many visits and much work. I am very grateful that I had such a great team."

Child

"I wasn't treated nicely at my first school. The kids were mean...I really didn't like going there and didn't know what to do about it. My mom said she would speak to the people at NYU and Making Headway... At my new school, my friends are more respectful, much nicer and not mean...the teachers are really nice... and I received a second set of text books to keep at home which makes school much easier for me. I like school now and am learning so much."

Educational Consultant on Making Headway's Ongoing Care Team

"My work included school visits; reviewing all the evaluations; meeting with the child, her family, the neuropsychologists, the physicians, and an attorney; and attending many Individual

Education Plan (IEP) meetings. All of this would have helped the Committee on Special Education to understand the educational needs of this child, but none of it would have meant anything without the parents' involvement, our communication with each other, the caring of the team and the coordination of school services. This family took advantage of all referrals that were made."

Special Educator and Professional Development Consultant for New York City Schools

"The role of parents is crucial. No one has the complete picture and it takes all stakeholders working together to understand the issues and plan effective support. When all the people involved in the child's life work together the child feels the support and develops a sense of optimism which is so essential."

Chairperson of a Committee on Special Education (CSE) District in New York City

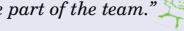
"We want success for all the students we work with and for their families and specifically for students who have been so very ill. We are ecstatic when the student is happy in his or her school setting and shows progress in areas of concern. We work collaboratively with Making Headway's Ongoing Care Team, parents and other professionals... At the CSE meeting for this child, the neuropsychologists came to help advocate for her. The child is so happy, smiling, learning and she loves school; thanks to all of you!"

Professor of Special Education and Former Administrator, New York City Department of Education

"It is always strategic to link together the diverse skills of a collaborative team to reach a goal. In the case of Making Headway, the coordination and teamwork of all interested parties results in coordination for a very special population where time is of the essence."

Attorney

"We need the parents on board to help the children. The parent knows the child best and must be part of the team."



Above: Gabriel Lipinski with Rocky, from the Good Dog Foundation.

Below: Amina Koueider with her mother, Soha.





Partying with a Purpose

- The Public House, in Manhattan, was the October 14 scene of ***Fight With Alexandra***, a night of food, drink, music and good company, hosted by Elizabeth and Marc Talbot. The event, which also included a silent auction, raised \$204,250 for use by Making Headway in funding clinical research projects dedicated to developing new treatments and a cure for low-grade pediatric brain and spinal cord tumors.
- Guests lucky enough to attend a ***Night of Giving***, held at the Westlake Men's Golf Club on December 5, enjoyed live entertainment and feasted on a sumptuous dinner of oysters, shrimp, crab claws and roast pork. The lively event, which also included a silent auction, was hosted by Ralph Arbia, his daughter, Kim Madsen and Steve Casale. It was a warm way to celebrate on a cold winter night, and the fact that it brought in \$28,500 for Making Headway made it that much warmer.
- On March 12 it was once again carnival time, as Lisa and Tom Fitzgerald hosted the fourth annual ***Mardi Gras Bash*** at the Cortlandt Manor in Westchester. A deluge of snow that delayed the festivities, originally scheduled for March 3rd, did nothing to dampen the spirits of party-goers who made their way to the postponed event. There they celebrated the season and raised money for the Thomas D. Fitzgerald III Memorial Fund; Making Headway was delighted to receive \$4,500 from the proceeds.

Care for a Cupcake with that Haircut?

- Visitors to Wendy Levy's beauty salon recently were tempted with an array of delicious baked goods. The ***Bake Sale***, an annual event, was organized by Wendy, her husband, David, and their son, Joshua. Each year, half the proceeds go to a local child in medical need. This year, the other half went to Making Headway in memory of the Levys' daughter—and sister—Jamie. Assisting in this year's bake sale was **Kim Stirling Lamb**, whose son, Jack, is a patient of Dr. Allen's. The tasty event resulted in a total of \$2,412 for Making Headway.
- Greg's Hair Shop was also the scene of some fundraising, when Ann and Greg Mannino raised \$400 for Making Headway in memory of their son, Vincent. They dubbed their fundraising drive ***In Memory of Vincent's Wish***; the wish was that all the sick get well.



Top Left: Marc and Elizabeth Talbot with Edward Manley at the Fight With Alexandra event.

Above (top): Alexandra Talbot with her cousin.

Above (bottom): Vasco Colazzo with his mom, Rosina.

Left: Peggy Fischer and her daughter, Marirose.

When Intermissions Are in on the Act

Thanks to Peggy Fischer, theater-lovers attending Pope John Regional High School's three spring showings of "Les Misérables" also had the opportunity to support Making Headway. Fischer organized a French-themed fundraising ***Concession Stand*** that sold \$1,145 worth of cupcakes and lemonade. Even those watching their weight could enjoy a feast for the eyes, as the cupcakes, contributed by 32 different volunteer bakers, were beautifully decorated and displayed.

Introducing the Long Term Follow-Up Program at Hassenfeld Children's Center

by Erin Hartnett, Pediatric Nurse Practitioner in Neuro-oncology, NYU Langone Medical Center

Is your child a survivor of a pediatric brain tumor who completed chemotherapy or radiation treatment two or more years ago? If so, he or she is eligible to join the Hassenfeld Children's Center Long Term Follow-Up Program.

The Long Term Follow-Up Program, launched in January, 2009, is based on guidelines developed by the Children's Oncology Group, an association of institutes dedicated to research in pediatric oncology. (For further information, download *Long-Term Follow-Up Guidelines for Survivors of Childhood, Adolescent, and Young Adult Cancers* at www.survivorshipguidelines.org.) Its purpose is to screen children for potential late effects of treatment, educating the family about these effects and how to address them. Children enrolled in the program are seen annually.

The initial visit is comprehensive, lasting approximately four hours and including appointments with six or seven members of the Long Term Follow-Up Team. It begins with a comprehensive medical history and physical examination conducted by the nurse practitioner (NP). The NP reviews the child's prior treatment and screens for possible effects of radiation or chemotherapy, making referrals to subspecialty providers and/or follow-up testing, as needed. The family is given a personal binder containing their child's treatment plan, which they are encouraged to share with their primary care provider. The binder also includes educational materials addressing each of the potential late effects, as well as a written plan for monitoring for these effects and preventing future problems.

During this initial visit, children are also seen by our neuro-psychologist for a baseline evaluation to determine if any school issues need to be addressed or if further testing is required. Follow-up

appointments are made as needed. The family then meets with the social worker for a psychosocial evaluation and a registered dietitian for a nutritional evaluation. Next, the child sees our recreational therapist, and, if needed, our physical therapist, to address exercise and therapeutic interventions. All these practitioners provide information and education, whenever appropriate. Toward the end of the visit, a medical librarian meets with the family to provide educational resources and guidance in using the web for further resources. Finally, the family meets once more with the NP to review the day's findings and receive any needed referrals.

Although it has been in existence for less than a year and a half, families that have taken advantage of the Long-Term Follow-Up Program have been very pleased with it and are eager to return for their annual appointments. And the program has an added benefit: it allows research coordinators at Hassenfeld Children's Center to track the late effects of chemotherapy and radiation, so that we can work toward strategies to prevent them in the future.

The Long Term Follow-Up Program is covered by most health insurance plans; in some cases pre-approval is required. To learn more about the program, or to make an appointment, contact Sandra: (212) 263-9907 or Erin: (212) 263-9935 at NYU Langone Medical Center.



Making Headway Foundation, Inc.
115 King Street
Chappaqua, NY
10514-3460
Tel: (914) 238-8384
Fax: (914) 238-1693
www.makingheadway.org

Making Headway thanks Linda Mudford-Lewis for her generous help with this newsletter. Special thanks to Erin Hartnett, Matthias Karajannis and Patricia Weiner for their contributions.

This newsletter is dedicated to our donors and supporters, whom we celebrate every day.

Managing Editors:
Robin Hardman
Audrey Manley

Photos:
Maya Manley
Todd Shapera

Design:
Cara Galowitz
Design Associates

Printing:
H & S Graphics

Below: Erin Hartnett with Hina Zahid.

