



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

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

Dr. Jeffrey Allen with Shalom Kayman.

New Directions for Making Headway

*A Message from Jeffrey Allen, MD
Director, Pediatric Neuro-Oncology, NYU Medical Center*

Making Headway Foundation's efforts to provide emotional and practical support for children with brain and spinal cord tumors and their families has succeeded beyond anyone's expectations. Any doubters need only spend a few hours at the Hassenfeld Children's Center, observing the smiles on children's faces as they create art, enjoy clown shows, do yoga, pet a dog, relax with a massage or play computer games—all while the IVs flow.

Beyond care and comfort, Making Headway's mission includes supporting efforts to improve treatment for the variety of tumors that affect our children. While surgery, radiation and chemotherapy can play an important part in treatment, each has its limitations. New drugs with fewer side effects that can target specific tumors are desperately needed.

What Science Tells Us

Cell biology is undergoing a revolution. Scientists have acquired the means to probe the genome of normal as well as cancer cells. As a result, we are learning that a tumor arises when very specific regions of the DNA in the nucleus of a normal cell become altered. The cell then often reverts to a more primitive, growth-promoting state, reactivating genes that were originally involved in forming the brain. But this time, there's a difference. When the genes in question were helping to form a fetal brain, other genes were on hand to inhibit an inappropriate proliferation of cells. In the cancer cell, these growth-promoting genes can no longer be restrained. Not only that, but new proteins develop on the surface of these cells, which can help the cancer cells survive and spread. The new cell populations that emerge in this way are capable of out-competing normal cells by generating new blood vessels, producing a mass in the brain where they arise and eventually spreading to other parts of the nervous system or beyond.

For many common cancers, scientists have begun to identify typical patterns of altered genes and the new proteins they produce. Receptor tyrosine kinases (RTKs) represent one class of these proteins. RTKs regulate many cell activities, including proliferation, new blood vessel growth and invasion. The medical research community and pharmaceutical industry have made enormous investments towards developing drugs capable of interfering with the activity of the RTK receptors of cancer cells. While most of the new drugs have been aimed at adult cancers, early research with pediatric brain and spinal cord tumor patients is starting to confirm that some of these drugs also have a positive effect on pediatric brain tumors—without the typical side effects of chemotherapy.

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Next Steps

Although cancers as a group share certain common mutations, each tumor type probably has a unique set of abnormally activated genes. Thus, we must study the specific genome of each type of tumor if we are to identify and then address the specific changes in DNA that have sustained its abnormal growth. But since pediatric brain tumors are relatively uncommon, it is unlikely that they will become the primary target of either pharmaceutical industry or NIH-funded research. This makes it imperative that we find other ways to raise funds earmarked exclusively for research on pediatric brain and spinal cord tumors.

Making Headway Foundation has already played a substantial role in facilitating this research. It has supported a full-time laboratory technician at NYU Medical Center to bank and preserve excess brain tumor tissue collected during surgery. The banked tissue, collected only with parental consent, is made available without charge to any scientist who submits a compelling research proposal. Tissue collected in this way is particularly valuable because it can be anonymously linked to a patient's clinical history, allowing researchers to correlate their scientific observations with actual clinical outcomes. The distribution of specimens from this tumor bank has already yielded important breakthroughs in laboratories not only at NYU Medical Center but throughout the U.S. and Canada.

Making Headway supports research in numerous other ways, as well. Last year, thanks to \$600,000 raised by many families, it began funding five innovative pilot laboratory research projects in pediatric neuro-oncology at NYU Cancer Institute. It also provides support to the clinical trials program through which new therapies are studied. Called "translational clinical research," this program requires a team of specially trained physicians, nurses and data managers. Funding from Making Headway helps cover the salaries of some members of this team.



Looking Ahead

This is just a beginning, however, and Making Headway has several ambitious goals for the next stage of the journey. It hopes to fund:

- a professorship in pediatric neuro-oncology to support present and future leadership of the clinical program;
- a pediatric neuro-oncology research laboratory which would recruit outstanding basic scientists and support staff; and
- a pediatric neuro-oncology clinical research program dedicated to translational research and new therapies.

Endowments for these programs will help insure a continuity of funding for this important work, regardless of the vagaries of pharmaceutical and NIH priorities. This security of funding will, in turn, increase our ability to recruit laboratory and clinical scientists of national renown.

We welcome input into the specific details of the laboratory and clinical research components, which are still under active discussion. For now, we anticipate the need to raise at least \$8-10 million over the next five years. Those of us who have relied on Making Headway Foundation to help us develop outstanding supportive care programs understand that these new goals will require a quantum leap in the scope of our fundraising. We will need to develop a cogent business plan and scientific rationale that explains our position with clarity and enthusiasm. We will need to reach beyond immediate friends and families to institutions, foundations and the business community.

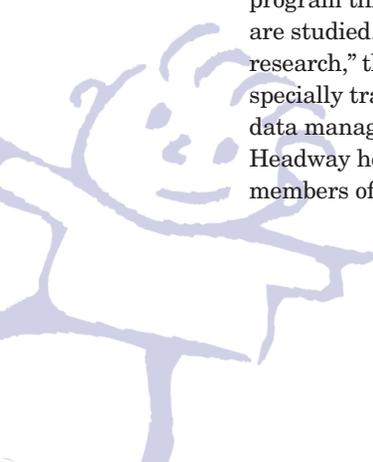
I would never have been able to accomplish many of my clinical career goals without the partnership of the families Making Headway serves. Let's come together and build on this strength to develop the premier pediatric neuro-oncology program in the country.



Top: Dr. Jeffrey Allen with Emily Ousouljoglou.

Middle: Lauren Lam.

Bottom: Jonah Shainberg.





Giving the Gift of Learning—
Announcing the Scott J. Reisser Memorial Scholarship Fund

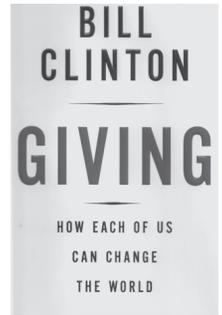
There was nothing Scott Reisser wanted more than to graduate from college. He worked extremely hard, despite learning challenges resulting from the surgeries, radiation and chemotherapy necessary to keep his brain tumor at bay. During his two years of study at Ramapo College, Scott excelled, earning induction into Alpha Lambda Delta, a national honor society for first year college students. He then transferred to the University of Delaware, where he managed to complete just one semester before his disease took a turn for the worse. Scott passed away in March, 2006.

In honor and memory of their son and brother, the Reisser family has established the endowed Scott J. Reisser Memorial Scholarship Fund. The purpose of the fund is to award scholarships to other brave survivors attending college or vocational programs. The scholarship committee is currently hard at work choosing the first recipient, who will be announced in late May. To learn more about the Fund and the application process, please call the Making Headway office at (914) 238-8384. 

Making Headway Showcased in Bill Clinton’s Book

“Making Headway is an excellent model for putting a good idea into action by asking for help from friends, family, neighbors, and those who share a passion for the cause.”

So writes President Bill Clinton in his latest book, *Giving: How Each of Us Can Change the World* (Alfred A. Knopf, New York, 2007). Clinton goes on to describe the history of Making Headway Foundation and the work we do, using it as an example of how simple, family-oriented fundraising events aimed at a gradually expanding network of family and friends can sustain a cause. We’re thrilled to have merited two full pages in this acclaimed book, and even more delighted that the former president donated a portion of his profits to Making Headway. Thank you, Mr. President! 

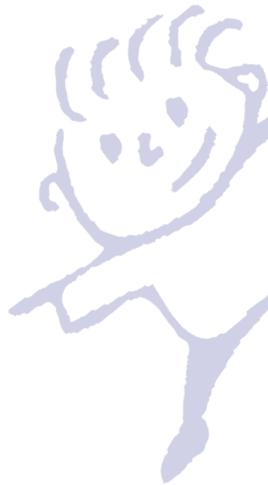


Top Left: Scott Reisser.

Bottom: Faith Griffin with Looney Lenny the Clown.

Announcing . . .
www.makingheadway.org!

Making Headway capped off a busy 2007 with the launch of our brand new website. Surf by and check out the brightly colored pages, filled with information about our work, news about events past and events to come, and pictures galore. The new site makes it easy for donors and those who want to help in other ways, with ideas for ways to contribute and a link to Paypal for making secure donations on-line. And if you missed a copy of our newsletter, you can find the full archive there, as well. Drop by for a visit soon!





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:

Teenage members of the **Horace Greeley Gridiron Club** scored a touchdown with their walk-a-thon, which raised an amazing \$13,288 for Making Headway.

Jeanne Egan and her family brought holiday fun and warmth to the Hassenfeld Children's Center when they delivered boxes of toys and soft, hand-crocheted baby blankets.

Once again, Bar and Bat Mitzvah teens were thinking generously and creatively. **Augusta Greenbaum** raised \$1,072 for Making Headway when she asked her friends and family to make donations in lieu of gifts on her big day. **Jake Harary** took the same altruistic stand, bringing in \$3,800 in donations. And **Alexandra Stein** decorated the synagogue with toys, rather than flowers, for her Bat Mitzvah—then donated the “decor” to Making Headway. Mazel Tov and thank you to these thoughtful young adults!

Ten-year-old friends **Lauren Lam** and **Stephanie LaPointe** were not too young to contribute their time and effort to the cause. The two sold their own hand-made magnets as well as more traditional items at a yard sale, bringing in a whopping \$1,272 for Making Headway.

Alice Ozaroff has requested that gifts in honor of her 80th birthday be made to Making Headway. To date, this selfless act has raised \$460. Thank you, Alice—and a happy birthday!

Making Headway Takes a Break

Time for a quiz: How do you do the Electric Boogaloo? What's the difference between “locking” and “popping?” *Essay:* Trace the history of Hip Hop Dancing from thirty years ago to today.

If you were able to answer these questions, it may be because you were among the 1,200 Making Headway families and friends who showed up for an extraordinary afternoon of fun and learning about a distinctive American art form, break dancing. *BREAK! The Urban Funk Spectacular* has brought its lively, interactive performances to audiences around the world. On January 27 it moon-walked its way into the Kaye Playhouse, delighting two sell-out audiences and earning \$500,000 for Making Headway Foundation. Now that's *sweet!*

Families Who Have Not Forgotten

Balls were flying at the fairways last fall as friends and families gathered to enjoy golfing and other festivities for a cause. Two recent events, in particular, suited Making Headway to a tee. On October 1, the sixth annual **Fore A Difference Golf Tournament**, hosted by Tracey and Stephen Casale, once again brought families together for a shotgun tournament, after which they feasted on a scrumptious barbeque lunch, enjoyed an awards presentation and tested their luck in a raffle. It was a lovely day, crowned by the \$48,000 it brought in for Making Headway. On the very same day the greens were busy at the Knickerbocker Country Club in Tenafly, New Jersey. One hundred fifty people showed up for **Driving for a Dream**, the Scott J. Reisser Memorial Scholarship Fund Golf Tournament. They golfed, dined, and bid up items at an auction, raising \$111,000 for Making Headway. The event was hosted by Joanne and Fritz Reisser.

Those lucky enough to attend the 4th annual **Thomas D. Fitzgerald III Memorial Walk** last June not only got exercise and fresh air, but had a lot of fun! In addition to the walk, the day included face painting, balloons, a raffle and a tasty barbeque—as well as songs and tributes. Not insignificantly, it also yielded \$2,000 for Making Headway.

Young musicians had a chance to practice their scales for a cause once again at the third annual **Aaron Gaberman Practice-A-Thon**, sponsored by Teri and Mark Gaberman in conjunction with the Suzuki Music School of Westport. Their hard work brought in \$5,259. Meanwhile, 45 boys and girls strutted their stuff on a runway at the **Looking Fabulous to Save Lives** fashion show, also sponsored by the Gabermans. The show yielded \$10,620. Both events were held to benefit Dr. Allen's clinical research program.



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

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Joanne Reisser with friends at the Driving for a Dream golf tournament.