



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.

Top: Dr. Jeffrey Allen and Dr. Fred Epstein.

Below: Nurse Erin Hartnett and Selina Jackson.

Future Prospects for the Pediatric Neuro-Oncology Program at NYU Medical Center

A Message from Dr. Jeffrey Allen, Medical Advisor

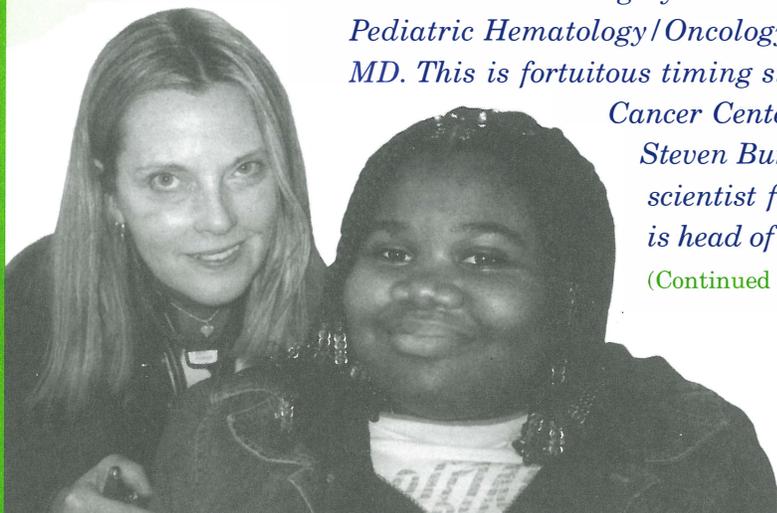
When Beth Israel Medical Center sold its Singer Division this past year, those at the Institute for Neurology and Neurosurgery (INN) witnessed the rapid dissolution of a unique multi-disciplinary program specifically designed for children with serious neurological disorders. The INN was created because of the vision and reputation of Dr. Fred Epstein and it succeeded because of the hard work and creativity of those who believed in his mission. We have all shared the frustration and sadness about the INN's untimely demise, recognizing the special people we had and how we miss them, including the gifted pediatric neuro-surgeons Fred Epstein, Rick Abbott, George Jallo and Karl Kothbauer; their dedicated nurse practitioner, Tania Shiminski-Maher; the always accommodating neuro-radiologist, Dan Lefton; the hard working pediatric neurologists, Walter Molofsky and Steve Wolf; the loving child life team headed by Honey Shields; the phenomenal nursing team; and the conscientious pediatricians headed by Ed Conway.



The Pediatric Neuro-Oncology Program is very fortunate to have been re-adopted by New York University Medical Center (NYU). There are great opportunities to improve on the quality of medical care as well as engage in clinical and laboratory research. As a large medical center, we have direct access to a greater range of pediatric sub-specialists and most of the medical needs of our patients can be handled within the institution. As a medical research facility, there are resources and a large community of scientists and their students who have dedicated their careers to the pursuit of understanding the biology of health and disease processes. Hopefully we can convince some of them to study our children's disorders.

We have been invited to integrate our Program with the Division of Pediatric Neurosurgery under the leadership of Jeffrey Wisoff, MD and Pediatric Hematology/Oncology under the leadership of William Carroll, MD. This is fortuitous timing since NYU has recently built a freestanding Cancer Center on 34th Street under the dynamic leader, Steven Burakoff, MD, a pediatric oncologist/physician scientist from Harvard Medical School. Dr. Burakoff is head of both the major basic science facility at NYU,

(Continued on next page)



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the Cancer Institute, as well as the Skirball Institute. He has placed a high priority on developing both clinical and laboratory neuro-Oncology and has appointed me Director of the Adult and Pediatric Clinical Neuro-Oncology Programs. We have the full support of the Dean of the Medical Center and the Director of the Cancer Institute.

Dr. Burakoff has appointed Moses Chao, PhD as Director of the Basic Science Neuro-Oncology Program and he has recently recruited four other investigators to submit a research application to the NIH which is designed to improve our understanding of the causes and identify potential new treatments for brain and spinal cord gliomas in both adults and children. I also plan to re-establish a pediatric neuro-oncology fellowship program and train pediatric neurology and oncology residents to take care of children with brain and spinal cord tumors.

NYU was my workplace for ten years (1986–96) before I moved to the INN. I can say with every confidence that our patients will have access to the highest quality of neurosurgical care from Drs. Jeffrey Wisoff and Howard Weiner, his associate. They are also hiring a third partner, David Harter, from the Westchester County Medical Center. I will share the oncology responsibilities with the entire Division of Pediatric Oncology, especially Sharon Gardner, MD. Many of you know Dr. Gardner because we have collaborated with her for many years when our children needed high



Top: Clinical Research Associate Jeena Chacko and Hina Zahid.

Bottom: Nurse Eileen Gillespie with Frankie Parasiliti.

Below: Dr. Jeffrey Allen and Anthony Parkin.

dose chemotherapy with peripheral stem cell support.

I was delighted when NYU generously offered to bring our pediatric neuro-oncology staff from the INN. Jose Acevedo, our child life specialist, still enchants children. Adam Auslander, our clown, continues to divert us. Eileen Gillespie, our skilled RN, is on hand full time. Erin Hartnett, PNP, our pediatric nurse practitioner, still works closely with me and other physicians, to secure the best care for our children. Jeena Chacko, CRA, our clinical research associate, continues to work diligently to obtain approval for our experimental treatment protocols. The Manleys and their staff at Making Headway grace us with their presence and with the support services they provide. NYU is also committed to enlarging the Hassenfeld Day Hospital in a new facility that should be constructed within the next 9–12 months.

As for me, I have never worked harder, both in intensity and number of hours, to make this transition a success. (Ask my wife!) However, I would and could not expend this effort if I did not believe that both my personal career goals and those I have set for the new Pediatric Neuro-Oncology Program at NYU were attainable in the near future. The conduct of clinical and basic research and the training of the future leaders in this field are readily accomplished at NYU. We continue to provide the highest quality of care to children with brain and spinal cord tumors and, together with Making Headway, we will continue to provide the personalized services that characterized our Program at the INN. We need all of your support and participation. 



Fall Fundraiser Waxes Joyful (No Pun Intended!)

Once again, thanks to the vigorous efforts on the part of Making Headway families and their friends, the fall fundraiser proved an enormous success, raising over \$400,000.

To celebrate, Maya and Edward Manley (under the steady gaze of a waxen Samuel L. Jackson) welcomed guests to Madame Tussauds Wax Museum on Sunday, January 23rd. All children received a gift shop voucher along with their ticket and held great expectations for the afternoon. They were not disappointed. The first stop was pure-party as visitors blew in Jennifer Lopez's ear and watched her blush; posed for a picture next to a bored been-there/done-that Madonna; and pitched balls to super-sluggo Derek Jeter. Kids got the biggest kick out of forecasting the weather with Al Roker and singing their favorite hit song under the watchful scowl of American Idol judge, Simon Cowell. The excitement was contagious. Parents tugged their kids over to meet their own idols: Helen Keller and Albert Einstein, Jimi Hendrix and Malcolm X, Salvador Dali and the Dalai Lama, Amelia Earhart and Andy Warhol.

The journey through Madame Tussauds was a blast but it wasn't over yet! Kids still had their vouchers. While there were no wax figures for sale, there was a "Wax Me" corner where kids could have their hands waxed in any pose. Those who didn't feel like dipping their hands in ice and liquid wax, opted for a unique I ♥ NY poster or crafty maze game.

By the time folks got back to the ground floor, one had to wonder: is that Maya and Edward or wax replicas? The warm hugs and sweet "Good-bye's" said it all. 🌱



Support Services from Making Headway

By Marcia Greenleaf, PhD

Dear Families,

The loss of the Institute for Neurology and Neurosurgery (INN) marked the end of an era for so many of us. We lost the setting whose design involved so many parents. And we lost Maya's magical playroom where children, parents, nurses, social workers, psychologists and physicians came for inspiration, cheer, refuge and amazing emotional and physical support. In the process of recreating this magic with the NYU staff, we want you to know that Making Headway continues to watch over and care for you. As long as there's a need, whether your child is in the first year of treatment or in the eleventh year of survival, we're available to support, guide, help and care for you.

While we've temporarily lost the intimate environment of the INN, we haven't lost the excellence in care that your children need. It will take time to get used to new surroundings in the various hospitals where your children are being treated and in the process, some of you may get discouraged or feel overwhelmed. Please turn to us—your support team—for help. No matter which hospital is treating your child, this is a service that Making Headway continues to provide for you and your family free of charge.

Lissa Parsonnet and I are available to help you manage the stress of diagnosis, recurrences, hospitalization, treatment and the impact of all of this on your family. Sallie Sanborn can help with your children. We offer help—especially by phone—with strategies and techniques to cope and deal with challenging issues from both hospital and home. To prevent losses in self-esteem, we help manage the problems that occur with your child who has the brain tumor as well as sibling reactions. Rebecca Mannis and Patty Weiner can help make sense of your child's learning difficulties, offer strategies to improve his or her ability to progress and help manage the overwhelming maze of people, places and forms in your child's school system.

With love,
Marcia



Marcia Greenleaf, PhD, Sallie Sanborn, CCLS, Rebecca Mannis, PhD, Patty Weiner, CCLS, and Lissa Parsonnet, PhD, and her team are available to help you. Please call the Making Headway office at (914) 238-8384.

Above: Dr. Marcia Greenleaf.

Bottom: Gene Jerskey-Long meets the Beatles at Madame Tussauds.



Superkids

Stories by Elizabeth Buttke

NICHOLAS

With a smile in his heart



A six-year-old camping in the woods might let his imagination run wild and see grizzly bears in the dark. But for seasoned camper Nicky, the

scariest thing that occurred on his family's 1996 camping trip was all too real. He looked across the road at his mother, Teri Mangione, and told her that he saw "two mommies."

For seven weeks prior, Nicky had been vomiting almost daily—getting thinner and thinner. Yet repeated trips to his pediatrician resulted in nothing more dire than diagnoses of food allergies.

With the onset of this new and alarming symptom, Teri became two mommies not just in her son's eyes, but in her determination to find both the cause and cure for his illness.

Nicky's pediatrician finally agreed to order a CAT scan, which found the cause. But when the doctor shockingly blurted out in front of Nicky that Nicky had a rather large malignant brain tumor and a slim chance of survival, Teri and her husband, Frank, proceeded to look elsewhere for the cure.

Their search led to Dr. Fred Epstein who, says Teri, "was like an uncle I never knew. He took charge and made us feel so safe and secure about things."

At the time, Nicky was only the third child to be admitted to the newly opened wing at the INN—where Teri and her family welcomed the much-needed support of the staff, other parents and Making Headway.

"I don't think we could have gotten through what we had to get through without it," Teri said, recalling the eight hours of surgery, the eleven days post-op

when Nicky was on a respirator, and almost three months of Nicky's being in a semi-vegetative state.

On top of that, Nicky had to endure six weeks of intense radiation followed by chemotherapy—to make sure every last bit of the cancer was gone.

Then there was the relentless rehab that Nicky needed. He had to re-learn just about everything he knew before his surgery: how to speak, how to eat, even how to sit up.

Nicky has come a long way since then. Now 14 years old, he has been in remission for 8 years. He has had surgery on his eye to help him see better, and several surgeries on his face to help him look better—because the thing Nicky misses most is his smile, which was affected by paralysis on the right side of his face.

But that doesn't stop Nicky from enjoying what he likes to do most. Outside of school, where he is in a special program that combines academic learning with physical, occupational and speech therapy, he loves drawing and playing computer games. He goes bowling with his 21-year-old sister, Tiffany, and goofs around with his brother Anthony, who is 20. He belongs to a bowling league, plays on a Little League team coached by his Mom, hangs out at the indoor baseball facility that his family owns, and goes camping every year.

Looking back, Teri has no regrets about any of the difficult decisions she and Frank made. She is confident they gave her son the best chance to be who he is today—"a little miracle boy" who hopefully will inspire other parents to never, ever give up on their children.

As for the ongoing challenges and deficits of the disease, Teri admits her son is not the same person he was before the long hard journey that began when he saw two mommies. But the way she sees it, she and her family have been given not just one, but two Nickys to love. 

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Top: Nicky Mangione.

Below: Peter Barbieri playing cards.

