

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:

Once again, **Marisa and Richard Stadtmauer** generously funded the annual cruise on **The Jewel**. One hundred and forty Making Headway family members enjoyed a delicious lunch and spectacular views of downtown Manhattan.

Meredith Seewald and friends donated the \$23 they made from their lemonade stand. The PTA at Meredith's school, **Mt. Pleasant Elementary**, raised \$4,554 for Making Headway in their annual walk-a-thon. **Tyler Epple's** school, **Abbey Lane Elementary School** raised \$298. **Springfield Gardens Middle School** donated \$1,000 through their Penny Harvest Program.

Bracelets and wristbands have been big this past year! Friends of the **Fitzgerald** family, **Brittany Sternberg** and **Meme Nichols**, sold blue jelly bracelets and donated the proceeds: \$600. The **Garone Family** raised \$500 when they sold Making Headway wristbands; **John Barrasso** raised \$135; and **Cassidy Tichner** raised \$50.

Brittany Marriott asked friends for Making Headway donations in lieu of her 11th birthday gifts, raising \$370. **Sara Weininger** gave \$2,500 in donations from her Bat Mitzvah. In honor of their Bar Mitzvahs, **Jordan Abramowitz** donated \$318 and **David Jacobson** gave toys for the children at NYU. In honor of **Michael Schwartz's** Bar Mitzvah, \$2,439 was contributed. His buddy, **Michael Salik**, donated an additional \$200.

Matthew and Jessica Greenzweig donated \$500 in lieu of wedding favors at their wedding. In memory of **Elizabeth Ryan**, **Laura Hall** donated \$500 in lieu of wedding favors.

Mack-Cali Realty Corporation chose Making Headway to be the recipient of the \$438 of donations they collected at their "Thanks for Giving" celebration.

Families Who Have Not Forgotten

Jeannie and Greg Trunz's ninth annual **Tulip Festival "All-is-onE" Dinner Dance** raised \$155,000 and honored Mindy and Sam Schwartz for their commitment and success in raising funds for research.

The **Little Bit of a Walk and Fun Run**, held yearly by Diane and Pat Ryan, raised \$22,000 for research.

Despite the torrents of rain that kept them from playing, the golfers who attended Lauren and Dan McKay's second annual **Kyle McKay Golf Tournament** enjoyed lunch and dinner, and raised \$23,000.

Christine and Tom Docu generously donated \$10,000 of proceeds raised at their fourth annual **Nicky Docu Memorial Golf Tournament**.

The Barbieri family held a barbecue fundraiser for family and friends in honor of their son, **Peter Barbieri**. They raised \$12,300.

Teri and Mark Gaberman organized the **Aaron Gaberman Practice-a-Thon** with support from the Weston Schools Administration. Students solicited sponsors for each minute they practiced. At their concert in June, Aaron and his fellow students presented Making Headway with a check for \$15,000, designated for research. It included proceeds from a previous concert featuring pianist (and brain tumor survivor) Matthew Zachary.

Family Fun Day

Maya and Edward Manley hosted their 14th annual **Family Fun Day** on June 19th. Each year, while their children swim, laugh and flutter from one fun event to the next, parents reunite with the special people they have met during their child's treatment: the dedicated professionals who, over the years, have become part of each family. This year, it was so lovely to see Renee Etra, Jean Donnelly, Adam the Clown, Erin Hartnett, Jeena Chacko, Eileen Gillespie and, of course, Dr. Allen and his lovely wife, Mary Dale. Photo-ops and secret service aside, it was wonderful to welcome back the delightful Senator Hilary Rodham Clinton and her charming husband, President Bill Clinton. 🌸



Above: Aaron Gaberman presenting a check to Maya Manley, Dr. Jeffrey Allen and Edward Manley of Making Headway at the Aaron Gaberman Practice-a-Thon.



Above: Timothy Roth at Family Fun Day. Photo courtesy of R.S. Walton Photography.

Bottom: Ellen and Megan Rasmussen at the Little Bit of a Walk and Fun Run.

support services

Our Twenty Something Support Group

By Justin Ferrelli with an introduction by Marcia Greenleaf, PhD

Many young adult survivors of pediatric brain tumors grapple with similar issues such as getting through college, finding (and keeping) a job and socializing. The idea for a twenty-something support group began when I received a call from a young woman who was ten years past diagnosis and treatment. Her request was simple: she wanted to connect with other survivors her own age with similar issues. With brain tumors, there are so many different recovery issues and stages, making the right match is important. I created a small group which met for the first time this past April. Justin Ferrelli was a big help and describes, below, his experience of the group. As we go forward, we hope other young adult survivors will be in touch with the Making Headway office so that we can help more young adults feel connected and able to move forward in the best possible way.

With love,
Marcia



I found that a compatible group of individuals made our group the therapeutic equivalent of an Oxford tutorial: the primary teaching and learning came from each other. The overlap of issues that we had was almost unbelievable. How much easier it would be to deal with childhood illness—of any kind—if one were able to discuss it with others in similar circumstances.

One of the nice things about working through issues as a part of a small group is that it permits the group to focus almost exclusively on one individual's concerns. The members of a small group can afford to do this because at the following

meeting the attention will be focused on someone else's.

I came to see this personally as I brought up an issue I wanted to address. The group generously and without hesitation turned to my questions about going solo to a party attended almost exclusively by couples. We didn't arrive at definitive solutions but several useful suggestions were made, most notably a comment about drawing confidence from something positive going on in my life.

As someone who makes sense of the world—even illness—by making connections between things which seem disparate, I couldn't help thinking of a newspaper article I had read about a group of trapped coal miners. The few who made it out alive were asked how they were able to survive. One of the miners said that the group as a whole sustained itself by focusing on the miner most in need at a given time. Among other issues, heat loss was a significant obstacle to survival. The group gathered around the individual most in need of warmth and insulated that person with their bodies.

This is an apt metaphor for the interactions that would ideally take place in any small group. They take place in our group in particular—be it a need to connect with other brain tumor survivors, a need to deal with relationship issues or awkward social experiences. The group members gather around the person most in need at any particular session. By doing so, we all end up better for it. 🌸



For more information about a Young Adults Support Group or other support services offered by Making Headway, please call our office at (914) 238-8384 or e-mail at info@makingheadway.org.



Above: Dr. Marcia Greenleaf.

Left: Justin Ferrelli.

Below: Amal Kharbouch.

in memoriam

Memorial to Fred Epstein, MD

By Dr. Jeffrey Allen

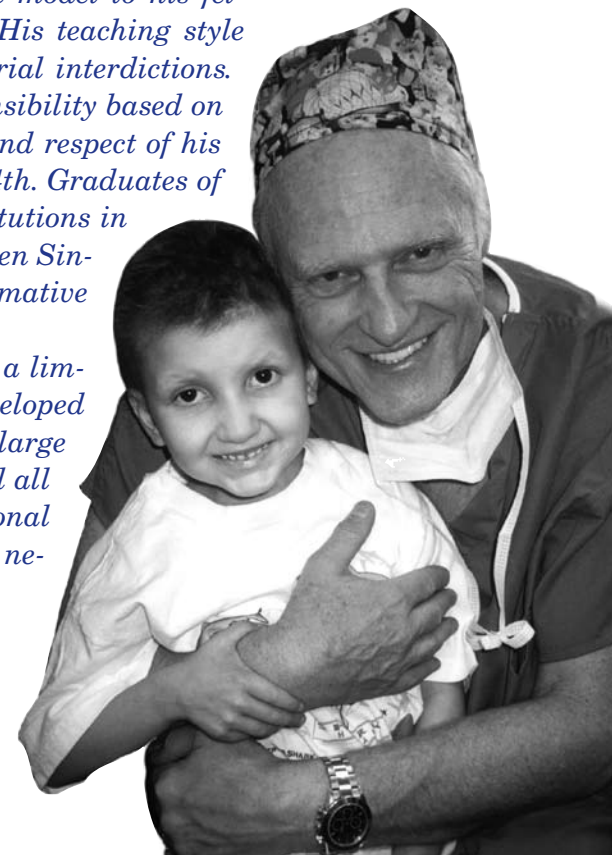
Dr. Epstein died on July 9, 2006, at home from complications of a malignant melanoma. I had the good fortune to partner with Fred for over 25 years as we unified our efforts to create comprehensive medical and supportive care services for children with brain and spinal cord tumors. Fred was the first Director of the Division of Pediatric Neurosurgery, created in 1985 at NYU Medical Center. Although he was trained and capable of treating a range of pediatric neurosurgical conditions, he remained passionate about the field of pediatric neuro-oncology. He ultimately was recognized as an international leader in the operative management of children with brain and spinal cord tumors and trained many fellows who are currently leading academic programs throughout the world.

Fred will be remembered for many reasons. As a surgeon, he had the courage to attempt to remove heretofore inoperable tumors in the brainstem and spinal cord. To enable this, he had to develop new technologies such as the Cavitron, a device which more gently fragmented tumors with ultrasonic vaporization without traumatizing surrounding healthy tissue. He encouraged the development of electrophysiological techniques to monitor the integrity in real time of vital neural pathways in the spinal cord so that the patient could be protected from harm even while under anesthesia. He insured that his operating room (OR) was equipped with the latest technology such as lasers, powerful operating microscopes, computerized navigation systems to assist in planning the safest route to a deep seated tumor and even an intra-operative MRI scanner to insure the completeness of the tumor resection before the patient left the OR.

As a teacher and mentor, he represented a unique role model to his fellows, both from a humanistic and medical perspective. His teaching style emphasized gentle persuasion rather than harsh dictatorial interdictions. Each trainee was granted graduated increments of responsibility based on knowledge and judgment. A testament to the adoration and respect of his trainees was apparent at his Memorial Service on July 14th. Graduates of his pediatric neurosurgery fellowship program from institutions in Manhattan as well as Cleveland, Denver, Worcester and even Singapore returned to honor Fred and acknowledge the formative role he played in their lives and careers.

Fred quickly realized that surgery was curative in only a limited number of conditions, that is, in children who developed low grade tumors amenable to total removals. This left a large group of children with unresectable low grade tumors and all of the children with malignant tumors who needed additional chemotherapy and/or radiation therapy. Fred foresaw the necessity (Continued on page 5)

Below: Dr. Fred Epstein with patient Shanna Church.





Continued from page 4

of collaborating with a person having training and interests such as mine—a pediatric neurologist with a knowledge of the medical aspects of neuro-oncology. We combined our efforts initially at a distance and eventually as partners and remained close friends, as well, for over 25 years. We first shared

mutual patients when I was an attending at Memorial Sloan Kettering Cancer Center and Fred was at NYU and then later when I joined him at NYU in 1986. Our Pediatric Neuro-oncology Program evolved rapidly during a period of dramatic technical and scientific development to comprise a large multi-disciplinary effort which included diverse medical subspecialties such as neurosurgery, neuro-oncology, neuroradiology, neuropathology, intensive care, specialized nursing, rehabilitation, child life, neuropsychology, endocrinology and social services. For a period of over 10 years at NYU, we managed approximately 10% of all children diagnosed with brain and spinal cord tumors in the US. Fred was aired regularly on Nightline and 20/20 and highlighted in Reader's Digest.

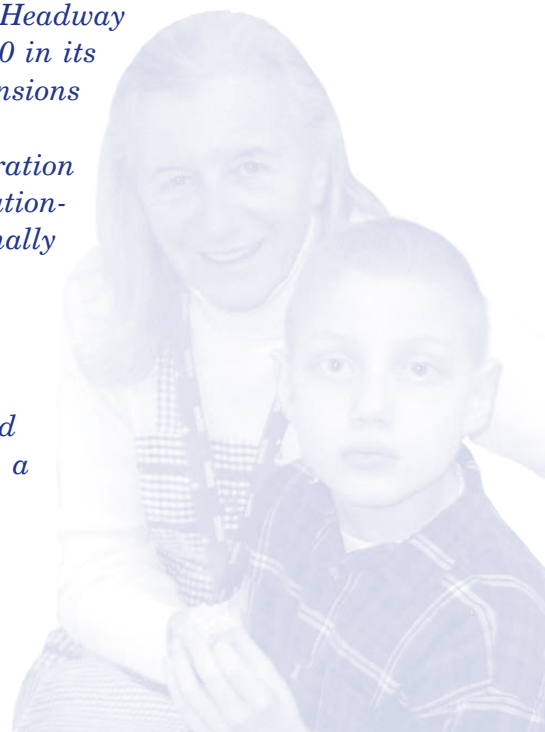
Fred soon realized that traditional hospital-based medical programs often failed to provide essential humanistic, spiritual and supportive care services that enabled the child to emotionally and physically reintegrate with his or her family, school and peer groups. With the raising of over \$50 million from Beth Israel Medical Center, a new home was established in 1996 at the Institute for Neurology and Neurosurgery (INN), in the former Doctor's Hospital on the Upper Eastside of Manhattan, where I joined Fred. There, we established a partnership with Maya and Edward Manley, the parents of a child I had treated. They wished to devote their energies to helping children and their families cope with the social and educational challenges that frequently accompany a serious chronic neurological illness. The Making Headway Foundation was established in 1996 and raised over \$400,000 in its first year to create complementary services to enhance the dimensions of Fred's vision of the INN.

From the INN's conception in the 1990's, and through its operation from 1996 until his accident in 2001, Fred remained the inspirational leader of a team of over 100 health care workers. He personally negotiated for the resources necessary to launch and maintain this unique program. He recruited most of the personnel and attracted the majority of the neuro-oncology patients. This was his ultimate dream.

Fred's accomplishments were well deserved but not achieved without perseverance, hard work and self-sacrifice. He had a

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

Bottom: Maya Manley with Alexander Storey.



unique, down to earth, welcoming personality and frequently took advantage of media opportunities to promote the program. Patients and their families loved and respected him and trusted him implicitly. His friendships with them were life long and he kept up by letter and phone. A little known fact was that he frequently helped numerous patients without neuro-oncology issues. If he was asked to review an MRI of a patient with a diagnosis which did not personally require his services, he would make every effort to find a physician with appropriate expertise.

Fred did have limitations, but like many persons who have enjoyed outstanding achievements, he was able to use many of these in a positive way. Although he had ADHD accompanied by significant learning difficulties, he was able to circumvent many handicaps with his intelligence and exceptional interpersonal skills and sensitivities. He channeled his boundless energies at work. Kathy, his devoted wife, tells us that because of his ADHD, he was used to frustration and defeat, but he tenaciously held to his vision and goals. I think he also learned much about competition and achievement through his love of sports. He was astute in recruiting medical professionals who supplemented his areas of weakness, and with motivation and encouragement from him, the success of the program both in the OR and on the hospital floors was profoundly enhanced. He loved fast cars, boats and bikes and even after his devastating bike accident and phenomenal recovery, he secretly ordered an adult tricycle which he used in his driveway.

What is Fred's legacy? Let the thousands of patients he treated tell you. He imparted incredible compassion and optimism which he even manifested in his own personal illnesses. If you ever mention his name in any public place in New York City, nearly every encounter will acknowledge some debt of gratitude or positive association as he personally or indirectly touched so many lives. Let the staff tell you what a pleasure and honor it was to work for him. Let his students tell you what a unique education and preparation they received as he generously shared his knowledge and experience. Let his family tell you that in spite of his long hours at work, he was always available to them and was completely devoted to their well being.

I do not think I will ever meet such a visionary, courageous and devoted physician. Fred served as a role model for many of us. My career accomplishments were intimately related to and dependent on my association with Fred and his pediatric neurosurgical colleagues, and the field of pediatric neuro-oncology was forever transformed by his presence. Fred would have wanted and expected all of us to continue his mission to advance the cause of children and their families afflicted with these devastating neurological illnesses.



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 Marcia Greenleaf, Justin Ferrelli and Jeffrey Allen for their contributions.

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

Managing Editors:
Maria Jerskey
Audrey Manley

Photos:
Maya Manley
Robin Walton

Design:
Cara Galowitz
Design Associates

Printing:
H & S Graphics

Above: Patrick Bowers.

Below: Luis Perez with his mother Elena.



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

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.

Above: Clint Greenbaum with his son Jake at Making Headway's first annual winter fundraiser in January of 1997.

Below: Lynn Nivins and her daughter Kait with Senator Hillary Rodham Clinton and President William Clinton at Making Headway's annual Family Fun Day. Photo courtesy of R.S. Walton Photography.

A 10th Anniversary Message from Clint and Elisa Greenbaum, Board of Directors

Please sing along: "Happy Anniversary to us, Happy Anniversary to us, Happy 10th Anniversary Making Headway, Happy Anniversary to us!"

Making Headway's 10th anniversary is somewhat bittersweet. We are an organization that wishes it didn't have to exist. We look back over the past ten years with pride about the accomplishments and sadness about the losses.

Making Headway's origins began in 1996 when the late Dr. Fred Epstein, along with Dr. Jeffrey Allen, began the Institute for Neurology and Neurosurgery (INN) at Beth Israel North. We wanted our foundation to give children with brain and spinal cord tumors a child-friendly hospital environment. The INN was like a modern, urban, kid's version of a M.A.S.H. unit. The hospital floors were routinely filled with clowns, music and sweet smells coming from Maya's playroom. Even Dr. Allen joined in the fun!

We had our setbacks. In 2001, Dr. Epstein suffered a serious brain injury as a result of a bike accident, leaving him unable to perform the magic of his surgeries. And then, in 2004, for reasons out of the control of Making Headway, Beth Israel North closed, marking the end of the INN as we knew it.

Dr. Allen and his team are now at New York University Medical Center, along with Making Headway.

While much has changed over the years, the hospital rooms of the pediatric brain tumor wing at NYU are still too full of patients. Making Headway has a lot of work to do. Our hope is the same as it was ten years ago: that we can accomplish our goal to cure childhood brain and spinal cord tumors, and that, along the way, we can fulfill our mission to care for and comfort the children and their families.

Over a period of ten years there are a lot of people to thank: the doctors, nurses, child life specialists, psychologists and clowns who have helped the children; the parents who run their annual fundraisers to benefit Making Headway; the parents who support our fall fundraiser by calling on their friends and families to buy tickets to the winter event; and the friends of Making Headway who generously donate their time and resources every year. We thank our administrators, past and present. And we thank our fellow board members, Ed and Maya, and Sam and his wife, Mindy, for their incredible work. And finally, to our long list of friends who have financially supported Making Headway over the years—THANK\$!

Even though you've sung the anniversary song and have been thanked doesn't mean you're off the hook. We continue to need your help now and in the future until the job is done.

