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

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Top-John Barrasso
Below: Meaghan Tully with her son Phil.
Each family whose child has been diagnosed with a brain or spinal cord tumor develops a quick and close relationship with their nurse practitioner. From diagnosis and treatment to recovery and long-term follow-up care, no one on the medical team is more intimately connected to the patient and family. It’s true that children undergoing chemotherapy in the care of Dr. Jeffrey Allen have distinct experiences, but Erin Hartnett, CPNP (Certified Pediatric Nurse Practitioner), plays a major role in each. She describes this role as the most rewarding and challenging she has ever had.

The intelligence and care that Erin brings equates to her specialized role as CPNP in neuro-oncology at NYU’s Hassenfeld Children’s Center. As what families of children with brain and spinal cord tumors need. This works out well for Dr. Allen, too. New York State requires the CPNP to work in a collaborative relationship with a physician. This relationship is a true partnership and most important to patient care. It’s clear that Dr. Allen and Erin Hartnett share a mutual respect and understanding. They have common goals and their different skills and styles complement each other. While Dr. Allen focuses on the illness, diagnosis and treatment, Erin works closely with the many outside organizations involved in the child’s continued care. Pediatricians, homecare agencies, occupational and physical therapists, schools, disability agencies, insurance companies, camps, hospice and equipment companies all need information (and many forms!).

Pediatric nurse practitioners are required to be recertified every year through continuing education credits or an exam. Erin keeps informed by reading professional journals and attending the Children’s Oncology Group meetings, nurse practitioner meetings, the Tumor Board, Pediatric Grand Rounds and several educational conferences throughout the year. Like the best care providers, however, Erin knows how to practice her practice than could ever be measured or recertified.

**Parents Who Have Not Forgotten**

Lauren and Don McKay gracefully and enthusiastically organized the first annual Kyle A. McKay Golf Classic in honor of their 2-year-old son Kyle who was diagnosed in 2004. Last spring, 116 golfers teed off at the Crab Meadow Golf Club in Northport raising $41,800. The June event was held by the Van Cortlandt Golf Classic. Above (bottom): Golfers and Dan McKay with Kyle A. McKay Golf Classic. The samples are then made available to operating room, flash frozen and stored. Nearly 160 specimens have been provided to researchers over the past three years, and eight papers have been published using the specimens distributed by Jeena.

The opportunity to engage in these clinical trials gives patients the best chances to experience a cure and facilitates the possibility of better treatments in the future. Jeena also oversees the maintenance of a clinical database that tracks all pediatric neuro-oncology patients at NYU. This resource—vital to a teaching institution like NYU—facilitates the preparation of many clinical research studies. Those will expand dramatically with continued funding from Making Headway.

**Fall Fundraiser Brings Winter Cheer**

Thanks to the hard work of Making Headway families and the generosity of their friends, the fall fundraiser proved a great success raising over $400,000. To celebrate, The Broadway Kids—a group of professional children who have starred in Broadway shows—sang and danced their favorite songs to a full house at two performances on January 29. The entire atmosphere of the Kasey Playhouse on 68th Street gave families a chance to say hi to each other away from the hospital atmosphere. Some, whose children have been out of treatment for years, marveled at how the children have grown. When the lights went down and the “Kide” pranced on stage singing “Tomorrow,” there was a sweet reminder of show-biz kid exuberance. Who hasn’t dreamed of getting up there and belting out, “The sun will come tomorrow;set your bottom dollar that tomorrow/there’ll be sun!” Adults and children alike were dazzled by the energy and flash of the terrific performances. Kas do go to Making Headway treasurer, Clint Greenbaum, for finding a great event and bringing sunshine to a rainy, January afternoon. What’s next, Clint?
Each family whose child has been diagnosed with a brain or spinal cord tumor develops a quick and close relationship with their nurse practitioner. From diagnosis and treatment to recovery and long-term follow-up care, no one on the medical team is more intimately connected to the patient and family. It’s true that children undergoing chemotherapy in the care of Dr. Jeffrey Allen have distinct experiences, but Erin Hartnett, CPNP (Certified Pediatric Nurse Practitioner), plays a major role in each. She describes this role as the most rewarding and challenging she has ever had.

The intelligence and care that Erin brings to her practice may be specialized, but the experiences of children and their families to review the progress.

Whether the child is treated in the hospital at NYU or as an outpatient at Hasenfeld, Erin liaisons with the staff and medical team as well as with Making Headway so that children receive the medical and psycho-social services that benefit them. Even after treatment, Erin works closely with the many outside organizations involved in the child’s continued care. Pediatricians, homecare agencies, occupational and physical therapists, schools, disability agencies, insurance companies, camps, hospice and equipment companies all need information (and many forms!).

Pediatric nurse practitioners are required to be recertified every year through continuing education credits or an exam. Erin keeps informed by reading professional journals and attending the Children’s Oncology Group meetings, nurse practitioner meetings, the Tumor Board, Pediatric Grand Rounds and several educational conferences throughout the year. Like the best care providers, however, Erin doesn’t believe her practice than could ever be measured. She’s learned that if you care for a parent as well as the child, you can see the difference you’re making a difference.

**Research Update**

Within the past year, Making Headway has funded two projects at the NYU Medical Center. The first is a $121,000 grant to support the Human Brain Tumor Bank. Making Headway previously funded the purchase of a minus 80 degree freezer and a technician to process and store tissue specimens. This grant covers the cost of a Research Technician and supplies. Pediatric and adult tumor tissue specimens are collected directly from the operating room, flash frozen and stored. The samples are then made available to research scientists at NYU, the Children’s Oncology Group (COG) research community and other research facilities to support their efforts to develop new biologically based therapies for brain tumor patients. Nearly 160 specimens have been provided to researchers over the past three years, and eight papers have been published using the specimens distributed from the bank.

The second grant covers the salary of Jeena Chacko, Clinical Research Associate and Coordinator of Protocol Development who has worked under Dr. Jeffrey Allen since 2004 at NYU. Because of her outstanding work in neuro-oncology, Jeena has been promoted to lead the Data Management Operations in the Division of Pediatric Oncology.

One of Jeena’s responsibilities is to coordinate the participation of NYU pediatric neuro-oncology patients in the COG clinical trials. COG is an international clinical trials organization coordinating clinical research for most childhood tumors. Over 350 children’s oncology centers participate from the US, Canada, South America, Israel, Switzerland and Australia. Jeena coordinates the submission of COG protocols to the Internal Review Board at NYU, a process that is becoming increasingly more complex: When a patient is eligible for a given protocol and informed consent has been obtained, Jeena registers the patient with the Operations Office in Los Angeles, and is then responsible to submit all reports of the patients’ progress as they complete the protocol. The opportunity to engage in these clinical trials gives patients the best chances to experience a cure and facilitate the possibility of better treatments in the future.

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**Making a Difference**

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Ninety golfers participated in the Nicky Doucet Memorial Golf Outing at Van Cortlandt Golf Course in the Bronx. The June event was held by Dan and Christian Doucet in memory of their daughter, Nicky. The Doucet generously donated $3,000 of the proceeds to Making Headway.

In September, the fourth annual Fuge A Difference Golf Tournament was hosted by Tracey and Stephen Caruso in honor of their daughter, Stophi, who was diagnosed in 1999. The event, held at the Roosevelt Golf Club in New Jersey, was attended by 118 golfers and raised $46,200.
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In September 2001, while the Barraisons were going through the trauma of 9/11 with the rest of the world, their own private world was shaken by the news that John’s tumor continued to grow. John would have to undergo surgery again—without Dr. Epstein, whom they had trusted so completely, because Dr. Epstein was referred to Dr. George Jallo, who is Dr. Epstein’s protégé. His protégé, Dr. George Jallo, stepped in to remove about half of John’s tumor. John was a few years older. They also met Dr. Allen, who gave John some medication that helped him right away.

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Before long, John developed another troubling symptom. He began feeling nauseous in the morning. A trip to his pediatrician resulted in more trips to more doctors: including a gastro-intestinal physician and an ear, nose and throat specialist. Eventually, an MRI found the cause of John’s illness: he had a tumor in his brain stem. As soon as the doctor delivered the devastating news to the Barraisons, he recommended Dr. Fred Epstein and set up an appointment for them to see Dr. Epstein the very next day.

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