

Superkids

Stories by Elizabeth Buttke

JOHN Going full speed ahead



In the winter of 2001 when five-year-old John Barrasso developed a cough, there was no reason for his parents, Alison and Peter, to suspect

anything more than a common cold. But when John's coughing became more intense and more persistent, they took him to their doctor.

Although the doctor originally thought it might actually be just a nagging cold and sinus infection, he ordered a CAT scan—which revealed that John's sinuses were in fact perfectly alright.

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 Barrassos, he recommended Dr. Fred Epstein and set up an appointment for them to see Dr. Epstein the very next day.

John's dad remembers the worry and fears the family experienced while sitting in the waiting room. John himself remembers Dr. Epstein's office the most. "It was really cool," says John. "And he had this brain, it would show you all the parts of the brain and where the brain stem is found."

When Dr. Epstein told them John's tumor was benign and could be taken care of, the Barrassos were greatly relieved. They learned the first step would be surgery, to be followed by radiation when John was a few years older. They also met Dr. Allen, who gave John some medication that helped him right away.

In May of 2001, Dr. Epstein was able to remove about half of John's tumor. John bravely recalls the experience in his own words. "I remember I drove like a little car into the operating room and then they laid me on the table and put me to sleep...."

He also recalls being very hungry when he woke up, and not being able to eat for a long time. The tumor turned out to be a pilocytic astrocytoma, which was in the medulla and impacted his swallowing. After surgery, they had to monitor his swallowing for what seemed like forever to a boy who absolutely loves to eat—even vegetables!

As difficult as that was, there were more difficult days to come. By summer John's tumor started to grow back, and Dr. Allen put him on a chemo regimen for a few months.

In September 2001, while the Barrassos 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 suffered a tragic bicycle accident that incapacitated him.

His protégé, Dr. George Jallo, stepped up to the plate and hit a home run. He removed 95% of John's tumor in mid-December. Less than a week later John was able to swallow well, and there were no deficits. His twin brother Andy and their cousins visited John with Christmas ornaments, but John was able to go home two days before the big day.

Today John is a fourth-grader with an A average, an award-winning artist who designs cars of the future and wins trophies for derby racing in cars he makes himself. He also likes writing, cooking and listening to pop, jazz and hip-hop. He has a huge collection of die-cast cars and is definitely on the fast track to a joyful life—with a head full of dreams and a brain so full of good ideas, it has no room for anything bad.

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Top: John Barrasso.

Below: Meaghan Tully with her mom Pat.



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

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Below: Sam and Mindy Schwartz with their children Mikey and Jackie.

A Message from Sam Schwartz, Board Member

I was honored when Making Headway recently asked me to serve on its Board of Directors. Not only do I share a commitment to the foundation's mission—the care, comfort and cure of children with brain and spinal cord tumors—but to serve with Ed and Maya Manley and Clint Greenbaum is very special to me. They represent the best people any charitable organization could have. I say this based on many years of seeing them act selflessly to help the children and their families. Ed, Maya and Clint have no interest in being personally recognized for their dedication, their service or for the substantial benefits their work on behalf of Making Headway has brought to so many children. They seek nothing but to advance the cause in tangible ways—putting a smile on a child's face while undergoing the difficulties of chemotherapy treatment or providing post-treatment educational support for kids (like our son Mikey) who have special educational needs.

I hope to bring to the Board of Directors an expansion of Making Headway's research efforts to make progress toward a cure for brain and spinal cord tumors. Great progress has been made in the last decade to substantially increase the survival rates for diagnosed children. I was very encouraged recently when Dr. Jeffrey Allen told me that the hope for the future is understanding the molecular biology and vulnerability of a specific tumor. That way, he said, we will be able to develop drugs that counteract the unique biology of the cancer cell without harming normal tissue the way radiation and chemotherapy do. Making Headway needs to do its share in devoting funds for research to accelerate the day when these diseases are no longer considered life-threatening.

My wife, Mindy, and I have seen first-hand the real difference Making Headway can make in the lives of children. Our son Mikey has participated in Making Headway's education support program for years and it has been highly beneficial in his significant educational progress post-treatment. Mindy and I were both so proud of Mikey as he achieved his Bar Mitzvah this past December. While Mikey chanted the prayers and spoke eloquently in Temple about his disease, I looked out in the synagogue and saw Ed and Maya and said to myself and later directly to them, "Thank you. Thank you for everything Making Headway has done for Mikey and all the kids." Now let's all continue the work to achieve the mission of Making Headway.



Skills, Knowledge, Experience and Care: Erin Hartnett, CPNP

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 equally to her specialized role as CPNP in neuro-oncology at NYU's Hassenfeld Children's Center are 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 focuses on the human experience of the diagnosis and treatment.

Erin meets families when they first come to Dr. Allen's office. She arranges the diagnostic procedures and, after a treatment plan is determined, she ensures that parents understand what needs to be done and that they feel comfortable

and supported while caring for their child. During treatment, Erin orders all bloodwork, medication and necessary procedures. She monitors each child's response to treatment and meets regularly with families to review the progress.

Whether the child is treated in the hospital at NYU or as an outpatient at Hassenfeld, 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 brings more to her practice than could ever be measured or recertified.

Parents Who Have Not Forgotten

Lauren and Dan McKay graciously 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, 112 golfers teed off at the Crab Meadow Golf Club in Northport raising \$41,800.

Ninety golfers participated in the **Nicky Docu Memorial Golf Outing** at Van Cortlandt Golf Course in the Bronx. The June event was held by Tom and Christine Docu in memory of their son, Nicky. The Docus generously donated \$3,800 of the proceeds to Making Headway.

In September, the fourth annual **Fore A Difference Golf Tournament** was hosted by Tracey and Stephen Casale in honor of their daughter, Sophia, who was diagnosed in 1998. The event, held at the Emerson Golf Club in New Jersey, was attended by 116 golfers and raised \$46,200.



Above (top): Lauren and Dan McKay with Edward Manley at the Kyle A. McKay Golf Classic.



Above (bottom): Golfers at the Kyle A. McKay Golf Classic.



Above: Christa Capaccio.

Left: Nurse Practitioner Erin Hartnett with Juan Ochoa.

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 tumor 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 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. These 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 hearts out to a full house at two performances on Sunday, January 29. The cheery, intimate atmosphere of the Kaye 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 "Kids" pranced on stage singing "Tomorrow" from **Annie**, it was a sweet reminder of show-biz kid exuberance. Who hasn't dreamed of getting up there and belting out, "The sun will come out tomorrow/bet your bottom dollar that tomorrow/there'll be sun!" Adults and children alike were dazzled by the energy and flash of the terrific performances. Kudos go to Making Headway treasurer, Clint Greenbaum, for finding a great event and bringing sunshine to a rainy, January afternoon. What's next, Clint?

Top: Clinical Research Associate Jeena Chacko with Kyra Torch at Family Fun Day in June of 2005.

Bottom: Dr. Jeffrey Allen with Francesca and Calvin Wagner and their three children at the Broadway Kids show.

