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 was 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 also recalls being very hungry after surgery, 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.
Profiles

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 is a true partner in this relationship with a physician. This relationship is a true partnership and most important to patient care. It’s clear that Dr. Allen, too, has a mutual respect for patient care. It’s clear that Dr. Allen is a true partnership and most important to patient care. It’s clear that Dr. Allen, too, has a mutual respect for patient care.

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Parents Who Have Not Forgotten

Lauren and Den 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. Lost event, 112 golfers took off at the Oak Meadows Club in Norwalk raising $43,800.

Ninety golfers participated in the Nicky Duce Memorial Golf Outing at Van Cortlandt Golf Course in the Bronx. The June event was held by Tom and Christine Duce in memory of their son, Nicky. The Duce family generously donated $5,000 of the proceeds to Making Headway.

In September, the fourth annual Kyle A. McKay Golf Classic was hosted by Trersey and Stephen Cardone in honor of their daughter, Sophia, who was diagnosed in 1996. The event, held at the Eisenhower Golf Club in New Jersey, was attended by 116 golfers and raised $46,200.

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 a Project on 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 those 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 hearts out to a full house at two performances on Sunday, January 29. The cheery, intimate atmosphere of the Kaye Playhouse on 508th 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 kids exuberance. Who hasn’t dreamed of getting up there and belting out: “The sun will come out tomorrow/bet your bottom dollar that tomorrow/it’ll be sunny.” Adults and children alike were dazzled by the energy and flash of the terrific performances. Ku and his Broadway Kids show.