



Child with infant botulism benefits from BIG treatment at MGHfC

An eight-month-old boy with infant botulism recently was treated successfully at MassGeneral Hospital for Children with a new FDA approved treatment that allowed him to recover faster and be discharged weeks earlier than the average length of stay for his condition.

Infant botulism is an intestinal-toxemia form of human botulism. It is the most common type and occurs when ingested spores of *Clostridium botulinum* colonize and grow in the large intestine. It is unknown how John Doe swallowed the botulism spores that activated to produce botulinum toxin. It is possible that he swallowed microscopic dust particles that carried the spores. Botulinum toxin is one of the most poisonous substances and can quickly become life threatening if the toxin is absorbed and moves through the bloodstream. Babies are thought to be vulnerable to spore germination, toxin production and ultimately contracting infant botulism because of their immature immune systems.

Diagnosing infant botulism is difficult because the toxin grows slowly over days or weeks, unlike the kind of human botulism that results from eating contaminated food items. Foodborne botulism is characterized by a rapid onset of disease after ingesting food with the botulism bacteria that produces botulinum toxin.

John Doe presented to MGHfC with the classic symptoms of infantile Type A *Clostridium botulinum* that included constipation and generalized weakness with cranial nerve findings. He had trouble breathing, developed eyelid drooping and pupil dilation. A flaccid paralysis developed so that the infant required a ventilator to assist with respiration in the Pediatric Intensive Care Unit (PICU).

After working closely with the Boston Department of Public Health to confirm the diagnosis, the team moved swiftly to begin infusion of the Human Botulinum Immune Globulin Intravenous (BIG-IV) or the FDA-labeled "Baby Big." BIG is enriched with antibodies to neutralize the toxin before it binds to nerves. It helps infants recover faster and experience less time on a ventilator and feeding tubes. It also reduces the hospital stay and costs by about half. The collaborative team effort was led by Kevin J. Staley, MD, Chief of Pediatric Neurology at MassGeneral Hospital for Children and included experts from Pediatric Infectious Disease and the PICU.

"There are only about 100 cases per year of infant botulism in the United States. It's particularly rare in New England, although we don't know why," says Dr. Staley. "Infant botulism is highly curable, but it's important to intervene early to reduce the severity of the illness and move the child toward recovery as quickly as possible."

Traditionally, treatment of infant botulism was limited to supportive care. But now, with the BIG-IV treatment and the expertise that provides early diagnosis, patients benefit significantly. "We were able to release John Doe one week after initiating treatment because of the efficacy of the BIG-IV treatment and the exceptional care by critical care and infectious disease experts here," says Dr. Staley. ■



Kevin J. Staley, MD, Kennedy Professor of Child Neurology at Harvard Medical School is the new Chief of Pediatric Neurology at MassGeneral Hospital for Children. Dr. Staley is a pediatric neurologist and replaces Verne S. Caviness, MD, DPhil, now Kennedy Distinguished Professor of Child Neurology and Mental Retardation, Harvard Medical School.

"In addition to the tradition of outstanding clinical expertise provided by the pediatric neurology department, we want to expand Dr. Caviness' highly regarded developmental research program, as well as initiate translational programs in epilepsy and neuromuscular disease," says Dr. Staley.

The department's interest in the pathophysiology of neonatal seizures and the different responses of developing vs. mature neurons' response to anticonvulsants has led to a new experimental therapy. The therapy is now being developed into a clinical trial. Investigations are also underway in clinical epilepsy and tuberous sclerosis.

"We have a tremendous opportunity in front of us," says Dr. Staley. "Our goal is to create new knowledge and expand our investigational activities. Enhancing our research efforts will help us develop new diagnostic and therapeutic approaches and apply them toward the many unsolved problems in child neurology."

Beyond borders: Newfound hope and a new home for Lu Yao at MGHfC

Already in her young life, Lu Yao Wang knows what it's like to journey far and experience the kind of upsets usually reserved for people decades her senior. Her ultimate triumph has been made possible by an international team of people who cared about her and remained focused on her success.

Lu Yao was born in China and spent the first five years of her life in the care of a woman she would consider her grandmother. At age four, she developed an orbital rhabdomyosarcoma. Lu Yao had surgery in China but needed chemotherapy and radiation. It wasn't available to her and the cancerous tumor returned with a vengeance.

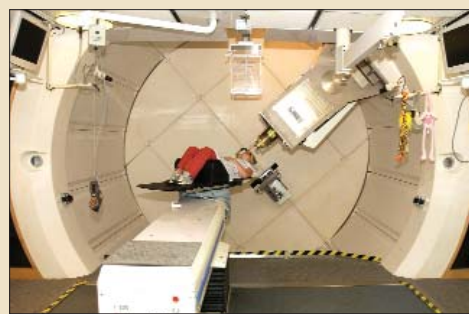
At that point, Lu Yao's caretaker felt that there wasn't much more she could do, so Lu Yao went to live in an orphanage. An American couple who were missionaries with an organization called Home of Hope worked with the orphanage where Lu Yao stayed. Home of Hope is a non-profit international organization that raises funds to improve the living conditions of orphaned and abandoned children.

The couple contacted Children's Medical Missions in western Massachusetts, an organization that finds host families for kids who need medical help. Ellen McDaniel, from Children's Medical Missions, then contacted Alison Friedmann, MD, a pediatric Hematologist and Oncologist at MassGeneral Hospital for Children. Dr. Friedmann had a clinical interest in Lu Yao's case and knew she could make a strong case for Lu Yao to receive care at MassGeneral Hospital for Children.

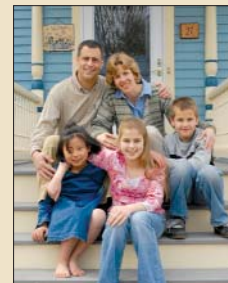
"By the time Lu Yao got here, she was quite ill," says Dr. Friedmann. "The tumor was infected and

completely covered her right eye and side of the face. But a CT scan showed her eye was still intact." Aaron Fay, MD, at the Massachusetts Eye and Ear Infirmary, performed the ocular plastic surgery Lu Yao needed to debulk the tumor. She also had six weeks of proton radiation therapy under the direction of Torunn Yock, MD. Lu Yao's integrated multi-disciplinary care at MGHfC included radiation oncology at the Francis H. Burr Proton Therapy Center, pediatric oncology and pediatric surgery.

"Orbital rhabdomyosarcoma is highly curable but we knew we needed to move fast with chemotherapy and proton therapy," says Dr. Friedmann. The Francis H. Burr Proton Therapy Center at Massachusetts General Hospital is one of five centers open at that time in the United States to use proton-based radiation to eradicate tumors and soft tissue sarcomas. It has led institutions on the cutting edge of radiotherapy.



In proton radiation therapy, protons are accelerated to near the speed of light in a cyclotron and are siphoned off into a beam. The beam has a defined range in tissue determined by the speed or energy of the protons. The major difference between proton radiotherapy and standard radiotherapy is that there is no exit dose to tissues beyond the



**Friedmann family.
Lu Yao, far left.**

tumor. This revolutionary approach spares normal tissue and thereby reduces side effects, a critical factor in developing children.

Dr. Friedmann developed a strong bond with Lu Yao throughout her stay

at MGHfC, and wanted her to be a part of her family. "My husband and I have two wonderful children but had thought about adopting internationally," she says. "When you meet Lu Yao, you see how funny and outgoing she is. She really captured our hearts. How could we not want to take her home?" Dr. Friedmann discussed her wishes with Howard Weinstein, MD, Chief of Pediatric Hematology and Oncology and her colleagues, who gave her their stamp of approval.

"Lu Yao didn't have a family. She needed one and she fits right in with ours," says Dr. Friedmann. "She's fluent in English now, after speaking Mandarin Chinese. Developmentally, she's right on track and is completing her first year of kindergarten." The formal adoption process is still pending, although the Friedmanns already consider Lu Yao a member of the family.

Lu Yao has regained her strength and her cancer is now in remission. She not only received the much needed care and affection, but also the expertise she needed, including the unique proton therapy exclusively offered at MassGeneral Hospital for Children. Her life today is about discovery and dreams. Lu Yao is living a better life because her heroes, both near and far, saved her. ■

MGHfC is a leader among pediatric hospitals in reducing medication errors

To reduce medication errors at the patient bedside, MassGeneral Hospital for Children (MGHfC) has implemented new “smart infusion pump” technology in its intensive care units as part of the hospital’s strategic efforts to increase patient safety.

In 2001, MGHfC participated in a study, which found that 13% of medication errors occurred during the administration phase. A multi-disciplinary team of experts at MGHfC, including Nathaniel Sims, MD, of the Smart Infusion Pump Learning Lab and representatives from Nursing, Pharmacy and Biomedical Engineering formed the MGHfC Pediatric Medication Process Team to study how to deliver medications safely in the most vulnerable patient population.

This effort was in place prior to the 2005 regulation by the Joint Commission on the Accreditation of Healthcare Organizations (JCAHO) to eliminate the Rule of Sixes at all pediatric hospitals by 2008, and convert to standardized concentrations as part of its National Patient Safety Goals.



The MGHfC Pediatric Medication Process Team’s goal was to eliminate the Rule of Sixes method of drug administration, establish standard concentrations for continuous infusion and implement smart infusion pump technology with MGHfC approved drug libraries. The team evaluated two types of “smart pumps” and conducted simulation trials in partnership with the Center for Medical Simulation in Cambridge, Massachusetts. The selected Medex® pump has now been in use in the intensive care units since summer 2005.

“We identified early on that something needed to be done to reduce the risk of medication errors,” says team member Kathryn Beauchamp, RN, Clinical Nurse Specialist in the PICU. “The timing of the JCAHO’s regulation was perfect, because MassGeneral Hospital for Children already was engaged in efforts to increase our patients’ safety.” In fact, MGHfC is one of the first children’s hospitals in the country to implement a pediatric drug library using standard concentrations to replace the Rule of Sixes.

The libraries are customized and determined by pediatric patients’ weight categories. Weight profiles have been identified for the pediatric drug library to guide dosing parameters, so the patient’s individual weight no longer drives the mixing calculations. The drug libraries contain standard concentrations with minimum and maximum dosing guidelines. With the new smart pump technology, the pharmacy prepares predetermined concentrations of drugs based on safe flow rates. In addition, the mixing guidelines are available at each bedside in a

book called the MGHfC Pediatric Medication Administration Process Manual. The Pharmacy Department provides par level inventories for each drug and concentrations are stored in each unit’s Omnicell automated dispensing cabinets. In an emergency, nurses can mix drugs at the bedside.

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— Kathryn Beauchamp, RN,
Clinical Nurse Specialist in the PICU

Also, soft “locks” on dosage concentrations assist clinicians to avoid under- or over-dosing and hard “locks” cannot be overridden to avoid over-dosing of electrolyte solutions. The technology is so advanced that it features bar code labeling to support wireless capabilities that will enable clinicians to calculate mixing concentrations from unit-based computers in the future.

“The collaboration among key clinical areas was instrumental to our success. Our new approach toward reducing medication errors also allows nursing staff to focus even more time on patient care,” says Beauchamp. ■



Cascades

NEWSLETTER TO PHYSICIANS **SPRING/SUMMER 2007**

New PICU now open

MassGeneral Hospital for Children opened its new, state-of-the-art Pediatric Intensive Care Unit (PICU) this spring! The expanded facility has been designed to support MGHfC's approach to family-centered care. It offers more bed capacity, equipment upgrades and additional amenities for families and staff.

All patient rooms are private and include sleep accommodations for family members, TV/DVDs for patients and headphones and individual televisions for parents. The family area includes

laptop computer hookups, internet access and a safe for valuables. Parents are invited to be with their child at any time during their stay in the PICU; there is no visiting hour policy in effect.

"The unit has the best available resources for pediatric critical care," says Brenda Miller, RN, PICU Nursing Director. "We look forward to caring for our patients in a new environment and to serving our referring physicians and families in a state-of-the-art manner."

The new
MGHfC PICU
now open

**For more information
please call us at**

617-724-4350

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