



MassGeneral Hospital  
*for Children*

# Pediatric Neurosurgical Services

*Providing children with family-centered, state-of-the-art care.*

# Ex world-renowned pediatric

Throughout this brochure are excerpts from interviews\* conducted with the families of four patients. Callie is now seven years old and we learn of her story through her mother, Maura. Ten year old Alex's story comes from both his own words via passages, printed as submitted, from an autobiography he wrote as an assignment for his fourth grade teacher, and from a discussion with his mother, Laurie. Illustrations in this brochure are from Alex's autobiography. Jake's mother, Moira, felt that by telling us the journey of her now ten year old son, she was in some small way saying thank you to the people who gave her child's life back to her. Sixteen year old Sam and his parents, Michael and Penney, recount the circumstances which brought them from an excellent community hospital to MassGeneral Hospital for Children. We are grateful to our patients and their families for their willingness to share their experiences with others.



The illustrations in this brochure were created by Alex Taylor as a part of his autobiography.



"My name is Alex and I am 10 years old. Two years ago I was diagnosed with a brain tumor. This story is about my journey through cancer treatment and the people who have helped me. From the beginning I have called this journey 'My Comeback'."

*excerpt from  
Alex's autobiography*

## The Pediatric Neurosurgical Service

*at MassGeneral Hospital for Children is world-renowned for its clinical accomplishments, state-of-the-art technology and pioneering research endeavors in the diagnosis and treatment of all neurosurgical conditions of infants, children and adolescents. Our faculty, recognized authorities in their field, work closely with multidisciplinary teams to bring our patients an unequalled level of experience and expertise. Our staff couples their superb medical skills with compassionate care that is comforting to children and reassuring to parents.*

MassGeneral Hospital for Children is a dedicated pediatric hospital within Massachusetts General Hospital, the first pediatric provider in Boston. While maintaining the integrity and atmosphere of a children's hospital, MassGeneral Hospital for Children thrives on the synergy that comes from being part of a larger hospital. We are in the unique position of seamlessly caring for patients from infancy through adulthood. Through our close association with our colleagues who treat adults, we can easily exchange ideas and extend all of the hospital's vast resources to our pediatric population.

Massachusetts General Hospital is consistently ranked among the top three hospitals in the country and its pediatric services in the top 1% in the nation by *U.S. News & World Report Annual Guide to America's Best Hospitals*. We were the first hospital in the nation to attain Level 1 verification in Adult Trauma, Pediatric Trauma and Adult Burn. Our Brain Tumor Center receives referrals from medical centers around the world to care for children whose care is most challenging.

"Jake had an identical twin who was lost at birth due to an umbilical cord accident. No one knew until Jake was six months old and having motor problems that he had suffered a stroke at the time of his birth that left him with left hemiplegia... At the age of five, he began having pretty severe seizures sometimes 10 to 12 times a day. The neurologist that we had been seeing at the time tried many medications, but we were getting nowhere and the medication made Jake groggy and at times, 'weird'. A friend told us about Dr. Cole, the director of the epilepsy program at Mass General. When we met him, my husband, Lance, and I felt instantly that Dr. Cole could do something for us. At our very first meeting, he talked of surgery as being a possibility for Jake's type of epilepsy. After trying medications for awhile, some of which would work for a week or two, Jake's care became a quality of life issue for Lance and me. We met with Dr. Cosgrove, a neurosurgeon, who believed that a functional hemispherectomy would cure Jake. He was right. Immediately after surgery Jake was seizure-free and still is now, two and a half years later."

*excerpts from an  
interview with Jake's mother*

# Expertise pioneering

"At age four, Callie had flu-like symptoms for a few days, but there was no fever or stomach pain...rather a terrible headache that seemed to have a rhythm and pattern. Our pediatrician ordered a CT scan at our local hospital. It revealed that Callie had a rare tumor in the pineal gland area, deep in the center of her brain. I was told it was 'untreatable, inoperable... there was nothing they could do'. Fortunately, both a friend of the family and my pediatrician had heard of Paul Chapman at MassGeneral Hospital for Children. At the point of being almost unconscious, Callie was immediately transferred there and had a shunt put in to relieve her pain. Dr. Chapman, who was away, was located and returned to the hospital quickly and over the next few days ran tests to gather as much information as he could before operating. The tumor was in the middle of Callie's brain and he had to separate the lobes to get at it. Saving Callie required the skills of a great surgeon."

*excerpts from an interview with Callie's mother*

**Mass General** is the largest of the Harvard Medical School teaching hospitals. It draws patients, scientists, physicians and students from all over the world. At MassGeneral Hospital for Children, we offer a large degree of subspecialization and experience and are the primary Partners HealthCare institution for pediatric neurosurgery.

Of special importance are the multidisciplinary clinics that bring to bear expertise within the MassGeneral Hospital for Children as well as facilities that are available within Massachusetts General Hospital, which is a world-wide referral center for the treatment of conditions requiring neurosurgery in patients of all ages. By working closely with our colleagues who treat adults, we are able to quickly apply advances in many areas, both common and rare, to children:



■ Fifteen percent of pediatric brain tumors are totally curable with surgery alone. For those tumors requiring more extensive treatment, our pioneering innovations in surgical techniques, chemotherapy and radiation therapy have led to minimizing adverse effects on cognitive and neuroendocrine development and improving survival rates.

■ Mass General has some of the most experience with pituitary disease in the world. We have much success in treating children with Cushing's disease and acromegaly.

■ Mass General has a large neurofibromatosis program, with emphasis on both scientific and clinical application, and was one of the first facilities to acknowledge the unique multidisciplinary problems that patients with neurofibromatosis and their families face.

■ We provide multidisciplinary management of inherited neurologic syndromes including Von Hippel-Lindau disease through a Neurogenetics Clinic.

■ Arteriovenous malformations are the most common cause of hemorrhagic stroke in children. Mass General performs more neurovascular procedures than any facility in New England, using a proven combination of surgery, radiosurgery and endovascular embolization.

■ After headache, epilepsy is the most common neurologic problem in children. Mass General offers a full range of medical management and all of the established and novel anti-epileptic drugs. When, after a careful evaluation of the child, surgical intervention is indicated, 60–70% of patients post-surgery become seizure-free or are dramatically improved, with the remaining patients having a reduction in their seizures.

## Among the surgical conditions for which MassGeneral Hospital for Children has special expertise:

Management of pediatric brain and spinal cord tumors

Vascular problems including arteriovenous malformations, aneurysms, moyo-moya disease

Hydrocephalus

Head and spinal cord injuries

Congenital anomalies of the spine and brain such as encephaloceles, Chiari malformations, syringomyelia, myelomeningocele, spinal lipomas, tethered spinal cord

All forms of surgical epilepsy treatment including cortical resections, lobectomies, functional hemispherectomies, callosotomies, multiple subpial transections, vagus nerve stimulation

"Deciding to proceed with a functional hemispherectomy for Jake was the most difficult decision we would ever have to make. We didn't know if the surgery would cause further damage to his left side. Up to this point, he used his left arm just a little, but he could run on his left leg. We even went out-of-state to get a second opinion, and were actually advised to continue trying more medications. But, we realized that we had a great deal of confidence that Dr. Cole and Dr. Cosgrove could cure Jake's seizure disorder. In fact, the night before his surgery, we were still deciding on a less radical surgical procedure, but the information Dr. Cole and Dr. Cosgrove gave us enabled us to make an informed decision about the course that we wanted for our son... Since his surgery, Jake is more coordinated, alert and receptive to learning. He plays on two soccer teams, enjoys tennis, swims, has an incredibly accurate one-handed basketball shot and is as bright as they come."

*excerpts from an interview with Jake's mother*

# Research Innovation

"It began when Alex was eight. He had been vomiting every morning and then more frequently. Several months and many tests later, our pediatrician gave us the diagnosis: Alex had a brain tumor. The tumor turned out to be cancerous... We felt like we were on a fast moving train that we couldn't get off... The staff at MassGeneral Hospital for Children gave us a great sense of hope because they had great confidence in what they were doing...and did everything they could to make it as comfortable as possible... Alex had proton beam radiation, which required him to stay very still. The radiation technicians would allow Alex to get up and scratch and wiggle. That may not seem like a big deal, but anyone who gave him options to control what was happening to him became his fast friend."

*excerpts from an interview with Alex's mother*

I met some very special people when I was sick. Dr. Ebb was my cancer doctor. I gave him a lot of trouble when I was sick, but now he is my best friend. Lois and Amy (radiation technicians) played Star Wars with me during radiation. Andy and Mac (valet parking attendants) were friendly faces when I visited the hospital. Anita (primary care nurse) who hates spiders played tricks on me when I came for treatment. And Bob (nurse anesthetist) held my hand during those MRIs."

*excerpt from Alex's autobiography*

**Committed** to offering children the most advanced treatment available, MassGeneral Hospital for Children pediatric neurosurgeons work steadfastly along with their counterparts in adult medicine to bring research innovations from bench to bedside.

Neurosurgery patients at MassGeneral Hospital for Children have access to resources found in few other facilities. The hospital is one of only ten facilities nationwide in the Pediatric Brain Tumor Consortium, and is also a member of the Children's Oncology Group, the primary North American Cooperative Group that develops clinical trials. As a result, our patients have quick access to innovative treatment of brain tumors.

Mass General pioneered stereotactic radiosurgery for use in treating brain tumors and vascular malformations in children and adults. This focused radiation technique substantially decreases the amount of radiation to normal tissue in selected, well-circumscribed brain tumors. Children also have access to unique, no-exit dose proton beam therapy, which directs radiation to the diseased tissue only. Special protocols for young children ensure that they can receive this radiation treatment more safely than other methods.

Mass General has some of the most advanced imaging capabilities in the world. In addition to standard CT and MRI, we offer PET (positron emission tomography) scanning for looking at the body's biochemical functions, functional MRI for providing 3D structural and functional brain imaging, MR spectroscopy for viewing the neurochemistry of the brain and special, high-resolution MRI scanning for furnishing exquisite anatomical views. MassGeneral Hospital for Children has the first FDA approved intraoperative MRI, which has axial imaging that allows our surgeons to operate through the smallest hole possible and view the brain from many angles during an operation in order to attain maximum tumor resection.



# T e c o m m u n i c a t i o n a m w o r k

**Technology** may drive the treatment, but it is the entire team of specialists working together that makes it all happen. We strive to organize all patient care through a team approach that is comprehensive, compassionate and personalized. At the core of the team are the child and the parents, who are involved in every decision along the way.

Based on the diagnosis, a child and family works with the pediatric neurosurgeon and a number of providers who specialize in the child's particular condition. This team meets initially to explore all treatment options and then presents their recommendations to the parents and, when appropriate, the child. Every specialist describes the steps that his or her therapy involves. Once the course of action is agreed upon, this team continues to meet as a group throughout the child's stay, making adjustments in treatment as warranted. This collaborative nature pushes the envelope to minimize complications and maximize efficacy in the management of the child's medical condition.

**Every child and family, based on their unique needs, has their own multidisciplinary medical team. Team members may include:**

|                                 |                                      |
|---------------------------------|--------------------------------------|
| Pediatric neurosurgeons         | Pediatric neurophysiologists         |
| Pediatric radiation oncologists | Pediatric epileptologists            |
| Pediatric medical oncologists   | Pediatric psychiatrists              |
| Pediatric anesthesiologists     | Pediatric nurse specialists          |
| Pediatric neurologists          | Child life specialists               |
| Pediatric neuroradiologists     | Social workers                       |
| Pediatric neuropathologists     | Occupational and physical therapists |
| Pediatric neuropsychologists    |                                      |



## Accessibility

**An essential element** of our pediatric neurosurgical service is our open and ongoing communication with all who are involved in the child's care. Our staff is dedicated to using their skills to evaluate the child, determine the way the child interacts with the environment, offer the best treatment options available and provide parents and the referring physician with enough specifics for them to make an informed decision about the child's care. After the child's surgery and discharge from the hospital, we continue to be easily available to complement the care provided by the child's pediatrician.

In keeping with our commitment to make our services easily accessible to the children and families we serve, MassGeneral Hospital for Children neurosurgeons also see patients for consultation at Newton-Wellesley Hospital and North Shore Children's Hospital.

"There is literally someone in place for every aspect of the child and family's life. The child life specialists would do all sorts of things with Callie, even coming to her bedside when she couldn't get up to play. The pediatric psychiatrist knew just what to say to both Callie and us. Our social worker was right on the floor and the nurses truly care about the children in their care... Callie was discharged after her surgery, with no follow-up therapy needed. Her check-ups since at the hospital have been good. At each of those appointments the whole team meets with us—Dr. Tarbell, the pediatric radiation oncologist, Dr. Ebb, the pediatric oncologist and Dr. Chapman, her pediatric neurosurgeon. In a way, seeing the other specialists there that Callie didn't need during her hospitalization is a reminder that Callie's tumor can recur. In another way, it's comforting to know that they are staying on top of her case and we know what to expect should her tumor ever come back."

*excerpts from an interview with Callie's mother*

"We liked the size of the brain tumor program—it allowed for personalized relationships and quick attention and response. Immediately after performing Alex's surgery, Dr. Butler brought Dr. Ebb, the oncologist, to meet us. Even before the confirmation of the pathology report, Dr. Butler was pretty certain of the outcome. We began talking that night about possible courses of chemotherapy and radiation treatment. At first my husband Bruce and I thought that Alex's medulloblastoma was going to be like a tonsillectomy—you just give some medication and the discomfort goes away... It was a phase of adjustment for us. But, it gave us some comfort when the doctors told us that everything that was happening to Alex was pretty normal. It was very clear that everyone involved in Alex's care was talking with each other."

*excerpts from an interview with Alex's mother*



# multidisciplinary Family-Centered Care

**At the very core** of our multidisciplinary team are the child and the parents. At each stage of treatment—evaluation, team meeting, family meeting, surgery, and follow-up care—we offer not only emotional support, but also intensive education. We respect that the family is the center of the child's life and welcome families to participate in every aspect of the child's care and encourage them to tell us their needs and those of their child.

We are committed to making the hospital experience as positive and comfortable as possible. In addition to the usual amenities a children's hospital offers, we also have:

- Rooming-in accommodations, including overnight stays adjacent to the Neonatal and Pediatric Intensive Care Units
- Comprehensive, one-on-one education for the child and family
- A back-up childcare center for the siblings of patients
- A comfortable, private, recently renovated and expanded surgical waiting area for patients' families
- Interpreter services for non-English speaking and hearing impaired patients
- An International Patient and Family Center offering translation services, assistance with accommodations, financial information and a wide range of guest services
- A chapel open 24 hours a day and a pediatric chaplain as well as access to clergy of every faith
- A family resource center containing the latest information about a wide variety of healthcare issues

"Once when Callie and I were out shopping, I looked at her incision and thought it might be opening up. I called Dr. Chapman using my cell phone and he said come in right away. So, we went straight from the store... I would call with questions all the time. There was always that access and availability. There weren't designated hours to reach some one. That would be torture for a family if there were."

*excerpts from an interview with Callie's mother*

"We live out-of-state and it was important to us that Alex receive as much of his follow-up care as he could near home. The MassGeneral Hospital for Children staff communicated all the time with our family pediatrician, and worked with our local hospital staff to treat infection between chemotherapy treatments."

*excerpt from an interview with Alex's mother*

# Pr o clinical f i l e s

## The following clinical profiles

provide more detail about Callie, Alex, Jake and Sam and the care they received at MassGeneral Hospital for Children.

**Callie.** Callie presented at age four years with a several day history of increasing headache, nausea, and drowsiness. A CT scan showed severe hydrocephalus secondary to a pineal gland tumor. An emergency shunt operation was done to relieve the raised intracranial pressure. The following week her benign pineal tumor was successfully removed in a six-hour operation. She has since then remained a normal, energetic child with no evidence of further difficulty on careful follow-up.

**Jake.** Jake presented at age 7 years old with severe, intractable seizures. He had a congenital left hemiparesis likely as the result of some perinatal/intrauterine insult. This left him with little or no useful movement of the left hand or arm, a weak left leg and a left homonymous hemianopsia. Nevertheless, he was able to run, attend school, play with his friends etc.

Video/EEG monitoring captured numerous seizures with a presumed right sided onset but these were poorly localized. MRI demonstrated a large porencephalic cyst and gliosis throughout the right hemisphere.

Jake had a large subdural grid of subdural electrodes implanted into his head over the right hemisphere to more accurately determine where the seizures began. The invasive EEG studies demonstrated seizure onset from the scarred cortex surrounding the cyst. We therefore performed a right functional hemispherectomy. He has done extremely well since surgery with no new neurological deficits. He has remained seizure free and is back at school and sports. He recently graduated from third grade with improved grades and is active in tennis, swimming and soccer.



**Alex.** Alex presented at age 8 with 3 months of progressively intense nausea and vomiting. Evaluation by blood test, abdominal CT, and endoscopy of his gastrointestinal tract however showed no abnormality. However when he developed headaches his doctors ordered a head CT scan, followed by an MRI. These studies showed a large tumor in the IVth ventricle, causing compression on neurological vomiting centers of the brainstem. His doctors then referred him to the Pediatric Neurooncology Center at MassGeneral Hospital for Children.

**Sam.** Sam presented at age 16 with vomiting for two weeks. He was admitted to North Shore Children's Hospital where his pediatrician realized that this was something more than the usual gastrointestinal illness. A CT scan revealed a tumor in the back part of his brain (cerebellum) that would require surgery. He was transferred to the MassGeneral Hospital for Children where multiple MR scans showed that this was his only tumor. The next day he underwent 8 hours of surgery. There was no visible tumor at the end of the surgery and none on the MR scan that was performed the next day. He was discharged 5 days following surgery and returned to school within the week. Unfortunately, the pathologic/microscopic examination of the tumor showed that it is a type that has a high risk of recurrence so that additional radiation therapy and chemotherapy will be needed to reduce his risk of recurrence.

"Callie was in bad shape when she was admitted to the pediatric ICU at MassGeneral Hospital for Children. I come from a very large family and they all live nearby. That night, the staff let the whole family into the ICU since no one knew what was going to happen to Callie... My mother just kept telling the doctors that they must have made a mistake... everyone was so patient with her and all of us. The entire team talked openly with us every day... I just knew Callie was in the hands of people who treated her case so personally... that whatever the outcome, Callie's father, Dan and I had made the right decision...we could sense the compassion and the level of caring... Dan and I needed that life-line relationship."

*excerpts from an interview with Callie's mother*

"I did have some fun during this experience... I got to go in the Bruin's locker room after a game and asked the players to sign my head with a permanent marker. The next day was Halloween and I had to go to Mass General for chemotherapy. We went trick or treating in the hospital and I went as an autograph book."

*excerpts from Alex's autobiography*

"When it came time to tell Jake that he was going to have surgery, I just didn't feel that I had the strength and courage to do it. I knew I would cry and that would make Jake feel afraid. I was so grateful when Dr. Cosgrove said he would tell him. He said, 'Jake, I have a way to stop the seizures'. When Jake heard that, he punched his right arm straight up in the air and said, 'yes!' 'But', Dr. Cosgrove continued, 'it means you have to have a little operation.' 'Okay,' Jake replied and then said to me, 'can we go to the gift shop now?'... Jake was very much into Star Wars at the time and called Dr. Cosgrove his Jedi knight—the savior who would make everything bad go away."

*excerpts from an interview with Jake's mother*

# Referrals

MassGeneral Hospital for Children is committed to making expert, state-of-the-art treatment available to children from across the community and beyond. The members of our network, which includes Newton-Wellesley and North Shore Children's Hospitals, as well as hundreds of community pediatricians and pediatric specialists, work together to ensure that this goal is met. The family of sixteen-year-old Sam, a patient diagnosed with medulloblastoma at North Shore Children's Hospital, describes this connection well:

"Sam's surgery went well and he now faces radiation therapy and chemotherapy. While he had his surgery at Mass General in Boston, he has seen Dr. Medlock for follow-up back at North Shore Children's Hospital. We had the convenience of our local hospital with the quality of care of a world-class hospital. For that, my family is very grateful."

Either families or physicians may make referrals to or inquiries about our Pediatric Neurosurgical Services by calling 617-726-3887.

Or you may refer to the enclosed insert (opposite) for specific referral information.

"Dr. Medlock is a pediatrician as well as a pediatric neurosurgeon. That combination gives him great people skills. Plus, he's very reassuring, competent and extraordinarily clear. When he gave us his card and told us to call him at any time, we knew he meant it. He suggested we keep a notebook and write in every person who came to treat Sam, record their name, what they did for him, and make sure we understood what they were doing. We continue to use that notebook to this day."

excerpts from an interview  
with Sam's father

"Having cancer has not changed my plans for the future. When I grow up I still want to be a goalie on the US men's soccer team and compete in the Olympics. I want to run the Boston marathon. And some day I want to build houses and drive a forklift. Having cancer has made me more aware of others who are going through cancer treatment. When I see people with cancer, I want to share my experience and offer encouragement to them."

"My comeback is still happening. I am getting glasses to help my double vision. I take medicine to fix problems caused by my treatment. And I am building my strength so I do not tire so easily. It has taken a long time to recover from this, but I am coming back!"

excerpt from  
Alex's autobiography



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\*While quotations are from MGH patients, photos are not.