

FACING THE FUTURE



FFC Celebrates 25 Years

Join us for our 25th anniversary celebration on May 19 from 6 to 11 pm at the Hyatt Regency Hotel in Cambridge, Mass. The semi-formal event will feature a sit-down dinner and dancing to live music provided by the "Four Guys in Tuxes." "We want to celebrate all that FFC has done for the past 25 years," says Ann-Marie Rogers, co-chair of the event with fellow Foundation board member Anne-Marie Gagnon. "We're hoping to have upwards of 250 people attend."

The celebration will include a slide show and talk by craniofacial surgeon John Mulliken, MD, who was instrumental in the founding of the organization. In addition, FFC will present its annual student scholarships.

Individual tickets are available for \$125. For information on tickets, program book ads, and other sponsorship opportunities, visit the FFC website at www.facesofchildren.org.

FFC Student Scholarships

Each spring FFC is pleased to award college and vocational school scholarships to young adults born with craniofacial differences. High school students or graduates living in New England (Connecticut, Maine, Massachusetts, New Hampshire, Rhode Island, or Vermont) are eligible to apply for the \$1,000 Jane C. McDaid Memorial Scholarships.

The application deadline of April 1 is fast approaching.

For more information, go to the scholarship application link on www.facesofchildren.org or call Mary Lania, scholarship committee chair, evenings or weekends at 781-255-8931.

This year's recipients will be honored guests at FFC's 25th Anniversary Dinner, where they will receive their awards.



Reshaping the Head: Treating Unilateral Coronal Synostosis

By John B. Mulliken, MD, Director, Craniofacial Centre, Children Hospital Boston

A baby's brain grows rapidly before birth and during infancy. The brain has room to grow, because, early on, the head is not solid. Instead, it consists of a number of bones, known as plates, separated by narrow openings. As the brain enlarges, the plates also gradually grow toward each other. The junctions where the plates meet are called *sutures*.

Sometimes, beginning during fetal development, these bony cranial plates fuse prematurely, a condition called *craniosynostosis*. As a result, the head fails to grow properly and becomes misshapen. Other bones, particularly in the hands, may also be affected.

Early fusion of the coronal suture is one of the most common types of craniosynostosis — occurring in about 1 in 10,000 births. This ring-shaped suture runs almost from ear to ear across the top of the head, behind the developing forehead. Premature closure can occur on both sides of the head (bilateral coronal synostosis) or only one (unilateral coronal synostosis or UCS).

The cause of UCS is unknown in most babies. In about 10-15% of affected babies, the cause is genetic mutation and is part of a syndrome. These mutations can be passed from one generation to the next in a family.

Examining Facial Features and Genes

Diagnosis of UCS is based on the child's physical appearance. Characteristic features present on the side of the coronal sutural fusion include: a flattened forehead, raised eye, deviated nose, and cheek that is slightly forward. Also, the ear is forward on the affected side (see drawing page 3).

Often the infant's head tilts upward on the involved side, which accentuates the asymmetry of the eyes and forehead. Known as ocular torticollis, this abnormal head position is adopted to compensate for an imbalance in the muscles that move the eyes and achieve binocular vision.

To ensure proper diagnosis and treatment, UCS should be managed by an experienced, interdisciplinary craniofacial team. The team geneticist can determine if the UCS is part of a syndrome caused by genetic mutation.

Two Types of Treatment

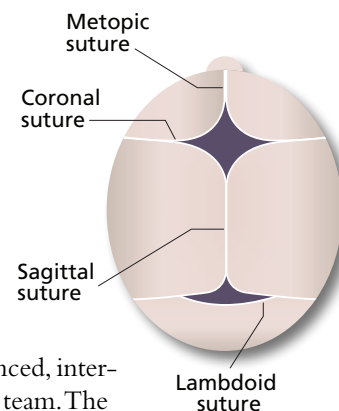
Babies with UCS need surgical treatment to reshape the head and align the features of the face. It is important that genetic testing be done prior to the corrective procedure because the DNA findings can help guide the surgeons.

The operation is typically performed by a neurosurgeon and plastic surgeon working together. There are two strategies for correction of UCS: 1) the traditional open technique and 2) the new semi-open endoscopic technique.

The standard procedure is done in late infancy, when the child is 9 to 10 months old. It involves repositioning the forehead and bony rims directly above the eyes, as well as straightening the nose. It also includes placing a paste of cells harvested from the cranium into the open areas between the plates to ensure complete healing.

The new procedure is a variation on the original operation for craniosynostosis, which involved cutting out a strip of the fused suture. This minimally invasive procedure, which is done before the child is three months old, uses an endoscope — a viewing tube — and small surgical instruments. The neurosurgeon inserts the endoscope through a small incision in the scalp and removes the fused side of the coronal suture.

Postoperatively, the baby's head is molded with a helmet for several months. This allows the growing



In Your Own Words

Madison's Story, By Teri and John Parks



We'll never forget when the doctor came into our hospital room on Christmas Eve day, only eight hours after our daughter was born, and said,

"We're taking Madison to have her head X-rayed because of the indentation on the left side. It may be a fracture that happened while she was going through the birth canal."

Both of our hearts sank. We were filled with shock and disbelief. One minute we were so caught up in the joy of bringing this new life into the world and the next minute we were facing an uncertain crisis. The X-rays taken had to be sent to specialists in New York City for more evaluation. Due to the holiday and lighter hospital staff on duty, we were not given a diagnosis of Madison's condition but were told there was no fracture to the skull and for now, treat her like a normal healthy baby.

The following week we took Madison to see her pediatrician, who suggested that we see a plastic surgeon in Syracuse who specialized in cleft lip and palate along with craniofacial issues. From that moment on, Madison's young life would be filled with numerous appointments with doctors, including neurosurgeons, plastic surgeons, geneticists, ophthalmologists, orthosurgeons, and not to mention several MRIs, CT scans, IV sedations, blood work, and surgeries.

Going into that first appointment, we saw babies with cleft lip in the waiting room and parents who looked as worried as we were. The doctor gave Madison an official diagnosis of unilateral craniosynostosis, a term that went right over our heads. As he described the details of the operation she faced in just a few short months and all the possibilities that come with surgery of this magnitude, we felt numb. As hard as we tried to listen and understand what the doctor was telling us, we couldn't retain anything or even believe this could be happening to our new family. It was truly devastating and the worst day of our lives.

After we got home that day, we received a phone call from our friend in Boston who offered to contact the neurosurgical team at Children's Hospital. The next morning the

surgeon himself, Dr. Proctor, called, and we explained all that had been told to us by the plastic surgeon in Syracuse. He said he was clearing a time slot in his schedule the next day for us to bring Madison to see him. We couldn't believe how fast things were moving and how positive the doctor sounded.

The next day we were there for our appointment. Sure enough, the diagnosis was correct, but the path we were about to take was much different than in Syracuse, where they wanted to perform surgery when Madison turned four months old. Our new team in Boston explained that they would wait until she was approximately eight months old—when the skull is soft enough still to manipulate by hand, yet hard enough to hold. We learned a clinical study showed 30 percent of the children who had this surgery at four months of age or younger had a relapse and had to repeat the surgery.

That day we met most of Madison's craniofacial team, including nurse Dotty MacDonald, who made us feel much more comfortable and confident in the success of her surgery. The fact that they performed three to four of this type of surgery per week compared to four to five surgeries per year in Syracuse and that families from all over the world brought their children with craniosynostosis to Children's Hospital Boston put us at ease and made us believe we were making the right decision for our daughter.

We finally felt like we could enjoy life with our baby. We had a great summer trip to Boston; Bar Harbor, Maine; and Nova Scotia that allowed us to take our minds off her surgery and just enjoy our baby girl.

In September 2004, we made our way back to Boston for her surgery. All the anticipation and worry for the last eight and a half months was finally going to be over. Our loving family and friends drove the five-plus hours from upstate New York to be with us. Their love, support, and prayers really got us through that stressful time. Madison's surgery team consisted of 23 people including doctors, nurses, and medical assistants, and took approximately nine hours. When we finally heard the words, "She did great, and everything went okay," the relief we felt was indescribable. Each doctor took time to speak with us after her surgery and answer all of our questions.

Immediately afterward, we spoke with the craniofacial team's ophthalmologist, Dr. Dagi, who explained that Madison had severe strabismus (eye crossing), which is common with children with craniosynostosis, and the next steps she faced. When we returned to Boston for her follow-up appointment, Madison received new glasses, and we got instructions to patch both of her eyes for several months to help correct the strabismus. She has since had three eye-muscle surgeries at ages 15 months, 21 months, and 4 ½ years.

Madison is 8 years old now, still wears glasses, and may possibly need to have one more eye-muscle surgery when she is a teenager. When she is 11 or 12 years old, she will also need dental work for problems caused by craniosynostosis. She has yearly checkups with her "team" in Boston.

Despite all the medical "adventures" she's faced in her young life, Madison is a healthy, very active 8-year-old girl. She plays hockey, lacrosse, swims, and does karate. Since we're a huge hockey family and believe in giving back, we connected with the Syracuse Crunch Hockey AHL team to arrange a charity hockey game to benefit the Foundation for Faces of Children.

This will be our 7th year participating and helping to raise money and awareness for the Foundation.

Our overall experience with Children's Hospital Boston's craniofacial team has been nothing but positive. The expertise and knowledge of the staff and genuine concern for the families who have children with craniofacial issues, in our eyes, is the best you can get. A year after Madison's surgery, they changed how they did that particular surgery due to updated research and new technology. The resources and information that Children's Hospital Boston makes available to families through the Foundation for Faces of Children attest to how excellent this organization is. We absolutely made the right choice for our Madison. ■



Baby Madison before her operation.



Women's Event a Success



On March 4, FFC held its first-ever women's event, "Brunch with Dotty," at the Embassy Suites in Waltham. A celebration of mothers of affected children and those who support them, the brunch drew a crowd of 115 women.

Craniofacial nurse Dotty MacDonald, RN, BSN, was the featured speaker. She spoke of her career at Children's Hospital Boston and the many physicians who have influenced her. In particular, she described how John Mulliken, MD urged her to find a passion, which she did — helping families understand cleft lip and palate. Dotty is currently working with FFC to produce an educational video on infant feeding, which will be released before the end of the year.

Some in attendance took the opportunity to publicly thank Dotty, including Jeanne McDermott, author of *Babyface*, and Hilary Hardman-Henning, an adult patient of Dr. Mulliken.

The event included a PURSEnality raffle with prizes of vintage purses by designers including Gucci, Ferragamo, Coach, and more. Many thanks to Closet Exchange in Needham for generously donating the handbags.

"The brunch was a huge success," says Ann-Marie Rogers, who co-chaired the event with fellow FFC board member Anne-Marie Gagnon. "We're already discussing making this all-women brunch an annual event."

Our thanks to this dynamic duo and to Terri Lowenthal, formerly of Children's craniofacial team, for making this a warm and wonderful occasion. We are also grateful to our raffle prize donors: Community Music of Needham, Elissa's Creative Warehouse, Fabric Place Basement, Grey Goose, Joanne Poirier (Avon), Life is good, Lola Tortola, Midtown Smokehouse & Grill, Not Your Average Joe's, Sew Easy, Taylor's Stationery, and Treat Cupcake Bar.

A personal note from Dotty MacDonald:

"Thank you to all my friends and family who came to the brunch. I was overwhelmed with all your stories and good wishes. As I said in my talk, 'I taught the moms and the mothers taught me.' I thank all of you from the bottom of my heart. I hope we can continue this tradition and honor other women who continue to influence our lives and work."



The first-ever FFC women's event drew 115 women.

Zumba Fitness Fundraiser

More than 100 Marlborough High School students and teachers danced to a Latin beat to benefit the Foundation for Faces of Children on November 22. The "Zumba for a Cause" fundraiser, sponsored by the school's chapter of the National Honor Society, raised over \$1,000 for FFC, while increasing awareness of craniofacial differences.

When the honor society proposed using Zumba — a popular dance exercise — to raise money for a charity, high school senior Laura Silverman was quick to nominate FFC. Laura's brother Connor, 13, was born with Apert Syndrome, a premature fusion of skull bones that affects the shape of the head and face, and fingers or toes.

"They voted for Laura's idea," says her mother Jane, "because they loved being able to do something to help children with craniofacial differences and to indirectly benefit one of their members."

The students created "Zumba for a Cause" buttons and sold them as tickets to the event. Four

local Zumba instructors volunteered their time to support FFC.

At the event, held in the school gym, the instructors took turns leading 45-minute workouts with refreshment breaks in between. Laura explained to those taking part about FFC's efforts to provide educational information to families and offer scholarships to students with craniofacial differences.

To thank them for their contribution to the cause, instructors received gift bags with FFC T-shirts and caps, and all participants were given teal FFC wristbands.

Go to *Connor's Book* under "News and Events" at www.facesofchildren.org to see the picture book created by Jane Silverman to teach Connor's kindergarten classmates about his condition. ■



Treating UCS

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brain to expand the opened suture and improves symmetry of the forehead and eye sockets.



A child with left-side UCS

Outcomes

Corrective procedures can improve the asymmetry of the child's forehead and eyes so much that any residual differences go unnoticed. However, as the child grows, a slight flattening of the forehead may reappear on the affected side. About one in three children require a minor correction of the forehead, which usually involves adding a bony substitute as a veneer. Sometimes a major secondary operation is necessary; this is more likely in a child with syndromic UCS. Operations to correct eye muscular imbalance usually alleviate the head tilt.

When the child is older, parents may note a slight rotation of the lower two-thirds of the face (nasal tip, chin, and dental midline) toward the non-affected side. This usually is a minor issue and rarely requires more than orthodontic adjustment.

Studies are in progress comparing the outcomes of the traditional operation to the newer endoscopic approach. ■

Meet a Foundation for Faces of Children Board Member

Ann-Marie Rogers



When Ann-Marie Rogers's first child, Daniel, was born with a severe unilateral incomplete cleft lip and palate, she was shocked and totally unprepared. Unfortunately, so was the staff at the small local hospital where she delivered, leaving Ann-Marie to wonder how she could feed and care for her infant.

"It made the experience that every mother dreams about turn into days of unanswered questions, misplaced anger, and swagging emotions," she says.

Then Ann-Marie went to Children's Hospital Boston, where a volunteer from FFC approached her in the waiting room as she sat holding her three-day-old infant and silently crying. "I only now know how much my son and I benefited from that short 10-minute conversation," she says.

During this first visit, Ann-Marie met with Craniofacial Centre nurse Dotty MacDonald, who she credits with saving her son's life. She watched with amazement and relief as Dotty cradled Daniel in her arms and got him to drink a whole bottle of milk. "It's going to be okay," Dotty reassured her, and for the first time, she believed it would be.

After Daniel's birth, Ann-Marie left her full-time job working for an insurance broker to become a stay-at-home mom. Six months later, she unexpectedly discovered she was pregnant again — this time with an unaffected girl.

Caring for a toddler with a cleft as well as an infant led her to join the support group Prescription Parents. Soon she became a

board member and the newborn coordinator in charge of sending information to interested parents. For more than 10 years, she helped plan the group's monthly meetings and events.

A year ago, following the partnership of Prescription Parents with FFC, Ann-Marie joined the Foundation's board. She brings both experience and a "can-do" attitude and has already volunteered to co-chair the "Brunch with Dotty" and FFC's 25th anniversary party this spring. (See "FFC Celebrates 25 Years," page 1.)

"I'm truly grateful for my FFC family and for all Dr. Mulliken and his staff have done for my son," says Ann-Marie. "This is a way to pay forward a little. Plus, I've met some wonderful people who I'll be friends with for years to come."

In addition to volunteering, Ann-Marie currently works part-time as a transaction coordinator for a real estate company. The Newton native now lives in Framingham with her husband and two children, Daniel and Emily, her stepdaughter Michele, and her three-year-old grandson Lucas.

So far, Daniel has had five surgeries, most recently a bone graft in November 2010. Ann-Marie describes her life now as "smooth sailing," but adds, "as smooth as it can be with a cleft-affected, 11-year-old pre-pubescent son." ■

The Foundation for Faces of Children is dedicated to improving the lives of children with craniofacial differences, including cleft lip, cleft palate, and other head and facial conditions.

Our mission is to:

- Provide patients and families with the most accurate, up-to-date, and accessible information about facial differences.
- Advocate for the best care possible for children with facial differences.

We achieve this by:

- Collaborating with leading specialists.
- Endorsing the team approach to care.
- Partnering with individuals and organizations with similar goals.

We are a not-for-profit organization entirely supported by private donations, grants, and fundraising initiatives. Please contact us if you would like to participate in or sponsor a fundraising event.

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