

FACING THE FUTURE

2013 FFC Scholarships

Applications are now being accepted for the 2013 Jane C. McDaid Memorial Scholarships. The Foundation awards these post-secondary education (college or vocational/technical school) scholarships annually to promising students born with a facial difference.

High school graduates or students currently attending college who are residents of New England (Connecticut, Maine, Massachusetts, New Hampshire, Rhode Island, and Vermont) are eligible to apply for the \$2,000 scholarships. The Foundation selects award winners based on their academic performance, extracurricular activities, and community service.

Applications are due April 1. 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.

Infant Feeding Video to Debut



Feeding a newborn with a craniofacial condition can be frustrating and worrisome for parents. Infants may have trouble getting the nutrition they need due to a lack of suction ability, airway obstruction, or uncoordinated sucking and swallowing. Slow weight gain may jeopardize the health of the infant and delay repair of a cleft lip and palate.

Help is now on the way in the form of a new instructional video, "Cleft Lip and Palate: Helping the Newborn Thrive." The 40-minute feeding guide, designed for clinicians, parents, and other caregivers, will debut this spring. FFC will distribute the video, along with a manual, to neonatal intensive care units, the

American Cleft Palate Association, and new parents.

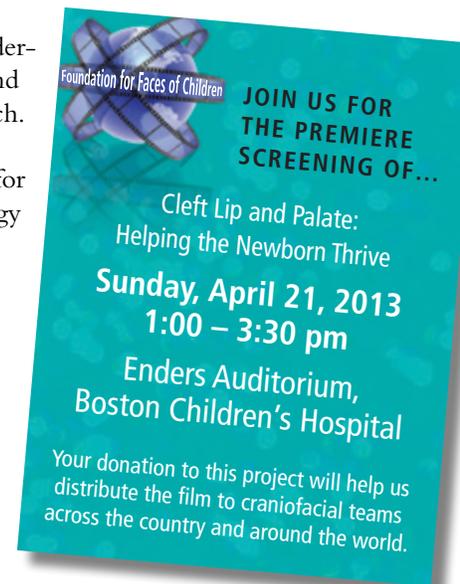
Each week Dotty MacDonald, RN, of the Craniofacial Centre at Boston Children's Hospital, sees two or three babies who have feeding issues. "To nurture, you have to nourish," says Dotty. "Learning modified feeding techniques can help ensure that babies receive adequate nutrition."

The video features a variety of topics, including: the role of genetics, understanding physiology, nursing support, nutritional needs, feeding your baby, and Robin sequence. Viewers can randomly select the sections they wish to watch.

Dotty launched the much-needed educational project at the urging of a pediatrician from Chicago. "There is not really good technical information for parents or clinicians," says Dotty. "It is important to understand the physiology of a baby's suck and swallow."

A team of experts at Children's, including nurses, a nutritionist, speech pathologist, and geneticist developed the concept for the video. Toby A. Smith wrote the script, and Robert Dressig of Playback Inc. served as director and producer. The production was made possible thanks to the generous support of the Patricia Gallup Foundation and other contributors.

In addition to professionals, parents "star" in the video. They talk about their own experiences and reassure other caregivers that they can succeed. By learning simple techniques, they emphasize, parents can find feeding pleasurable and a wonderful way to bond with their baby. ■



Remembering a Pioneering Surgeon, Scientist, and Teacher

by John B. Mulliken, MD

Plastic surgeon, Dr. Joseph E. Murray, died at age 93 on November 26, 2012 at the Brigham and Women's Hospital, where he performed the world's first successful human kidney transplant between identical twins (1954). Dr. Murray was awarded the Nobel Prize in 1990 for this landmark operation and other groundbreaking contributions to organ transplantation.

Although famous as the "Father of Transplantation," Dr. Murray devoted his later career to craniofacial surgery, especially in children. He did the first midfacial advancement in the U.S. (1996) in a boy with Crouzon syndrome. He started the first plastic surgical training program in Boston and was the chief of plastic surgery at the Brigham and Children's Hospital from 1969 to 1986.

Dr. Murray stressed the importance of working as a team. He and his young colleagues, Dr. John Mulliken (plastic surgeon), Dr. Leonard Kaban (maxillofacial surgeon), and Dr. Joseph Upton (hand surgeon) formed a world-renown craniofacial center. Dr. Mulliken recalls that Dr. Murray taught him to think logically about clinical problems, but most importantly, he passed on to all those privileged to work with him, the qualities of curiosity, compassion, and boundless optimism.

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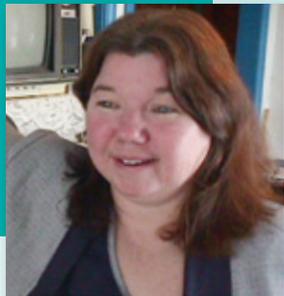


Dr. Murray (third from left) with Drs. Leonard B. Kaban, Joseph Upton III, and John B. Mulliken at his 90th birthday celebration in 2009.

Photo courtesy of A. P. Chiu, MD

In Your Own Words

Barbara Hartley Seltzer, past president of Prescription Parents, a support group for parents of children with cleft lip and palate, died on December 4, 2012 at age 62. She was active for 29 years with the organization, whose board of directors merged with the Foundation's board in 2010. Barbara and her husband Richard's third child, **Michael**, was born in 1980 with bilateral cleft lip and cleft palate. She wrote the following when he was a teen:



Seventeen years ago I became a parent—again, but it could have been for the first time—so many things were different and new. On June 14 my son Michael was born with a complete bilateral cleft lip and palate. The experiences I lived through helped me grow and mature as a person. Having Michael taught me the true sense of responsibility. A child came into the world who needed me and showed me what courage is.

Mike is my stubborn one, the one who won't be told what to do. He is an extremely private person, but he also is my child with a heart. He's the one whose life has been most out of his control. He would get involved with sports, but have to stop for fear of hurting his repair. He was teased when young because he looked different and talked different. He always had operations and speech therapy and occupational therapy and orthodontics to look forward to.

Michael was born on his due date. He was eagerly anticipated by his brother Bobby, aged 5, and his sister Heather, aged 3. I had an ultrasound earlier in the pregnancy because the doctor feared twins. I was so big. But there was only one baby—no problems were noticed, except the doctor thought it would be a big baby.

My water broke while I was helping my husband build a fence. I felt silly going to the

hospital with no contractions. Less than one hour later and two major painful contractions, out came Michael. He was 6 pounds, 8 ounces. So much for a big baby...

I actually had a big umbilical cord!

Since there was no time to go to the delivery room, I didn't think anything when they took the baby away for a few minutes. But then the doctor came back with a serious look on his face, saying Michael had a birth defect, a cleft. (A cleft occurs when parts of the upper lip and/or palate do not grow together. The tissue is all there, but there is a gap.) My husband and I had never even heard that term before. The baby was taken to the Special Care Nursery, where the nurses knew how to feed him. I visited him there but could not breastfeed him.

When I finally saw him, I was amazed how small he was. He had (and has) beautiful large blue eyes and was perfect, except he had a gap between his nose and mouth. It was like a little button. Over the next two months, the family became used to it. It was part of Mike, and he was awfully cute.

It took a long time to tell people that Mike had a cleft. While in the hospital, I could cope with telling only one person a day. The doctors painted a bleak picture. They mentioned a heart murmur. (They didn't mention that a lot of babies are born

with murmurs that go away.) The surgeon said it was one of the worst cases of cleft he's ever seen. I cried the most I ever had or ever would.



The Seltzer kids, Christmas 1999 (Michael is the one with the beard.)

Experts told me Mike would be a difficult baby—hard to feed, hard to get to sleep, fussy. Experts mean well, but they are not always right. Mike slept through the night at two weeks and was on a schedule of 4 meals a day at 3 weeks. He was the definitive easy baby I could take anywhere and did. He could not suck because of the cleft, so I could not breastfeed him or even use a normal bottle. At first, only a few family members learned how to feed him his formula from a “brecht” feeder, which worked like a turkey baster. Later, after he began cereal, he got the bulk of his milk through a spoon and feeding became easier. A musical swing could always get him to go to sleep.

When I took him out and people would ask about his face, I freely told them it was a cleft. It was my way of educating the public.

He had his first operation at 8 weeks old. One side of the lip was repaired. Just before he went into surgery, I wanted to stop the doctors and cancel it. He looked great to me. But I knew it wasn't realistic. He needed the operation done. The hardest thing for a parent is to see your child after surgery. Mike's face was all bloody and bandaged and he was in a mist tent. He looked like he had been on the losing side of a fight.

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Remembering Dr. Joseph E. Murray

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Dr. Murray was a man of faith and devoted to his family. He lived in Wellesley Hills with his wife Virginia “Bobby” Murray; they were married for 67 years and had three daughters and three sons. For Dr. Murray, every day was “magical.” He loved poetry, and he found inspiration in the works of Emily Dickinson and John Keats.

His autobiography, *Surgery of the Soul: Reflections on a Curious Career*, tells of a life well-lived with moving accounts of his pioneering years in transplantation and stories of the many patients who inspired him. There is a quotation by Dr. Murray above a permanent exhibit honoring his contributions, located in the Rotunda at the Brigham: “Service to society is the rent we pay for living on this planet.” ■

Join Our Team!



Run in 2013 New Balance Falmouth Road Race for FFC! Whether you are a casual jogger or a seasoned runner, you are invited to join the FFC team and take part in the 41st annual race on Sunday, August 11, on Cape Cod. The seven-mile scenic route follows along the shoreline from Woods Hole to Falmouth Heights.

FFC has been selected to receive entry numbers through “Numbers for Non-Profits,” a charity fundraising program. (These coveted numbers are otherwise only available to Falmouth residents or winners of a registration lottery.) Each runner must commit to raise (or donate) a minimum of \$1,000 to participate. FFC will pay each participant’s entry fee of \$150.



For details on the race, go to www.falmouthroadrace.com. For information about signing up for the team, contact FFC’s representative Kate Clark at Kateclark19@gmail.com. Participants will receive additional information about the race and weekend activities after registration is complete.

To support the FFC team with a donation, please visit our website at www.facesofchildren.org.

Fond Farewell

Johanna “Joey” Smith will step down as president of FFC in April. She has led the organization since January 2001. (She served as co-president with Jane McDaid until her passing in 2009.) A lawyer with the non-profit affordable housing development company The Community Builders Inc., Joey joined the FFC board 15 years ago. Although none of her own four children is affected by a craniofacial condition, Joey has shown true devotion to the Foundation’s cause. She has set high standards for the organization and provided calm, quiet, and effective leadership.

Joey thanks all for their support through the years. “I especially want to thank Mairi Fuller, who has been so instrumental to the success of the Foundation, and who has been the face of the organization in recent years,” she says.

Joey will continue working after leaving the FFC board but hopes to spend more time with her new grandchild.



Outgoing president Joey Smith at the registration table for the 2011 “Paces for Faces” Walk and Family Picnic.

Mark your calendars for our fun-filled annual fundraiser in Wakefield, Mass.



To volunteer to help organize this year’s walk, contact walk co-chairs Melina Fortin at melina.fortin@yahoo.com or Jennie Keniston at jennie.keniston@gmail.com

Family Fun with FFC

Join FFC for family outings in the Greater Boston area. Connect to one another through common interests. Recent activities planned for preteens, teens, and parents have included bowling, skating, and attending a college basketball game.

“This is an opportunity to meet other families and spend time together,” says coordinator Kara Jackman. “Kids can see other kids with facial differences and build a network of support.”

Most activities are focused on 8- to 13-year-olds. These “twens” typically have palate expanders and are preparing for bone grafts. Meeting peers can help both kids and parents feel less alone in the experience and foster mutual support.

Kara encourages families to submit ideas for future outings, volunteer to help out, and recruit others. Upcoming event ideas include a painting party, a trip to a museum, and outdoor adventures at beaches and local parks when the weather gets warmer.

Check the FFC Facebook site for details on events. See the link to our Facebook page at www.facesofchildren.org or contact Kara directly at karajackman@yahoo.com.



Michael *continued from page two*

You learn to cope and live through things. You stay at the hospital, commiserate with other parents, and realize your son has a repairable problem, long, ongoing, but repairable. You're so lucky compared to others.

Mike had four surgeries before he was one-year-old—one side of the lip at 8 weeks, the other side at 4 months, the columella (and one undescended testicle—we try to get the most for our money) at 9 months, and the palate at 11 months. He was tied down with a “strait-jacket” (so he couldn't touch the stitches) and hospitalized for one quarter of his first year. He developed a dislike for doctors.

Children born with cleft lip/palate tend to have ear infections and require tubes. Mike's first set was put in at 11 months, the second was put in at day surgery when he was two. They lasted (some sort of record, I'm told) for six years. He didn't need them after that. But for the first eight years of his life, he had to protect the ears from water. He wore ear molds and headbands (to keep the molds in) when he took baths or went swimming.

Michael had speech therapy and because his arms were tied down for

so much during his first year, he needed handwriting practice. Mike also had a learning disability called Sensory Integrative Dysfunction, where too many things going on can overload the senses, which required occupational therapy.

When Mike was 13, he had his first bone graft—bone marrow from his hip to his gum. He had a second graft at 15. His doctor is quite pleased with the results. At 16 he had his nose reconstructed and a deviated septum corrected. His orthodontist wishes Mike would brush more, but he's a teenager! He will need implants and several new false teeth in the next few years, and his jaws may have to be moved.

Through all this Mike has been a “trooper.” He has never fought me about the surgery. He stoically endures pain and puts up with the limitations the operations bring to his life. He doesn't complain or blame or ask “why him.” He just copes.

How have I coped? When I first had Mike, I wanted to learn everything I could. I read everything I could find and joined Prescription Parents, a local support group. I went to their meetings and talked to other parents of newborns. I went to lectures by the professionals. I coped.

I tried to figure why it happened. Was it my fault? My husband's? Our genes? The environment? We don't know. One child with a cleft is born for every 700 births. It might be a one-sided cleft (unilateral) of the lip or both sides (bilateral). It might be with a cleft of the palate or without. It might be just a cleft of the palate. No one knows what causes a cleft, but all the usual suspects are suspected.

Mike is now 17, a senior in high school, the school treasurer, has his own car, a part-time job, and takes the phrase “independent” to an extreme. He has more surgeries to endure, but he's his own person, and, if you can take a mother's word, a good-looking kid.

He's a teenager who drives me crazy, but I'm very proud of him. Do I wish he never had a cleft? Of course. But given that the past can't be changed, I watch him grow and mature and come into his own. He's lived through a lot (character-building, so they say), but he's okay...

So am I. ■

Check the FFC homepage for a listing of dates and times for parent support group meetings.



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 fund-raising initiatives. Please contact us if you would like to participate in or sponsor a fundraising event.

Foundation for Faces of Children

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