

# FACING THE FUTURE

## A CLASS ACT

Fifth graders at Immaculate Conception School in Lowell, Massachusetts, collected cans and bottles to raise funds for the Foundation for Faces of Children. Through their efforts, the class, taught by Mrs. Mary Carnevale, raised almost \$150 to donate to the cause. The students also purchased toys and collected more than 100 books for the waiting area of the Craniofacial Centre at Children's Hospital Boston. Some of the students delivered the toys, books, and donation to the hospital over the April vacation week. They were warmly received by the doctors, nurses, and staff of the Craniofacial Centre.

## Feeding Babies

In times past, sterling silver gravy boats with long spouts were used to feed infants with cleft palate. Others were spoon-fed milk.

"The feeding device you use is not as important as knowing that a child has to be nourished," says Dotty MacDonald, RN, Clinical Coordinator of the Cleft Lip/Palate and Craniofacial Program, Children's Hospital Boston. "To nurture is to nourish."

Modified feeding techniques help ensure that babies who have difficulty nursing or using a bottle receive adequate nutrition. Infants with cleft lip/palate, hemifacial microsomia, and syndromes like Apert and Crouzon may have trouble feeding due to a lack of suction ability, airway obstruction, uncoordinated sucking and swallowing, or tongue movement problems.

An assessment of a child's suck and swallow reflexes can help determine which feeding technique will work best. Finding out if the baby can feed and breathe at the same time is basic but critically important.

MacDonald uses an effective, although hardly high-tech, test as part of her assessment. "I always put my finger in a baby's mouth to determine their sucking ability," says MacDonald. "I check to see if the tongue comes down and their lips want to purse around my finger."

## How Much Is Enough?

If breastfeeding is too difficult or physiologically impossible, because the baby doesn't have the ability to create suction within the mouth, mothers are encouraged to pump and feed. The American Academy of Pediatrics strongly advocates breast milk feeding as the best way to ensure an infant's health. If breast milk is not an option, health care providers can help parents choose an appropriate formula.

Newborns can quickly digest breast milk and may want to feed as often as every two hours. Average feeding time is about 30 minutes, including burping. Unsynchronized sucking and swallowing may cause a baby with cleft lip/palate or other craniofacial condition to take in a lot of air and need to burp frequently.

The total volume of milk that a baby receives in 24 hours is more critical than the amount in



each individual feeding. "During the first week, a full-term baby needs one ounce of milk per pound of weight," says MacDonald. "That's a minimum requirement for the day. Above that is fine within limits."

While a loss in weight of up to eight ounces may occur initially, after the first week, babies typically gain an ounce a day. Each week feedings should increase by half an ounce per pound (1½ ounces during the second week, 2 ounces during the third week, and 2½ ounces during the fourth week).

Weekly weight checks help make sure babies are growing. "Many of our babies require more calories since they work so hard to eat," says MacDonald. "If they're getting their calories but not gaining weight, we may adjust their formulas or augment the breast milk to increase the calories. Normally, each ounce has 20 calories. Sometimes we use additives to bring that up to 24 or more per ounce."

## Feeding Options

Specially designed bottles and nipples make feeding easier for babies with cleft or craniofacial conditions. These devices permit milk to flow at a comfortable rate with little or no suction, while not interfering with the normal swallowing action.

Perhaps most commonly used is the Haberman feeder by Medela, which has a soft silicon nipple with a ring that can be rotated to allow variable flow rates—slow, moderate, and heavy. It also has a compressible reservoir that enables the parent to pulse the milk in synchrony with the baby's sucking and swallowing.

Another alternative is the cleft palate nipple and baby bottle by Pigeon. The nipple, cut in the shape of a Y, has a thick and thin side to allow for easier tongue compression and successful use by babies with cleft palate.



The Foundation for Faces of Children (FFC) is pleased to announce the winners of the 2006 scholarships: **Leah Dion**, **Maren Gray**, and **Emily Wood**. The awards recognize the students for their outstanding character, academic achievement, participation in extracurricular activities, and commitment to further education. Each will receive a \$1,000 scholarship for college expenses.



Leah Dion

**Leah Dion** is a graduate of Bishop Guertin High School in Nashua, New Hampshire. A member of the National Honor Society, she was on the crew and swim teams and also played piano and flute in the band. She participated in the Spanish Club and Cornerstone Service Club. In addition, she is active in her church, serving as a CCD (Catholic religious education) teacher and youth ministry leader. Leah will attend Mount Holyoke College in the fall and hopes to become a doctor.

**Maren Gray** graduated from Tewksbury Memorial High School in Massachusetts. She was a National Honor Society member and on the school yearbook committee. A dancer,



Maren Gray

Maren also competed in gymnastics, track, and swimming. In addition, she volunteered at a local Animal Hospital and took part in community clean-up efforts. She plans to attend the University of New Hampshire and then study to become a veterinarian.

**Emily Wood** is a 2006 graduate of the University of Southern Maine and plans to use her scholarship money toward earning a master's degree. While an undergraduate, she was on the Dean's list and a member of Psi Chi, the national honor society in psychology. She also volunteered at several community schools and was a member of the Temporary Assistance for Needy Families Advisory Council and the Coalition for Family Success. Emily is a single mother, bringing up a young son, while working and attending college. Her future plans are to work as an advocate for the disabled or "anyone whose voice is not heard."



Emily Wood

"We congratulate these impressive students on their scholastic achievements and ability to overcome challenges," says Mary Lania, Scholarship Committee Chair. For more information on the FFC scholarship program, visit our website at [www.facesofchildren.org](http://www.facesofchildren.org) or call 617-355-8299. 


## Feeding Babies, *continued from page 1*

Also popular is the Ross nipple, which is soft and shaped like a funnel to direct the flow of milk to the back of the mouth.

In some cases, the baby's tongue is not long enough to use a nipple. "Sometimes with a child with Robin sequence, the tongue is so glossoptotic or far back in the throat," MacDonald says, "that there is no place to rest the nipple, and the airway obstructs when the child tries to swallow. These children may need to be fed on a temporary basis with a nasogastric tube, a tube that runs down the nose to the stomach."

If oral feeding continues to be a problem, then a gastrostomy tube may be necessary. This tube, typically inserted through a small incision in the abdominal wall, allows feedings to go directly into the stomach. Many times the jaw or tongue will grow over a period of four to six months, making oral feedings possible.

Some care providers recommend using an obturator, a plastic plate that fits into the roof of the mouth and blocks the cleft while feeding. But MacDonald disagrees. "You do not need an obturator to feed," she says. "An obturator causes irritation of the roof of the mouth and prevents the natural closing down or narrowing of the cleft palate [as the child grows]."

Regardless of the feeding system, says MacDonald, the goal is to bond with the baby, be comfortable, and see feeding as pleasurable for parent and child. 



## F E E D I N G T I P S

Here are some practical tips on feeding from Dotty MacDonald, RN, Clinical Coordinator of the Cleft Lip/Palate and Craniofacial Program, Children's Hospital Boston:

- Establish that the baby is eager to eat before starting to feed. Stimulate the tongue and lips with your finger.
- Swaddle the baby to keep the arms out of the way, allowing the mouth to be the focus.
- Hold the baby in a comfortable, upright position so his or her chest is higher than the stomach.
- Be sure you're in a comfortable seat, holding the baby securely and comfortably. (Mothers often prefer to hold the baby close to their breasts, while fathers often like to cross their legs and put the baby in front of them.)
- Hold any feeding device between the first finger and thumb like a pencil. Cup the chin with the second and third finger of the same hand.
- If your child has a normal suck/swallow reflex, place the nipple on the tongue and lower lip. Then, if the upper palate is intact at all, bring the nipple toward the intact upper palate, so that the upper and lower gums can squeeze the nipple.
- If the baby has no suction ability, pulse the feeding into the mouth in synchrony with the suck/swallow. Stop when the infant stops suckling.

Don't be afraid to ask for help. Find another parent who has been through this experience or a clinician who is knowledgeable about feeding infants with clefts.

And, make sure several people know how to feed the baby. "I learned that a long time ago from a mother who never left her house for a year, because she was the only one who could feed her child," says MacDonald.

"Most importantly," she adds, "enjoy your infant."



## Tenth Annual FFC Walkathon:

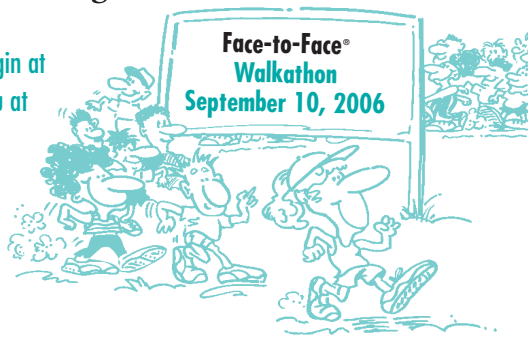
# Face-to-Face®

- Preregister by e-mailing [info@facesofchildren.org](mailto:info@facesofchildren.org) or by calling **617-355-8299**. Give us your name, phone number, and the number of walkers in your group so we will know how many to expect.
- For directions to the walkathon, or to download sponsor sheets for anyone wishing to participate, visit [www.facesofchildren.org](http://www.facesofchildren.org).
- Be sure to bring your sponsor sheet the day of the walk along with any monies already collected. Mail remaining monies no later than November 10, 2006 to:

Foundation for Faces of Children  
258 Harvard Street, #367, Brookline, MA 02446

**Questions?** Call us at **617-355-8299** or visit our website, [www.facesofchildren.org](http://www.facesofchildren.org).

Registration and walk begin at  
12 noon. Hope to see you at  
Lake Quannapowitt,  
Wakefield, MA...



The **Foundation for Faces of Children** is dedicated to improving the lives of children with craniofacial conditions, including cleft lip, cleft palate, and other head and facial differences. We concentrate our efforts on education, training, family support systems, and the dissemination of accurate and timely information. We also fund targeted research about the causes, treatments, and outcomes of these congenital conditions. The goals and strategies of the Foundation for Faces of Children are to...

- Provide leadership and advocacy through research and education.
- Distribute accurate and timely information as quickly and widely as possible to children, families, medical professionals, and the community at large.
- Endorse the team approach to treatment of craniofacial conditions; we believe that the best outcomes result from collaborative treatment by an experienced group of specialists.
- Partner with organizations that have similar goals and values.

We are a 501(c)3 not-for-profit organization supported entirely by private donations, grants, and fund-raising initiatives. We receive no government funding. If you are interested in having a board member speak to your group about our organization, or if you wish to participate in or sponsor a fundraising event, please write to **Foundation for Faces of Children, 258 Harvard Street, #367, Brookline, MA 02446** or call us at **617-355-8299**.

### Foundation for Faces of Children

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