

Making a world of difference in a world of facial differences

Feeding

The Challenges, The Options

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When new parents first learn that their child has a cleft lip/palate, their thoughts immediately turn to what surgeries will be needed, will their child talk normally, what will s/he look like later? These parents soon realize that the first challenge is not the operating room, it's the bottle.

A surprising number of hospitals are not equipped to properly feed a baby born with a cleft palate. If the hospital does have the special feeders on hand, the nursing staff may not know how to use them, or may not even be able to find them when needed. Often a parent is given a preemie nipple with the hole enlarged and is told that this is sufficient for feeding their baby. Some mothers are even told that they will be able to breastfeed their infant. While this is sometimes possible when the child has a cleft lip only, a cleft palate makes it almost always impossible for the infant to create enough suction to nurse. These are some of the many reasons why it is imperative for new parents to be put in contact with a cleft/craniofacial team for information and guidance.

One of the first visits the parents will make with their new infant is to the team's feeding specialist. There they will receive one of several types of bottles. The three main bottles used to feed infants with a cleft are the Mead Johnson bottle, the Medela SpecialNeeds™ feeder, and the Pigeon feeder.

The Mead Johnson (MJ) bottle is a thin walled plastic bottle that is easy to squeeze. It comes with a special MJ cleft nipple, but is also often used with a cross-cut Nuk nipple. The MJ bottle works because the parent is able to squeeze milk into the infant's mouth,

so no sucking is required. It takes some practice for the parents to learn the squeeze & swallow rhythm for their child, but most report that this does not take long to learn.

The Medela SpecialNeeds™ feeder is a hard plastic bottle with a special nipple and valve. The valve is a "one-way" valve so the nipple stays full and eliminates the need for the baby to create negative pressure to suck; the infant is able to express milk by gumming on the nipple. It has a slit instead of a hole and markings on the nipple allow the parent to position it for low, medium, and fast flow. The nipple



also has a large chamber that the parent is able to squeeze to assist the infant in getting milk. The actual bottle for this nipple is a small size, so many parents search for a larger bottle that will work with the nipple.

The Pigeon cleft nipple also comes with a valve and a semi-hard plastic bottle. One side of the nipple has thinner walls than the other side and the infant is able to express milk by gumming the nipple or moving the tongue in a suckling motion. The parent can assist the infant by squeezing the bottle. Many parents prefer this bottle because its appearance is more like that of a standard baby bottle. In some cases the infant feeds faster than the nipple can vent and it collapses. Parents report that this problem

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can be solved by using the nipple with vented bottles such as the Playtex Ventair or the Dr. Brown's bottles.

Once the proper feeding system is in place, the feeding specialist can then observe the parent and infant with the bottle and make suggestions or demonstrate ways to help make the whole process easier on both parent and child.

Positioning of the infant is a very important aspect in feeding. Parents are encouraged to feed their infants in an upright or semi-upright position. This reduces the amount of milk that may flow into the nose through the open cleft and allows the infant to better coordinate swallowing and breathing. There is also the added benefit of allowing less fluid to collect in the eustachian tubes when this position is used, which could decrease the occurrence of ear infections.

Gas and burping are problems often related to feeding infants with clefts, as they tend to swallow more air as they feed. The feeding specialist can recommend different positions and techniques to burp the infant such as leaning the baby forward as s/he sits upright, or placing the baby on the shoulder or across the legs. The key to burping an infant with a cleft is frequency! The infant may need burping once every ounce or once every five minutes to avoid discomfort and spitting up. Even with proper burping some infants still have problems with gas pain. Laying the infant on his back and peddling the legs as if riding a bicycle can help move the gas along and provide comfort. Parents may also be encouraged to talk to their pediatricians about adding Mylicon Drops or Gripe Water.

The feeding specialist will also observe for problems in feeding, listening for smacking sounds (poor seal on the bottle) and watching to see how hard the infant must work to drink. If the infant is working too hard or working too long (usually over 30 minutes) to take in an appropriate amount, s/he can burn up more calories feeding than taken in. Often the specialist will then suggest a different feeder or have the parent assist the infant in some way. If the baby is showing signs of excessive choking, sputtering, or discomfort when eating, an x-ray swallow study may be ordered. If there are no apparent problems with feeding and the infant is still having problems with weight gain, returning to the pediatrician and seeing

a gastrointestinal (GI) specialist may be needed. If the infant seems to have a problem with oral aversion (not wanting anything in or near their mouth) the feeding specialist may be able to recommend specific therapies to treat this. Simple massage with flavored gloves and vibrating tools can help these infants learn not to fear. If no swallowing issues are present, a syringe-type nipple may be used for the infant who will not tolerate a larger nipple in his mouth.

If the infant seems to have a problem with spitting up or reflux, the parents can also bring this up with their feeding specialist. The specialist can then help them get in contact with a GI specialist for the proper screening and tests to see if reflux exists and what the best course of treatment would be.

It is important to remember that the feeding specialist is often the first contact a parent will make with their cleft/craniofacial team.

With proper guidance from these caring individuals, feeding a baby with a cleft palate, although it may seem like a large obstacle to overcome, can have simple solutions. If tube feeding does become necessary, it is important to continue working with the specialist to try to move the infant to oral feeds.

Parents talk to parents, and they are great resources to discuss what helped or wasn't as helpful with their child when it came to feeding their baby. However, it is important to remember to discuss any questions, concerns, or significant changes with your child's feeding routine with your team feeding specialist and pediatrician.

For more information on cleft palate nursers and nipples, as well as sippy cups for toddlers with repaired cleft palates, visit the cleftAdvocate website at www.cleftadvocate.org/feeders.html.

POSITIONING

PATIENCE

GUIDANCE

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PATHFINDERS

The Premier Family-to-Family Support Network

These are just a few of the comments made by parents contacting the Pathfinder Outreach Network, the premier support program of AmeriFace, designed to bridge the gap between medical professionals and families faced with uncertainty when their child is born with a cleft or other craniofacial anomaly.

Pathfinders share their personal experiences on a wide range of subjects related to craniofacial care. Volunteers are available via telephone, e-mail and sometimes even in person to answer questions about feeding and speech issues, surgery, recovery, post-operative expectations and coping with prenatal diagnosis. They also provide information regarding community resources such as early intervention services and children with special health care needs (CSHCN) programs.

Equally as important, Pathfinders provide a safe haven for individuals and families to express their feelings and ask questions not usually addressed by medical and other professionals. Many develop friendships beyond the circumstances that initially brought them together.

New and expectant parents are encouraged to call the toll-free hotline at (888) 486-1209 as soon as possible after their baby's diagnosis.

"We're not replacing the guidance families get from their cleft/craniofacial teams," stressed Debbie Oliver, AmeriFace Executive Director. "We're working to enhance the relationship between all parties by bringing families together in a relaxed, comforting atmosphere of support."

Some local/regional Pathfinders host informal local gatherings like picnics and play dates and distribute information packets to area birthing hospitals and ultrasound facilities; others work to educate medical professionals and other service providers about what families need. The focus of the program, however, is one-to-one family support.

"I vowed I would someday make a difference to other parents, and now I have that opportunity being a Pathfinder volunteer." Melissa House from Ohio participates at the Family-to-Family Connection (FTFC), the organization's on-line support network. The electronic aspect of the FTFC allows her to answer questions for new parents around her busy schedule, any hour of the day or night. She often refers families to the AmeriFace (www.ameriface.org) and cleftAdvocate (www.cleftadvocate.org) websites. "No family should feel they're going through this alone."

"The Pathfinder program originally launched with a newborn outreach agenda," remembered Oliver. "We quickly realized it was not only parents of newborns who needed assistance, but that families and patients of all ages could benefit from peer counseling and outreach."

There are a number of teens and adults with facial differences who regularly assist through the program. Some have congenital anomalies, while others have acquired facial differences from trauma or disease. Not only is this beneficial for those with the same or similar conditions, but it is often of great guidance and comfort to parents wondering just how their child is dealing with surgeries, school and social situations.

Potential Pathfinder volunteers are sometimes concerned they don't have the skills or resources to assist others. "No matter what your level of experience or where you are on this journey, we need your help," said Program Director Joyce Bentz. "We also make it a point to work with other craniofacial organizations and their members to ensure rapid response for those in need." These are known as Pathfinder Partner Organizations.

AmeriFace hosts live teleconference training on a monthly basis, offering guidance and materials to assist Pathfinders in their efforts. Training modules address the various roadblocks to outreach, from time constraints for volunteers to the willingness of families to seek assistance outside their own family support system or cleft/craniofacial team members. Annette Woods of Amarillo, Texas said she attended a live workshop to "...learn more about networking families of children with special health care needs here in our home town." Live Pathfinder workshops are scheduled at various venues around the country throughout the year, and in conjunction with the annual North American Craniofacial Family Conference (NACFC).

"Pathfinder volunteers are really the heart and strength of the organization," said Robin Remele, Action Team Coordinator. "They truly are making a world of difference in a world of facial differences."

"When we left the hospital, we didn't know what to expect for our son."

"I never felt so alone...we didn't even know how to feed our baby."

"Everyone kept saying, 'we can fix that'...but I kept wondering...how?"

**Need a Pathfinder? Want to volunteer?
Visit our website at www.ameriface.org
or contact us at (888) 486-1209
for additional information.**

Making a world of difference in a world of facial differences...

Inspiration

- **AmeriFace** is a national organization providing information and support for persons with facial differences and their families. Thousands make contact with us every month, via telephone, e-mail and our websites.
- **AmeriFace** supports people whose facial differences are present at birth, such as cleft lip and palate, vascular malformations, Crouzon, Goldenhar and Treacher Collins syndromes, and other craniofacial conditions. Support is also available for those whose facial differences were acquired as a result of illness, disease or trauma.
- **AmeriFace** provides access to a broad range of written and audio-visual information about various craniofacial conditions. Community-based resources can also be provided to help families adapt to the challenges of living with a craniofacial condition/facial difference. A school program is also available.
- **AmeriFace** provides individuals and families opportunities to connect with others facing similar challenges through the **Pathfinder Outreach Network**.

Education

- **Media Outreach** – Newspaper and magazine articles, public service announcements and special events raise public awareness about the causes and treatment of craniofacial anomalies.
- **Healthcare Professionals** – While promoting family-centered care and always stressing the importance of a team approach to craniofacial treatment, **AmeriFace** provides in-service presentations to students, teams and other medical staff who feel they can benefit from understanding the patient and family point-of-view.
- **Medical Conferences and Tradeshows** – By presenting workshops and exhibiting at various trade shows and conferences, **AmeriFace** builds relationships with medical and other professionals, encouraging them to refer patients, request information and become volunteers.

Support

- **The Pathfinder Outreach Network** – The Pathfinder database is the foundation for networking individuals by region, condition, age and procedure. Services include prenatal and newborn outreach and one-to-one family support; adult and teen peer counseling is also available. Families and volunteers stay in touch across the miles through the interactive forum at the **Family-to-Family Connection**.
- **Newsletter** – Highlighting personal stories of challenge and triumph and providing a variety of local, regional and national resources, the **AmeriFace** newsletter reaches thousands of families via mail and the internet throughout the year.
- **Websites** – Visit us at www.ameriface.org and www.cleftadvocate.org for the best information on the web! Links to community services and partner support organizations are provided for families in need of additional services. Special announcements as well as the most recent newsletter are published on these sites.
- **The North American Craniofacial Family Conference (NACFC)** – Bringing individuals and families together with healthcare and other professionals, the NACFC provides the very best educational and social opportunities for the craniofacial community. Parents, patients, siblings and friends are encouraged to attend the annual event. Professionals are always welcome!

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