Adoption

I am interested adopting a child with special needs, such as a child with cleft lip and palate. What are some good Internet resources?

Missouri Department of Social Services – Adoption Services
http://www.dss.mo.gov/cd/adopt.htm

Kansas Department of Social Services
http://www.srskansas.org/services/adoption.htm

KidsHealth for Parents
http://www.kidshealth.org/parent/positive/family/medical_adopt.html

I am interested adopting an international child with special needs, such as a child with cleft lip and palate. Can you explain the process and some Internet resources?

International adoptions typically are more time-consuming than domestic ones. Birth families typically are less involved in the process, but government agencies are more involved. (Source: Child Welfare League of America; National Adoption Information Clearing House, U.S. Department of Health & Human Services.

Here is an “Adoption & Foster Care” link:

Family Village Community Center - Special Needs Adoption Resources
Adopting The International Child With Special Needs A Practical Guide
http://www.familyvillage.wisc.edu/frc_adpt.htm

These resources and others are available in the Kreamer Family Resource Center, ground floor of the Sutherland Tower in Children’s Mercy Hospital, or call 816-234-3900 to arrange for pick-up from the Children’s Mercy south Information Desk. If you are not a patient of Children’s Mercy Hospital & Clinics, books may be borrowed through interlibrary loan: contact your local librarian.

Once I have brought my newly adopted international child home, is there a screening process required before visiting the Cleft Palate/Craniofacial Team?

Adopting an international born child can be a very rewarding experience, but certain safety precautions should be taken to protect the parents, the child, and other patients. Although we will schedule a date to visit the Team, your child will need to first be seen by his/her primary care physician prior to coming to the Cleft Palate Clinic. Depending on the country the child was adopted from, physicians may want to give special tests to identify certain infections and screen for nutrition status and overall development. Tests that were performed in other countries are not always reliable, so those test should be repeated in the United States. Please bring a record of the physician visit, along with any test results, to your first Team visit, so that we can include as part of our medical record.
FAQ's
Cleft Palate/Craniofacial Clinic

Dental/Orthodontics:
When should my child see the Dentists on the Team?
Starting at age one our dentists will see your child as part of their regular Team visit.

An orientation summary will be provided for parents of newborns. If you have questions after reviewing this information, please ask to talk with one of our dentists during your team visit.

What type of dental/orthodontic care will my child need?
Please click on the following American Cleft Palate Foundation's link for dental Care information.
http://www.cleftline.org/publications/dental.htm

Here is another good source of general dental information:
American Academy of Pediatric Dentistry FAQs :
http://www.aapd.org/pediatricinformation/faq.asp

Why is orthodontics important for my child?
Orthodontics is the art of aligning teeth to each other and between the upper and lower jaws. This gives a normal teeth relationship for correct function and aesthetics. Many children with cleft palate may also need preliminary orthodontics (such as palatal expansion) prior to alveolar bone grafting.

Feeding

I need Haberman bottles for my baby. Who should I call?
Call (816)234-3677 to request Haberman supplies if your child is a clinic patient.

Why is it important to feed my child nearly upright?
If a child with a cleft palate is fed with minimal incline from a flat position, either by a caregiver or by giving an older infant the bottle while lying flat or inclined on a pillow, there is an increased tendency for formula to be directed into the palate and the cleft. This may irritate the child and lead to shortened feedings and sneezing.

An easy way to remember how much to incline the child is to seat their bottom on the thigh that is on the same side as the arm used to support the child upright, making sure to not allow the caregiver's arm to rest too far out from their trunk and making sure to support the head so that it doesn't fall back. If the child's head falls back, the child is more likely to have difficulty sucking and may be more likely to cough, leading to shortened feeds. Bouncy seats are fine when baby cereal is started. Highchairs are recommended at about 7-8 months of age or when the child can otherwise sit with low trunk support. Never allow the child to hold their own bottle if it means that they have to lie down to do so. We are confident that they will eventually learn to hold their own bottle when they are a bit older!

Why do I need to have my child off of a bottle and onto a non-spouted cup by the time of palate surgery?
After the cleft palate repair, the child is not allowed to have any feeding instrument that is intrudes into the mouth and may potentially damage the delicate repair. This includes nipples and cup spouts. The time of palate repair is made easier if the child is already on a non spouted cup before their surgery instead of attempting this transition when they are trying to restart eating after surgery. So begin offering cups at least by 8 months of age. Don’t get discouraged if they only start out with single sips or sequence 2-3 sips at a time. Rimmed cups are preferred. They will not protrude into the mouth excessively. At this age, it is important that the caregiver hold the cup for the child until their cup holding skills improve.

Why is it important to start table food before the time of palate surgery? I am worried about food getting stuck up in the cleft.
The palate repairs are best done at about a year of age. This is about the time when infants normally begin to get a little particular about how they eat. They often stop eating favored foods and go on jags where they want to eat a lot of certain foods. With a 3 week interruption in the types of foods that the child can have after surgery, it is easier to re-introduce familiar foods than to introduce new foods. Actually it is not typical for foods to get caught into the palate.

How can an Occupational Therapist help with my child’s feeding problems?
Occupational therapists treat children with feeding difficulties. All aspects of the feeding environment – physical, cultural, and social--have an impact on feeding. Occupational Therapists identify oral structural/postural concerns, potential gastrointestinal concerns and other health issues which may influence feeding, posture and positioning, swallowing, oral sensory processing, adaptive feeding equipment, handling techniques, and behaviors associated with feeding. Occupational therapists collaborate with the nutritionist to address growth and tube feeding issues. Occupational therapists support parents and caregivers by offering feeding recommendations and suggestions to promote safe, age appropriate feeding and eating skills.

Parent Support
Is there a parent support group to help families?
The Parent-to-Parent Program is available for parents with children diagnosed with cleft palate or craniofacial difference. The purpose of this program is to allow parents the opportunity to discuss with other parents, by phone or e-mail, the joys and challenges of raising these special children. If you are a parent with a child who attends the Children’s Mercy Cleft Palate Craniofacial Clinic and you would like to talk with a parent listed in the Parent-to-Parent Directory, please contact Sandra Lybrand at (913)696-8324. She will make arrangements for a parent who has gone through a similar experience to contact you.

Speech/Language
How will a Speech-Language Pathologist help my child?
Families with newborns are provided orientations at their initial Team visit. Then the first speech/language evaluation is performed around one year of age. Regular evaluations will help you decide if speech therapy services or other types of interventions are needed. Craniofacial conditions and their
correction usually affect the structures required for functional speech. Children are evaluated and treated both pre- and post-operatively by a speech-language pathologist. Evaluations can include diagnostic technology such as video fluoroscopy and video nasoendoscopy if indicated. These techniques allow visualization of anatomic movement during testing and offer valuable information to the plastic surgeon should surgical intervention be necessary.

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**Surgery**

**At What Age Will My Child Have Surgery Performed?**

<table>
<thead>
<tr>
<th>Surgery: Repair of cleft lip (and nose)</th>
<th>Age: After 3 - 4 months of age</th>
</tr>
</thead>
<tbody>
<tr>
<td>Surgery: Repair of cleft palate (soft, soft and hard); Vestibuloplasty (deepening of lip sulcus); and in a few cases repair of the alveolar cleft (gum cleft)</td>
<td>Age: After 10 - 12 months of age</td>
</tr>
<tr>
<td>Surgery: Speech surgeries of palatal lengthening</td>
<td>Age: After 4 years of age</td>
</tr>
<tr>
<td>Surgery: Lip and nose revision in a few patients (may be combined with speech surgeries depending on the situation)</td>
<td>Age: After 4 years of age</td>
</tr>
<tr>
<td>Surgery: Bone grafting to the alveolus</td>
<td>Age: After 6 years of age</td>
</tr>
<tr>
<td>Surgery: Upper jaw advancement surgery (in cases of insufficient growth in the upper jaw – (usually 13-15 years of age in girls and 15-17 years of age in boys)</td>
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<tr>
<td>Surgery: Rhinoplasty after jaw advancement surgery</td>
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**Please Note:** The patient will need orthodontic care for palatal expansion before bone grafting.

**Do I need to call to get my child’s surgery pre-authorized?**

No, Children's Mercy Hospital and Clinics has a Preauthorization Department that handles this. If there are any questions or problems, parents will be contacted.

**Why is lip taping important?**

It helps stretch the lip tissue and reshape the nostril. In combination with a palatal appliance, it also helps in the molding of the alveolus (gums). Eight or more weeks of lip taping are helpful in obtaining better surgical outcomes.

**Why does food and milk come out of my child’s nose after palate surgery?**
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Due to swelling from recent surgery, the palate becomes temporarily stiff and does not move up to prevent leakage of milk into the nose. Although the palate (soft and hard part) has been repaired, the alveolus (gum part) is still open and your child will learn over several months to control leakage from the front.

Why are stents important? What should I do when I can’t keep them in?
Although the nose is shaped at surgery, it has a tendency to distort from swelling after surgery and later from scar contraction (up to 6 months). Cleft tissue also has some inherent memory to return back to its original shape and this may also be from the delicate infant tissue. Since nose constantly forms mucous for lubrication and clearing dust particles from air on breathing, it is likely to cause slippage of stents. Children may also sneeze them out. You will be shown how to remove, clean, and replace the stents. It is important to follow your surgeon’s recommendations to achieve the best possible result from your child’s surgery. Repeated surgeries cause more scarring and may further compromise the outcome.

How long does my child have to wear the stents?
3-6 months

Team

What if my baby is diagnosed with a cleft lip and/or cleft palate prenatally?
We offer prenatal consultation services. You can call the Coordinator at 816-234-3759 to receive information and arrange a time to meet.

When does my baby/child need to be seen by the Cleft Palate/Craniofacial Team?
Children with cleft lip, cleft palate and/or craniofacial anomalies need special medical attention. You should make an appointment for the clinic as soon as possible within the first weeks of birth so that you can meet the team members and develop a treatment plan.

Call (816)234-3759 for an initial visit.
Call (816)234-3677 to arrange any follow-up visits.

How often does the Team meet?
The Cleft Palate/Craniofacial Clinic is held the first three Fridays of each month at our main campus and the fourth Thursday of each month at the South campus. Team specialists provide individual consultations at both locations. New families check in at 7:45 a.m. and clinic generally lasts until 12:30 or 1:00 p.m. at the main campus. South campus starts at 8 a.m. and generally finishes by noon.

What should I bring to clinic?
If your child is a newborn, please provide date of PKU testing and location. You will also need to know if your child passed his/her newborn hearing screening.

Bring enough formula for your infant to have up to two feedings as there are many team members anxious to meet you and it can take several hours for the assessments to be completed and your questions answered. Bring their own bottle, cup, and feeding instruments.
FAQ's
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If your child has been receiving speech therapy services, dental or orthodontic services, please bring a copy of current records or have them sent to our clinic.

Will any tests be done at my child's first visit?

If your baby passed his/her hearing screening at the birthing hospital, we will not need to repeat it. Otherwise, we will plan for your baby to have an ABR (Auditory Brainstem Response) test during the team visit. Early detection is important because untreated hearing loss can interfere with a child's ability to speak.

At each team visit older children will be tested in the sound booth. Because children with cleft palate/craniofacial anomalies are susceptible to ear infection, which can lead to hearing loss, frequent hearing tests are necessary.

Is your Team credentialed?

Each member of the team has chosen children's health care as his or her career, and is highly qualified for the challenges associated with pediatric health care. The Cleft Palate/Craniofacial Clinic meets standards and follows protocols established by the American Cleft Palate-Craniofacial Association. Children's Mercy Hospital is accredited by the Joint Commission on Accreditation of Healthcare Organizations. Staff members are fully trained in their field of specialization, and are either board eligible or board certified. Hearing and Speech services are accredited by the Professional Services Board of Examiners in Speech/Language Pathology and Audiology.

Why does my child need to see a “Team” and who makes up the Team?

Children born with a cleft lip and/or palate often need the skills of several medical professionals to correct associated problems. The care of a child with a cleft or craniofacial anomaly involves a coordinated group of professionals who follow these children. In addition to needing plastic surgery to repair the cleft, these children may have feeding, dental, hearing, speech, or developmental problems. Team specialists include the Team coordinator, the plastic surgeon, nurses, audiologists, ENT (Ear, Nose & Throat) physician, Speech/Language pathologists, nutrition and lactation specialists, occupational therapist, genetics counselors, social worker, dentists, and an orthodontist. The expertise of other professionals is available if needed, including child development specialists, neurosurgeons, ophthalmology surgeons, radiologists and child psychologists.

Does your clinic see children with craniofacial syndromes?

Yes, syndromes include Apert’s, Beckwith-Wiedeman, Freeman-Sheldon, Goldenhar, Mobius, Pierre Robin, Stickler, Treacher-Collins, Vaters and Velocardiofacial Syndrome.

Who will see my child for other cranial anomalies?

For diagnoses such as plagiocephaly (misshapen head), craniosynostosis or torticollis, contact Margie Beery, R.N. the Plastic Surgery Clinical Nurse Manager, at (816)234-3687, to arrange an appointment in the Plastic Surgery Clinic.