

Cleft Lip/Cleft Palate



A NEW WAY TO SUPPORT FAMILIES

Welcome to the Missouri Developmental Disability Resource Center (MODDRC). You are receiving this letter with an enclosed packet of information because a request was made by you (or someone on your behalf) to the MODDRC.

We have compiled information from a number of sources and have included them in this packet, which is divided into the following sections:

- **Overview of a specific disability, special health care need, or other major topic**
- **Current practices**
- **Personal Stories**
- **Family support, advocacy and services**
- **Missouri Service Systems**

The MODDRC, which has now expanded to include Missouri's Family-to-Family Health Information Center, seeks to inform and connect individuals with disabilities or special health care needs and/or their families to peer support. We also provide opportunities for leadership development and volunteerism. When contacting the MODDRC, you are connecting to staff that have first-hand knowledge about disability related issues because they have the experience of living with the disability, either as an individual, parent or family member.

Thank you for using the MODDRC. This packet of information is one of the many ways that the MODDRC can support you in your journey with disability. We hope you will connect with us again.

Missouri Developmental Disability Resource Center/Family-to-Family Health Information Center is housed within Missouri's University Center for Excellence in Developmental Disabilities Education, Research and Services (UCEDD) at the University of Missouri-Kansas City, Institute for Human Development.

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Overview

The purpose of this section is to help you gain a better understanding of a specific disability or special health care need. It is intended to provide a basic explanation of the disability and possible causes and characteristics.

If you would like more in-depth information on this topic, other topics of information or if it is not the topic you requested, please feel free to contact us again.



Overview: Cleft Lip/Cleft Palate

More children are born each year in the United States with cleft lip/cleft palate (CL/P) than any other congenital disability. Around 6,800 babies enter the world with a cleft lip, cleft palate, or both¹, about 19 every day of the year. More often these children are born into Asian, Native American, and Latino families², but cleft lip/cleft palate occurs in every ethnic group and community.

When a newborn comes into the world with cleft lip/palate, parents often go through different feelings of shock, sadness, anger or worry. While this is normal, it helps to know that CL/P is not caused by anything a parent has done. Also, it is good to know that doctors today have many tools to treat CL/P, and most babies born with a cleft grow up to be healthy adults.

What is cleft lip?

Cleft lip is an opening in the upper lip. It can be a small notch or slit in the lip or a large gap reaching all the way up to the nose. The cleft can be on one or both sides of the child's mouth. It may also affect the gum above the upper teeth.



Baby with cleft lip

¹ (Bartoshesky, 2008)

² (March of Dimes, 2007)

What is cleft palate?

Cleft palate is an open space in the roof of the inside of the mouth. Children with cleft palate have too little tissue in their mouths. The tissue they do have did not grow all the way together before birth. This opening may be in the hard (front) or soft (back) part of the palate. Sometimes both parts are open. This may change the way the child's teeth are formed inside the mouth.



Baby with cleft palate



Cleft palate

Doctors and nurses can spot cleft lip and cleft palate at birth, just by looking. Even before a baby is born, an ultrasound may show when a baby will be born with CL/P. Most of the time, a baby with a cleft will have surgery in the first year of his or her life to close the gap. Usually, this will happen between three and six months of age for cleft lip and between nine and fourteen months for cleft palate. One surgery is often enough, but some people may need more surgery later to improve their looks or speech.

Areas of special need or care

Babies born with cleft lip/cleft palate are usually healthy in other ways. But some special care may be needed besides surgery. This might include extra help to learn feeding and speaking skills, and in solving problems with teeth, ear infections,

or hearing issues that can sometimes come with cleft lip/cleft palate. (See Current Practices section for more information on this topic.)

Learning about cleft lip/palate can be confusing. Don't be afraid to ask questions of your doctors, other families who have gone through it too, and our staff here at the Missouri Developmental Disability Resource Center/Family-to-Family Health Information Center. We're here to help.

Works Cited

1. Bartoshesky, L., MD, MPH (2008, October). *The Nemours Foundation*. Retrieved May 7, 2010, from KidsHealth: <http://www.kidshealth.org>
 2. *March of Dimes*. (2007, February). Retrieved June 7, 2010, from <http://www.marchofdimes.com>
- Illustrations courtesy of Centers for Disease Control





Current Practices

The purpose of this section is to provide you with the most current techniques and procedures for supporting people with developmental disabilities or special health care needs. These could include such things as:

- Information on therapies
- Medical treatment
- Accommodations
- Interventions

If you would like more information on current practices, please feel free to contact us again.



On the following pages, you will find more information on cleft lip/cleft palate from sources the MODDRC regards as respected and trustworthy. All information has been reprinted with permission and is for educational purposes only. For more information regarding your personal situation, please consult your team of medical professionals.



Cleft Lip/Cleft Palate: Complications

Kids with a cleft lip or palate tend to be more susceptible to middle ear fluid collections, hearing loss, and speech defects. Dental problems - such as missing, extra, malformed, or displaced teeth, and cavities - also are common in kids born with cleft palate.

Many children with clefts are especially vulnerable to ear infections because their eustachian tubes don't drain fluid properly from the middle ear into the throat. Fluid accumulates, pressure builds in the ears, and infection may set in. For this reason, they may have special tubes surgically inserted into their ears at the time of the first reconstructive surgery.

Feeding can be another complication for an infant with a cleft lip or palate. A cleft lip can make it more difficult for a child to suck on a nipple, while a cleft palate may cause formula or breast milk to be accidentally taken up into the nasal cavity.

Special nipples and other devices can help make feeding easier; you'll get information on how to use the specialized feeding equipment and where to buy it before you take your baby home from the hospital. In some cases, a child with a cleft lip or palate may need to wear a prosthetic palate called an obturator to aid in proper eating.

If your baby has problems with feeding, your doctor can offer other suggestions or feeding aids.

Treatment

Thanks to medical advancements, reconstructive surgery can repair cleft lips and palates and, in severe cases, plastic surgery can address specific appearance-related concerns.

A child with oral clefting will see a variety of specialists who will work as a team to treat the condition. Treatment usually begins in the first few months of life, depending on the health of the infant and the extent of the cleft.

Members of the cleft lip and palate treatment team usually include:

- a geneticist
- a plastic surgeon
- an ear, nose, and throat physician (otolaryngologist)
- an oral surgeon
- an orthodontist
- a dentist
- a speech pathologist (often called a speech therapist)
- an audiologist
- a nurse coordinator
- a social worker and/or psychologist

The specialists will evaluate your child's progress regularly, and monitor hearing, speech, nutrition, teeth, and emotional state. They'll share their



recommendations with you, and can forward their evaluation to your child's school and any speech therapists that your child may be working with.

In addition to treating the cleft, the specialists will work with your child on any issues related to feeding, social problems, speech, and your approach to the condition. They'll provide feedback and recommendations to help you through the phases of your child's growth and treatment.

Surgery for Oral Clefting

Surgery is usually performed during the first 3 to 6 months to repair cleft lip and between 9 and 14 months to repair the cleft palate. Both types of surgery are performed in the hospital under general anesthesia.

Cleft lip often requires only one reconstructive surgery, especially if the cleft is unilateral. The surgeon will make an incision on each side of the cleft from the lip to the nostril. The two sides of the lip are then sutured together. Bilateral cleft lips may be repaired in two surgeries, about a month apart, which usually requires a short hospital stay.

Cleft palate surgery involves drawing tissue from either side of the mouth to rebuild the palate. It requires 2 or 3 nights in the hospital, with the first night spent in the intensive care unit (ICU). The initial surgery is intended to create a functional palate, reduce the chances that fluid will develop in the middle ears, and help the teeth and facial bones develop properly. In addition, this functional palate will help speech development and feeding abilities.

The need for more operations depends on the skill of the surgeon as well as the severity of the cleft, its shape, and the thickness of available tissue that can be used to create the palate. Some kids require more surgeries to help improve their speech.

Additional surgeries may also improve the appearance of the lip and nose, close openings between the mouth and nose, help breathing, and stabilize and realign the jaw. Later surgeries are

usually scheduled at least 6 months apart to allow time to heal and to reduce the chances of serious scarring.

It's wise to meet regularly with the plastic surgeon to determine what's most appropriate in your child's case. Final repairs of the scars left by the initial surgery may not be performed until adolescence, when facial structure is more fully developed. Surgery is designed to aid in normalizing function and cosmetic appearance so that kids will have as few difficulties as possible.

Dental Care and Orthodontia

Children with oral clefting often undergo dental and orthodontic treatment to help align the teeth and take care of any gaps caused by the cleft.

Routine dental care may get lost in the midst of these major procedures, but healthy teeth are critical for kids with clefting because they're needed for proper speech.

Kids with oral clefting generally need the same dental care as other kids — regular brushing supplemented with flossing once the 6-year molars come in. Depending on the shape of the mouth and teeth, your dentist may recommend a toothette (a soft sponge that contains mouthwash) rather than a toothbrush. As your child grows, you may be able to switch to a soft children's toothbrush. The key is to make sure that your child brushes regularly and well.



Children with cleft palate often have an alveolar ridge defect. The alveolar ridge is the bony upper gum that contains teeth, and defects can:

- displace, tip, or rotate permanent teeth
- prevent permanent teeth from appearing
- prevent the alveolar ridge from forming

These problems can be fixed by grafting bone matter onto the alveolus, which allows the placement of the teeth to be corrected orthodontically.

Orthodontic treatment usually involves a number of phases. The first phase, which starts as the permanent teeth come in, is called an orthopalatal expansion. The upper dental arch is rounded out and the width of the upper jaw is increased. A device called an expander is placed inside the mouth. The widening of the jaw may be followed by a bone graft in the alveolus.

Your orthodontist may wait until all the permanent teeth come in before starting the second phase, which may involve removing extra teeth, adding dental implants if teeth are missing, or applying braces to straighten teeth.

In about 25% of kids with a unilateral cleft lip and palate, the upper jaw growth does not keep up with the lower jaw growth. If this occurs, these kids (as teenagers or young adults) may need orthognathic surgery to align the teeth and help the upper jaw develop.

For these kids, phase-two orthodontics may include an operation called an osteotomy on the upper jaw that moves the upper jaw both forward and down. This usually requires another bone graft for stability.

Speech Therapy

Kids with oral clefting may have trouble speaking — the clefting can make the voice nasal and difficult to understand. Some will find that surgery fixes the problem completely.

Catching speech problems early can be a key part of solving them. A child with a cleft should see a

speech therapist between the ages of 18 months and 2 years. Many speech therapists like to talk with parents at least once during the child's first 6 months to provide an overview of the treatment and suggest specific language- and speech-stimulation games to play with the baby.

After the initial surgery is completed, the speech pathologist will see the child for a complete assessment. The therapist will evaluate developing communication skills by assessing the number of sounds the child makes and the actual words he or she tries to use, and by observing interaction and play behavior.

This analysis helps determine what, if any, speech exercises a child needs and if further surgery is needed. The speech pathologist often will continue to work with the child through additional surgeries. Many kids will work with a speech therapist throughout their grade-school years.

Dealing With Emotional and Social Issues

Society often focuses on appearances, and this can make childhood — and, especially, the teen years — hard for someone with a physical difference. Because kids with oral clefting have a prominent facial difference, they might experience painful teasing that can damage self-esteem. Part of the cleft palate and lip treatment team includes psychiatric and emotional support personnel.

Ways that you can support your child include:

- Try not to focus on the cleft and don't allow it to define who your child is.
- Create a warm, supportive, and accepting home environment, where each person's individual worth is openly celebrated.
- Encourage your child to develop friendships with people from diverse backgrounds. The best way to do this is to lead by example and to be open to all people yourself.



- Point out positive attributes in others that do not involve physical appearance.
- Encourage autonomy by giving your child the freedom to make decisions and take appropriate risks, letting his or her accomplishments lead to a sense of personal value. Having opportunities to make decisions early on — like picking out what clothes to wear — lets kids gain confidence and the ability to make bigger decisions down the road.

Consider encouraging your child to present information about clefting to his or her class with a special presentation that you arrange with the teacher. Or perhaps your child would like you to talk to the class. This can be especially effective with young children.

If your child does experience teasing, encourage discussions about it and be a patient listener. Provide tools to confront the teasers by asking what your child would like to say and then practicing those statements. And it's important to keep the lines of communication open as your child approaches adolescence so that you can address his or her concerns about appearance.

If your child seems to have ongoing self-esteem problems, contact a child psychologist or social worker for support and information. Together with the members of the treatment team, you can help your child through tough times.

Reviewed by: Louis E. Bartoshesky, MD, MPH
Date reviewed: October 2008



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How Can Parents Help Kids Handle Teasing?

My son has a cleft lip, and other kids have been making fun of him. How can I help him handle the teasing?
- John

Most kids experience teasing at some point and it can be very difficult for them to handle. Kids with a cleft lip or other physical differences can be easy targets because the differences are so visible.

But you can help your son by encouraging him to express how he feels, showing him that you understand, and talking through some strategies for dealing with it. For example, teach him to be assertive (but not aggressive) and to use a proud voice to tell the child who is making fun of him to stop.

Other strategies might include ignoring or walking away, finding a "safe" person or a friend to be near, or telling a teacher or another adult. Some kids like to think of short phrases or jokes to say in response to teasing, but remind your son not to tease back, fight, or say something hurtful in return, which can only make the situation worse.

You also can help him become more resilient by offering your support, and encouraging activities and friendships that develop his strengths. Get

him involved with organized activities — like music or sports — that he enjoys and where he can thrive.

Many schools now have programs to deal with bullying and promote positive relationships between kids, so you may want to talk with school personnel, such as a teacher, guidance counselor, or principal, about it. For instance, if teasing tends to occur in specific settings (like at the bus stop or during recess), work with school personnel to develop solutions.

If you're concerned about ongoing issues or if you notice sudden changes that concern you (like your son doesn't want to go to school, seems sad, or seems to have a hard time separating from you or family members) talk with a counselor or mental health professional for additional support.

Reviewed by: Julie Simons, PhD
Date reviewed: May 2007



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Personal Stories

The purpose of this section is to provide you with the perspective of parents, family members and those living with the disability or special health care need. These stories give you insight of what life was like growing up and what life looks like now, as well as some of the joys and challenges that were experienced.

Written personal stories are one way of connecting to others who have similar experiences. Another way of connecting with others is through the Sharing Our Strengths peer support network. This service of the MODDRC provides you with an individualized match specific to what you want. This may include being matched to mentors with a similar disability experience, a mentor located in a similar part of the state or around a specific issue. If you are interested in being matched or in becoming a mentor for someone else, please contact us.



Sharing Words of Wisdom

An interview with the mother of a child with cleft palate

Taylor was born with cleft palate as the result of Kabuki Syndrome, a rare condition that affects the heart, spine, hearing, and growth hormones. The following questions were asked in an interview with her mother when Taylor was 14 years old.

Tell us about your experience of raising a child with cleft palate.

The first thing that comes to mind is that I thought I had done something to bring this on. I also wondered why it was not caught in the ultrasound. I regret not going to a specialist in cleft palate. Instead, we had a small town local doctor do Taylor's surgery. After seeing a specialist and a Cleft Lip and Palate team, I learned that I probably could have gotten better care for Taylor.

What pointers or tips would you share with a parent who is just starting out?

Be prepared and patient with many doctor appointments. Always treat your child like a healthy baby – cleft palate is not a deformity. It is merely that a normal developmental process did not occur. Your child's cleft alone will not cause them any pain.

What were your best times/biggest joys?

When Taylor started to gain weight like a healthy baby it was really exciting. After the surgery was also a great joy, seeing how easily cleft palate could be repaired.

What were your biggest challenges?

Although it was a joy to have the surgery done, it was also a challenge, seeing your one-year old go through surgery. Since Taylor's speech was difficult to understand at first, it was a challenge to figure out what she was saying.

What do you want other parents to know?

I want other parents to know that, out of all the possible things that could go wrong with a baby, cleft palate would be one of the more positive problems. It is easy to fix and it brought our family close together. We are pleased to get to share our story.



A Mother's Experience and Tips for Raising a Child with Cleft Lip/Palate

a featured "story of the month" from the Cleft Palate Foundation. Visit www.cleftline.org for more stories like this:

Everyone knows, in the back of their minds, that there is a possibility that the birth of their child will have some complications, but we rarely speak of these things.

I thought that my husband and I were well read on the "what to expect" until delivery day arrived. Then I quickly realized that we knew nothing about what to expect and we were so unprepared for most of what happened.

After 30 hours of labor with virtually nothing accomplished, the baby's heart rate began to go down. My obstetrician, Dr. Linda, recommended a C-section. In spite of the shock and our total lack of preparedness, we were okay with it. At that point, our only concern was getting our baby out alive.

Finally, at 7:50 a.m., my beautiful baby boy was born—Jarom Michael —weighing just under seven pounds. I held my breath, waiting to be happy until we heard him cry. Then I heard the doctor say, "Baby has a cleft lip." In my mind was one huge "?????" The only thought I dared allow myself was, "It doesn't matter."

I got one little glimpse of my baby—dark hair, dark eyes, healthy cry, and a gap in his upper lip—before he was whisked away to be cleaned up and examined for any other problems. As Dr. Linda sewed me back up, I lay there on the table trying to figure out what this meant.

I don't remember if anyone explained to us then what it was or told us about his palate or anything. I can remember searching my memory for any information on "cleft lip". The term meant nothing to me but I thought it might be what used to be called a "hare lip". What an awful term. Then I remembered a waiter at the Denny's restaurant I frequented in college who had a slight scar on his lip. Is that all it was?

I really had no idea what it meant but I kept telling myself over and over, "It doesn't matter. He's my baby and I will love him and he will be beautiful no matter what. It doesn't matter."

In retrospect, I think I was afraid to let myself feel anything in regards to Jarom's cleft. I was afraid of betraying my baby if I allowed myself to feel anything negative. When I finally got to hold Jarom, an agonizing hour and 20 minutes after his birth, I didn't spend any time counting fingers or toes. I just held him and examined his funny little face.

It took a few looks to become accustomed to his appearance. The gap in his lip was about half of an inch wide on the left side. His right nostril and the right side of his lip were normal. On the left side it just looked like his mouth was open into his nose.

Since Jarom's palate was also cleft, the gap was also on the inside of his mouth. When he cried really hard, you could see that about half of it was missing.

When our pediatrician, Dr. Deborah, stopped by the hospital, she was quick to point out that all the tissue Jarom needed was there, it just needed to be "smooshed" together. Dr. Deborah was a relatively new doctor, but she had spent time during her residency with Dr. Constance (who would be our plastic surgeon), so she was familiar with clefts and was very matter of fact, calm and positive.

During our first few days together, there was a song that went through my head every time I held my baby: "Beautiful Boy" by John Lennon. We saw the movie Mr. Holland's Opus while I was pregnant and Richard Dreyfus—a.k.a. Mr. Holland—sings this song to his son. I didn't remember very much of the song, but the chorus came into my head every time I held my baby: "Beautiful, beautiful, beautiful, beautiful boy."



This song continued to come back to me over the next few weeks and months. I couldn't remember any other words to the song so we eventually had to watch the movie (while I wrote down the words) to get the whole song!

Initially, Jarom had a hard time eating because his cleft was so wide. We did not realize how many different bottles there were for cleft-affected babies.

At 6 days old, he was admitted to the University Hospital in Columbia Missouri because he lost too much weight, was dehydrated and jaundiced and we needed help getting him to eat. We were so thrilled when he drank 1/2 ounce in 30 minutes!

What he needed was 2-3 ounces every 2-3 hours and he just couldn't get it. So after almost a week, he came home with a nasal gastric feeding tube that went in the right nostril and down his throat into his tummy. This helped him to get all the milk he needed without burning all the calories in the process. He had 20 minutes to drink what he could from the bottle (a modified playtex nurser), and what was left went down the tube. Thankfully, Jarom only had the ng tube for about two weeks.

At 19 days old, Jarom had his first surgery--lip adhesion. The lip adhesion pulled the sides of his lip together. This did not give his lip a normal appearance but made his lip more functional. He was then able to eat from the modified playtex nurser alone. We had to squeeze the bottle to help him (no suction without a full palate), but no more feeding tube.

At 3 months of age, Jarom had his next surgery—a hernia repair and ear tubes. He was supposed to have had his lip repaired at the same time but his hemoglobin was low and the doctor did not want him to lose that much blood until his hemoglobin went up. And so, Jarom was almost 4 months old when his lip was repaired just in time for Christmas. His lip was repaired December 19 and stitches were removed December 24. Jarom's palate was repaired a few months later when he was 9 months old. That was the hardest

of all the surgeries up to that point. The surgery took longer and the recovery was much harder. It seemed like he did not drink or sleep for 6 weeks!

Excluding ear tubes, Jarom's next surgery was when he was 5 years old. By this time, we had moved to Kansas City and were seeing the team at Children's Mercy Hospital headed by Dr. Virender Singhal. Jarom was scheduled for a palatal lengthening, septoplasty, turbinectomy, and lip and nose revision with ear cartilage graft. All of this was to improve speech and total function of the mouth and to give Jarom a better airway. This was a difficult surgery because it seemed like Dr. Singhal would be taking apart everything that had been done and re-doing it!

The surgery was long, recovery was slow and before we got home, we had learned so much about the strength of a 5 year old! This was our first surgery where Jarom was old enough to know what was going on and it was quite a change. We prepared him for a lot but forgot to prepare him for the fact that he would look different afterwards. After the initial shock, Jarom adjusted and finally announced a few weeks later the he thought his nose looked great!

Jarom is now 10 years old. His bone graft surgery was last spring and went very smoothly. He is in fourth grade and he is as normal as any other 10 year old boy! He is both smart and funny. He excels at school and is a whiz on the computer. AND he bickers with his sisters, talks too much at school, tries my patience and challenges my ability to answer questions!

So far, he has had eight surgeries and is wearing braces. Truly, the cleft is a very small part of our lives right now. Jarom is smart and happy and busy getting into normal boy trouble.

For parents who are just starting out, I would encourage you to enjoy your baby. Get the information you need, particularly on feeding, but try not to overwhelm yourself with too much information. It's best to digest the new information a little bit at a time.



What you need to know at the beginning is how to feed your baby, what team will care for your baby, and when the first surgery will be. Get through that before you worry about what will happen when your child is 4 or 6 or 16.

I would also encourage parents to take lots of pictures before the first surgery. This is the first face of your baby that you will fall in love with. You may find after lip repair that you miss your baby's first smile. It's okay if you feel that way and it's okay if you don't --but you will want pictures either way. Also, don't avoid going in public with your baby before lip repair, just try to prepare a light response that you can give when people ask questions.

One thing that I wish I would have done differently is that I wish I would have allowed myself to feel my genuine emotions (even if they were negative at first) when Jarom was born. I was afraid to let myself think or feel anything except "everything will be just fine". I spent my energy denying my own feelings and reassuring everyone else. How silly! There is nothing wrong with having a reaction to the unexpected news that your baby's face is different and that feeding and speech will be difficult and he is going to need surgery to put everything back together. There is nothing wrong with feeling a little overwhelmed at what lies ahead.

Really, as Jarom got older and I let myself relax a bit, having a good cry as surgery approaches is a good way to let off steam and, even, to prepare mentally for what lies ahead. I'd so much rather be emotional the week before surgery than to fall apart on the day of.

Our biggest joys have really been the normal joys of parenting any child---his first step, his first word, this first time he asks a question that we don't know how to answer. We have had the additional joy of making it through the first year

and thinking, "thank goodness we don't have to do that again for a while!" and the joy of seeing our son grow to the point where the cleft lip and palate he was born with are NOT the biggest issues in his life.

Our biggest challenges have, at times, been related to Jarom's cleft. Getting through any surgery, no matter how routine it is to the doctor performing surgery, is ALWAYS a challenge. It is emotional and exhausting in ways I could never have imagined.

Feeding Jarom was a big challenge when he was young, both before and after surgery. Actually, feeding was still a challenge after his last surgery (at age 9). We had to find creative ways to keep Jarom eating (which was really drinking since he had to be on a liquid diet for a couple of weeks) so he would get enough calories after surgery even when he had very little appetite for anything that wasn't a cheeseburger!

At his age, we have also had to deal with some fear surrounding medical procedures. Our son has always been very cooperative with doctors, dentists and any manner of medical professionals. One bad experience with an oral surgeon changed all of that. Now we have a son who is very frightened of new doctors and terrified of surgery. At the moment, our only comfort in that arena is that there is nothing else to be done in his immediate future.

If we let our imaginations take over, we often imagine some pretty awful things and we can worry until we make ourselves sick. With the current abundance of reality TV, it seems to be "in style" to have huge, public, negative reactions--to "freak out" over any problem. In real life, that isn't really the best or most natural course. It's okay to allow yourself whatever emotions you really feel, and then pick up, move on and enjoy your life!





Family Support, Advocacy and Services

The purpose of this section is to provide you with a listing of organizations specifically designed to meet the support needs of individuals with developmental disabilities or special health care needs and their families. This listing includes parent organizations, support groups or other advocacy organizations.



Support for Families

Sharing Our Strengths (SOS) Peer Support Network

215 W. Pershing Road, 6th floor
 Kansas City, MO 64108
 Toll free: 800-444-0821
 Web: <http://www.sharingourstrengths.com>

SOS is a statewide support network of parents, family members, individuals with developmental disabilities or special health care needs, and professionals who are matched with peer mentors to share experiences, offer emotional support and to network with others. You can request an individual parent to parent or peer support match with another parent or individual who has experienced similar circumstances.

Show Me Smiles

provides support for individuals with facial differences and their families, and education for the public
 Coordinator: Angelia Ham, MSW
 Springfield, MO
 Phone: 417-326-8702
 Web: <http://www.showmesmiles.org>
 Email: angelia.ham@gmail.com

Cleft Advocate –Missouri

contact information for local cleft lip/palate advocates
 Web: <http://www.cleftadvocate.org/MO>

American Cleft Palate Foundation

1504 East Franklin Street, Suite 102
 Chapel Hill, NC 27514-2820
 Phone: 919-933-9044
 Toll free: 800-24-CLEFT
 Web: <http://www.cleftline.org/parents>
 Email: info@cleftline.org

Daily Strength Cleft Lip/Palate Support Group

online parent discussion board on raising a child with cleft lip/palate
 Web: <http://www.dailystrength.org/c/Cleft-Lip-Palate/support-group>

AboutFace USA

information, services, support, camps and education programs related to facial differences
 PO Box 751112
 Las Vegas, NV 89136-1112
 Batavia, IL 60510-0969
 Toll free: (888) 486-1209
 Web: www.aboutfaceusa.org
 Email: info@aboutfaceusa.org





Missouri Service Systems

The purpose of this section is to provide you with a listing of agencies focused on areas such as educational, medical care or social services to individuals with developmental disabilities or special health care needs. This includes listings such as state or local agencies, hospitals, clinics or education systems.



CL/P Specialty Surgery Teams

Columbia

University of Missouri Children's Hospital

Division of Plastic Surgery
Lynette Baker, pediatric plastic surgery nurse
One Hospital Drive, M329
Columbia, MO 65212
Phone: 573-882-4176
Web: www.smilesforkids.missouri.edu
Email: BakerClar@health.missouri.edu

Kansas City

Children's Mercy Hospital

Cleft Palate/Craniofacial Clinic
2401 Gillham Rd.
Kansas City, MO 64108
Phone: 816-234-3677
Web: <http://www.childrens-mercy.org>

Mid-America Regional Cleft & Craniofacial Institute

4620 JC Nicholas Parkway, Suite 503
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Cleft Palate and Craniofacial Institute

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Center for Cleft Lip/Palate & Craniofacial Deformities

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St John's Mercy Cleft Lip/Palate and Craniofacial Deformities Center

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