

Crafting Better Lives For Kids With Clefts

Where others might see deformity,
a dedicated team of health care professionals
at OUHSC's Cleft Palate-Craniofacial Clinic
see beautiful children with challenges
that can be overcome.

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The brother of eight-week-old Adriana kisses her cheek before returning to his toy cars on the waiting room floor of the John W. Keys Speech and Hearing Center. Sheri, the children's young mother, cuddles her baby as she explains about the surgery Adriana will have in a few weeks.

Adriana was born with a bilateral cleft lip and palate. The clefts in her upper lip extend into her nostrils, with the flap of tissue between the two clefts almost looking like an extra tongue. In spite of her deformity, tiny Adriana manages a gaping smile in response to her mother's cooing.

Sheri is both apprehensive and hopeful about the surgery. It will be easier to feed Adriana after the surgeon closes her lip, but Sheri knows how worried she will be with her baby

on an operating table. And there will be other surgeries. It is scary, she admits.

The surgeon says that all of Adriana's parts are there, Sheri continues, smoothing the front of the baby's pink dress. He just has to move them around and get them connected correctly.

Sheri is grateful that a sonogram revealed the problem before Adriana was born. The prenatal counseling she received through the Cleft Palate-Craniofacial Clinic at Keys helped prepare her. She knew about feeding problems and how the deformity would look. She knows that Adriana faces multiple problems in addition to repairing the clefts. There will be orthodontia and speech therapy. She might have some hearing loss.

For the next 20 years or so, Sheri

Resident Dr. Todd Evans observes as Dr. Kevin Smith examines his patient, Jason Genson, being held by his mother, Sheryl. The cleft team will monitor carefully Jason's progress until all treatment is completed, probably about age 20.

and her daughter will return regularly to the OU Health Sciences Center. Sheri will be guided through the lengthy habilitation process by the professionals of the Keys clinic. They will evaluate each stage of Adriana's progress and make recommendations for the next step.

Now celebrating its 40th anniversary, this remarkable clinic looks after patients the staff affectionately refer to as "kids with clefts." A program of John W. Keys Speech and Hearing Center in the Department of

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—Dr. Ann Owen

Communication Sciences and Disorders, College of Allied Health, the Cleft Palate-Craniofacial Clinic is recognized as a pioneer in the interdisciplinary team approach to evaluating children born with clefts and other craniofacial anomalies and recommending a course of care for them.

“Forty years ago, the team approach was very new,” says speech-language pathologist Dr. Ann Owen who, along with oral and maxillofacial surgeon Dr. Kevin Smith, directs the Keys Cleft Palate-Craniofacial Clinic.

The Keys clinic was one of the first such programs in the nation. In 1959, Dr. Donald Counihan came to OU from Northwestern University to establish a cleft program based on the team approach. Other directors have been Drs. Floyd Emanuel, 1961-67; Glenda Ochsner, 1967-88; and Judith Black, 1988-95. Owen, a professor of communication sciences and disorders, and Smith, a faculty member in the colleges of dentistry and medicine, have served as co-directors since 1995.

Before the clinic was established, Owen points out that parents were on their own to educate themselves about what their child was going to need and find appropriate professionals for each phase of care.

In addition to Smith and Owen, the Keys cleft team is composed of an orthodontist, pediatrician, pediatric dentist, prosthodontist, audiologist and otolaryngologist. When needed, the team consults additional surgeons, nutritionists, geneticists, social workers and other professionals. OU speech-language pathology and audiology graduate students also see the patients alongside clinic professionals as part of their master's degree program.

A cleft team is one of the largest interdisciplinary groups found in a health sciences setting, Owen and Smith point out.

When a child with a cleft is referred to Keys Speech and Hearing Center, the child always is seen by



this team. “The child must go through our clinic,” Owen says. “That’s how parents and children are best served.”

The Keys clinic sees patients from all over the state and region. They follow children from birth until all treatment has been concluded, usually around age 20. Currently, they are following 174 patients.

“Our team offers a road map,” Smith explains. “We make recommendations to parents and recall the children periodically to see what’s been done and if there are any problems. For example, maybe the parents haven’t been able to find an orthodontist in their area.”

The clinic team often helps parents locate appropriate health care professionals in their home community. Frequently, however, parents elect to have their children’s surgical and specialized dental services performed at the OU Health Sciences Center. Some also return to Keys for speech and hearing care, but those services often are available closer to home.

Many of the needed services are covered by standard medical insurance. The staff at Keys will work

Since kids with clefts have a higher incident of ear infections, Lori Chessmore, left, brings her 20-month-old daughter, Carrie, to the Keys clinic for frequent hearing tests by audiology graduate student Lee Jones. Carrie’s cleft lip was closed at 5 months, and the first palatal closure was performed at 13 months; a second palatal closure will be performed later.

with the Oklahoma Department of Human Services and other agencies to arrange coverage for uninsured children. “We never turn down patients because of an inability to pay,” Owen says.

Owen and Smith try to see the children as soon as possible after birth. Smith usually sees them in the hospital. Owen meets with them as soon as they are released. The parents are invited to bring their child to the first regularly scheduled meeting of the monthly cleft clinic or are seen sooner by specific team members if there is a need.

The clinic experience offers a



LEFT: Michael and Sheryl Genson visit the Keys clinic with their 16-month-old son, Jason, for a regular reassessment by Brooke Rosen, a graduate student in speech-language pathology. Born with a right unilateral cleft lip, Jason had his initial corrective surgery at 2½ months.

LOWER LEFT: Speech-language pathology graduate students, seated from left, Brooke Rosen, Jennifer Kelley and Caryn Warnock study before-and-after photos of Cleft Palate-Craniofacial Clinic success stories under the supervision of co-director Dr. Ann Owen, left, and coordinator Kay McVay.



Feeding is the first major hurdle parents face with babies with clefts and has become a special area of expertise for Owen. When she gets a frantic phone call from parents having trouble feeding their baby, she schedules an immediate meeting. "When parents are having trouble feeding, I drop everything," she says.

For years, babies with clefts were fed with a syringe, but aspiration was a problem, and pneumonia could result. Various specialized feeders now are available; Owen's favorite is the Haberman feeder, which was invented by a frustrated mother. Owen has a grant that allows her to keep the expensive and difficult-to-find feeders on hand to give to new parents.

While it is widely believed that babies with clefts cannot be breast fed, Owen works with mothers and lactation consultants to find a technique that may be successful.

The treatment of children with clefts has come a long way since the days when the anomaly was referred to as a "hare lip," and they usually went through life with unintelligible speech and surgical closures that would be considered primitive by today's standards.

Smith explains that the first surgery, usually performed between 10 and 12 weeks of age, closes the lip and

chance for parents to see children at all stages of treatment and compare notes with other parents. During Sheri's second visit with Adriana, she is introduced to a mother and her two-year-old daughter. The little girl's bilateral cleft had been repaired by Smith. "You can't even tell she had it!" Sheri exclaims.

As with Adriana, more and more clefts are being diagnosed with prenatal sonograms, and Owen and Smith are able to consult with the parents before their baby is born.

"This really helps parents prepare for the birth of their child," Smith says. "I discuss surgical issues, and Dr. Owen discusses feeding."



LEFT: Lori Chessmore, right, offers encouragement to Sheri Patterson, left, whose daughter, Adriana, will undergo the surgery and post-operative therapy that Lori's daughter, Carrie, has experienced over the past 15 months.

LOWER LEFT: Dr. Ann Owen specializes in helping parents overcome feeding problems, the first major hurdle facing babies with clefts. Her favorite among the customized feeders now available is the Haberman feeder, developed by a frustrated mother. A grant allows Owen to supply new parents with the expensive and difficult-to-find feeders.



Then there are several years of specialized orthodontics and possible jaw surgery. In addition, there may be the need for prosthetic dentistry and the use of dental implants.

"Following that, there may be additional revisions of the lip and nose," Smith says. "Usually treatment is finished between 18 and 21 years of age."

With some children, the process is even more complicated. More than 15 percent of cleft cases are associated with some other syndrome or condition, a common one being the Pierre Robin sequence. With this condition, children also have an abnormally small lower jaw and often an obstructed airway.

Before-and-after pictures of Smith's patients are remarkable. Frequently it is difficult to tell the children ever had a deformity. While most of his patients are children, he sometimes works on adults to revise previous surgeries and improve appearance and function.

In addition to his practice at the OU College of Dentistry, Smith makes regular philanthropic trips to Guatemala, where he repairs clefts on patients of all ages. His oldest patient to date has been a 60-year-old man.

usually involves some "remodeling" of the nose. If there is a cleft in the palate, it usually is closed between 12 and 15 months. If needed, surgery to correct hypernasal speech is performed at age three or four years.

There may be a nasal revision, but more typically, the next surgery is between 7 to 12 years when a bone graft is used to expand the upper jaw.

While the incidence for clefts among Caucasian children is one in 750 live births and only one in 2,000 for black children, the rate is one in 500 among Hispanics, Asians and Native Americans. Smith says that the rate in Guatemala among some isolated groups of indigenous people is even higher. In the Quiche area he visits, a nun notifies families in outlying villages. When Smith arrives, lines of people are waiting for him.

About one-third of Smith's OU practice deals with cleft lips and palates. Almost all of those children are followed by the Keys Cleft Palate-Craniofacial Clinic. He and Owen are staunch believers in the team approach to caring for these children.

When asked if they sometimes feel as if they are performing miracles, Owen and Smith just smile. Not miracles exactly, but what they do is *very* satisfying. With their help, children born with cleft lip and palate can live normal lives.

That is what Adriana's mom hopes for—a normal life for her "kid with a cleft."