Craniofacial Clinic

The craniofacial cleft lip and palate team at Boys Town National Research Hospital is the only accredited craniofacial team in the state of Nebraska. About 80 percent of our patients have cleft lip and palate, and then the remainder, are kids with ears problems, malformed ears, undeveloped ears, no ear canals. Team care is well accepted as the best way to care for children with craniofacial abnormalities. There are issues before the cleft surgery, and after the cleft surgery. And most children need more than just surgery to close the lip, and surgery to close the palate.

“We’re going to go right in here, buddy.”

Our team follows about 500 individual children. We meet every week and we see, usually anywhere from 10 to 12 children a week. And those can be children of all stages in the process of cleft care. All the way from a newborn baby to a 21 year old about to age out of our clinic and move into the world of adult care. As a multidisciplinary team, it’s really our obligation to find the very best providers we can for our patients and I think we’ve done that. We have used resources within Boys Town. With the input of our ear, nose, and throat surgeon, our audiologists, we have cutting edge technology and forward thinking ways of approaching children with cleft lip and palate, with ear abnormalities and the hearing loss that frequently accompanies that. We also have our developmental pediatrician who will see these kids who have developmental challenges. Those are all doctors and practitioners who practice at Boys Town and see other patients at Boys Town.

We get other expertise from other doctors in the community. Dr. Jason Miller, who’s a fellowship trained pediatric plastic surgeon, primarily practices at UNMC but sees kids in our cleft clinic and does most of that surgery here in the Boys Town surgery center. Dr. Val Desa is an oral and maxillofacial surgeon, and he also practices at UNMC primarily. We have an orthodontist and a pediatric dentist, Dr. David Mohs, who comes from Creighton. And as kids get older that’s very important so that any surgical needs are coordinated with their orthodontic needs.

Some of the kids have genetic abnormalities or other syndromes. Our medical geneticists are based primarily at UNMC but provide that genetic support to our families. I’ve seen it to just be a great example of community collaboration. It’s not about where the patient is seen or who sends a bill; it’s about where the patient can get the best care.

“Can you say Hi?”

“Hi”

“Good job, buddy!”
We really consider it and I think many families consider it, a convenience for them to get to see all these providers in one morning in one spot. To get good care, a child with these problems, needs to see a number of different medical specialists. We get to come up with a plan for the patient, tailored to their individual needs.

We really want to have an impact. We know we have a local impact. We have a regional impact because of the distance to get to another team and we have an international impact. About 50 of our kids that we follow in the clinic, out of the 500, are internationally adopted, many from China.

They both had similar situations but it was on the opposite sides. We kind of played around with the idea that they balanced each other out with their clefts.

Yeah, Boys Town National Research Hospital, they do craniofacial, that’s great. But what does that mean? I don’t know. Now we know it means everything.

The miraculous transformation after that first surgery, if children have a cleft lip, that’s life-changing. Beyond that we make sure their hearing is tested, we go on to monitor their speech closely and make sure they are getting the speech therapy services that they need. So there are a lot of things that happen in that first 7 to 10 years of life that are very important for kids to have school success.

They definitely walked us through a step at a time, what was going to happen and what was going to happen in the future. They don’t just stop after the surgery and say, you’re done and you can recover on your own. You have follow-up appointments and they call and make sure everything is ok.

“By boppy a puppy.”

“Good.”

We have loved speech at craniofacial. We actually go to private speech and have been taking the boys there for five years.

Eli is in school, in 2nd grade now, and the kids don’t know anything that he has experienced these surgeries and what he has gone through. His speech has come so far.

I listen to other kids in his class and sometimes I’m like, oh, he sometimes has better speech than they do.

“Tape.”
“Tape.”

Noah goes on a bi-weekly basis. He needs a little bit more of intensive speech than Eli needed.

“Did you get a red?”

“Yup.”

“You can play the red.”

We went from a period where you kind of wonder, are they going to be able to speak? Are they going to be able to develop language? And now they have no problem speaking. There is plenty of speaking going on in the house. It’s amazing where we have come in the last five years.

I could not imagine doing it without Boys Town. This is not easy, but it’s doable. We have the support and we have the resources to make these kid’s lives amazing, and then that, in turn, makes our lives amazing.

I think the craniofacial team exemplifies the mission of Boys Town, which is changing the way America cares for kids. I think our focus on function as well as form, good hearing, good speech and good school performance. I think that’s part of what supports the families and gives them hope for the future.

“Give me five.”

“That a boy!”