

# Barrow Cleft and Craniofacial Center



↑ Kids with facial differences often need speech therapy throughout their lives.

**A** **BOUT 200 CHILDREN** are born each year in Arizona with a cleft lip or palate or craniofacial syndrome such as craniosynostosis (a skull that cannot expand to accommodate the growing brain) or craniofacial microsomia (one part of the face is smaller than normal). These children and adults face a challenging future of multiple surgeries and multiple specialist visits, as well as the psychological and emotional impacts of living with a facial difference. The Barrow Cleft and Craniofacial Center was founded in 1986 on the principle of the interdisciplinary team approach. Health professionals in more than 15 specialties – including plastic surgery, neurosurgery, orthodontics, speech pathology and psychology – collaborate in providing comprehensive care. The doctors and therapists meet regularly, creating an interdisciplinary plan to address the needs of each patient and their family. In some cases, this plan begins before the child is even born.



**ABOUT 200**

children per year born in Arizona with cleft lip, palate, or other facial difference



Cleft lip/palate is the **MOST COMMON** facial birth defect



Barrow Cleft and Craniofacial Center founded in **1986**

## BY THE NUMBERS



### CLINICAL IMPACT

**100,878**

BNI Clinic Visits

**77,000+**

Patients Treated

**5,000+**

Brain & Spine Surgeries



### GLOBAL IMPACT

**47**

Visiting Scholars from  
Argentina, Austria, Brazil,  
China, Chile, Colombia,  
Germany, India, Italy, Ireland,  
Israel, Mexico, Pakistan,  
Philippines, Portugal,  
Romania, Russia, Spain,  
South Korea, Turkey,  
United Kingdom

## PROGRAM ACCOMPLISHMENTS

The Barrow Cleft and Craniofacial Center is the first in Arizona to be approved by the American Cleft Palate-Craniofacial Association as both a cleft team and a craniofacial team serving families expecting a child with a craniofacial difference into adulthood, a dual approval it has maintained since 2010. The Center is committed to serving patients from across the Southwest, and families from as far away as Georgia travel to Phoenix because of the Center's expertise and reputation.

The COVID-19 pandemic had a profound effect on the community and on the Center's operations. The Center established safety guidelines and was able to continue seeing certain patients in the clinic, for instance, infants who may have needed help feeding. The Center adapted swiftly to offer speech therapy and psychology services via telehealth. The Center's team spent hours on the phone each day, talking to families, ensuring the needs of patients were being met. Despite the pandemic, the Center's outreach program was able to hold a few virtual events to keep families connected to one another and to their care providers.

The Barrow Cleft and Craniofacial Center strives to provide the best care possible while contributing to the body of knowledge around facial differences. The Center is participating in two grants from the National Institutes of Health. The first is the Cleft Outcomes Research Network (CORNET) *Outcomes Project*. This study compares the effectiveness of speech and surgical treatments using a Cleft Palate Registry/Research Outcomes Network. The goal of the second grant is to develop technology that can provide an objective, reliable assessment of speech when compared with expert speech-language pathology ratings.

## RESEARCH ADVANCES

Researchers at the Barrow Cleft and Craniofacial Center are collaborating with Arizona State University on a project to measure speech outcomes of children with cleft palate. ASU is developing an artificial intelligence algorithm to analyze the speech characteristics of children with hypernasality, which is when too much sound resonates in the nasal cavity during speech. The algorithm results will be compared to evaluations of the same samples by expert speech therapists. This important work will improve the reliability and quality of speech evaluations for patients with cleft palate.

Participation in this study and several other projects is possible with the addition of a part-time research assistant, Debra Karam, RN, MPH,



The Barrow Cleft and Craniofacial Center held several virtual events to keep patients and their families connected during the COVID-19 pandemic.

CPHRM. Ms. Karam’s thoughtful approach to tasks related to research has created a positive experience for the participants of these projects and their parents. Eventually, these projects will help guide the care of future patients with cleft conditions.

## ON THE HORIZON

Babies born with cleft lip and cleft palate face multiple surgeries and many require intensive speech therapy at different times throughout their lives. The Center will be expanding the clinic with dedicated speech therapy, psychology, and social work spaces to continue providing the best care possible for all patients. Also, an additional orthodontist will be added to the team. This will allow the Center to effectively coordinate care with providers, and ensure the team is treating the “whole” child with the best in medical care and emotional support. Additionally, the Center plans to complete another collaborative project, with Phoenix Children’s Hospital, to examine the benefit of early speech therapy with a parent training component for patients with cleft palate.

## BY THE NUMBERS



### RESEARCH

**1,377**

Active Research Studies

**959**

Patients Enrolled in Clinical Trials

**\$11.3 MILLION**

Federal Research Grant Support



### DONOR IMPACT

**\$2.4 MILLION**

Basic & Translational Research

**\$5.28 MILLION**

Strategic Initiatives

**\$1.63 MILLION**

Education and Fellowship Programs

**\$1.97 MILLION**

Community Outreach Programs



## THANK YOU FOR YOUR SUPPORT

Thank you so much for your support of the Barrow Cleft and Craniofacial Center. We all want the best for our families, and our patients become like our family. Your generosity allows Barrow to offer them the best care – from corrective surgery to speech therapy, to emotional support. Barrow cannot make the lives of patients more manageable without your partnership, nor could the Center participate in groundbreaking research to improve the lives of those born with cleft lip and palate in the years to come.

With Gratitude,  
Dr. Stephen P. Beals  
Co-Director, Barrow Cleft and Craniofacial Center  
Barrow Neurological Institute

↑ Baby Rory and her family have worked with specialists at the Barrow Cleft and Craniofacial Center since before her birth.

Barrow Neurological Foundation's mission is simple: to be the catalyst of our donors' passion for transformation by providing the resources for Barrow Neurological Institute to achieve its mission of saving human lives through innovative treatment, groundbreaking, curative research and educating the next generation of the world's leading neuro clinicians.



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