

The VCU Center for Cleft and Craniofacial Care: Comprehensive, Compassionate Care for Children with Facial Differences

*Submitted by: Jennifer L. Rhodes, MD
Assistant Professor of Plastic Surgery and Pediatrics,
Medical Director, Center for Cleft and Craniofacial Care
VCU Children's Medical Center*



Jennifer L. Rhodes, MD

Every year an estimated 300 infants are born with an anomaly of the craniofacial region in Virginia. Craniofacial anomalies are a diverse

group with marked variation in presentation, and a heterogeneous etiology. Orofacial clefting represents the most common craniofacial anomaly, affecting an estimated 150 infants in Virginia each year, according to the Virginia Department of Health. Skeletal abnormalities of the bones of face and skull follow in prevalence, affecting around 100 of Virginia's children each year. Hemifacial microsomia is the most common of this group, followed by craniosynostosis. Other conditions seen less commonly include Pierre Robin sequence, microtia, microphthalmia, frontal encephalocele, craniofrontonasal dysplasia and hypertelorbitism. Lastly, there are a large number of syndromes which affect the craniofacial region. A brief list includes Crouzon, Apert, Pfeiffer, Carpenter, *Saethre-Chotzen*, and Treacher Collins syndrome.

The craniofacial region in children can also be affected by tumors or lesions. Hemangiomas are diagnosed in close

to 1000 infants in Virginia, and the vast majority of these benign tumors appear in the head and neck region. Vascular and lymphatic malformations along with vascular birthmark syndromes are seen less commonly. Other conditions which can affect the craniofacial region of children include pediatric tumors of the head and neck such as fibrous dysplasia, eosinophilic granuloma, and orbital tumors. Sadly, the full spectrum of pediatric trauma can also involve the craniofacial region

Conditions which affect the craniofacial region are best treated by a team of pediatric specialists. In keeping with Department of Health and Human Services' *Healthy People 2010* initiative, craniofacial teams can serve as the medical home for these children coordinating their complex needs. It is not possible for a single physician to effectively treat all of the complex and varied medical, dental, educational, psychological and communication needs of this population of children. Problem-focused treatment by a single provider may be seen as a missed opportunity for assessment and intervention in other fundamental health areas. For example, facial hemangiomas in young children may not require active intervention by a surgeon, but families may benefit from discussions about coping strategies in social situations with a team psychologist, thus

abrogating avoidable family stress. Team care maximizes health care delivered to children and families while minimizing the impact on their lives, and ensures care is efficient and coordinated.

Since 1976 **The VCU Center for Cleft and Craniofacial Care** has been providing coordinated interdisciplinary care for a wide range of complex and unusual craniofacial anomalies. The center prides itself on being a resource center for families and community health care providers. Knowing the center is there for support and advice, as well as comprehensive treatment, is a real help for families. "We're here to help our patients and their families with all aspects of care related to their conditions. During new patient evaluations, we spend as much time as needed with families – no family leaves with any questions unanswered," said Jennifer Rhodes, MD.

Dr. Rhodes became the Director of the VCU Center for Cleft and Craniofacial Care at the VCU Medical Center in 2008. Dr. Rhodes is the only dedicated pediatric plastic surgeon and affiliate member of the AAP Section on Plastic surgery in Virginia. Dr. Rhodes attended medical school at the University of Pennsylvania and completed residencies in general surgery and

Continued to page 7

The VCU Center for Cleft and Craniofacial Care: Comprehensive, Compassionate Care for Children with Facial Differences

Continued from page 6

plastic surgery in New York City at St. Vincent's Hospital and Montefiore Medical Center respectively. She completed her craniofacial and pediatric plastic surgery fellowship at The Craniofacial Center in Dallas, Texas, under the direction of Dr. Jeffrey A. Fearon.

Dr. Rhodes strongly believes in providing coordinated interdisciplinary care for children with complex and unusual craniofacial anomalies. **Her team consists of pediatric specialists** from craniofacial surgery, neurosurgery, ophthalmology, dermatology, interventional radiology, audiology, otolaryngology, genetics, speech pathology, psychology, dentistry, orthodontics, oral and maxillofacial surgery, occupational therapy, clinical anthropology, orthopedics, nursing and a dedicated clinic coordinator. The interdisciplinary team meets several times a month to evaluate patients and develop an individualized, coordinated and integrated treatment plan for each patient.

The clinic's coordinator, Ruth Trivelpiece, MEd, provides support and education to families and talks to parents about their emotional needs. Her role requires her to coordinate between health care providers, community agencies, and schools. She is an invaluable resource for families and community health care providers alike.

The VCU Center for Cleft and Craniofacial Care provides a variety of services - **prenatal consultation** for expectant parents, **pre-adoption**



counseling, feeding evaluation for infants with craniofacial conditions, **neonatal airway evaluation**, and **pediatric dental medicine**. The center also works with community and school speech therapists to ensure patients receive the very best services available for their condition. In addition to the cleft and craniofacial clinics, a biweekly **Infant Skull Clinic** offers screening of infants with concerns related to head shape, ensuring no family ever waits more than 2 weeks to be seen.

The Center is proud to announce the development of a **multidisciplinary Vascular Birthmark Clinic**. The first clinic in August was a great success for families and providers alike. This team brings a much needed service to Central Virginia's children.

The Center are currently accepting referrals for the **"Girl's Night Out" program**. This program is designed to foster self-esteem and self-confidence in preteen and teenage girls with facial differences. The event takes place each quarter for a different group of patients. Teenagers with facial differences often feel isolated, not realizing there are other teens facing the same problems. The program provides girls with facial

differences the opportunity to be a part of a peer network, an important aspect of normal adolescence. Teens can also "burn out" while going through their lengthy and complicated treatment plans. This treatment fatigue, along with the normal adolescent struggle to assert independence, can contribute to less than ideal patient compliance. Dr. Rhodes and Ms. Trivelpiece hope the program will allow the teens to realize the team is working with them to achieve their potential in many different areas.

"Growing up is hard to do, but when you have a facial difference, the teenage years can be especially harsh," said Dr. Rhodes. "We want to support our patients' emotional needs by doing what we can to help boost their self esteem. Getting together with peers who have had similar life experiences really helps our girls feel comfortable and accepted."

To learn more about Dr. Rhodes, The VCU Center for Cleft and Craniofacial Care, or the "Girl's Night Out" program, please call 804-828-3042. Visit us on the web at www.craniofacial.vcu.edu