Craniosynostosis: Developing Parameters for Diagnosis, Treatment, and Management

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Introduction/Background: A multidisciplinary meeting was held from March 4-6, 2010, in Atlanta, Georgia, USA, sponsored by the Centers for Disease Control and Prevention (CDC) entitled “Craniosynostosis: Developing Parameters for Diagnosis, Treatment, and Management.” The goal of this meeting was to create parameters for the care of children with craniosynostosis.

Material and Methods: Fifty-five conference attendees represented a broad range of expertise, including anesthesiology, craniofacial surgery, pediatric dentistry, genetics, hand surgery, intensive care medicine, neurosurgery, nursing, ophthalmology, oral and maxillofacial surgery, orthodontics, otolaryngology, pediatrics, psychology, public health, radiology, social work, and speech-language pathology. Representatives from sixteen professional societies as well as editors of relevant peer-reviewed journals also attended the conference. The current state of knowledge related to each discipline was reviewed. Based on areas of expertise, four breakout groups were created to reach a consensus and draft specialty-specific parameters of care based on evidence-based literature or, in the absence of such literature, broad clinical experience. In an iterative manner, the specialty-specific draft recommendations were presented to all conference attendees. Participants discussed the recommendations in multidisciplinary groups to facilitate exchange and consensus across disciplines.

Results: Consensus was reached among the 55 conference attendees in 18 areas of craniosynostosis care. Longitudinal parameters of care were developed for the diagnosis, treatment, and management of craniosynostosis in each of the 18 specialty areas of care from prenatal evaluation to the completion of care at more than 18 years-of-age.

Conclusion: To our knowledge, this is the first multidisciplinary, concerted effort to develop parameters of care for craniosynostosis. These parameters were designed to help: 1) facilitate the development of educational programs about craniosynostosis for the patient, families, and
professionals; 2) create a national database and registry to promote research, especially in the area of outcome studies; 3) improve credentialing of interdisciplinary craniofacial clinical teams; and 4) improve the availability of health insurance coverage for all individuals with craniosynostosis.