Craniofacial Society Mission
To encourage communication among the members of the Society in order to increase the knowledge base and improve the quality of care provided to individuals with craniofacial anomalies.

Help!
We need your help to make this newsletter successful and useful for everyone.

What would you like to see in this bi-annual newsletter? Please contact any officer regarding ideas, topics, presentations, tricks & tips or pictures by visiting the Craniofacial Society Website.

What are you looking for from the Craniofacial Society? Please help us meet your needs by letting us know what those needs are.

Plagio Cuties
To share a picture in the next issue, please make sure that you have a release signed, and e-mail your picture to Ellie at: eboomer@bostonbrace.com

A Note from the Craniofacial Society Chair
For years the Craniofacial Society’s main focus has been improving communication among practitioners who treat infants with plagiocephaly, brachycephaly and scaphocephaly with cranial remolding orthoses. While the use of CROs and patient care continues to be very important to the Society, one of our goals has been to expand our focus to related craniofacial topics. With this in mind, we hosted a seminar at the Academy’s 37th Annual Meeting & Scientific Symposium in March 2011 on the postoperative care of infants undergoing endoscopic craniosynostosis surgery and the treatment protocols in place around the country. More recently, the Craniofacial Society sent out surveys on modifying techniques for producing a CRO. We are coordinating efforts with the CAD-CAM Society to develop guidelines for computerized modification as more firms leave behind plaster modification and transition to CAD-CAM systems. Our goal is to create a consensus that can form a database for these modification programs. A third area of interest for the Craniofacial Society is the use of custom facemasks for the treatment of burns and traumatic injuries. Society members are currently preparing an article covering fabrication techniques, materials and treatment protocols.

As always, there is plenty of opportunity to get involved. The Society welcomes your involvement in these projects and others. If you have an interest in one of these areas or a related topic, please feel free to contact Barbara Ziegler, CPO, chair of the Craniofacial Society.

Not A Member Yet?
If you would like to become a member of the Craniofacial Society, or know someone who would like to join, please contact an officer of the Society or call the Academy at (202) 380-3663. Details are available at the Academy’s website: http://www.oandp.org/membership/

The views expressed in this newsletter are those of the contributors or authors of the Craniofacial Society and do not reflect the views of the American Academy of Orthotists & Prosthetists or its Board of Directors.

Contact us by visiting www.oandp.org/membership/societies/cranio
Craniofacial Society site
Our Craniofacial Society’s networking website is up and functional and we want to encourage more communication and usage. Newsletters, articles, photos and discussions can be found on the site and you are encouraged to comment and add to the material. We encourage you to join and visit the Craniofacial Society’s networking website. The following article is an example of the information found at the site:

SIDS and Serotonin Levels

Introduction
Sudden Infant Death Syndrome (SIDS) is the sudden death of an infant under one year of age due to causes that remain unexplained after an autopsy and death scene investigation. Typically the infant is considered healthy and dies during a sleep period. The child is presumed to have died while sleeping or during one of the many sleep to wake transitions. The Back to Sleep Campaign, instituted after the prone sleep position was defined as a risk factor for SIDS, reduced the rate of SIDS deaths by 40%. However, SIDS remains a leading cause of post neonatal mortality in the United States and the reduction in mortality rates has reached a plateau. Research continues to study the causes of SIDS and to try to isolate the mechanism and identify the infants at risk.

Triple Risk Model for SIDS
Dr. Hannah Kinney and Dr. James Filiano published a triple risk model for SIDS in which SIDS occurs when three risk factors intersect. The three factors are defined as 1) an infant with an underlying vulnerability, 2) an infant in a critical period of development and 3) an external stressor. For SIDS, an abnormality in the brainstem that controls basic functions such as breathing, heart rate, body temperature and arousal is the latent vulnerability. The critical age is birth to 6 months with the highest risk at 2-4 months of age. External stressors, such as prone sleeping, smoke exposure, soft bedding, blankets and stuffed toys are a challenge that a normal baby may overcome, but a vulnerable child might not.

Serotonin Levels
Serotonin is the brain chemical that relates messages between cells and plays a key role in regulating breathing, heart rate, temperature and sleep. A large research group, again led by Dr. Hannah Kinney, proposed that SIDS occur when there are abnormalities in the brainstem that controls the autonomic and breathing functions in the critical first year of life. They believed that the abnormalities were associated with inappropriate levels of serotonin and tryptophan hydroxylase (an enzyme needed to make serotonin). To test this theory, researchers analyzed brainstem tissue samples collected from over 50 infants. The study population consisted of 41 infants who had died from SIDS, 7 infants who died suddenly of a known cause other than SIDS and 5 infants hospitalized with chronic oxygenation disorders. They measured serotonin and tryptophan hydroxylase levels. In addition, they examined data from parental interviews, medical records, and death scene inspections. They found that serotonin levels were lower in the SIDS group when compared to the control group by 26%. Tryptophan hydroxylase levels were 22% lower. This suggests that a lack rather than an excess of serotonin may characterize SIDS. These results appear to fit the triple risk model of SIDS.

The low serotonin level is the underlying vulnerability that is present in the critical first few months of life. With the addition of an external stressor that the infant is unable to overcome, SIDS is often the result. The best advice for reducing the risk of SIDS is to have the infant sleep on his back, alone in a crib on a firm mattress with no blankets, bumper pads or soft toys, and avoid smoking around the baby.
**SIDS and Serotonin Levels cont.**

Research will continue to study the mechanism behind SIDS and to develop a blood test to measure an infant’s serotonin level and identify those infants most at risk for SIDS.

**Sources:**


**2010 Literature Review on Topics Related to Babies with Head Shape Deformities**

**Torticollis Cont.**

performed the exercises every day, three to five times per week and also included special carrying positions and prone positioning.

The babies were measured for rotation and lateral flexion using an arthradial measurement tool, and an estimate was made of lateral muscle strength. Frequency and timing of these measurements was not mentioned. Infants in both groups reached good ROM. Time needed to reach good rotation and lateral flexion was significantly shorter in the PT group (9 months versus 3.0 months for the parent group). Symmetrical head position was achieved significantly earlier in the PT group (2.5 months versus 4.5 months for the parent group). Limitations of the study were the small study size and difficulty generalizing the program components to other centers. At the beginning of treatment, 18 of the 20 children had some degree of plagiocephaly. At the end of treatment, only two of the children had plagiocephaly.

**Mandibular Asymmetry**

Kawamoto AK and Kim SS. *Differential Diagnosis of the Idiopathic Laterally Deviated Mandible.* Plast Reconstr Surg. 2009.Nov, 124(5):1599-609 is a descriptive article intended to assist specialists in determining the cause of a laterally deviated mandible. Both deformational plagiocephaly and congenital muscular torticollis are discussed as common causes of the laterally deviated mandible, a condition that may require surgical intervention at some point.

**Craniosynostosis**

Koshy JC, Chike-Obi CJ et al. *The Variable Position of the Ear in Lambdoid synostosis.* Ann Plast Surg.2010 Oct 13 is a review of the literature and a retrospective review of ear position at a craniofacial center in Texas. This paper exposes the inconsistency of ear position and concludes that the diagnostic significance of the external ear position as a differentiation between deformational plagiocephaly and lambdoid craniosynostosis is unclear at this time. The authors suggest that clinically, the most distinguishing feature of lambdoid synostosis is the presence of ipsilateral occipitomastoid bossing.

**Contact us by visiting** www.oandp.org/membership/societies/cranio
Craniosynostosis Cont.

Smart JM Jr, Elliott PM et al. Analysis of Differences in the Cranial Base and Facial Skeleton of Patients with Lambdoid Synostosis and Deformational Plagiocephaly. Plast Reconstr Surg. 2010. Sept 23 compared CT scans of nine babies with lambdoid synostosis and 12 babies with deformational plagiocephaly using craniofacial landmarks. There were significant differences between the groups. All lambdoid synostosis patients had deviations of the posterior cranial fossa on the affected side. Deformational plagiocephaly patients had variable deflection. All lambdoid synostosis patients showed marked posterior displacement of the contra-lateral TMJ. Deformational plagiocephaly patients had either symmetric TMJ or slight posterior displacement. Other specific cranial landmarks were present on CT scan in the babies with lambdoid synostosis but absent in patients with deformational plagiocephaly.

Kini, Hurst JA et al. Etiological heterogeneity and clinical characteristics of metopic synostosis: Evidence from a tertiary craniofacial unit. Am J Med Genet Part A, 2010, June:152 A(6)1383-9 reviewed 110 patients retrospectively with a diagnosis of metopic synostosis. 65.5 percent of the patients were determined to have non-syndromic metopic synostosis. 28.9 percent had global developmental delays including significant speech delays. 7.2 percent of the infants with metopic synostosis had exposure to VPA, a drug used for epilepsy, prenatally.

Chieffo D, Tamburrini G. Long term neuropsychological development in single suture craniosynostosis. J Neurosurg Pediatr. 2010 Mar, 5(3), 232-7 used the Wechsler test to determine whether babies with single suture synostosis had developmental issues later in childhood. The 65 children without syndromes who were recruited for the study were operated on at a mean age of 7.2 months, and followed up at a mean age of 12.7 years. This group was compared to a control group of children with no history of synostosis recruited from a regular classroom. The authors compared the Wechsler test results by type of synostosis and found that visual, spatial and planning deficits were present in the children who had sagittal synostosis, and verbal fluency and executive function were affected most in children with anterior plagiocephaly (coronal involvement).

The authors found that early surgery did not eliminate a predisposition to neuropsychological delays as demonstrated in neuropsychological tests in many children with single suture synostosis.

Jimenez DF, Barone CM. Multiple-suture nonsyndromic craniosynostosis early and effective management using endoscopic techniques. J Neurosurg Pediatr. 2010 Mar,5(3)223-31 is a case report of 21 children with craniosynostosis with more than one suture including 13 males and eight females without syndromes. The authors used post-op cranial remodeling ortheses for 10 to 12 months following their endoscopic procedure, which has previously been widely noted as a technique used on children with single suture synostosis. Infants were scanned with a STARscanner for a cranial remodeling orthosis and fit with a custom surlyn orthosis on post-op day six. Hospitalization was one day, there were no intra-operative blood transfusions, no deaths, hematomas or infarctions. The children’s head growth showed normal growth curves, and the helmet was discontinued at 12 to18 months. There was no comparison of endoscopic treatment with other surgical strategies.

Deformational Plagiocephaly

Lee A, Van Pelt AE et al. Comparison of perceptions and treatment between neurosurgeons and plastic surgeons for infants with deformational plagiocephaly. JNeurosurg Pediatr.2011.Apr 5 is a study based on an online survey. The survey assessed each discipline’s views on helmet therapy for infants with deformational plagiocephaly. Although the survey was sent to 302 neurosurgeons and 470 plastic surgeons, only 71 neurosurgeons and 64 plastic surgeons responded. Despite the low response rate of 14 percent there was a significant difference between the disciplines regarding helmet therapy. When cost is taken into consideration, neurosurgeons were less likely to recommend helmets than plastic surgeons. Both groups agreed that 12 months was the maximum age for referring babies for orthotic treatment. Both agreed that the typical treatment duration was 4 months. Neurosurgeons said that the parental influence was a great determinant of referring a baby for a helmet, while for plastic surgeons this was only a moderate determinant.
Deformational Plagiocephaly Cont.

Neurosurgeons felt that they prescribed helmets for 21 percent of the babies referred to their clinic, while plastic surgeons felt they referred 35 percent of the children seen in their clinics for helmets. Only 8 percent of the neurosurgeons felt that helmets were more beneficial than therapy while 26 percent of the plastic surgeons felt helmets were better. Ten of the 71 neurosurgeons and 14 of the 64 plastic surgeons saw more than 200 patients with deformatonal plagiocephaly per year. Both groups had the same prescription rate for mild deformatonal plagiocephaly and plastic surgeons were more likely to refer babies in the moderate to severe range. Interestingly, both neurosurgeons and plastic surgeons felt they saw 66 percent of the patients in their area (and that the other discipline saw the other third). The authors concluded that: “[p]arents of children with deformatonal plagiocephaly are faced with a costly treatment decision that may be influenced more strongly by referral and physician bias than by medical evidence.”

Almosukarto I, Shapiro LG. Three-dimensional head shape quantification for infants with and without deformatonal plagiocephaly. Cleft Palate Craniofac J. 2010 July, 47(4)368-77 attempted to develop a system whereby the 3DMD scanning system could efficiently and reliably differentiate babies with plagiocephaly from those without the condition. They compared typical measurements used to determine deformatonal plagiocephaly (Hutchison) to the 3D scan measurement analysis the authors devised which did not require landmark placement. Two-dimensional histograms were extracted from 3D mesh data and used to compute asymmetry measures. In the subject selection, the authors found poor agreement between the ability of the observers to differentiate cases from non-cases, partly because many of the non-cases also had deformatonal plagiocephaly. The 3D analysis was consistently able to determine the side of the flattening, and the Asymmetry Score they developed was more sensitive in the discrimination of head shapes between case and non-case subjects than the Oblique Cranial Length Ratio (Hutchison) the authors approximated.

Wilbrand JF, Wilbrand M. Value and reliability of anthropometric measurement of cranial deformity in early childhood. J Craniomaxillofac. Surg. 2010. Apr 23 is a study that sought to compare inter-rater and intra-rater reliability using caliper measurements in their practice. Ten patients in three groups: (plagiocephaly, brachycephaly and combination head shape deformities) were measured six times by three examiners. It is difficult to compare their accuracy to that of other studies because they used a different type of analysis (variance components estimation procedure). The authors state that their protocol, positioning of the patient, and training was highly reproducible and resulted in inter- and intra-rater reliability with a maximum variability of 2mm of variance. The results of this study differed from the results of Mortensen et al., who found that anthropometric measurements were unreliable.

Schaff, H, Malik CY et al. Three-dimensional photographic analysis of outcome after helmet treatment of a nonsynostotic cranial deformity. J Cranio Surg.2010 Nov,21(6):1677-82 studied 122 infants with head shape deformities: 70 with plagiocephaly, five with brachycephaly and 47 with combination head shapes. The authors compared standard anthropometric measurements with measurements taken from digital photographs. The photographic method used Quick Ceph software. Two clinicians measured the Cephalic Index and Cranial Vault Asymmetry Index from a digital photo in 70 infants. When the two systems were plotted against each other, the photo method satisfied the “limits of agreement.” The authors state they had excellent agreement between observers ( .982 Cephalic Index and .940 Cranial Vault Asymmetry Index) and concluded that digital photos are reliable for quantifying non-synostotic cranial deformities.

Katzel E, Koltz PF et al. Treatment of Plagiocephaly with Helmet Molding Therapy: Do Actual Results Mimic Perception? Cleft Palate Craniofac J. 2010. Apr 21 prospectively reviewed 91 STARscanner scans of infants who had been treated with a cranial orthosis. Sixty parents rated their child’s head shape on a one to ten scale, (ten was normal) at the beginning and end of treatment.
Deformational Plagiocephaly Cont.

The authors found that parents perceive larger correction despite "relatively small changes," with parental assessment changing from 2.99 at the beginning of treatment to 7.88 at the end of treatment. Children were not divided into groups by deformity, which may have produced different numerical results. Pre- and post-cephalic ratio dropped from 89 percent to 87 percent. Cranial vault asymmetry index changed from 7.2 percent to 4.8 percent. The overall symmetry ratio (volume) changed from 87 percent to 90 percent.

Hutchison BL, Stewart AW. *A randomized controlled trial of positioning treatments in young infants with positional head deformities*. Acta Paediatr. 2010. Oct.99(10) 1556-60 studied 126 babies diagnosed with deformational plagiocephaly who were randomly placed into an education only program for deformational plagiocephaly or an education program and sleep positioner (SafeT Sleep Positioning Device). Head shape was assessed using digital Heads Up software and neck range of motion and shape were assessed at three, six, nine and 12 months of age. At the 12 month visit, both groups had the same results with 42 percent of the babies in the normal range for head shape as defined by Hutchison (Cephalic Index <93, and Oblique Cranial Length Ratio <106). Poor improvement was most common in the babies with a combination head shape and late referral to the plagiocephaly clinic. At the beginning of the study, the head shape of 51 percent of the babies were considered severe, with only 8 percent falling into the severe range at 12 months. No infant in the study was fit with a cranial remolding orthosis. The Oblique Cranial Length Ratio improved more in the first three months than in the subsequent nine months. Of the 80 babies with neck muscle dysfunction at the beginning of the study, only five had mild or intermittent dysfunction at 12 months. “Parents should be made aware of the possibility that some head shapes do not revert to normal and they should be very attentive to positioning strategies while the infant is still very young.”

Hutchison BL, Stewart AW et al. Deformational plagiocephaly: a follow up of head shape, parental concern and neurodevelopment at ages 3 and 4 years is a longitudinal cohort study of infants with deformational plagiocephaly followed since birth. The researchers used both a subjective (parent survey) and objective (Heads Up digital software) tool, and the AIMS Ages and Stages Exam to assess attitudes and head shape changes over time. 61 percent of the head shapes reverted to the normal range. 4 percent of the head shapes stayed in the severe range. Brachycephaly improved more than plagiocephaly. Facial and frontal asymmetry reduced to "almost nil" (no facial measurements—observations only). "By 3-5 years developmental delays reduce to what might be expected in the normal population." 13 percent of the infants were considered to have poor improvement. Initially 85 percent of parents reported being somewhat or very concerned. At follow up this reduced to 13 percent. The percentage of children with one or more developmental delays was reduced from 41 percent initially to 11 percent at follow up. "Further research into long term development...is needed, especially in children whose head shapes do not revert to normal".

Introducing
http://craniofacial.ning.com/

The Craniofacial Society networking website is a new resource for members of the Craniofacial Society of the American Academy of Orthotists and Prosthetists. This site will enable dialogue and the sharing of ideas, images and events among members. To use the site, browse the tabs above or the features that are available from the main page. You may communicate with individual members or pose questions to the entire group, post notes, submit to the forum or upload images or video.
Deformational Plagiocephaly Cont.

Speltz ML, Collett BR et al. Case Controlled Study of Neurodevelopment in Deformational Plagiocephaly. Pediatrics. 2010. Mar. 125(3) e537-42 is a long range study comparing 235 infants diagnosed with deformational plagiocephaly with 237 infants without head shape problems. Both groups of children were evaluated by three experts using 3D images of baby heads ranging from no deformity to severe deformity. The authors also examined the association of torticollis to plagiocephaly. The BSID-III was given to all subjects. This is the first study to compare infants with plagiocephaly and controls on the same test, rather than just comparing the plagiocephaly group to the test norms, a critique of previous studies on this subject. The authors found that when controlled for gender, age, and socioeconomic factors, case subjects performed more poorly on all BSID-III scales and subscales. Case subjects scored significantly lower on motor, cognitive and language subtests. Case subjects’ gross motor deficits were worse than fine motor deficits. There was no association between BSID-III performance and the presence of torticollis or infant age at diagnosis. Further research is planned to study these same cohorts at 18 and 36 months to determine whether there is stability in the findings. The authors stress that they have not determined that deformational plagiocephaly causes the delay, but that developmental delay is a marker for elevated risk of delays. They advise pediatricians to closely monitor infants with this condition.

Lipira aB, Gordon S et al. Helmet versus active repositioning for plagiocephaly: a three dimensional analysis. Pediatrics. 2010. Oct 126(4) e936-45 is a study that used the 3DMD system to document head shape changes after exposure to two different conservative treatments. Scans of 35 children who were to receive an active repositioning protocol and 35 infants who were to receive a helmet were assessed. The groups were matched for severity. Scans were compared to a symmetric template, and maximum and mean asymmetry values were determined. Parental preference determined whether the infant was in the repositioning or helmet groups. Thirteen babies in the repositioning group were lost to the othotic treatment group at the parents’ request. Helmets provided a statistically significant improvement over the treatment group immediately after the intervention. There was a greater reduction in the maximum and mean asymmetry in the treatment group, and the greatest difference was localized in the occiput. The repositioning group completed treatment in 5.2 months, and the helmeted group completed treatment in 3.1 months. The authors plan to continue studying these two groups to establish the clinical significance of the results, define pathology, and determine whether the superiority of helmet treatment endures over time.

Ask your Craniofacial Society

Please submit to us questions and responses to begin dialogue of troubleshooting tips and tricks.

Question: When an insurance company does not cover a cranial remolding orthoses, are there other options available?

Barbara: For families in Missouri and Illinois, Variety Club has financial assistance for DME, including orthotics & prosthetics. For patients with Tricare, we recommend Carecredit.com.

Ellie: We recommend that patients go through the appeals process to try and overturn a denial. Sometimes after two denials it is turned over to the State department for an independent medical review. In 2003, Ian Doris wrote Slingshot: A Lawyer’s Guide To Getting Your Child’s Cranial Orthosis Covered By Your Medical Insurance Plan, which can be a useful tool in fighting an insurance battle.

If the insurance company simply does not cover a CRO, or it is listed as an excluded item, we often suggest a local funding source such as a church group, or the Navy-Marine Corps Relief Society for those with Tricare.