Regional Perinatal Forum Annual Conference  
October 19, 2005

The 4th Annual Hudson Valley Regional Perinatal Forum (RPF) Conference was a huge success. The room was packed with almost 330 attendees eager to participate in the development of a Regional Action Plan to eliminate perinatal disparities in the Hudson Valley. The conference entitled, “Prematurity and Low Birth Weight in the Hudson Valley Region: Developing a Regional Action Plan to Eliminate Racial and Ethnic Disparities” featured Dr. Joycelyn Elders, former US Surgeon General as the keynote speaker and Pediatric Grand Rounds lecturer, the State of the Regional Perinatal Centers and Regional Perinatal Forum, presented by Dr. Edmund LaGamma, Chief, Division of Newborn Medicine, Maria Fareri Children’s Hospital at Westchester Medical Center, Dr. C.D. Hsu, Director of OB/GYN and Chief, Maternal Fetal Medicine at Westchester Medical Center, Stephanie Sosnowski, Maternal Child Health Coordinator, Maternal Infant Services Network of Orange, Sullivan and Ulster Counties, and Cheryl Hunter-Grant, Executive Director, Lower Hudson Valley Perinatal Network and the Public Health Commissioners (or Directors) for each of the seven counties of the Hudson Valley Region. Dr. Elders’ Grand Rounds lecture, Health Care in the 21st Century and keynote address, Health Care Issues in the Minority Community focused on national issues of health care, while the State of the Regional Perinatal Center and Regional Perinatal Forum and seven county health commissioner panel addressed local county level challenges and programs addressing prematurity and low birth weight.

“To achieve the goal of 100% access to health care and 0% disparities, we have to do things differently,”
Continued next column:

Dr. M. Joycelyn Elders’ stated. She informed the audience that currently less than 3% of the U.S. health care dollars are spent on keeping people well, and 97% is spent on sick care. Health is more than just the absence of disease. Of the preventable deaths: 50% are social or behavioral; 20% are environmental; 20% are genetic and 10% are related to access to care. Dr. Elders’ stressed that the focus must be on prevention:

P – Policy
R – Research
E – Educate, Educate, Educate
V – be the voice of powerless children in need of a powerful friend
E – Empower women to get prenatal care
N – Nutrition assessment and Needs assessment
T – use the Tools of commitment, your Time, Talent and Treasure
I – be Informed – what we put in children is an Investment
O – take every Opportunity you get – be Open
N – do it now!

Physicians, Nurses, Social Workers, Community Health Workers, Administrators, Lactation Consultants, Parent Involvement Specialists, Nursing Students, Medical Students, Residents, Fellows, Public Health Educators, Health Department Workers and Officials, Research Scientists, Family Assessment Workers, Case Managers, Psychologist and Counselors were among those who attended the all day session. Both verbal feedback and completed evaluation forms rated the conference very highly. Evaluations forms were submitted by 41% percent of the attendees. 100% of the participants who completed evaluation forms believed the conference met the stated objectives. 93% rated Dr. Elders’, keynote speaker as good to excellent; 94% stated the presentation on the “State of the Regional Perinatal Center and Regional Perinatal Forum” was good to excellent; 86% rated the seven county health commissioner panel as good to excellent and the “Developing a Regional Action Plan” session was rated good to excellent by 93% of respondents.

The conference was presented by the Hudson Valley Regional Perinatal Forum and sponsored by Maria Fareri Children’s Hospital, Westchester Medical Center, Maternal Infant Services Network of Orange, Sullivan and Ulster Counties, New York Medical College Office of Continuing Education and the Lower Hudson Valley Perinatal Network. Major co-sponsors were: MedImmune, iNO Therapeutics, March of Dimes, Cord blood Registry, Matria Health Care and Fidelis Care, and co-sponsors included: MVP Health Care, Materna Manager, Hudson Health Plan, Medela and Wyeth Pharmaceuticals.

The on-going work of developing a Regional Action Plan will be conducted through the 3 Action Committees of the RPF: Data Management, Access to Care and Breastfeeding. Anyone interested in joining a committee should contact the committee chairs: (please go to bottom of pg. 2.)
Mandibular Distraction in the Neonate

The primary defect in Pierre Robin sequence appears to be a failure of the lower jaw to develop normally during the first trimester, allowing the tongue to descend from the upper oropharynx and the palate to fuse in the midline. The frequency ranges from 1 in 2,000 to 30,000 births. The anomaly may be an isolated set of findings or appear in the context of another syndrome, such as velocardiofacial or Treacher Collins, among others. Parents who have had one child with isolated Robin Sequence probably have roughly between a 1 and 5% chance of having another child with this condition. Environmental teratogens may include alcohol or hydantoin.

The presentation of Pierre Robin sequence may be variable among affected infants. Problems with breathing and feeding in early infancy are most common. The care of the patient with micrognathia and airway compromise should involve multiple experienced personnel, including the neonatologist, the plastic surgeon, the otolaryngologist, the anesthesiologist, the medical geneticist, the pulmonologist, and the gastroenterologist.

Proper supine positioning in mild or moderate cases is important. In these milder cases, the mandible may demonstrate rapid catch-up growth during the first year of life. In many children, the facial profile around four to six years of age looks normal. In more severe cases, positioning alone may not be sufficient, and more invasive options may be required. The cleft palate, if present, is closed around 1 to 2 years of age.

Traditionally, respiratory difficulty warranted either continuous prone positioning or surgery to improve the airway. Tracheostomy is perhaps the gold standard but presents numerous problems for both the infant and the parents. The risks to the neonate include tracheitis, recurrent bleeding, subglottic stenosis, and speech and communication problems. For the parents, care of the tracheostomy can be time consuming and difficult.

Surgical adhesion of the tongue to the inner aspect of the lip, often with a button placed at the posterior aspect of the tongue for support, has been performed to pull the base of the tongue away from the posterior pharynx so as to enlarge the cross-sectional area available for respiration. Distraction of the mandible is now becoming an accepted technique for pushing the base of the tongue away from the posterior pharynx with a similar effect.

The history and principles of distraction osteogenesis in the craniofacial skeleton began in the early 1990’s when McCarthy, et al. first distracted the canine mandible and noted excellent bone growth across the osteotomy site.

Neonatal distraction of the mandible has been described on several occasions as a means of correcting upper airway obstruction due to micrognathia and retrodisplacement of the tongue and avoiding early tracheostomy.

Candidates for mandibular distraction should not have other causes for the obstruction, such as central sleep apnea, severe gastroesophageal reflux, or a secondary airway lesion. A sleep study should be obtained to rule out central sleep apnea, a milk scan may be ordered to rule out esophageal reflux, and rigid and flexible laryngoscopy may be performed to evaluate the presence of epiglottal collapse, a tracheal web, or a vascular lesion. Incisions for access are placed off the face under the angles of the jaw and inside the mouth. After exposing the bone, symmetrical osteotomies of the ramus are made with a saw avoiding injury to the alveolar nerve. The devices are attached to the bone across each osteotomy with the turning handles exiting through the mouth.

A latency period is allowed followed by a period of activation in which the handles are turned two or three times a day until adequate length is achieved. At that time, removal of the endotracheal tube is usually possible. A consolidation period ensues in which the architecture of the bone becomes more organized. The distraction devices are removed two to three months later.

Successful distraction osteogenesis for the treatment of hypoplasia of the mandible in a patient with muscular dystrophy (MD) has recently been performed. MD is a disease that primarily affects skeletal muscle, however pathologic changes in the adjacent bone have been described. In the two more common muscular dystrophies, Myotonic Dystrophy and Duschenne’s muscular dystrophy, there is a high prevalence of cleftbite and resultant skeletal malocclusion. This is likely due to the aberrant growth of the craniofacial skeleton that results from involvement of the muscles of mastication. The mdx mouse is a model of X-linked muscular dystrophy. In assessing the recovery of bone from muscle disuse, Anderson et al. noted several histopathologic findings in the tibial bones of mdx mice. Adjacent to the weakened tibialis anterior muscle, it was noted that there was reduced radiographic density and cortical thickness, and increased porosity compared to control animals. Functionally, less force was required to break the bone.

In summary, neonates who present with airway compromise as a result of micrognathia, either in the face of Pierre Robin sequence or otherwise, should be considered for early distraction of the mandible to improve airway size and thus avoid tracheostomy.

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The ARPPN (Association of Regional Perinatal Programs and Networks) in collaboration with the NYS DOH (Bureau of Women’s Health & Vital Records) is forming a committee consisting of representatives from the Regional Perinatal Centers to review Core (Electronic Birth Certificate) & NICU modules of the State Perinatal Data base System (SPDS). In anticipation of the first meeting scheduled in Albany for early 2006, they have asked the committee representatives to submit data questions they would like to see added to the modules. They suggest using the following question as a guide to developing these elements, “Exactly what would be different if we knew this thing?” In other words, how would your practice be affected if you had this additional data?

We welcome any suggestions you may have in answering this question in regard to the SPDS modules. Please keep in mind that there is a fine balance between adding data elements and maintaining the user-friendliness of the SPDS. Feel free to include data elements that you feel are not useful and could be removed as well. Thank you for your assistance.

Please forward your submissions to:

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Maria Fareri Children’s Hospital at Westchester Medical Center
Email: dozord@wcmc.com

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**Maternal-Infant Services Network (MISN)**

Sponsoring: Children’s Oral Health Month: A Call To Action – Integrating Maternal-Child and Oral Health

**WHEN:** Thursday, February 23, 2006 8:30 AM-4 PM

**WHERE:** Ramada Inn, Newburgh, NY

**Registration Fee:** $30 includes continental breakfast & buffet lunch. (Discount fee for students)

**Registration Brochure:** Please contact: Stephanie Sosnowski, ICCE M/C Health Program Coordinator, MISN
Phone: 845-928-7448, ext. 15  E-mail: stephanie@msinisn.us

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**35th Annual Nelson Rosenthal Convocation for Students**

**AUTISM TODAY**

Keynote Speaker - Rebecca Landa, PhD, CCC-SLP6
Director of the Center for Autism & Related Disorders & of the REACH research program, Kennedy Krieger Institute

Associate Professor, Psychiatry
John Hopkins University School of Medicine

Tuesday, March 14, 2006
12:00M-2:00 PM Box Lunch Provided

New York University
Eisner & Lubin Auditorium
Kimmel Center for University Life
60 Washington Square South, New York City

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**Save the Date**

March of Dimes Greater New York Chapter
Invites you and your students to the

**Franklin Delano Roosevelt Student Convocation**

Keynote Speaker: W. Ted Brown, MD, PhD, Director, New York State Institute for Basic Research in Developmental Disabilities

Dr. Brown will speak on genetics and the environment in relation to autism and birth defects.

Tuesday, February 7, 2006
9:30 AM – 1:00 PM

Franklin D. Roosevelt Presidential Library and Museum
Hyde Park, NY

**For more information contact Susan B. Rose at 1-845-454-8850**
or email srose@marchofdimes.com

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To Register, Submit a Teacher’s Award Project, a Student Essay & all other correspondence, Contact Madeline Britt at the March of Dimes.

PHONE (800) 353-8267  FAX: (212) 475-2972  E-mail mbritt@marchofdimes.com

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We are interested in providing you with a newsletter that is relevant and of interest to you. Please contact us with perinatal topics you would like to see addressed.

For a copy of our newsletter or to be placed on our mailing list contact us by phone or e-mail.

Please see below the NYMC neonatal web site address to locate other issues of The Perinatal Gazette:
http://www.nymc.edu/neonatology

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