

Perinatal Genomics – The Future is Here

The 2006 NYSPA Conference was held 6/9-10/06 at the Academy of Medicine in New York City. The Board of Directors and Conference Planning Committee led by Karla Damus took a bold step in deciding to dedicate the 2006 conference to Genetics and Genomics as related to perinatal care. At the closing session of the conference Sharon Chesna, President-elect of the National Perinatal Association (and NYSPA Board member) was asked to provide a review of the information presented throughout the conference and identify challenges and action steps which are needed in order to ensure integration of the emerging genetic and genomic information into daily perinatal practice.

Following is an overview of the conference wrap-up focusing on Opportunities and Challenges and action steps for both:

Definitions: *Genetics is the study of inheritance, or the way traits are passed down from one generation to another. [Genes carry the instructions for making proteins, which in turn direct the activities of cells and functions of the body that influence traits such as hair and eye color.] Genomics is a newer term that describes the study of all the genes in a person, as well as interactions of those genes with each other and with that person's environment.*

Key Message – *Genetics and environment go hand in hand.* Genetics is a rapidly and continually evolving field that will inform health care management and improve care for both public and personal health.

The findings from emerging research must not be held only by the genetic researchers and scientists – it must be shared with – and utilized by public and private health care practitioners as well as individuals in order to further improve health and health care – especially in reproductive health.

Opportunities

1. Family History is one of the most important risk factors for health problems like heart disease, stroke, diabetes and cancer.
Providers must be astute about gathering family history as a part of all patients' health assessment.
Patients/Consumers/ each of us need to ask immediate and extended family members questions about health conditions, record health information and remember to share this information with health care practitioners.

Action Step – Promote awareness of the MY FAMILY HEALTH PORTRAIT website and others <http://www.hhs.gov/familyhistory/>

2. Perinatal Testing is a critically important tool *and opportunity* for identifying pregnancies at increased risk for genetic disorders or birth defects and may be given even when there are no risk factors.
Providers should educate and evaluate pregnant parents about the purpose, value and range of newborn testing
Pregnant Women and their partners need to become more informed of the range and benefits of perinatal testing and the opportunities for genetic counseling when determined appropriate.

Action Step – Promote awareness of the purpose, value, and range of perinatal testing opportunities available to pre-conception and pregnant woman and their partners.

3. National Children’s Study has been established to examine the effects of environmental influences on the health and development of more than 100,000 children across the United States, following them from before birth until age 21. The goal of the study is to improve the health and well-being of children.

Action Steps:

1. **Advocate to ensure continued funding**
2. **Promote awareness of the purpose and expected benefits of the study.**
3. **Monitor and report the progress of the study.**

4. Citizenry – Bruce Jennings

1. Importance of our self awareness and knowledge of the impact of genomics on personal and community/public health.
2. Promote and de-mystify for the general community, awareness of the linkage between family and personal health about genomics and environment.

Action Step – Promote health literacy.

5. NYS Legislation (Ann Wiley) 345 32A/A8062 Licensing of genetic counselors

Action Step – Advocate for passage.

Challenges

1. Reaching the general clinical, community and public health perinatal professionals in embracing genetic genomics
2. Funding – Public Funding is always challenging and competitive:
 - health against health
 - health against war, bioterrorism amongst hundreds of other competing issues
3. Pharmo cogenetics:
 1. patient treatment as part of statistically larger population
 2. individually prepared pharmacological treatment based on genetic testing.

General Recommendations/Discussion for conference participants:

1. Advocacy – State agencies should embed genomics in perinatal requests for proposals (RFPs)
2. Reach key entities such as the MCHB Advisory Council and educational institutions to promote and advocate for multidisciplinary awareness of opportunities related to genetics and genomics.
3. Ensure appropriate and ethical use of information
4. Be prepared to address public (possibly negative) reaction to information.

Suggested Action Steps for New York State Perinatal (and other related) Associations/groups:

1. Include “Genomics Corner” in quarterly newsletters
2. Develop/use perinatal genomic modules
3. Host a legislative breakfast/other program on genetics.

Conclusion: The New York State Perinatal Association and its members are committed to continuing to advance professional and consumer knowledge and understanding of genetics and genomics. To that end, the Board of Directors has agreed to provide a copy of the conference syllabus which contains copies of presentations and research materials referenced at the conference to every Regional Perinatal Center in NYS, and to promote the availability of the syllabus and the conference format to any other state perinatal association interested in replicating all or part of the conference. For more information on the program, or to request a copy of the syllabus, contact the Enid Jones @ the NYSPA office @ 1-877..... Or ejones@nyspa.org