

**Indiana Genetics Advisory Committee  
Meeting Minutes  
April 7, 2009  
12 – 3 pm  
ISDH Room 8T**

**ATTENDANCE:**

Full Members				Ad-hoc Members	
Alexander, Mary		Humbert, Larry		Bowman, Bob	X
Bader, Patricia	X	Lesko, Barb	X	Burrus, Connie	
Bingle, Glenn	X	Mendenhall, Gordon		Dumm, Sue	X
Cohen, Stephanie	X	Olsen, Donna Gore		Eddy, Courtney	X
Cushman, Lisa	X	Quaid, Kimberly	X	Ganser, Judith	X
Darroca, Roberto	X	Radford, Meggan		Hutsell, Gayla	X
Downer, Dawn		Rautenberg, Fr. Joe	X	Mani, Lisa	
Escobar, Luis F.	X	Reed, Terry	X	Meade, Nancy	
Eugster, Erica		Smith, Lisa		Silva, Ruwanthi	X
Fielden, Cheryl		Stone, Kristyne		Stone, Iris	X
Gill, Nicole		Torres, Wilfredo		Warner, Dolly	
Grover, Spencer		Weaver, David			
Hainline, Bryan	X	Zunich, Janice	X		
Hendrix, Jon	X				
Hodgin, PT	X				

**Welcome – Dr. Zurich & Dr. Quaid**

**Minutes from October 2008 were approved without correction.**

**Genetics Clinics' Updates**

**Dr. Bader:**

- The new clinic at the Comprehensive Cancer Center has been scheduled to open June 1<sup>st</sup>. Dr. Bader's new contact information will be as follows:
  - 11143 Parkview Plaza Drive, Suite 311, Fort Wayne, IN 46845
  - Phone and fax numbers will remain the same. Dr. Bader's Parkview extension will be 69288 (260.266.9288).
- Dr. Bader provided a 6-month activity report. Her clinics have seen 846 unduplicated patients within the past 6 months. Of those patients, 332 have a diagnosis of fetal alcohol syndrome (FAS), and 54 were diagnosed with organic encephalopathy.

**Dr. Hainline:**

- Chris Griffiths, MD, has been hired beginning July 1, 2009.

**Dr. Zurich:**

- Dr. Zurich reported an approximately 50% increase in number of patients being seen, due to the restart of maternal-fetal medicine (MFM) clinics at Methodist.
- A new cancer risk assessment clinic has been opened, which is held twice per month.
- Dr. Zurich still has an opening for a full-time genetic counselor.

**Medicaid and Reimbursement for Services**

- Dr. Zurich asked Dr. Ganser for a status update on the white paper regarding reimbursement for 1<sup>st</sup> trimester screening, which was submitted last fall.
  - Dr. Ganser informed the Committee that the Medicaid Policy Advisory Committee is currently not meeting, and that there is a new Medicaid director.

- Dr. Ganser will follow up with Medicaid to find out what happened to all the issues that were before the Policy Advisory Committee prior to the reorganization.

### **GINA – Dr. Quaid**

- The Genetic Information Nondiscrimination Act (GINA) was passed into law on May 21<sup>st</sup>, 2008. Senator Ted Kennedy called GINA the “first civil rights legislature of the 21<sup>st</sup> century.”
- There are two basic parts to GINA: 1) health insurance (to be implemented beginning May 2009) and 2) employer provisions (to be implemented November 2009). Both parts prevent these parties from requesting/obtaining information about patients’ genetic information (including genetic testing).
- **GINA does *not* cover disability, life insurance, or long-term care insurance.**
- **Members of the military are *not* covered by GINA.**
- Insurance companies can still underwrite policies based on symptoms.
- Companies who violate the provisions of GINA will be fined.
- Dr. Quaid brought up two major questions about the implementation of GINA:
  - What type of educational campaigns have been planned to educate healthcare providers and the general public about GINA?
    - Dr. Zunich recommended checking the ACMG website to determine whether a campaign for healthcare providers has been planned.
  - Who will respond to accusations of violations?
- Fr. Joe Rautenberg asked whether the ethical consequences of GINA were broached with legislators—what would be the impact of not telling certain employers (e.g. truck drivers, companies with heavy machinery) about testing results of patients with diseases that could impair skills (e.g. Huntington’s)?
  - What is the responsibility of healthcare providers? Duty to warn vs. privacy?

### **SNP Testing for *BRCA* – Lisa Cushman Spock**

- **Lisa’s talk is attached with these minutes as a separate PowerPoint file.**
- Genome-wide association studies (GWAS) performed
  - GWAS studies for other conditions (e.g. prostate cancer, myocardial infarctions) coming
- GWAS studies for *BRCA* compare genomic changes in patients compared to those in controls
  - Changes = single nucleotide polymorphisms (SNPs); change in single base at one point in genetic code
    - SNPs responsible for approximately 90% of genetic variation in humans
  - Researchers looking for SNPs found more commonly in patients—these SNPs would be more likely to be linked or associated with breast cancer
- Concerns about selection of cases (patients) and controls within these studies
- Tests do not require FDA approval (not uncommon for genetic tests)
- Tests do not currently have Center for Medicaid/Medicare Services National Coverage Determination
- Not offered directly to consumers yet, although company websites advertise tests and the media has been notified

### **Miscellaneous Issues**

- Licensure of genetic counselors: Stephanie Cohen reported that the proposed bill requiring licensure of Indiana genetic counselors unanimously passed the state Senate and has gone to the House. She also informed the Committee that some language was stripped from the licensure bill and added to another bill, which is scheduled to be heard April 8<sup>th</sup>. After the 8<sup>th</sup>, the bill will go to a conference committee for approval before moving to the governor’s desk.
- *BRCA* testing for Latina women: Dr. Zunich informed the Committee of a recent *JAMA* publication that discussed the development of a *BRCA* array containing the 18 most-common mutations in Latina women. Dr. Zunich discussed the benefits of this array, which included increasing the number of Latina women who would receive *BRCA* testing, as full sequencing is often prohibitively expensive for these patients.

**Discussion of Future Topics**

- Committee members recommended inviting additional representatives from Medicaid /Medicare to attend the next meeting. Dr. Ganser advised the Committee to wait until the Medicaid Policy Advisory Committee has been reorganized before selecting invitees.
- Fr. Joe Rautenberg requested a discussion regarding duty to warn vs. privacy related to releasing information currently protected under GINA. Dr. Quaid recommended inviting a representative from the IU Law School to provide insight into the legal obligations related to this issue.

At this point, the Committee moved to adjourn the meeting. This motion was approved without dissent.

**Next Meeting Date: October 6<sup>th</sup>, 2009 (teleconference vs. in-person format TBD)**