

**Indiana Genetics Advisory Committee  
Meeting Minutes  
October 6, 2009  
1 – 3 pm  
IUPUI**

**ATTENDANCE:**

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

**Welcome – Dr. Zunich & Dr. Quaid**

**Minutes from April 2009 were approved without correction.**

**Genetics Clinics' Updates**

**Dr. Bader:**

- Increase in number of new patients (769 unduplicated new patients within past fiscal year)
- 610 unduplicated follow-up patients within past fiscal year
- New NP & NPA on staff

**Dr. Hainline/Dr. Weaver:**

- Chris Griffiths, MD, joined Biochemical & Molecular Genetics Department as faculty
  - Dr. Griffiths is seeing clinical & biochemical genetics patients, doing consults
- Increase in number of new mitochondrial patients (4 – 10 new mito pts/month)
  - Also seeing increase in number of patients with autism/autistic features who actually have mitochondrial condition
  - Approximately 10 – 15% of patients with autism have identifiable mitochondrial condition
  - These patients typically present with hypotonia, mild developmental delay, unusual behavior
    - Typical presentation = Normal within first 1 – 2 years of life, followed by loss of (neurological) function
- Reopening Adult Marfan Clinic at Methodist Hospital (joint offering between cardiologist, thoracic surgeon, and Biochemical & Molecular Genetics Department)

**Stephanie Cohen (St. Vincent Center for Cancer Care):**

- Not seeing increase in patients as a result of Myriad *BRCA* direct-to-consumer testing campaign

**Kristyne Stone (IU Prenatal Diagnosis):**

- Clinic now has 5 practicing maternal-fetal medicine physicians, 2 full-time genetic counselors, and 1 part-time genetic counselor

**Dr. Bingle (Community Prenatal Diagnosis):**

- Number of patients is steady
- Discussions to reopen cancer genetics clinic at Community

**Dr. Zunich:**

- Decrease in cytogenetics laboratory specimens, resulting in decrease in income
- Only one cytogenetics lab tech (down from three)
- Greater than ½ of patients are seen in out-of-office clinics; > ½ of Dr. Zunich's time is spent out of office at other clinics
- Number of maternal-fetal medicine patients has increased

**Subcommittee Reports**

**FASD:**

- Educational DVD for high school & middle school teachers has stalled in process of getting DVD copied
- High school/middle school curricula are available on ISDH Genomics/NBS website at: <http://www.in.gov/isdh/23935.htm>
- Dr. Zunich asked whether the DVD needed to be approved by a member of the state Dept. of Education—in response, Lisa Cushman reported that a Dept. of Ed. representative was on the FASD Task Force and did not mention the need to have the DVD approved.
- Indiana received a \$10,000 sub-award from the Great Lakes FASD Regional Training Center at the University of Wisconsin
  - Sub-award targets training of healthcare & allied healthcare professionals & students
  - Award expected to extend for a second year
  - Currently waiting to receive final version of sub-award

**Newborn Screening:**

- ISDH was awarded a three-year, \$1.2 million *Effective Long-Term Follow-up in Newborn Screening* grant from HRSA for FY 2010 – FY 2012
  - Funding will be used to develop Indiana Newborn Screening Tracking & Evaluation Program (INSTEP)
    - Includes development of web-based application for healthcare providers across the state to utilize in accessing newborn screening information
    - Also will be used to collect & track follow-up information on those children diagnosed with a newborn screening condition
    - INSTEP & the ISDH NBS Program are HIPAA-covered entities; all applications will follow federal & state HIPAA guidelines as required by law

**Indiana Birth Defects & Problems Registry:**

- Reported annual data to the National Birth Defects Prevention Network (NBDPN) in August 2009
  - Covered children reported to the IBDPR who were born in 2003 – 2006
- New online physician reporting system has been fully implemented
  - Currently have 33 healthcare providers (including psychologists) who have registered with the online reporting system

**Medicaid and Reimbursement for Services**

- New Policy Director for Medicaid = Dr. Tony Pelezo
  - Former ER physician
  - Responsible for making recommendations re: new state Medicaid policies to OMPP
    - NOT final decision
- Special guest = Dr. Ted Grisell
  - Dr. Grisell recommended that the Committee resubmit the 1<sup>st</sup> trimester screening white paper (written by Dr. Zunich) to Dr. Pelezo, with a cc: to Dr. Grisell

- Also mentioned that Dr. Pelezo would be interested in meeting personally with members of IGAC to discuss policies related to genetic testing
  - IGAC offered to be a resource for Dr. Pelezo in making decisions about these policies
  - Committee will gather list of state's genetics services providers, including their contact information & specialties/interests, to provide Dr. Pelezo with a resource for use when evaluating policies related to genetics

### **Direct-to-Consumer Testing for Breast/Ovarian Cancer**

- Myriad has launched regional advertising campaign to raise awareness of their BRACAnalysis direct-to-consumer test for breast/ovarian cancer
  - TV commercials; also targeting OB/GYN offices with reps providing on-site information
- In response, CDC initiated multi-state effort to develop a response (IN, KY, OH, MO, IL)
  - Wanted to create educational pieces for patients with questions re: BRACAnalysis
  - Developed posters (English/Spanish); working on patient brochure/flyer
    - Materials will be distributed to mammography clinics, women's health centers, local health departments, OB/GYN offices, etc.
  - Posters have been distributed to some state cancer genetics clinics
    - Please contact Courtney Eddy at [CEddy@isdh.IN.gov](mailto:CEddy@isdh.IN.gov) if you would like to receive copies of the posters (include desired # of English & Spanish posters plus mailing address)
  - Materials available on ISDH website at: <http://www.in.gov/isdh/24678.htm> (materials for patients) and <http://www.in.gov/isdh/24679.htm> (materials for professionals)
- CDC also wants to develop standard list of criteria for regional physicians to use when assessing whether cancer genetic testing is appropriate for a patient

### **Discussion of Future Topics**

- Dr. Reed asked for an update on CF newborn screening. Dr. Hainline and Courtney Eddy agreed to work with the state NBS lab & genetics clinics to gather necessary data.
  - Dr. Hainline stated that the IU genetics clinics have not seen an increase in the number of patients seeking genetic counseling for CF carrier status; clinics have seen an increase in number of patients diagnosed with CF seeking genetic counseling.
- Fr. Joe Rautenberg suggested evaluating the Myriad DTC ads and assessing whether or not state legislation is warranted. Other Committee members suggested discussing/developing an educational campaign about DTC testing tailored for physicians. Lisa Cushman-Spock suggested inviting the IN genetic counselor who is currently visiting OB/GYN offices to advertise the Myriad DTC campaign.

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

**Next Meeting Date: April 13<sup>th</sup>, 2010 (teleconference vs. in-person format TBD)**