

**Indiana Genetics Advisory Committee  
Meeting Minutes  
April 8, 2008  
12-3 pm  
ISDH**

**ATTENDANCE:**

Full Members			Ad-hoc Members		
Abernathy, Mary Pell		Lesko, Barb	X	Bowman, Bob	X
Alexander, Mary		Mendenhall, Gordon		Burrus, Connie	
Bader, Patricia	X	Moore, Marva		Dumm, Sue	X
Bingle, Glenn	X	Olsen, Donna Gore		Eddy, Courtney	X
Cohen, Stephanie	X	Quaid, Kimberly	X	Ganser, Judith	X
Cushman, Lisa		Radford, Meggan		Gillette, Melissa	
Darroca, Roberto	X	Rautenberg, Fr. Joe	X	Hutsell, Gayla	X
Downer, Dawn (Melissa Battin, proxy)		Reed, Terry	X	Ignaut, Jim	X
Escobar, Luis F.		Shou, Jianyong		Meade, Nancy	X
Eugster, Erica	X	Smith, Lisa		Silva, Ruwanthi	X
Fielden, Cheryl		Stone, Kristyne	X	Smith-Bonds, Tasha	X
Grover, Spencer		Torres, Wilfredo		Stone, Iris	
Hainline, Bryan	X	Weaver, David	X	Waller, Carolyn	
Hendrix, Jon	X	Zaidi, Syed-Adeel			
Humbert, Larry	X	Zunich, Janice	X		
Hodgin, PT	X				

**Welcome and Introductions – Dr. Zunich**

**Minutes from October 2007 were approved without correction.**

**Discussion of “Covering Kids and Families” Insurance Document – Larry Humbert**

- There is no single governing body overseeing all reimbursement organizations. The Office of Medicaid Policy and Planning (OMPP) is the main administrative organization, and uses subcontractors.
- A listing of amounts Medicaid will pay for various reimbursements can likely be obtained by talking to OMPP. This issue may be handled through the Electronic Data System Corp. (EDS), which performs claims processing.
- Individual states’ Medicaid programs vary due to the combination of federal and state guidelines. All state programs must follow the federal guidelines, but each state has its own rules, and subsequently, Medicaid programs differ from state to state.
- The IPN handout is available electronically (this has been e-mailed to all IGAC members) and on the IPN website at <http://www.indianaperinatal.org/files/Health%20Insurance%20FAQ%203%2008.pdf>.

- Dr. Zurich also asked Larry whether IPN advocates for prenatal patients (it does) and whether IPN would be willing to be an advocating partner regarding Medicaid coverage for first trimester screening (yes).

#### **FASD Task Force – Jim Ignaut**

- Task Force has put together four FASD curricula for use by Indiana middle school and high school educators. Materials available also include instructions, a letter of introduction, a lesson plan template, and an evaluation form.
  - These materials were promoted at the annual Hoosier Association of Science Teachers, Inc. (HASTI) conference via a booth and presentation.
  - The Task Force recruited 125+ teachers to utilize these materials in the pilot test phase.
- The materials have been reviewed and approved by the IGAC Ethics Subcommittee, IU School of Medicine, and the Board of Education. The materials are currently being reviewed by ISDH. Dr. Monroe has yet to review them.
  - Once the Office of Public Affairs (OPA) at ISDH has given final approval of the materials, they will be sent out to all IGAC members for review.
- Jim Ignaut stated that the FASD Funding Committee is beginning to collaborate with the Prenatal Substance Abuse Commission to implement prevention objectives.
- Jon Hendrix asked whether the FASD Task Force members had planned to send a reminder letter to all pilot test volunteers, since this is the end of the school year. Jim Ignaut will get a mailing list together and send a reminder e-mail/letter to all volunteers.
- Jon Hendrix suggested that the FASD Task Force evaluate and report on the demographics of the current pilot test group (location, rural/urban, public/parochial).
- Jon Hendrix also suggested that on-site evaluations be performed to determine how well the materials are being utilized by the pilot teachers, in addition to evaluation forms.
- Fr. Joe Rautenberg requested that the FASD Task Force provide a summary of feedback on these materials at the next IGAC meeting.

#### **Genetics Clinics' Updates:**

##### **Dr. Bader:**

- Provided a handout on clinic visit numbers.
- Her clinic and laboratory will be moving to a new location (move expected to be complete by December).
- Seeing the same volume of patients.

##### **Dr. Hainline:**

- The Clinical and Biochemical Genetics Divisions were combined.
- Currently, each clinic (Clinical Genetics and Biochemical Genetics) is seeing approximately 165 new patients/year; 800 return patients/year; and 100 – 150 hospital admissions/year (increased from 10 – 20/year in 1990).
- Patients are coming from all over the state; there are issues involved with coordinating care.
- The Biochemical Genetics clinic is also seeing an increase in the number of infusions given per year (200 infusions/year for lysosomal storage diseases alone, increased from 75 last year).
- Recruitment and reimbursement for services (including genetic counseling) continue to be issues.

##### **Dr. Zurich:**

- South Bend cancer genetics clinics running monthly, in addition to regular genetics clinics 5 times/year.
- Starting on-site services at Women's Diagnostic Center in Munster (mainly primary cancer risk assessments).
- Prenatal population is increasing; a maternal-fetal medicine provider is returning to the area, and will add 1 – 2 clinics/week as a result.

**Dr. Bingle:**

- Clinic moved to new headquarters.
- Focusing on prenatal counseling.
- Numbers have increased by approximately 10%.

**ISDH Updates:**

- Joe Haddix joined the ISDH team as the MCH epidemiologist.
- Cystic Fibrosis NBS update:
  - As of April 1, 181 newborns had a positive CF NBS (13 newborns were positive for 2 *CFTR* gene changes; 168 positive for 1 *CFTR* gene change).
  - Of the 168 newborns positive for 1 *CFTR* gene change, 10 had positive sweat chloride tests as of February 2008.
  - A letter reminding family practitioners, general practitioners, and OB/GYNs of the addition of CF to the NBS will be mailed in spring 2008.
- Trainings for the EHDI Alert Response Systems (EARS) began in 2008. Three trainings have been held so far, with 7 additional trainings currently scheduled.
- The IU NBS Laboratory was awarded the NBS contract, and will continue to provide NBS services to Indiana through 2010.
- The IBDPR auditors have completed audits for children born between 2003 – 2005. IBDPR staff will begin preparing a report for submission to the National Birth Defects Prevention Network in mid-April.

**Medicaid and Reimbursement for Services**

- Dr. Zunich asked that IGAC members who offer prenatal services provide their approximate prices for nuchal translucency (NT), amniocentesis (with and without the lab costs for chromosomes), sequential screening, etc. Members are asked to e-mail this information to Courtney Eddy by Friday, April 18<sup>th</sup>.
- IGAC members stated that the Committee wishes to have an initial meeting with OMPP staff to establish IGAC's presence as an ad-hoc workgroup that would be willing to advise OMPP on issues related to genetics.
  - Dr. Ganser suggested writing a draft of the three main issues (coverage for first trimester screening, coverage for medical foods, and reimbursement for genetic testing) with a cover memo from IGAC. She reported that there is a new process in place to handle policy questions, and agreed to provide additional information after the meeting.
    - Dr. Ganser provided a template and instructions for approaching OMPP with policy questions/issues. This information was distributed to members of the IGAC Reimbursement Workgroup via e-mail on April 10, 2008.
- Dr. Bader will be meeting with a person in the insurance field who has agreed to give her copies of the directives re: genetic testing that insurance employees receive. Dr. Bader will report this information to the Committee at the next meeting.

- Dr. Zunich stated that Johns Hopkins has a sample letter of medical necessity for genetic testing available on its website. This letter is available at <http://www.hopkinsmedicine.org/dnadiagnostic/MNLSamplelet.pdf>.

#### **Miscellaneous Issues**

- Nancy Meade informed the Committee that an insert titled “Power Over Addictions” (sponsored in part by ISDH) was available in the most recent issue of *Indianapolis Woman* magazine.

#### **Discussion of Future Topics:**

- Suggested topics for the October 2008 meeting:
  - Direct-to-consumer genetic testing
  - Jim Nocon, MD – Director of the Substance Abuse Program at Wishard
- Also requested for the next meeting
  - Review of recent studies regarding neural tube defects (NTDs) and folic acid; to be provided by Sue Dumm

**Next Meeting Date: October 7<sup>th</sup>, 2008, IUPUI**