

**Indiana Genetics Advisory Committee
Meeting Minutes
October 9, 2007
12-3 pm
IUPUI**

ATTENDANCE:

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

Welcome and Introductions – Dr. Zurich

Minutes from April 24th, 2007, were approved without correction.

Updates:

Meeting format has changed to allow for more brief updates. This will allow for more education sessions during these meetings.

Several individuals did mention that their membership information needed updating. Dr. Zurich recommended that everyone take a look at their information as it is currently presented and report any necessary changes.

Cystic Fibrosis Newborn Screening

- Bob Bowman reported for Connie Burrus.

- Pilot test screening has begun and will continue through 12/07. The plan is to go live with this program 1/08.
- ISDH has received reports of its first two children who have screened positive for this disorder.
- The primary care physician can report by fax to ISDH when a screening is scheduled.
- If the screening is positive for 2 mutations, the child is then referred to a Cystic Fibrosis Foundation (CFF) accredited clinic.
- Children who screen positive for 1 mutation are referred to a CFF-accredited laboratory for sweat chloride testing.
- There is genetic counseling information in the packet sent to primary care physicians. All genetic counselors in the state are included in this packet.
- There are four qualified testing clinics in Indiana and their locations are in Indianapolis, Ft. Wayne, South Bend, and Evansville.

Genetic Counseling Licensure

- Stephanie Cohen reported on this issue.
- It is low priority in the legislature at this point due to the property tax issue.
- There have been no changes since the last meeting.
- It is the hope that this will be considered in the January session.

FASD Taskforce Update

Dr. Weaver:

- This group is continuing to work on FASD curricula. They are working with Becky Kennedy from the Department of Education.
- SAMSA has put out another FASD state grant application
- One group objective is to get physicians to recognize children with FASD
- Another objective is for the state to implement programs and assist children with FASD

Gordon Mendenhall:

- Group is working on curriculum geared toward high school teachers as well as special education teachers by working on specific teaching strategies for those children affected by FASD.
- ISDH will be a presence at the HASTI Conference in February. One of the objectives of attending this conference is to discuss FASD
- Gordon will be attending NABT in Atlanta and will present FASD information while there.

Genetics Clinics' Updates:

Dr. Bader:

- Provided a handout on clinic visit numbers
- There has been an increase in total Medicaid patients

- The patients seen in her clinic are mostly children, but the numbers of adults have increased
- The clinic is also seeing more follow up patients.

Dr. Hainline:

- His clinic has experienced a reorganization of services
- They have a new part time physician and are currently interviewing a Biochemical Geneticist to primarily focus on glycerol metabolism
- They will additionally be adding another clinical geneticist in the hopes that they will increase their research base.

Dr. Zurich:

- Her clinic has added another genetic counselor
- Her Medicaid load is also high – 70% of mothers in Lake County receive Medicaid.

Dr. Bingle:

- His clinic currently sees 300+ patients.
- They do not see Oncology patients. They are instead referred to St. Vincent's or IU.

ISDH Updates:

Bob Bowman

- There have been four new hires since the last meeting – Courtney Eddy, Genetic Specialist; Leslie Hine, parent consultant for EHDI; Gayla Hutsell, EHDI Program Coordinator; and Connie Burris, Cystic Fibrosis Coordinator
- There was a recent CDC site visit to ISDH, which went well.
- IBDPR submitted information for the years 2003 – 2004 to NBDPN in late June. They are looking for 5 years of information on birth defects in the state.
- There is a report being prepared for the Indiana legislature
- ISDH is currently presenting Public Health Nurses training. After the training, nurses can take an online quiz.

Ruwanthi Silva

- There has been an increase in the number of hospitals that regularly report to the IBDPR.
- There has been no significant increase in the number of physicians reporting until February 2007. In February, a reminder was mailed out to physicians requesting that they report.

Jim Ignaut

- The Fall/Winter edition of Transcriptions is to go out soon.
- The articles have been written but are currently under review.

- Each issue will be thematic, with the topic of the current issue to be FASD
- Once complete, several thousand copies will be sent electronically to health professionals throughout Indiana.

Medicaid Panel

- Slightly more than 50% of all Hoosiers are on Medicaid
- Panel members: Mona Green from EDS and Wendy Michalski from ISDH
- Reimbursement is often times an issue – both in getting reimbursement at all for services provided and for getting adequate reimbursement for services.
- According to the panel, an appeal needs to go through the legislature in order for any changes to be made in current coverage and reimbursement.
- EDS is an independent contractor. They pay Medicaid claims according to current policies and procedures. They are *not* responsible, however, for setting pricing for procedures.
- To see the current fee schedule, go to www.IndianaMedicaid.com. Enter the appropriate CPT code for the current fee schedule.
- IGAC members had many questions about Medicaid that were unable to be answered by the panel. **Therefore, by October 31st, any member who has a question is asked to send that question (preferably in the form of a specific scenario) to Courtney Eddy.** These will be compiled and sent to someone within the Medicaid system.
- IGAC members also requested the ability to meet with Dr. Monroe and/or Mary Hill sometime in November or December regarding Medicaid reimbursement.

Discussion of Future Topics:

- Bring back answers to Medicaid questions.
- Legislative issues.

Next Meeting Date: April 8th, 2008, ISDH