

**Indiana Genetics Advisory Committee
Meeting Minutes
October 7, 2008
1 – 2:30 pm
Teleconference**

ATTENDANCE:

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

Welcome and Introductions – Dr. Zunich & Dr. Quaid

Minutes from April 2008 were approved without correction.

Discussion of Licensure for Genetic Counselors – Stephanie Cohen

- The IN Network of Genetic Counselors (INGC) met with Senator Miller, who agreed to sponsor this bill again. Senator Miller stated that the licensure bill should be heard in Committee during this session, and that she has ideas of people within the House who would be willing to sponsor the bill.
- INGC members are reviewing the bill's language and currently collecting letters of support.
 - Letters of support submitted during the previous round can be updated with correct dates and names/signatures.
 - INGC will also accept letters of support from individuals (instead of organizations).
 - Please return these letters to Stephanie Cohen before January 1, 2009.

Genetics Clinics' Updates:

Dr. Hainline (reported by Dr. Weaver):

- Lisa Cushman has decreased her days in the office to 2 per week.
- Abby Stevens has been hired as a full-time genetic counselor.

Dr. Zunich:

- Melissa Gillette, Dr. Zunich's genetic counselor, accepted a teaching/coaching position in August and has left the practice. Dr. Zunich states that she intends to advertise the genetic counseling position in the near future.
- More outreach clinics have begun in northwest Indiana; Dr. Zunich stated she is spending approximately 50% of her time out of the office at these clinics.
- Increased number of patients being seen, due to the restart of maternal-fetal medicine (MFM) clinics at Methodist.

ISDH Updates:

- Jim Ignaut accepted a position as a Field Epidemiologist for ISDH; his final day with Genomics and Newborn Screening was October 3rd.
- The EHDI program added a new position, the EARS Follow-Up Coordinator, which has been filled by Julie Schulte.
- The ISDH Office of HIPAA Compliance recently announced that the NBS and Genomics Programs will be HIPAA-covered entities. This conversion began in September 2008, and is expected to be finished by mid-2009. Courtney Eddy has been named HIPAA Program Privacy Coordinator for Genomics and NBS.
- The Operational Data Store (ODS), which is used by both Genomics and NBS programs, is undergoing a major renovation. The new version of the data store will be called the Integrated Data System (IDS). This renovation requires converting all applications that use the current system, and has delayed the development of the NBS heelstick datamart.
 - **Addendum to Minutes:** Per Alan Schoeff, ISDH ODS Data Analyst – The ODS to IDS conversion is being done for a number of reasons, including separating the current Oracle database from the federally-funded PHER servers, implementing logic to provide increased data integrity and allow for better auditing of data usage (as required by HIPAA), and implementing measures to provide better quality data (such as reducing duplicate records) and regulating how other users access program areas' data. ISDH IOT personnel are working with officers within the ISDH Office of HIPAA Compliance (OHC) to assure that the IDS, the data it stores, and all applications which consume that data follow HIPAA requirements. All web-based applications currently used by Genomics/NBS are affected by this conversion.
- The physician reporting system for the IBDPR will be performed through a web-based application called the Health Data Center Gateway, effective January 1, 2009. The Gateway system replaces the current Teleforms (fax) method of reporting.
 - Information related to this change will be published in newsletters for the following physician organizations: The IN chapter of the American Academy of Pediatrics, the IN chapter of the American Academy of Family Practitioners, the IN State Medical Association, and the IN Psychological Association. These announcements will be published prior to January 2009.

Region 4 Genetics Collaborative Update

- Region 4 is in year 2 of a 5-year, \$5,000,000 grant from HRSA (grant cycle: 2007 – 2012).
 - The Priority 2 workgroup has developed and is implementing a comprehensive Inborn Errors of Metabolism Information System (IBEM-IS). This HIPAA-compliant registry will include all diseases screened for using tandem mass spectrometry (MS-MS).
 - Creation of DocSite
 - Web-based registry that contains patient demographics, contact information, allergies, current medications, managed conditions, list of providers, etc.
 - IBEM-IS currently includes elements for 28 NBS conditions
 - 8 centers within Region 4 have been trained for use of IBEM-IS
 - Total of 141 patients enrolled (as of July 2008) from 5 of 8 trained centers

FASD Prevention Task Force Update

- Sue Dumm has taken over Jim Ignaut's position within the Task Force.
- Notices regarding the FASD prevention curricula were sent to teachers during the past semester.
- The Task Force's emphasis for the next year will focus on obtaining additional funding to expand the programs.

Medicaid and Reimbursement for Services

- Dr. Zunich submitted a "white paper" regarding coverage for 1st trimester prenatal screening to the Office of Medical Policy and Procedures (OMPP) in September.
 - This action was prompted by the knowledge that there is currently no Medicaid coverage for 1st trimester screening, and that 70% of pregnant women in Lake County alone are on Medicaid.
 - ACOG recommends offering 1st trimester screening to all women seeking prenatal care before 13 weeks' gestation.

- Dr. Darroca asked whether additional ultrasound measurements (beyond the nuchal translucency) were referenced in this white paper, as individual ultrasound measurements (e.g. nasal bone) are commonly considered independent factors when evaluating the risk of genetic conditions prenatally.
 - Dr. Zurich stated that she did not include these additional measurements in the paper, as she hopes to expand the request for coverage to include sequential and 2nd trimester screening at a later time.
- The OMPP Policy Committee responded to this submission with a request to complete a particular form; Dr. Zurich stated that she returned the form and has not heard any additional information since.
- Dr. Ganser stated that, as a member of the policy committee, she knows that this submission has been assigned a number and is waiting in a queue to be reviewed by the committee, but had no specific date(s).
- Dr. Zurich requested that Drs. Bader and Hainline format their submission to a 2-page document (maximum) which includes some historical information and references. As Dr. Hainline was absent from the call, Dr. Zurich agreed to contact Dolly Warner (Clinical Manager at IU Biochemical and Molecular Genetics, 317.274.1061 or caswarne@iupui.edu) to pass along information to Dr. Hainline.
- Jon Hendrix proposed gathering a list of IN insurance companies and reviewing their lists of covered genetic tests, if available.
 - Donna Gore Olsen recommended that the Committee contact the IN Department of Insurance to identify the person(s) responsible for adding covered benefits to fully-insured plans. Jon Hendrix offered to make this contact on behalf of the Committee, and received the Committee's approval to act as its emissary.
 - Kristyne Stone proposed that the Committee also ask the IN Dept. of Insurance for more information regarding billing using the new CPT code for genetic counselors (96040), as billing varies between institutions and this code is currently not well-covered.
 - **Addendum to Minutes:** Jon Hendrix reported to Dr. Zurich that he spoke with Carol Cutter's secretary within the IN Dept. of Insurance. Ms. Cutter's secretary said that they file all of the recently issued policies from various companies, but that they have no database from which to determine what genetic testing each company covers, nor does she have any data on CPT code #96040 and coverage for genetic counselors.

Miscellaneous Issues

- Dr. Quaid informed the Committee of articles recently published regarding issuance of cease-and-desist orders for companies offering direct-to-consumer genetic testing. One article is available in the *LA Times* at <http://articles.latimes.com/2008/jul/14/health/he-closer14>. Most of the orders are based upon laws that require physicians to order genetic testing and/or licensing for laboratories performing genetic testing.

Discussion of Future Topics:

- The Committee requested a presentation on the Genetic Information Nondiscrimination Act (GINA) at the April 2009 meeting. Dr. Quaid volunteered to identify a presenter within her office.
- Stephanie Cohen also brought to the attention of the Committee a new test offered through DeCode, which looks at 8 single nucleotide polymorphisms (SNPs) to modify breast cancer risk in unaffected women with no family history and/or the risk for women who are known carriers of a *BRCA* mutation.
 - When asked about the availability of statistical data used by DeCode, Stephanie reported that the DeCode representative stated the data was available and that she (Stephanie) had received some articles with more information.
 - The Committee requested that Dr. Gail Vance at the IN Familial Cancer Clinic review this data and present her findings and opinion at the April 2009 meeting.

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

Next Meeting Date: April 7th, 2009, in room 8T at ISDH