

**Indiana Genetics Advisory Committee
Meeting Minutes
April 19, 2011
From 2-3PM**

ATTENDANCE:

Full Members				Ad-hoc Members	
Bader, Patricia	X	Hodgin, PT	X	Bowman, Bob	X
Bingle, Glenn	X	Humbert, Larry		Dumm, Sue	
Cohen, Stephanie	X	Lesko, Barb	X	Eddy, Courtney	
Cushman, Lisa	X	Lovchik, Judith		Ganser, Judith	
Darroca, Roberto		Mendenhall, Gordon		Hensley, Malorie	X
Escobar, Luis F.		Olsen, Donna Gore		Hutsell, Gayla	
Eugster, Erica		Quaid, Kimberly	X	Mani, Lisa	
Gill, Nicole	X	Rautenberg, Fr. Joe	X	Payne, Victoria	
Hainline, Bryan	X	Stone, Kristyne	X	Silva, Ruwanthi	X
Hendrix, Jon	X	Weaver, David	X	Stone, Iris	X
Hinton, John		Zunich, Janice	X		

Welcome – Dr. Zunich & Dr. Quaid

- Sent out minutes from the last meeting for approval. Once change was noted in Dr. Zunich’s clinic update from the last meeting. Her genetic counselor’s name is Mary Post, not Marie, as was written in the Oct. 2010 meeting minutes. This change has been made.

Genetics Clinics’ Updates

- **Dr. Bader:**
Clinic continues to see growth. In the second quarter they have had a 12% increase of new patients and 20% increase of follow-up patients. They had 449 unduplicated patients in second quarter. This growth is attributed to the fact that they have a treatment component such that if a PCP cannot follow a patient due to their complex medical condition, Dr. Bader’s office provides the patient with quarterly appointments. They also have been working with children with FAS and medications to help improve their condition.
- **Stephanie Cohen:**
Not too much new right now. They are working on a collaborative project with St. Joe and doing some outreach and triage with patients and staff up there. They are serving 100% more patients than they were in Kokomo.
- **Dr. Hainline:**
Part of the region 4 group for newborn screening, as of April 15 they activated a grant for a 5 year study for inborn errors of metabolism with 15 different centers from all over the country, which will have a

coordinator to investigate long term follow-up. This project could evolve into clinical trials for these patients.

Dr. Zurich:

- Opening an onsite cancer risk assessment clinic at Methodist Hospital in Merrillville. They have gone for NAPBC accreditation, which requires a genetic counselor to be part of the clinic. Dr. Zurich may look into getting the wording changed to state “genetic specialist” which would include geneticists and Ph.Ds instead of specifically genetic counselor. It is a good thing that they recognize that a genetic risk assessment is beneficial for their patients. A problem can arise where some genetic counselors have been contacted from smaller hospitals who want to write their name down on accreditation application, but we don’t know if they are actually referring their patients.

Subcommittee Updates and Current Issues

Newborn Screening Subcommittee:

- Process of NBS and SCIDs: meeting on April 8. We all feel that SCIDs testing is necessary and the technology is available to perform this test. The subcommittee is prepared to propose to undertake the formal process of recommending that SCIDs be added to the newborn screen and ISDH will need to start this process off.
- At the last subcommittee meeting we discussed how to move forward in terms of putting together a formal proposal and identifying experts/professionals to be included in a task force. This task force would draft a proposal and bring it back to IGAC to let everyone see what we were looking at then it would come internally through ISDH and up the hierarchy. The screening test can identify many types of immunodeficiency and follow-up gene testing is still an “art.” The test is cost effective as transplants for children detected early can cost \$500,000 to \$1 million, but children without treatment right away can cost much more due to long and intensive hospital stays followed by a transplant once they are healthy enough. We are following through with the IGAC’s approval from the last meeting that recommends that SCIDs be added to the newborn screen.

Dr. Bader, Medicaid Reimbursement:

- Her clinic has had problems getting reimbursement from Medicaid. She will get responses from Medicaid like “other geneticists don’t order this test.” She is wondering if it would help to create a statement/consensus from this group, stating that we (IGAC) back the statements from the ACMG regarding genetic testing for tests related to hearing loss, Marfan syndrome, microarray, etc.
- Dr. Bader proposes that a motion be made that the IGAC of ISDH supports the consensus statement that members of IGAC support the statements from ACMG. This motion was seconded. Dr. Bader will draft a statement for IGAC, which will be helpful for her practice and possibly others. Dr. B appreciates the support and will draft a statement and Malorie will distribute it to all IGAC members.
- Dr. Zurich added that hospitals in her area will not draw sample unless payment is identified, so she is having trouble getting samples drawn and wanted to know how Dr. Bader deals with this issue. Dr. Bader works with Baylor, St. Francis, and Greenwood, because they will take Medicaid and the amount Medicaid pays. Dr. Zurich can only order tests at Mayo, as hospitals will only draw those samples for labs that they have a contract with. Dr. Bader said that Baylor is an Indiana Medicaid provider so will accept what Medicaid pays them. Dr. Bader stated that Baylor will accept Ehlers-Danlos syndrome, connexin, and samples for any other testing they perform. So now Dr. Bader’s clinic can order many more tests since Baylor is an Indiana Medicaid provider. They have it set up so that if Indiana Medicaid goes to Baylor an Indiana hospital will draw the sample and Baylor will accept the sample.
- Dr. Weaver co-wrote an article for Signature Genomics since they have a similar problem for reimbursement from companies for CGH, which also talked about the ACMG guidelines. He will see if Signature will be willing to share this article with Dr. Zurich and Dr. Bader.

Stephanie Cohen, Medicaid Recognition:

- Medicaid does not recognize genetic counselors. She would like to know if anyone in the group has worked with Medicaid to get them to recognize genetic counselors. No one has worked directly with any one person or group from Medicaid.
- Dr. Zurich stated that she had last sent things to Dr. Peleezo and the Medicaid Policy Advisory Committee. No one is sure if this committee still exists through the Office of Policy and Planning. At

one point, they were disbanded. Dr. Zurich was sending things to Medicaid starting in September, 2008 and sent the last letter in November, 2009, which went to Dr. Peleezo.

- Kristyne Stone wondered if getting genetic counselors credentials would include recognizing the 9640 billing code that is used.

Stephanie Cohen, Licensure:

- A few months ago, a place doing BRCA testing was quoted in a paper as doing genetic counseling. When, it does not appear that this is the case. This was brought to the attention of the attorney general and they are investigating this claim. So the licensure law has proven itself in a short time.

Dr. Weaver, Genetic Counseling Program:

- They had 110 applicants for the 6 positions, interviewed 40. Match day is next Monday.
- He has been operating an Adult Marfan Syndrome Clinic with Dr. Ali Shahriari who is a thoracic surgeon, specializing in aortic surgeries. Feel free to refer any patients to this clinic.

Meeting minutes from the last meeting in October 2010 were approved with one change to Dr. Z clinic update.

Future Meeting Date

- October 4 from 1-3pm at ISDH

Discussion of Future Topics

- Please email Malorie Hensley at MHensley@isdh.in.gov with the suggestion of future topics.

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