



**CENTER FOR CONGENITAL AND INHERITED  
DISORDERS ADVISORY COMMITTEE** Chair -Daack-Hirsch

**Friday, October 23, 2015 1:00 pm to 3:00 pm  
Drake Community Library, Grinnell, IA**

**Iowa Nurses Association**  
Sandra Daack-Hirsch, PhD, RN  
Chair

**American College of Obstetrician  
& Gynecologists**  
Stewart Boulis, MD

**College of Public Health**  
George Wehby, PhD

**Consumer Representatives**  
Sarah Dricken, CLMA  
Lori Murphy-Stokes, IHA

**Maternal Screening Programs**  
Andrea Greiner, MD

**INMSP Medical Director,  
Division of Medical Genetics, U  
of I**  
Val Sheffield, MD

**Iowa Academy of Family  
Physicians**  
Dan Rowley, MD

**Iowa Dept. of Education**  
Kate Small

**Iowa Insurance Agency**  
Bobbi Buckner-Bentz

**Iowa Osteopathic Medical  
Association**  
vacant

**Iowa Senate**  
Senator Amanda Ragan

**Iowa House**  
Representative Beth Wessel  
Kroeschell

**American Academy of Pediatrics**  
Shannon Sullivan, MD

**Iowa Child Health Specialty  
Clinics**  
Tom Scholz, MD

**Iowa Association of Social  
Workers**  
Kelly Schulte, LMSW

**Parent Representatives**  
Kelsey Baker  
Kori Ensley  
Kathleen Cady  
Becky Lutgen Gardner  
Kari Atkinson  
Ericka Sherman  
Elisa Seeber

**University of Iowa  
Clinical Genetics Staff**  
Hannah Bombei, MS CGC

**Voluntary Agency**  
**March of Dimes**  
Michelle Gogerty  
**American Heart Association**  
Stacy Frelund

**University Hygienic Lab**  
Stanton Berberich, PhD

**Ethics/Bioethics Representative**  
Francis Dominic Degnin, PhD,

**Iowa Registry for Congenital and  
Inherited Disorders**  
Paul Romitti, PhD

**Attorney-at-Law**  
Sarah Grotha, JD

	<u>TOPIC</u> <u>Presenter</u>	<u>DISCUSSION</u> <u>POINTS</u>	<u>ACTION INDICATED</u>	<u>HANDOUT</u>
1:00 pm	<b>Call to Order</b> <i>Daack-Hirsch</i> <b>Roll call</b> <b>Minutes</b> <b>Announcements</b>	Review minutes	Approval of Minutes	April 24, 2015 minutes July 24, 2015 minutes
	<b>Election of Officers – Vice Chair/Chair elect</b> <i>Daack-Hirsch</i>		Elect vice chair/chair elect	Committee Roster
	<b>Iowa Newborn Screening Information System update</b> <i>Carol Johnson</i>	Update of INSIS		
	<b>Informed Consent Subcommittee report</b> <i>Sandy Daack Hirsch</i>	Timeline and amendments to IAC		Informed consent booklet and form
	<b>Newborn Screening Panel Management Subcommittee report</b> <i>Jenny Marcy</i>	Review and discuss policy #003		Draft policy #003 – Management of Iowa’s Newborn screening Panel
	<b>Public Comment - ALD</b> <i>Ericka Sherman/Elise Seeber</i>			
	<b>Research Proposal Inflammation, the IGF system, and growth in infants with CF</b> <i>Alexandra Ianonne</i>			Proposal, presentation, supporting documentation
	<b>Iowa CoIIN timeliness in newborn screening program</b> <i>Berberich</i>	Update of Iowa CoIIN project		
	<b>Agenda Items Next Meeting January 22, 2016 Conference Call</b> <i>Daack-Hirsch</i>			SFY2016 schedule
3:00 pm “ish”	<b>Adjourn</b>			

**Congenital and Inherited Disorders Advisory Committee**  
**Minutes**  
**April 24, 2015**  
**1:00 p.m. to 3:00 p.m.**  
**Drake Community Library, Grinnell**

**M i n u t e s**

<u>Members Present</u>	<u>Members Absent</u>	<u>Others Present</u>
Sandra Daack-Hirsch		Kimberly Noble Piper
Stewart Boulis	Sarah Dricken	Carol Johnson
Lori Murphy-Stokes	Andrea Greiner	Lisa Neff-Letts
Val Sheffield	Stacy Frelund	Travis Henry
Shannon Sullivan	Kari Atkinson	Ben Darbro
Bobbi Buckner Bentz	Michelle Gogerty	Tonya Millard
Mary Larew	Kelly Schulte	
Cathy Evers/Hannah Bombei	George Wehby	
Sarah Grotha*		
Kate Small		
Stanton Berberich		
Francis Degnin	Representative Wessel Kroeschell	
Paul Romitti	Senator Ragan	
Dan Rowley	*via phone	

<b>Topics</b>	<b>Discussion/Action</b>
<b><u>Call to Order</u></b>	<ul style="list-style-type: none"> <li>▪ Degnin called the meeting to order at 1:05 pm.</li> <li>▪ Roll call attendance was taken – quorum is present.</li> </ul>
<b><u>Approval of January 23, 2015 minutes</u></b>	<ul style="list-style-type: none"> <li>▪ Minutes approved by exception vote.</li> </ul>
<b><u>Announcements</u></b>	<p>Retirements – Kim Horton and Cathy Evers from the University of Iowa Division of Medical Genetics are both retiring at the end of May. There will be a retirement party May 29 at the Vine in Coralville. Everyone is invited. If interested in attending, please let Lisa Neff-Letts know. Hannah Bombei will be the new Coordinator of the Regional Genetics and Consultation Clinics upon Cathy’s retirement.</p> <p>Dr. Bernat, a metabolic geneticist, will begin working at the Division in July. Dr. Bernat has an interest in lysosomal storage disorders.</p> <p>Subcommittee reports –</p> <p>Informed Consent –Daack-Hirsch reported that the subcommittee will meet in May to discuss options for informed consent. Daack-Hirsch and Piper have collected information about costs to store residual dried blood spots and costs for managing consent. Once a decision is made about the consent process, the issue of storage of the residual specimens and management of the consents goes back to the use of residual newborn screening specimens subcommittee.</p> <p>Residual Specimens – Romitti reported that this subcommittee is on hiatus pending the recommendations from the informed consent subcommittee.</p> <p>Adding Conditions – Piper – The subcommittee looking at the addition of lysosomal storage disorders is recommending this subcommittee be expanded and called the Subcommittee for management of the newborn screening panel. Jenny Marcy has</p>

	<p>agreed to chair that subcommittee. Additional members would be brought to the subcommittee on an ad hoc basis depending on the condition(s) being discussed. Members approved the recommendation for the new subcommittee on a voice vote.</p>
<p><b><u>Request for LOS for carving hemophilia and clotting disorders treatments out of Medicaid Managed Care</u></b></p>	<ul style="list-style-type: none"> <li>▪ Tonya Millard, Executive Director of Hemophilia Iowa, requested a LOS from CIDAC members to have hemophilia carved out of the Iowa Managed Care Act RFP and remain a fee for service model; if a carve out is not an option, then at the least that clotting factor be on a fee for service schedule. Letters from the National Hemophilia Foundation to the director of Iowa DHS was shared. Tonya also shared copies of informational sheets about Medicaid Managed Care and Hemophilia and a legislative fact sheet.</li> <li>▪ Members request an opportunity to review the information Tonya provided before deciding on whether to provide a letter of support. Piper will disseminate the information, and members will have an opportunity to vote to provide a letter of support via email or SurveyMonkey. Tonya noted that there are over 100 Medicaid patients in IA, and that it averages \$250,000 to treat one person with hemophilia per year.</li> </ul>
<p><b><u>Policy for release of data</u></b></p>	<ul style="list-style-type: none"> <li>▪ Members reviewed the draft of the policy for the release of CCID data, including newborn and maternal prenatal screening data. Edits were suggested. Piper will make the recommended edits and post it for approval via email or SurveyMonkey.</li> </ul>
<p><b><u>Research proposal</u></b></p>	<ul style="list-style-type: none"> <li>▪ Dr. Ben Darbro and Dr. Travis Henry presented a research proposal “Newborn screening and Genotype-Phenotype Associations in Immunodeficient Children with 22q11.2 Deletion. (Presentation and proposal attached.) 22q11.2 is the most common and significant SCID “false positive” – screen is not positive for SCID, but is significant for the secondary disorder of 22q11.2 deletion. This project would benefit newborns as it validates the screening process for targeting 22q11.2 deletion specifically. The project aims are to 1. Establish performance metrics for the detection of the 22q microdeletion by the TREC assay (current assay used for SCID screening). 2. Establish the correlation between TREC assay positive 22q deletion patients and the incidence of functional immune system dysfunction and an alternative measure of T-lymphocyte numbers. 3. Discover candidate modifier genes for T-lymphocyte depletion and immune dysfunction in children with 22q deletion. The researchers propose to use retrospective 22q samples from TREC assays already completed through the SCID pilot (half TREC + and half TREC -) linked with an already completed chart review to conduct a Proximity Ligation Assay (PLA) to determine those appropriate for Exome Sequencing. The development of this testing process may improve SCID screening; provide confirmation of immune defects and provide benefit to the Iowa Newborn Screening Program; and 22q deletion sequencing data may identify genes associated with impaired immune response and provide improved clinical intervention at an earlier time.</li> <li>▪ Discussion:</li> <li>▪ Dr. Paul Romitti – What is the project specifically asking this committee? - Darbro – Asking to associate data from previous TREC assays from SCID pilot with their database, and to use residual newborn screening specimens from + and – specimens to test PLA.</li> <li>▪ CIDAC Members – Is this considered newborn screening new test development or is this considered research? Is informed consent required? Henry – U of I IRB has waived consent because this is</li> </ul>

	<p>using data already collected. Not sure of new test QA/QI vs. research.</p> <ul style="list-style-type: none"> <li>▪ Piper – suggested PIs discuss proposal with Heather Adams, IDPH Assistant Attorney General, for opinion of new test development vs. research, prior to proceeding with presentation to RERC.</li> <li>▪ Boulis – Is there potential to compare 22q deletion testing through non-invasive prenatal screening with specimens collected through this project? – Darbro – That would be beyond the scope of this specific proposal, but would be an interesting study. Boulis – Labs providing non-invasive prenatal testing have not demonstrated the efficacy of this screening. Would be beneficial to compare. Darbro – All these labs’ work is proprietary, so it would be interesting to do a comparison study.</li> <li>▪ Romitti moved that the premise of the research proposal be approved, pending Heather Adams’ recommendation. Boulis seconded. Motion passed on voice vote with two abstentions.</li> </ul>
<b><u>CoIIN Timeliness in Newborn Screening Project</u></b>	<ul style="list-style-type: none"> <li>▪ Carol Johnson presented an overview of the state’s timeliness in newborn screening Collaborative Improvement and Innovation Network project. Iowa has a goal of 95% of newborn screening collection forms being received by the State Hygienic Laboratory in Ankeny within 60 hours of birth. Birthing facilities will be provided with infographic reports on at least a quarterly basis that will describe their status in meeting the state goal. CoIIN team members will work with birthing facilities to lead a QI process specific to their organization’s needs in order to meet the goal. CoIIN Team members are Stan Berberich, Team lead; Carol Johnson; Laura Malone from the Iowa Hospital Association; Kristen Ernsperger from Mercy Medical Center Des Moines; Ashley Comer from the State Hygienic Lab; Kim VonAhnsen from UnityPoint Des Moines’ Lab, and Kim Piper.</li> </ul>
<b><u>Next meeting date and agenda</u></b>	The next meeting will be July 24 from 12:00 pm to 2:00 pm “ish” via conference call.
<b><u>Adjournment</u></b>	Meeting adjourned at 3:20 pm.

**Congenital and Inherited Disorders Advisory Committee**  
**Minutes**  
**July 24, 2015**  
**12:00 p.m. to 2:00 p.m.**  
**Conference Call**

**M i n u t e s**

<u>Members Present</u>	<u>Members Absent</u>	<u>Others Present</u>
Sandra Daack-Hirsch	Stewart Boulis	Kimberly Noble Piper
Bobbi Buckner Bentz	Sarah Dricken	Carol Johnson
Christina Trout	Lori Murphy-Stokes	Scott Williams, baebies
Stanton Berberich	Val Sheffield	Hannah Bombei
Francis Degnin	Andrea Greiner	
Paul Romitti	Stacy Frelund	
Kelly Schulte	Kari Atkinson	
	Michelle Gogerty	
	Mary Larew	
	George Wehby	
	Shannon Sullivan	
	Dan Rowley	
	Kate Small	
	Sarah Grotha	
	Representative Wessel Kroeschell	
	Senator Ragan	

<b>Topics</b>	<b>Discussion/Action</b>
<b><u>Call to Order</u></b>	<ul style="list-style-type: none"> <li>▪ Degnin called the meeting to order at 12:05 pm.</li> <li>▪ Roll call attendance was taken – we do not have a quorum of voting members.</li> </ul>
<b><u>Approval of April 24, 2015 minutes</u></b>	<ul style="list-style-type: none"> <li>▪ Vote on minutes deferred as no quorum present.</li> </ul>
<b><u>Announcements</u></b>	<p>Carol Johnson – Dr. John Bernat joined the Medical Genetics Faculty on July 1. His expertise is lysosomal storage disorders. Dr. Oleg Shchelochkov has taken a position with NIH and has left UIHC.</p> <p>Recruiting two medical geneticists.</p>
<b><u>INSIS Update</u></b>	<p>Carol Johnson – The Iowa Newborn Screening Information System, the new data system for the blood spot, hearing and critical congenital heart disease screening programs, is beginning its beta-testing phase this month. The INSIS will import newborn screening results from the State Hygienic Laboratory via HL7 messages. Beta testing will trial the functionality of the system and provide feedback to the vendor for further development/changes.</p>
<b><u>Policy for release of data</u></b>	<ul style="list-style-type: none"> <li>▪ Members voted via Survey Monkey to approve CCID Policy 002 Release of Data. A copy is provided in your meeting materials.</li> </ul>
<b><u>Informed Consent Subcommittee Update</u></b>	<ul style="list-style-type: none"> <li>▪ Dr. Daack-Hirsch – acknowledged other committee members. Background given for new committee members. Subcommittee is to develop a consistent, comprehensive policy and procedure for obtaining informed consent from parents for the storage and release of their child’s de-identified residual blood spot specimen to researchers. The committee is trying to be very conscious not to</li> </ul>

	<p>bias the parents in their decision. Other modes to provide information to parents and to obtain active consent are being explored, e.g., electronic, verbal, etc. Much depends on the federal recommendations from the NIH regarding requirements for informed consent for identifiable and de-identified residual newborn screening specimens. One challenge is a lack of financial resources to sustain a consenting process. IDPH has opened up the administrative rules 641 IAC 4 to amend the date for having policies &amp; procedures for obtaining informed consent developed from January 2016 until July 1, 2017, and making it dependent on available funding. This would help us pilot consenting procedures, examine federal regulations, and perhaps find funding to support.</p> <ul style="list-style-type: none"> <li>▪ Action item = vote to approve change in date policy and process for informed consent is due. As there is no quorum to vote, Piper will pose the question to voting members via Survey Monkey along with a background of the issue, current administrative rules, and the proposed amendments to the timeline. Stan Berberich suggested adding the definition of “de-identified” specimens.</li> </ul>
<p><b><u>CoIIN Timeliness in Newborn Screening Project</u></b></p>	<ul style="list-style-type: none"> <li>▪ Stan Berberich updated the members on the state’s timeliness in newborn screening Collaborative Improvement and Innovation Network project. Iowa has a goal of 95% of newborn screening collection forms being received by the State Hygienic Laboratory in Ankeny within 60 hours of birth. Birthing facilities will be provided with infographic reports on at least a quarterly basis that will describe their status in meeting the state goal. CoIIN team members will work with birthing facilities to lead a QI process specific to their organization’s needs in order to meet the goal. CoIIN Team members are Stan Berberich, Team lead; Carol Johnson; Laura Malone from the Iowa Hospital Association; Kristen Ernsperger from Mercy Medical Center Des Moines; Ashley Comer from the State Hygienic Lab; Kim VonAhnsen from UnityPoint Des Moines’ Lab, and Kim Piper. The project is currently in the pilot phase with seven hospitals testing the infographic and making recommendations for changes. Once the infographic is approved and “automated,” it will be distributed statewide. The pilot hospitals are excited to see the data and their performance, and are very engaged. From the beginning of the project, the state average was 65% of specimens received within 60 hours of birth to now 75% of specimens are received within 60 hours of birth – just from the improvement of the pilot hospitals. As important, the percent of specimens received over 80 hours from birth has dropped from 11% in March to 6% in June. We have seen a number of opportunities to improve other metrics with hospitals. Educational sessions and more data have been provided to hospitals as an outgrowth of this project. Stan’s “aha” is that even though we have worked with the hospitals for years, the difference in telling the hospitals what to do versus engaging the hospitals in deciding how they make the changes has been very obvious.</li> </ul>
<p><b><u>Next meeting date and agenda</u></b></p>	<p>The next meeting will be October 23 from 1:00 pm to 3:00 pm “ish” in Grinnell.</p> <p>Christina Trout – should we add program reports from the clinical programs? Piper will add to the agenda.</p> <p>Dr. Degnin – need to elect officers – Dr. Daack-Hirsch assumes position as Chair, and need to nominate and vote for Vice Chair/Chair Elect.</p>

<b><u>Adjournment</u></b>	Meeting adjourned at 12:45 pm.
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# CIDAC Roster 2015

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## CONGENITAL AND INHERITED DISORDERS ADVISORY COMMITTEE (CIDAC)

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### Iowa Department of Public Health

**Appointed by Director, Iowa Department of Public Health**

**Iowa Administrative Code, Chapter 4, Sections 641-4.1-4.7**

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**American Academy of Pediatrics, Iowa Chapter**

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Term Expires 10/17

And

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## Exofficio Members

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