

OPEN MEETING MINUTES

Name of Governmental Body: Wisconsin Council on Birth Defect Prevention and Surveillance			Attending:
Date: 8/21/2024	Time Started: 9 am	Time Ended: 10:07 am	
Location: Zoom Meeting ID: 161 796 0366			Presiding Officer: Susan Davidson

Minutes

Meeting Invitees (Required):

X	Krishna Acharya	X	Anne-Marie Coy	X	Susan Davidson, chair	/	Maureen Durkin
X	Nate Keeley		Emily Kittell	/	Kia Kjensrud	X	Kyle Mounts
X	Jennifer Neugart	X	Hanna Rakovec	X	Dana Romary	X	Jessica Scott Schwoerer
X	Dany Sun, cochair	X	Jasmine Zapata		Ann Zenk		

Meeting Invitees (Optional):

/	Jennifer Camponeschi		Vince Milisauskas	X	Isabella Walters	X	April Hall
X	Dr. Robert Steiner	X	Kimberly Haugstad				

Council Staff:

X	Melissa Olson, program epidemiologist	X	Kaitlin Tolliver, staff lead				
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Agenda:

Topic:	Lead:	Follow-up Items:
Meeting Opening: <ol style="list-style-type: none"> Welcome and Roll Call Attendees Approval of Minutes from May 8, 2024 Review of Agenda Public Input 	Susan Davidson	<ol style="list-style-type: none"> Introductions Minutes reviewed. Kyle motioned. Second by Dany. All in favor. Agenda reviewed. No public input.
Presentation: Baby Badger Network	Jessica Scott Schoerer	<p>Presentation attached.</p> <p>Key points:</p> <ul style="list-style-type: none"> When genetics started, depended on phenotyping. As time has gone along, testing has improved. Karyotype (pieces of a chromosome missing or extra), Sanger Sequencing (looking at one single gene), Chromosomal Microarray (looking very closely at extra or missing material), and now can look at several or all of the genes to see if they can find a genetic diagnosis. Exome or Genome (preferred) sequencing is now the standard of care in the NICU. Studies have been released demonstrating that testing in an NICU provides higher diagnostic rates, and therefore, improved management of care. We need to do more to ensure access of genomic testing for everyone. Wisconsin challenges and considerations: limited genetic services (4 locations with pediatric geneticists, 3 with pediatric genetic counselors), geography, healthcare landscape, insurance (lots of state, local, and national plans). In 2021, exome sequencing started to be covered by WI Medicaid (only on an outpatient basis).

		<ul style="list-style-type: none"> - State Programs for rGS (Baby Bear, Baby Manatee, and Baby Deer). R stands for rapid. - Funding through Advancing a Healthier Wisconsin grant. - Pilot study runs through December 2024. Participants are St. Vincent Hospital and Aurora BayCare in GB. - Cigna and UHC are providing some coverage for rGS. - Some states have new coverage for rGS (not WI). - Next Steps: evaluation and expansion to more NICU sites. <p>Looking for funding for further work. Applying for funding this fall from Advancing a Healthier WI – longer term and more expansive.</p>
Program Updates <ul style="list-style-type: none"> - WBDR Updates - Administrative Rule - Potential position 	Melissa Olson Kaitlin Tolliver	<p>UW is prepared to submit data. CW and Marshfield are getting ready for testing. SSM has their data ready to go but has had a staff turnover, so we need to take a step back for training. All health systems have been asked to go back to 2020 to submit data. SSM has that data prepared.</p> <p>Isabella is going to update an article for the Wisconsin Medical Journal on WBDR.</p> <p>DHS completed the Statement of Scope on Admin Rule 116. JCRAR did not request a preliminary public hearing. The Secretary did sign the scope. Kaitlin to meet with the legal team again to create a work plan for continuing to move forward.</p> <p>CYSHCN Unit Director has identified some funding to hire a part-time contract position to support the work of the birth defect program. Position description being written.</p>
Birth Defect Council – strategic planning	Susan Davidson	<p>Susan discussed wanting to organize a small group to begin prioritizing where we want the birth defect program to go and what the priorities should be. This is in preparation for the upcoming budget cycle. We need to improve our program to qualify for future grant funding.</p> <p>Krishna volunteered to participate. Susan will reach out to other Council appointees. Group will meet 1-2 times prior to November meeting.</p>
Next Steps	Susan Davidson	2024 Meeting Schedule: November 13, 2024, from 9 am – 11 am
Adjourn		10:07 am

Prepared by: Kaitlin Tolliver on 8/26/2024.

These minutes were approved by the governmental body on: 11/13/2024