

## Wisconsin Division of Public Health Immunodeficiency Subcommittee Meeting

Teleconference Call: (877) 820-7831, passcode: 169380

## Monday, April 20, 2020 11:00 am -12:30 pm

Minutes

Me	Meeting Members:					
Χ	Dr. Mei Baker	Χ	Mary Hintermeyer	Χ	Dr. Jack Routes	
Χ	Dr. Sharon Fleischfresser	Χ	Tami Horzewski	Χ	Dr. Chris Seroogy	
Χ	Dr. James Gern			Χ	Dr. James Verbsky	
Meeting Guests:						

## **Purpose of Meeting:**

The Immunodeficiency Subcommittee serves in an advisory capacity to the Umbrella Committee and NBS Program regarding the specific screening-related condition(s) in the following areas:

**Expert Knowledge in Condition-Specific Clinical Care and Research** 

• Advises on condition-specific clinical care including ongoing changes in treatment options for affected individuals, emerging newborn screening technology, and condition-specific research.

### **Quality Assurance**

- Reviews de-identified screening and confirmatory testing data to monitor screening test performance, such as screening positive predictive value, screening false positive rate and false negative rate.
- Recommends changes in NBS practice to the Umbrella Committee and NBS Program.

#### **Education for Families and Providers**

• Reviews and provides feedback on information and education materials for general public, families, and providers to assure accuracy of health information related to the specific condition(s).

#### **Addition/Deletion of Conditions**

Recommends and/o	or reviews nomination	s for addition and deletion of	of conditions related	I to the subcommittee
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Facilitator/Chair:	_Dr. Baker/Dr.Fleischfresser	Recorder:	_Tami Horzewski
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Info Decision Discuss.	Time:	Topic(s)	Follow-up Items Decision/action: Name: Date due:	Content-focused minutes
	11:00	Welcome and Introductions Review and Approve Minutes (Dr. Baker (Co-Chair))		Motion to approve the April 29, 2019 minutes First motion: Dr. Gern Second motion: Dr. Seroogy
Info		Department of Health Services (DHS) (Dr. Fleischfresser)		<ul> <li>Dr. Fleischfresser shared the following DHS Updates:         <ul> <li>Dr. Gary Kirk resigned as Chief Medical Officer and Umbrella Committee chair at DHS. This position is currently vacant.</li> <li>CPT IA and SMA were added by rule to the Newborn Screening panel of conditions in early January 2020.</li> </ul> </li> <li>Pompe Disease was nominated for addition to the Newborn Screening panel of conditions. Pompe is currently being reviewed through the nomination process and has been recommended for addition by the Secretary's Advisory Committee on Newborn Screening (SACNBS). The SACNBS is preparing a report for the Secretary for final recommendation. If Pompe is recommended for addition to the panel it will need to go through the rule writing process.</li> </ul> <li>A nomination for review of Krabbe Disease was recently submitted and is moving through the review process. Krabbe was nominated previously in 2015 and relooked at by the metabolic subcommittee in 2017 as well.</li>



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		DHS has been busy managing the COVID-19     response and several administrative staff are currently working in this role, including the DHS administrator/state health officer.
Info	Lab Report Verbiage: INTERPRETATION: Undetectable or low number of TREC indicates a low number of newly formed (naïve) T cells in the peripheral blood. It could be an indication of SCID or other primary immunodeficiencies. It is also found in other medical conditions.  There is a section of recommendation on the report, and contacting an immunologist has been included in the recommendation.  (Dr. Baker)	Dr. Baker asked for any issues to report regarding the current lab report verbiage. No primary care physicians' issues were reported with the current reporting structure. No changes made to current lab report verbiage.
Info	2019 SCID Screening Summary (Dr. Baker)	Dr. Baker presented 2019 SCID screening summary (attached), SCID cases and Severe T-lymphopenia cases will be summarized separately in the future.
	Plan Next Meeting/Agenda Items	Next meeting is scheduled for Monday, April 19, 2021 from 11 am - 12 pm.

Confirm next meeting date: Monday, April 19, 2021

"Parking Lot" Items: