



Wisconsin Department of Health Services
Wisconsin Division of Public Health
Secretary's Advisory Committee on Newborn Screening (SACNBS)
March 4, 2022

10:00 am – 11:30 am

<https://zoom.us/j/703030685?pwd=Vm5obnQwT2tTWE5vcVBkTEYzbHh5dz09>

Meeting ID: 703 030 685

Password: 803528

Or call by location +1 312 626 6799 US (Chicago) or +1 646 876 9923 US (New York)

Minutes

Meeting Members:

| | | | | | |
|---|-------------------------|---|-----------------------|---|---------------------|
| x | Dr. Mie Baker | | Dr. Arthur Derse | x | Dr. Kevin Josephson |
| x | Dr. Dr. Jeffrey Britton | x | Dr. Norm Fost (Chair) | x | Dr. Steve Leuthner |
| x | Christine Brown | | | x | Dr. David Wargowski |
| | | | | | |

Meeting Guests:

| | | | | | |
|---|--------------------|---|-----------------------------------|--|--|
| x | Dr. Robert Steiner | x | Elisa Seeger, ALD Alliance Member | | |
| x | Jonette Arms | x | Shayna Hill | | |
| x | Dr. Jennifer Kwon | x | Miranda McAuliffe | | |
| X | Ashley Bergeron | | | | |
| x | Gary Roth | | | | |
| x | Elfatih Mohieldin | | | | |
| x | Martha McCamy | | | | |

Agenda:

Friday, March 4, 2022

| Time: | Topic: | Lead: | Follow-up Items: | Notes: |
|---------------|--|------------------|------------------|--|
| 10:00 – 10:10 | Welcome and Introductions | Dr. Fost (Chair) | | |
| 10:10-10:55 | <ul style="list-style-type: none">Review of the Nomination of X-Linked Adrenoleukodystrophy (X-ALD) for Addition to the WI Newborn Screening Panel of Conditions: Metabolic SubcommitteeX-ALD Review Summary Umbrella Committee | Dr. Kwon | | <p>PowerPoint. Overview, why screening, issues of follow up (benefits of early diagnosis)</p> <p>Recommendations to include in NBS, with follow up neurology visits from 12 – 24 months, after age 36 every 6 months</p> |



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| | | | | <p>No recommendation for follow up with girls who are carriers.</p> <p>25 states have included it in NBS.</p> <p>Committee members discusses the merits of the recommendation.</p> |
| 10:55 – 11:00 | Public Comment | | | <p>Shayna – Superior Wisconsin - Son with ALD. He did not get early dx. Wants babies in Wisconsin to have a chance at a healthy life.</p> <p>Miranda – Resident of NY – Son was one of the first to benefit from dx and treatment. Six other family members were consequently dx (one of whom was father aged 70). Clean scan after 8th MRI due to the treatment.</p> <p>www.aldnewbornscreening.org</p> <p>Elisa – It's not just about identifying that one baby. This can benefit siblings, family members, decisions about whether or not to have more children.</p> |
| 11:00-11:05 | Review and Discussion of Nine Criteria | Dr. Fost/SACNBS | | <p>Committee members voted on eight of the nine criteria (Criteria 7 was deemed not applicable)</p> |



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| | | | | <p>Members voting, Dr. Britton, Brown, Dr. Josephson, Dr. Leuthner, and Dr. Wargowski in favor and unanimously adopted the measure.</p> <p>A Motion by Dr. Britton and Seconded by Dr. Wargowski for the addition of X-ALD to the NBS panel.</p> <p>Members voting, Dr. Britton, Brown, Dr. Josephson, Dr. Leuthner, and Dr. Wargowski in favor and Dr. Baker abstained for being a co-presenter.</p> <p>Motion approved.</p> |
| 11:05-11:45 | <ul style="list-style-type: none">Vote on Umbrella Committee's proposed changes to the condition nomination process. | Dr. Fost/SACNBS | | <p>Dr. Fost provided background on the three agenda items noted for discussion and voting.</p> <p>Dr. Stainer presented the four current state criteria for the nomination process.</p> <p>11:25 am</p> <p>A Motion by Dr. Britton and Seconded by Dr. Leuthner for the vote on Umbrella Committee's proposed changes to the condition nomination process</p> |



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| | <ul style="list-style-type: none">Vote on Umbrella Committee's recommendation to increase the timeframe for storage of NBS Dried Blood Spots (DBS) to ten years. | | Getting the committee charter | <p>Members voting, Dr. Britton, Brown, Dr. Josephson, Dr. Leuthner, and Dr. Wargowski in favor.</p> <p>Motion approved.</p> <p>11:40 am</p> <p>A motion by Dr. Josephson and seconded by Dr. Leuthner to increase the timeframe for storage of NBS Dried Blood Spots (DBS) to ten years.</p> <p>Members voting, Dr. Britton, Brown, Dr. Josephson, Dr. Leuthner, and Dr. Wargowski in favor.</p> <p>Motion approved.</p> |
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| | <ul style="list-style-type: none">Vote on Umbrella Committee's recommendation to create a small subcommittee of Umbrella Committee members to develop a written policy guiding consideration of NBS research requests for review by the Umbrella Committee. | | | <p>The process the committee comes up with might include the director of the lab.</p> <p>11:40 am</p> <p>Brown makes a motion and seconded by Dr. Wargowski to develop a working group to review research proposals using blood card information.</p> <p>Members voting, Dr. Britton, Brown, Dr. Josephson, Dr. Leuthner, and Dr. Wargowski in favor.</p> <p>Motion approved.</p> |
| 11:45 | Summary of Recommendation and Next Steps | Dr. Fost/ SACNBS | | Adjourn 11:50. |

“Parking Lot” Items: