Nebraska Newborn Screening

ADVISORY COMMITTEE

OCTOBER 29, 2025

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Agenda

I. Open Meeting Act Announcement

II. Introductions

III. Review/ approval of minutes from the July 2025 meeting.

IV. Laboratory update

a. Lab updates (Revvity Omics)

b. Shipping Delays

V. Legislation, Regulation, and Policy

i. National and State Updates: (Jillian Chance)

ii. Regulation (s) Update

VI. Presentation on Metaleukodystrophy (MLD) (Orchard Therapeutics)

VII. BREAK

VII. Bioinformatics Fellow Update

IX. Case Management and Birth Defect Registry Dashboard Demo (Derek)

X. Request to place information on the Department Website Regarding How to add a Condition. Discussion on creating a nomination form for advocates to fill out. (Jill) XI. APHL Everyday Life Saver Award

XII. Other Business

XIII. Data (Sarah Ward)

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I. Open Meeting Act Announcement

WELCOME TO THE OCTOBER 2025 MEETING OF THE NEBRASKA NEWBORN SCREENING ADVISORY COMMITTEE. IN ACCORDANCE WITH THE "OPEN MEETINGS ACT", THIS MEETING WAS ANNOUNCED TO THE PUBLIC BY POSTING ON THE STATE OF NEBRASKA PUBLIC MEETING CALENDAR BEGINNING ON FEBRUARY 22, 2025. A COPY OF THE "OPEN MEETING ACT" AND AN AGENDA FOR THIS MEETING CAN BE FOUND ATTACHED TO THE MEETING NOTICE IN THE ONLINE CALENDAR.

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II.Introductions

III. Review/approval of minutes from the July 2025 meeting

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IV. Laboratory update

a. (Revvity Omics)

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IV. Laboratory update
b. Shipping Delays

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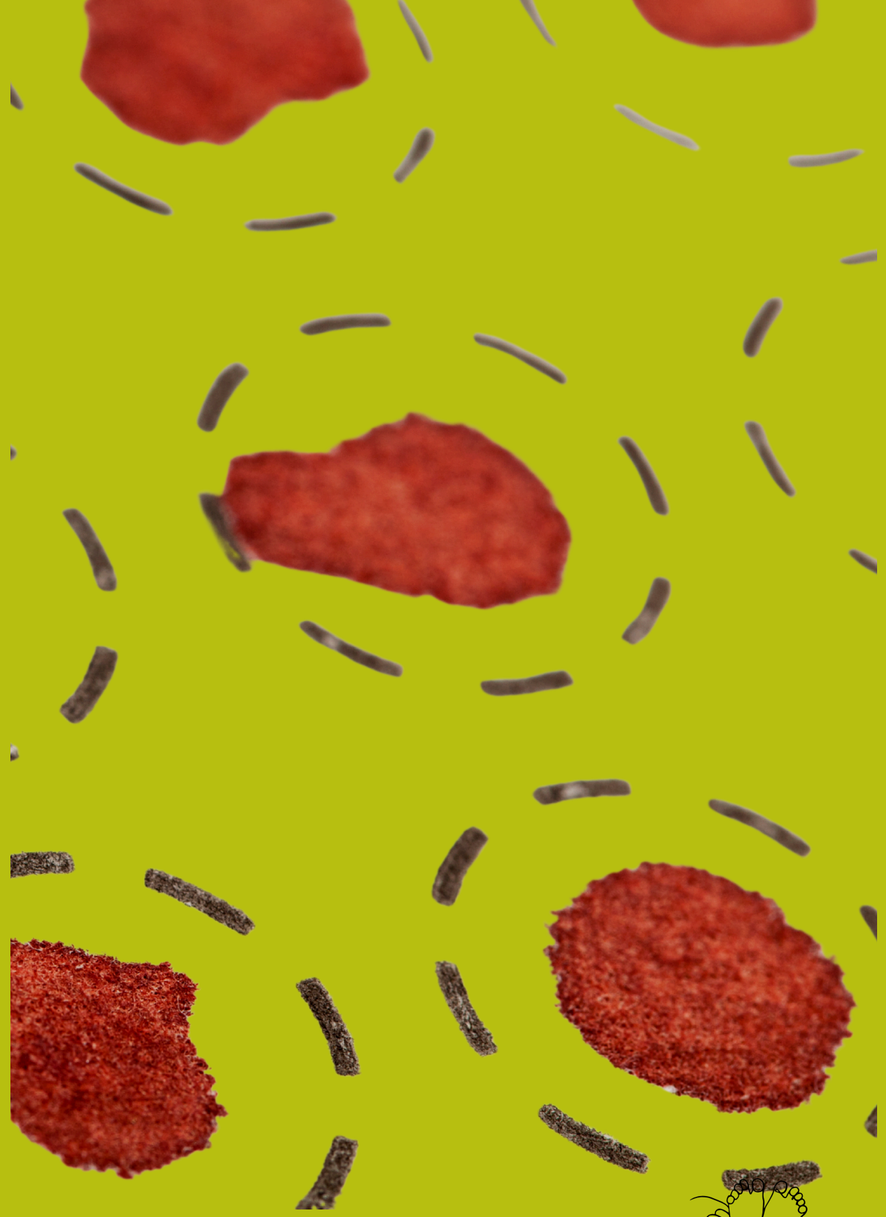
V. National and State Updates:

i. National and State Updates – Updates from the Secretary's Adisory Replacements



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V. National and State Updates Cont.:

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VI. Presentation on Metaleukodystrophy (MLD) (Orchard Therapeutics)

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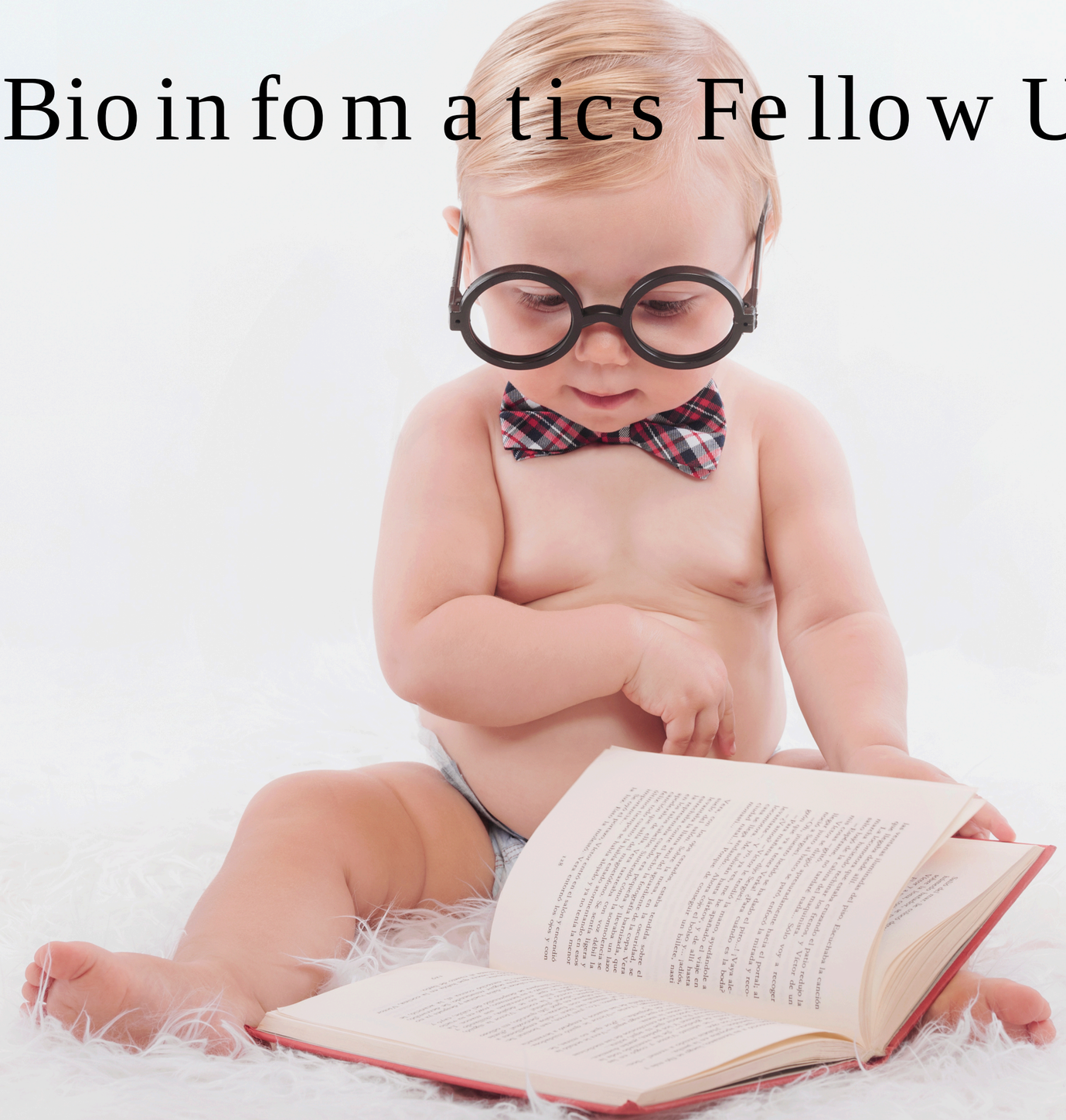
VI. Break

VII. Bioinfomatics Fellow Update



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IX.Case Management and Birth Defect Registry Dashboard Demo (Derek)

X. Discussion on nomination form

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The Need for Transparent Condition Nomination Processes in State Newborn Screening Programs

Deterring Legislative Mandates Through Clear Policy

Newborn Screening (NBS) is a critical public health system that protects infants by identifying treatable conditions early. For the system to remain effective, it must adapt to new medical advancements by adding treatable conditions.

However, a lack of a clear process for adding new conditions often pushes well-meaning advocates to seek **legislative mandates**, bypassing your state's established public health review. In this current era, without a federal mechanism to add conditions to the RUSP, this is more necessary than ever.

If they aren't aware of the process, they aren't going to follow it.

At **Patient Advocacy Strategies**, we have done extensive research on the state-level NBS landscape to better understand how to guide advocates seeking to add a condition.

Current Reality	Desired Outcome
Only **ten states** currently provide a clear nomination pathway for advocates on their NBS website.	Every state NBS website should feature a **clear, accessible nomination process** for new conditions.
Advocates often engage in unpredictable and lengthy **legislative** actions to add conditions, which risk politicizing NBS and may lead to additional challenges for the NBS Program, such as unfunded mandates.	Advocates are empowered to use the state's **evidence-based, expert-driven** review process because it is easy to find.

The Pennsylvania Example: A Successful Model

After listening to advocate input, Pennsylvania's NBS Advisory Board developed a process modeled after other states that includes a **nomination form** and a clear **workflow** that advocates can easily access on the state's NBS website. This model channels advocacy efforts directly into the state's expert review system, strengthening the program while maintaining scientific rigor.

Patient Advocacy | Strategies

Five Key Elements for a Transparent NBS Website

If your state can add **non-RUSP** conditions, it is important to provide advocates with the process you have established. To proactively engage advocates and ensure the strongest possible NBS system, your state's website should provide unambiguous answers to the following questions:

Key Information	Why It Matters
Advisory Board Details	**Transparency:** Clearly state the **Board's authority** (add conditions vs. recommend to legislature), meeting schedule, and public access points.
Nomination Pathway	**Accessibility: Confirm that a process exists** for the public/advocates to officially nominate a condition for consideration.
Detailed Process Outline	**Clarity:** Publish the **step-by-step workflow** from initial submission to final decision. Provide a link to the official **nomination form**.
Criteria for Addition	**Expectation Setting:** Clearly list the **scientific, clinical, and public health criteria** a condition must meet (e.g., condition is serious, treatable, and a reliable screening test exists).
Community Engagement	**Partnership:** Articulate **how the advocacy community can best support** and strengthen the state's NBS system (e.g., help educate, fund pilot studies, or collect data).

Call to Action: Channeling Passion into Policy

A transparent, accessible process isn't just a convenience— it's a crucial component of sound public health policy. It gives rare disease families a roadmap to follow to effect change and benefit the work you do as a state NBS program.

By implementing a clear nomination process on your NBS website, your state can:

- **Deter legislative intervention** and protect the integrity of your expert-review process.
- **Empower advocates** by giving them an accessible, official pathway to contribute.
- **Ensure that all NBS additions are evidence-based**, maximizing public health benefit.

XI. APHL Everyday Life Saver Award

The Everyday Life Saver Award in Newborn Screening honors a person working in newborn screening or a family, patient, advocate or individual who has made significant contributions to the field of newborn screening. This award highlights the ongoing ways the recipient contributes to the morale of a newborn screening team and/or the operations of a newborn screening program, or ways in which the recipient champions the growth, knowledge-transfer and/or ethos of the newborn screening system. This year's award recipient is:

Jill C. Skrabal, PhD
University of Nebraska Medical Center
Assistant Professor of Pediatrics,

Nebraska Newborn Screening
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XII. Other Business

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Entering Closed Session for Data Review
(Advisory Committee Members and Staff Only)
Next Meeting January 27th, 2026
Children's Home Society Omaha
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XIII. Data Presentation (Sarah)

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XI. Adjourn

Next Meeting January 27th, 2026

Children's Home Society Omaha

Nebraska Newborn Screening