



Meeting Minutes

Information Clearinghouse on Developmental Disabilities Advisory Council (ICDDAC)

Thursday, January 25, 2024

10:00 – 11:00 a.m. EST

Microsoft Teams Video Conference

Member Name	Seat Appointment	Present	Absent
Kristine Benson	Governor Appointment	X	
Vacant	Speaker of the House of Representatives Appointment		
Janet Caramello	Governor Appointment		X
Lori Fahey	President of the Senate Appointment		X
Kiersten Finchum	Speaker of the House of Representatives Appointment	X	
Camille Gardiner	President of the Senate Appointment	X	
Shannon Moss	President of the Senate Appointment		X
Jenna Persons-Mulicka	Speaker of the House of Representatives Appointment		X
Vacant	Governor Appointment		

Others Present: Carolyn Hasty (Florida Department of Health), Maggie Dilger (Florida Department of Health), Emily Grosshans

I. **Welcome and Roll Call** – *Maggie Dilger, Florida Department of Health*

The meeting was called to order at 10:05 a.m. Roll was taken, and a quorum was not established. Maggie Dilger with the Department updated the council that Justin Breidenstein recently resigned from the council, leaving two vacancies.

II. **Approval of Meeting Minutes** – *Council Members*

Approval of January, April, July, and October 2023, meeting minutes will be moved to the next quarterly meeting on April 11, 2024.

III. **Google Analytics Quarterly Report** – *Maggie Dilger, Florida Department of Health*

Maggie provided an overview of the October – December 2023 Google Analytics Report and reviewed updates to the Bright Expectations (BE) website following the October 11, 2023, ICDDAC meeting. For the next meeting of the council, the Department was asked to compare Q4 2023 and Q1 2024 data with prior 12-month data to analyze if there are any indicators the addition of navigational buttons to the BE landing page affected page traffic.

IV. **Website Resources Review** – *Council Members*

Maggie shared two resources the Department received for consideration for the BE website (Amora's Mission Inc and the Epilepsy & Pregnancy Medical Consortium). Members of the council suggested adding Amora's Mission Inc (<https://amorasmision.org>) under the support groups within the Down Syndrome resources page. Members also requested Epilepsy & Pregnancy Medical Consortium (<https://epilepsypregnancy.com>) be added to the Epilepsy resources page.

Maggie explained that in the second paragraph within the Autism resources page, Asperger/Autism Spectrum Education Network (ASPEN) had an expired domain. The group noted ASPEN is no longer in service and requested the link and paragraph be removed from the BE website.

Kris Benson provided her resource findings for Kernicterus, Pallister-Killian Syndrome (tetrasomy 12p) (PKS), and Phenylketonuria (PKU). Members of the council agreed the following resources should be added to the BE website:

Condition: Kernicterus

- PICK (<https://pic-k.org/>) - Founded in 2000, PICK is a parent-run, non-profit organization on a mission to “kick the K”. This website provides easy-to-read information about jaundice and “the K”, a starting place for those facing a new diagnosis, and a list of family support options. This website provides videos, family photos, easy to understand information, and a blog-style page for newly diagnosed families. Kris recommended adding the home page and highlighting the newly diagnosed page (<https://pic-k.org/family-support/newly-diagnosed/>)]
- NORD Kernicterus - <https://rarediseases.org/rare-diseases/kernicterus/> - This website provides clinical information about the condition. Kris noted there are very few resources for this condition and this website provides additional information for families.

Condition: Pallister-Killian Syndrome (tetrasomy 12p) (PKS)

- PKS Kids - <http://www.pkskids.net/> - PKS Kids provides updated and hopeful information to parents and families along with links to resources.
- Unique – Pallister-Killian Syndrome - 2023 version:
<https://www.rarechromo.org/media/information/Chromosome%2012/Pallister->

[Killian%20syndrome%20FTNW.pdf](#) - This booklet provides information about the syndrome along with family insights and pictures.

Condition: Phenylketonuria (PKU)

- National PKU Alliance - <https://npkua.org/> - The National PKU Alliance works to improve the lives of families and individuals associated with PKU through research, support, education, and advocacy. The Recent Diagnosis page (<https://npkua.org/Resources/Recent-Diagnosis>) is worth highlighting.
- PKU - <https://www.pku.com/> - This site provides a variety of tools and resources to help individuals with PKU and their families learn how to manage the condition. There is an extensive community and support section that contains recipes, videos, links, and resources.
- Cook For Love - <https://cookforlove.org/> - Cook For Love is a culinary non-profit organization focused on empowering members of the PKU community to improve their health through cooking and education. This site provides a host of recipes, cooking videos, tips, and resources for the PKU community.

Kris will send text for the website to the Department for each condition: Kernicterus, Pallister-Killian syndrome (tetrasomy 12p) (PKS), and Phenylketonuria (PKU).

Moving forward Kris will research resources for Muscular Dystrophy, and Camille Gardiner will research resources for Traumatic Brain Injuries.

V. **Future Agenda Items Discussion** – *Council Members*

Kris asked for an update during the April 11, 2024, ICDDAC meeting about council vacancies. Maggie explained there are currently two council vacancies, and she will review the website and files to ensure the term expirations posted are correct. She also noted the links to the appointments offices are also on the ICDDAC website: <https://www.floridahealth.gov/provider-and-partner-resources/icddac/membership.html>. Maggie will follow up with the council regarding reappointment requests.

VI. **Public Comment**

No public comment was made.

VII. **Adjournment** – *Maggie Dilger, Florida Department of Health*

The meeting adjourned at 10:47 a.m.