



Meeting Minutes

Information Clearinghouse on Developmental Disabilities Advisory Council (ICDDAC)

Thursday, April 11, 2024
10:00 AM – 11:00 AM 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: Maggie Dilger (Florida Department of Health)

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

The meeting was called to order at 10:02 a.m. Roll was taken, and a quorum was not established. Maggie Dilger with the Department updated the council that anyone seeking reappointment should visit <https://fl-appointment.azurewebsites.net/>.

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

Approval of January, April, July, October 2023, and January 2024, meeting minutes will be moved to the next quarterly meeting tentatively scheduled for July 17, 2024.

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

Maggie provided an overview of the January – March 2024, Google Analytics Report and shared data from October 2022 – March 2023, compared with data from October 2023 – March 2024, in order to

analyze the addition of navigational buttons to the BE landing page in November 2023. It was noted that more than 11,000 more page views were recorded from October 2023 – March 2024 in comparison to the same time frame the previous year. The council discussed the average engagement time and requested the next Google Analytics Report be sorted by the average engagement time.

IV. **Website Resources Review** and Member Updates – *Council Members*

Maggie provided findings from a recent website review and noted links that were no longer accessible. She explained that in the first paragraph within the Anencephaly resources page, Anencephaly Information (<https://www.ninds.nih.gov/Disorders/All-Disorders/Anencephaly-Information-Page>) was no longer a working link. Council members discussed creating a Neural Tube Defects resource page in the future and suggested adding the few anencephaly resources under that heading. Additionally, the council requested that Fetalhealthfoundation.org be added to all corresponding conditions on the BE site and in the General Resources tab.

Maggie also noted that in the second paragraph of Congenital Heart Defects resources, Mended Little Hearts (mendedlittlehearts.org) no longer linked to a webpage. Council members found the new webpage (<https://mendedhearts.org/about-us/about-mended-little-hearts/>) and suggested adding the Young Mended Hearts (<https://mendedhearts.org/about-young-mended-hearts/>) to the Congenital Heart Defects page as well.

The council was also notified that within the third paragraph under Epilepsy resources, Suncoast Epilepsy Association (<https://www.suncoastepilepsy.org/>) was no longer a working link. Finding no other alternative webpage for the association, the council asked for the link to be removed from Bright Expectations.

Lastly, in the second paragraph of Mental Health Disorders resources, the Federation of Families of Florida, Inc. (South Bay, FL) (<https://ffamilies.net/>) no longer linked to a webpage. Finding no other alternative site for the association, the council asked for the link to be removed from Bright Expectations.

Shannon Moss provided resource findings for Deaf/Hard of Hearing (DHH). Members of the council agreed the following resources should be added to the BE website:

Condition: Deaf/Hard of Hearing (DHH)

- American Speech Language Hearing Association (asha.org) - The site is geared more towards professionals but includes resources and supports for families. The site has information about

best practices and finding practitioners. Topics include hearing and balance, speech and swallowing, health insurance, early identification. Resources for English and Spanish speakers.

- Florida Department of Health, Florida Coordinating Council for the Deaf and Hard of Hearing (floridahealth.gov) - Resource for Deaf and Hard of Hearing Floridians who need assistance with everyday needs. The site serves as an advisory and coordinating body to recommend policies. Technical assistance, resources, agencies and organizations, links to pre- and post-school education, employment, medical and legal.
- Family Center on Deafness (fcdpinellas.org) - Mission is to empower Pinellas County's deaf community by providing opportunities to enhance communication and education. Social meetups for children and people of all ages. Includes playgroups and networking opportunities.
- Florida Hands and Voices (Flhv.org) – Parent-led and professional collaborative organization. Dedicated to serving families with DHH. Nationwide site with a chapter in Florida. Includes information on the Family Leadership in Language and Learning Center.
- Sertoma Speech and Hearing Foundation of Florida (familyhearinghelp.org) - Resource for Florida families with information about a hearing aid program. Its mission is to provide hearing related services across Florida. Access to videos and inspirational stories.
- Florida School for the Deaf and Blind: Florida School for the Deaf and the Blind (fsdbk12.org)

Shannon will provide council staff language for this condition to be added to the Bright Expectations website.

Kris Benson provided her resource findings for Dup15q Syndrome (15Q 11.2-13.1 duplications). Members of the council agreed the following resources should be added to the BE website:

Condition: Dup15q Syndrome (15Q 11.2-13.1 duplications) - Includes: 15q11.2-q13.1 duplication syndrome, Inverted duplication 15 (inv dup15), Partial trisomy 15, Isodicentric chromosome 15 syndrome [Idic(15)], Supernumerary marker chromosome 15 (SMC15), Partial tetrasomy 15q, Chromosome 15q tetrasomy, Duplication/inversion 15q11, Non-distal tetrasomy 15q, Non-telomeric tetrasomy 15q, Tetrasomy 15q

- Dup15q Alliance (<https://dup15q.org/>) – There is a page for “Newly Diagnosed” patients. The site has medical information, links, family stories, a sibling matters program, and contact information. It has a resources by state link to help families find local support.
- Idic(15) – Unique
([https://www.rarechromo.org/media/information/Chromosome%2015/Idic\(15\)%20FTNW.pdf](https://www.rarechromo.org/media/information/Chromosome%2015/Idic(15)%20FTNW.pdf)) - This links to a 28-page pdf about the syndrome. There is a lot of clinical information in the

booklet, but also includes what to expect at different stages of life. At the end, there are links to other PKS support sites.

- Isodicentric chromosome 15 syndrome – NIH
(<https://rarediseases.info.nih.gov/diseases/5153/isodicentric-chromosome-15-syndrome>) - Medical terms are defined in common language, and there is a “Living with the Disease” tab that provides links to resources and advocacy and support groups. As this condition is considered rare, there are not as many sites as some of the other conditions.

Kris will provide council staff language for this condition to be added to the Bright Expectations website.

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

Maggie reminded the council that the next meeting was scheduled for Wednesday, July 17, 2024, at 10:00 a.m. EST. There was no other discussion.

VI. **Public Comment**

No public comment was made.

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

The meeting adjourned at 10:58 a.m.