



Meeting Minutes

Information Clearinghouse on Developmental Disabilities Advisory Council Meeting Minutes

September 19, 2017
9:00 – 10:00 a.m.

Florida Department of Health
2585 Merchants Row Blvd., Room 345Q
Tallahassee, FL 32399

Members Present by Dial-in Conference Call Line: Camille Gardiner, Kristine Benson, Amber Davis, Dr. Carlos Pozzi

Members Not Present: Patricia Tice, Shannon Moss, Crystal Hopkins, Janet Caramello, Susan Prater DeBeaugrine,

Others Present: Anna Simmons, Elizabeth Gonzalez, Sarah Beard

I. Welcome and Roll Call – Anna Simmons

Anna welcomed everyone to the call and took attendance.

II. Approval of Minutes – Kris Benson

The meeting minutes were reviewed for approval. A motion was made by Amber Davis to approve all outstanding meeting minutes; Camille Gardiner seconded the motion. The motion passed unanimously.

III. New Business – Kris Benson

Anna reminded council members that promotional materials are available for distribution. Promotional materials include posters, postcards and fans. If interested, council members should email Anna.

Amber Davis asked about having someone promote Bright Expectations at different events. Anna explained that Bright Expectations had a booth at the Family Café over the summer. Anna agreed to research opportunities to promote Bright Expectations at various community events.

The council discussed adjusting the meeting times to accommodate more council members. The council agreed to meet bi-monthly on the third Tuesday of each month from 10:00 – 11:00 am EST. The council asked to have a calendar reminder sent for each meeting.

IV. Website Reviews – Council Members

Kris Benson shared the following websites and recommendations:

Fragile X Syndrome:

- | | |
|---|----------------|
| - https://fragilex.org | Include |
| - https://www.fraxa.org | Include |
| - https://www.fragilexregistry.org/ | Include |
| - https://rarediseases.org/rare-diseases/fragile-x-syndrome | Include |
| - https://qhr.nlm.nih.gov/condition/fragile-x-syndrome# | Do Not Include |



Meeting Minutes

- <https://www.dailystrength.org/group/fragile-x-syndrome>

Do Not Include

Epilepsy:

- <http://www.efof.org>
- <http://www.epilepsyservices.com/>
- <http://epilepsyassociation.com>
- <http://epilepsyu.com>
- <http://www.epilepsy-services.org>
- <http://www.epilepsy.com>
- <https://www.aesnet.org>

Include
 Include
 Include as Support Group
 Include
 Include as Support Group
 Include
 Include

Camille Gardiner shared the following website and recommendations:

Phelan-McDermid Syndrome

- <http://www.pmsf.org>
- <https://rarediseases.org/rare-diseases/phelan-mcdermid-syndrome/>

Include
 Include

Cystic Fibrosis:

- <https://www.cff.org/>

Include

Amber Davis researched resources for Fetal Alcohol syndrome and agreed to share those at the next meeting.

Council members agreed to research additional resources:

- Kris Benson: Angelman syndrome
- Camille Gardiner: Central Auditory Processing Disorder, Tourette’s syndrome
- Carlos Pozzi: Intellectual Disability, Bipolar Disorder, Learning Disability

V. Next Steps – Kris Benson

- Council members will research and submit website reviews for additional conditions.
- Anna will research the capabilities for promoting Bright Expectations at community events.

IV. Adjourn – Kris Benson

Camille Gardiner made a motion to adjourn the meeting. Amber Davis seconded the motion. The motion passed unanimously and the meeting was adjourned.

Next Meeting Date: November 14, 2017 10:00 am – 11:00 am EST