

**Information Clearinghouse on Developmental Disabilities Advisory Council
Meeting Minutes**

**January 21, 2014
9:00 – 11:00 a.m. EST**

**Florida Department of Health
2585 Bald Cypress Way, Room 345Q
Tallahassee, FL 32399**

Members Present by Dial-in Conference Call Line: Dr. Carlos Pozzi, Janet Caramello, Camille Gardiner, Ryan Tyson, Kristine Benson, Patricia Tice

Members Not Present: Dr. Ricardo Ayala, Dr. Janet Flowers, Dr. Scott Vanlue,

Others Present: Carol Scoggins, Jane Correia, Lou Ann Long, David Blodgett, Jackie Schaffer, Anna Simmons, Stacy VanCamp-Garcia (by phone), Ashley Anderson (by phone)

I. Call to Order and Introductions – Carol Scoggins

The meeting was called to order at 9:03am – Carol Scoggins, Department of Health, facilitated the meeting.

II. Approval of Minutes – Carol Scoggins

The December 16, 2013 meeting minutes were presented for approval. A motion was made by Janet Caramello to approve and seconded by Camille Gardiner. The motion passed unanimously.

III. Selection of Chair and Vice Chair – Carol Scoggins,

Camille Gardiner nominated Janet Caramello for Chair and Kristine Benson for Vice Chair. Kristine Benson seconded Janet Caramello's nomination and Janet Caramello seconded Kristine Benson's nomination. The motion passed unanimously.

IV. Gap Analysis of Existing Website – Carol Scoggins

Council members brainstormed a draft list of goals they would like to accomplish:

- Make the website more user friendly
- Include personal stories and photos for parents
- Incorporate information for physicians on ways to deliver a diagnosis
- Include a rollover map of Florida that provides county resources as you rollover each county
- Review the Kentucky Prenatal and Postnatal Down Syndrome Diagnosis website for comparison
- Ensure that the standard set by Rose's Law is included on the website (best practices)
- Create a one stop place for physicians and families to find up to date, accurate information quickly and easily

- Include ways to help with the bonding process at birth (review attachment literature from Texas Christian University)
- Include a glossary page and prioritized glossary (words parents need to know quickly) and include the type of specialist associated with each of the terms
- Create a page of practical, everyday advice, including a section to share advice and tips (page management in a binder, printables)
- Include a list of parent support groups (Review Brighter Tomorrows website for examples)
- Include a place to click to for a specific diagnosis and get more information
- Include physician training on the treatable conditions associated with Down syndrome
- Include a page for people who want information on how to support parents of children with Down syndrome (friends, family members)
- Include tabs for parents that make it easier to understand a diagnosis. i.e. “Start Here button”; “What will my child be like?” “What are the possibilities?” – show positive things (photos and stories of young adults who are exceeding)
- Include council member’s personal stories with positive family photos

V. Review Resource Criteria – Carol Scoggins

Carol reviewed the handout that details the requirements for selecting materials or linkages for the website. The handout was provided to the council members with the agenda on January 17, 2014.

VI. Meeting Schedule for 2014 – Carol Scoggins

The council members agreed to meet on the third Tuesday of each month from 9:00 a.m to 11:00 a.m. EST for the next six months. The next meeting is scheduled for February 18, 2014.

VII. Next Steps – Carol Scoggins

- Council members will submit their personal stories and any accompanying pictures, via email, to Carol Scoggins by February 7, 2014
- Council members will submit any suggested name changes for the council and website, via email, to Carol Scoggins by February 7, 2014
- Council members will submit ideas for a new council name and website to Carol
- Carol Scoggins will send out calendar invites to schedule council meetings for the next six months
- Carol Scoggins will send consent forms to the council member in order to use their personal stories and photos on the website
- Carol Scoggins will send out the website address for the current *Information Clearinghouse on Developmental Disabilities* website

Kristine Benson motioned to adjourn the meeting and Camille Gardiner seconded the motion. The motion passed unanimously.

The meeting was adjourned at 10:34 a.m. **Next Meeting Date:** February 18, 2014, 9:00 a.m to 11:00 a.m. EST