



Rare Disease Advisory Council Meeting Minutes

Wednesday, December 11, 2024

11:00 a.m. EST

Virtual Meeting via Microsoft Teams

Welcome/Introductions

Melissa Jordan, Chair, opened the Rare Disease Advisory Council meeting and welcomed the following newly appointed members: Alexis Bakofsky, Chief of Staff for the Florida Office of Insurance Regulation; Colleen Bartlett, DNP, with BayCare Chronic Complex Clinic; and Blake Shay, PharmD, with BayCare Health System. It was also noted that Melissa Jordan and Jonathan Hawayek were reappointed to the Council.

The following members or designees were in attendance:

Representative Adam Anderson

Alexis Bakofsky

Colleen Bartlett

Eric Biernacki

Dr. Barry Byrne

Ann Dalton

Dr. Anita Davis

Jonathan Hawayek

Kathy Hebda, Vice-Chair

Melissa Jordan, Chair

Dr. Scott McClelland

Dr. Divya Patel

Dr. Blake Shay

India Steinbaugh

Jennifer Sutherland

Dr. Mustafa Tekin

Dr. Rajan Wadhawan

Guests and Staff:

Yolanda Bonds, Florida Department of Health

Jon Conley, Florida Department of Health

Maggie Dilger, Florida Department of Health

Tara Leigh Gingrich, Pennsylvania Rare Disease Advisory Council

Gillian Hooker, Tennessee Rare Disease Advisory Council

Michael J Davis, Florida Department of Health

Marie Conley, Pennsylvania Rare Disease Advisory Council

Erica Barnes, Minnesota Rare Disease Advisory Council

Ashley McMinn, Vanderbilt University Medical Center

Jennifer Wescoe, Pennsylvania Rare Disease Advisory Council

Jhoanny Cardenas, National Organization for Rare Diseases Florida Volunteer Rare Action Network

Christina Hooker (Unverified)

Lisa Rawlins, The Garner Group

WFSU-TV The Florida Channel

1. Approval of October 2024 Meeting Minutes

Jonathan Hawayek motioned to approve the October 7, 2024, Meeting Minutes, and India Steinbaugh seconded. All were in favor and the motion carried.

2. State Rare Disease Advisory Council (RDAC) Panel Discussion

Moderator: Chair Jordan

Speakers:

- Erica Barnes, MA, CCC-SLP, Executive Director, Minnesota RDAC
- Marie Conley, Co-Chair, Pennsylvania RDAC
- Gillian Hooker, PhD, Secretary, Tennessee RDAC

Each state discussed its RDAC's composition and compared differences in funding and structure noting advantages and disadvantages. There was discussion on creating, funding, and distributing surveys, and how data is being used. Collaborative efforts with research institutions, hospitals, trade associations, and advocacy groups has helped achieve the goals of each RDAC. [Project ECHO](#), a learning model providing training and mentorship to fill gaps in specialty care, was mentioned as a success in Minnesota.

Each RDAC committed to continue working together and sharing ideas to increase awareness and resources for the rare disease community.

3. Next Steps

January Subcommittee meeting dates are as follows and additional 2025 meeting dates will be shared soon.

- Thursday, January 9, 2025, at 12:00 p.m. – Health Care Providers Subcommittee Meeting
- Thursday, January 23, 2025, at 12:00 p.m. – Academic Research Institutions Subcommittee Meeting
- Wednesday, January 29, 2025, at 12:00 p.m. – State Agencies Subcommittee Meeting

A reminder of the application and review cycle for the Pediatric Rare Disease Advisory Grant was given:

- The Funding Opportunity Announcement was released in mid-November 2024.
- The Department is currently taking Letters of Intent and held an Informational webinar December 10, 2024.
- The Department is taking written questions until December 17, 2024.
- The main application window will open on, or around January 21, 2025, with applications due on February 20, 2025.
- The anticipated award will be no later than May 20, 2025.

4. Public Comments

No comments from the public were given.

5. Adjournment:

The meeting adjourned at 1:02 p.m. EST.