



Rare Disease Advisory Council Workgroup on Grant Guidelines Meeting Minutes

Monday, September 16, 2024

11:30 a.m. EST

Virtual

Welcome:

The meeting started at 11:33 a.m. EST, and Representative Adam Anderson, Chair, welcomed everyone and provided a brief overview of the meeting.

The following Rare Disease Advisory Council members were in attendance:

Representative Adam Anderson

Eric Biernacki

Zana Dupee

John Hawayek

Melissa Jordan

Dr. Rajan Wadhawan

Guests and Staff:

Michelle Beekman, Advent Health

Yolanda Bonds, Department of Health

Robert Brooks, Department of Health

Jon Conley, Department of Health

Maggie Dilger, Department of Health

Aleskia Fernandez, Advent Health

Marnie George, Johnson and Blanton

Bridgette Morton, Department of Health

Christina Samper, Advent Health

Jennifer Yaden, Advent Health

Discussion Topics:

1. Approval of Meeting Minutes:

Representative Anderson motioned to approve the August 2024 Meeting Minutes, and Melissa Jordan seconded. The motion passed unanimously.

2. Review and Approval of Pediatric Rare Disease Grant Application Guidelines Draft

- Motion was made by Zana Dupee to remove bullets two and four from 3.1 Definition of Conflict of Interest and add Section 112.3143, Florida Statutes. The motion was seconded by Eric Biernacki, and all were in favor. The motion carried.
- Representative Anderson motioned to continue the Workgroup, and Ms. Jordan seconded. All were in favor. The motion carried, and a final vote will be taken by the Rare Disease Advisory Council at an upcoming meeting.
- Representative Anderson motioned to accept the draft with the discussed changes, and staff will update and distribute the Guidelines and Conflict of Interest Policy via email to the Workgroup for final review before sending to all members of the Rare Disease Advisory Council prior to the October 7, 2024, meeting. Dr. Rajan Wadhawan seconded. All were in favor, and the motion carried.

3. Next Steps:

- Staff will update the Guidelines and Conflict of Interest Policy based on today's discussion and distribute to the Workgroup for final review.
- Staff will share the finalized policy with the full council prior to the October 7 meeting.
- Representative Anderson will provide a brief overview of the policy at the October 7 RDAC meeting.
- The workgroup will not need to meet again until applications are ready for review in early 2025.

4. Public Comments/Open Discussion:

No public comments were received.

5. Adjournment:

Dr. Wadhawan motioned to adjourn, and Ms. Dupee seconded. All were in favor, and the meeting adjourned at 12:15 p.m. EST.