



Rare Disease Advisory Council Workgroup on Grant Guidelines Meeting Minutes

Tuesday, August 13, 2024

12:00 p.m. EST

Virtual

Welcome:

The meeting started at 12:00 p.m. EST, and Jon Conley with the Department opened the meeting and provided a brief overview of the agenda.

The following Rare Disease Advisory Council members were in attendance:

Representative Adam Anderson

Eric Biernacki

Dr. Barry Byrne

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

Opening Remarks:

Mr. Conley provided an overview of the role of the Rare Disease Advisory Council (RDAC) in the Andrew John Anderson Pediatric Grant review process. The goal of the first meeting is to develop criteria for the Council's review that safeguards against any conflicts of interest.

Discussion Topics:

1. Review of RDAC Responsibilities:

Dr. Robert Brooks with the Department presented the following information for the Andrew John Anderson Pediatric Rare Disease Grant Program (381.991 F.S.) to the Workgroup.

Grant Overview:

- The purpose of the grant is to advance the progress of research and cures for rare pediatric diseases by awarding grants through a competitive, peer-reviewed process.
- Grants shall be awarded by the Department of Health, after consultation with the RDAC, based on scientific merit, as determined by a competitive, peer-reviewed process to ensure objectivity, consistency, and high quality.
- The RDAC is to establish guidelines on how to handle applicants that could potentially have a conflict of interest.

Third Party Review:

- Conduct a full-scale review from start to finish, by taking responsibility for any of the review's component parts or operate as an extension to your current staff.
- Draw upon a proprietary network of more than 24,000 global subject matter experts and numerous other expert databases to support peer review process.
- Independent third party with decades of experience managing all phases of the scientific peer review and merit review process.
- A fully-integrated peer review and grants management system.
- Logistics management for reviews, workshops, and meeting of any size.

Ethical Conduct:

- There was an overview of the Florida Biomedical Research Advisory Council's and the National Institute of Health's grant review standards and conflicts of interest for the Workgroup to have as examples.
- Rare disease research is a niche type of research and many of the applications are expected to come from only a few research institutions in the state.

2. Procedural Activities: Selection of Chair

Jon Hawayek nominated Representative Adam Anderson as Chair of the Workgroup. Eric Biernacki seconded, and the motion passed without any opposition. Representative Anderson accepted.

3. Timeline of Events:

Members of the Workgroup agreed to the following timeline of events to ensure guidelines would be completed.

- Hold a September meeting of the Workgroup to review framework provided by staff.
- Present guidelines to the full RDAC in October to seek approval.

4. Next Steps:

- Following this meeting, RDAC staff will use the discussion from the Workgroup to build a framework of the guidelines and share with the Workgroup at least one week prior to the September Workgroup meeting (tbd).
- The Workgroup will review the framework and finalize during the September meeting.
- The Workgroup will share with the full council prior to the October and seek approval.

5. Public Comments/Open Discussion:

No public comments were received.

6. Adjournment:

The meeting adjourned at 12:56 p.m. EST.