

# Rare Disease Advisory Council Health Care Providers Subcommittee Meeting Minutes

Thursday, January 9, 2025

Noon, EST Virtual

# Welcome/Introductions

The meeting was called to order at 12:04 p.m., EST, by Anita Davis, PT, DPT, CNPT, Physical Therapist, Brooks Rehabilitation (Chair). Dr. Anita Davis welcomed the members.

# The following members were in attendance: (Quorum not established)

Anita Davis, PT, DPT, CNPT, Physical Therapist, Brooks Rehabilitation (Chair)
Zana Dupee, JD, MBA, Regulatory Compliance and Biotech Operations Expert
India Holroyd, MA, Cabinet Affairs Director, Florida Department of Agriculture and Consumer Services

#### **Guests and Staff**

Karen Finn, MBA, Springfield Cultural Partnership Incorporated Jon Conley, Strategic Initiatives Manager, Florida Department of Health Yolanda Bonds, Council staff liaison, Florida Department of Health

#### **Business**

# 1. Approval of Meeting Minutes

The minutes from September 17, 2024, were not approved and will be voted on at the next meeting. The Health Care Providers Subcommittee (Subcommittee) requires four members present for a quorum.

## 2. Member Updates

No member updates were provided.

#### 3. Discussion Topics

## A. Insights from December 11, 2024 – Other States' Rare Disease Advisory Councils

The Subcommittee members shared their thoughts and what they learned from the other states' Rare Disease Advisory Councils, which was presented at the previous full Rare Disease Advisory Council (Council) meeting.

Dr. Anita Davis expressed interest in the idea of a survey of rare disease practitioners. She also requested access to the other states' survey questions to assist in creating preliminary questions for a Florida survey.

The members mentioned a desire to gather information on genetic screening awareness availability of grant funding and patient referral processes being used within the state. Additionally, members expressed concern about updating resources gathered by the Council in order to start working toward presenting resources online.

#### **B.** Recommendations Review

The Subcommittee members discussed their review and update to the Council recommendations from the previous year. The Subcommittee members will review past annual report recommendations under their purview and work toward approving revised or new recommendations for the next annual report.

# C. Next Steps/Future Subcommittee Meeting Dates

Dr. Anita Davis requested the survey questionnaire from the other states from the December 11, 2024, meeting, which staff can share with the Council members.

Due to lack of a quorum, staff indicated they would schedule another Subcommittee meeting in the near future.

# 4. Public Comment

No public comments were received.

# 5. Meeting Adjournment

The meeting adjourned at 12:55 p.m., EST.