



Rare Disease Advisory Council Meeting Minutes

Wednesday, March 4, 2026
10 a.m. EDT
Virtual

Welcome/Introductions:

Melissa Jordan, MS, MPH, Assistant Deputy Secretary for Health for the Florida Department of Health, and Chair of the Rare Disease Advisory Council (Council) called the meeting to order at 10:05 a.m., EDT. After allowing several minutes for additional attendees to join, roll call was conducted.

The following members or designees were in attendance: (Quorum was established)

Melissa Jordan, MS, MPH, Assistant Deputy Secretary for Health, Florida Department of Health (Chair)
Kathy Hebda, Chancellor, Division of Florida Colleges, Florida Department of Education (Vice Chair)
Eric Biernacki, JD, Managing Shareholder, Andrews Biernacki Davis
Ann Dalton, Assistant Deputy Secretary for Medicaid Policy, Agency for Health Care Administration
Jonathan Hawayek, MBA, Director, State and Local Government Affairs, Spark Therapeutics, Inc.
Blake Shay, PharmD, BCPS, Pharmacy Manager, BayCare Health System
Alexis Bakofsky, MA, Deputy Commissioner, Florida Office of Insurance Regulation
India Holroyd, MPH, Cabinet Affairs Director, Florida Department of Agriculture and Consumer Services
Rajan Wadhawan, MD, Advent Health
Colleen Bartlett, DNP, BayCare Chronic Complex Clinic
Mustafa Tekin, MD, University of Miami Miller School of Medicine
Barry Byrne, MD, PhD, UF Health Advanced Therapeutics and Powell Gene Therapy Center
Anita Davis, PT, DPT, CNPT, Brooks Rehabilitation

Guests and Staff

Yolanda Bonds, Council Coordinator, Florida Department of Health
Jade Tindle, Senior Public Health Services Manager, Florida Department of Health
Shanta Dhar, PhD, University of Miami
External # 813-428-3049
Jennifer Garzia, Patients Rising
Cathy Whaley, Parent of children with rare disease

Approval of November and January Meeting Minutes:

Dr. Bryne made a motion to approve the November 2025 and January 2026 meeting minutes. Jon Hawayek seconded the motion to approve the minutes.

Business

1. Grant Recipient Updates:

University of Miami – Dr. Dhar

Dr. Dhar presented updates on her Pediatric Rare Disease Research Grant project focused on Barth Syndrome. Her team is developing mitochondria-targeted nanoparticles enriched with cardiolipin and CoQ10 to restore mitochondrial function in affected cells. Preliminary findings show improvements in ATP production, reduced oxidative stress, and successful mitochondrial targeting without toxicity. The project has advanced through cellular modeling, nanoparticle stability testing, and early biodistribution analysis.

Council members engaged in discussion with Dr. Dhar regarding delivery mechanisms, tolerability, targeting skeletal and cardiac muscle, and alignment with ongoing clinical research related to mitochondrial disorders.

2. Subcommittee Breakout Discussions

a. Academic Research Institutions

The subcommittee discussed development of a statewide rare disease resource website with assistance from Florida State University. Topics included website governance, inclusion of adult and pediatric specialists, enhanced transition-of-care resources, and multi-institution representation. The group also discussed forming a centers of excellence network across the state to coordinate rare disease clinical care, research, training and biobanking resources.

b. Health Care Providers

The subcommittee reviewed strategies for identifying rare disease populations using commercial insurance, Medicaid, and state employee health plan claims data. They also addressed transportation barriers, disaster preparedness, and resource mapping for medically complex individuals, along with developing diagnostic red-flag tools for clinicians.

3. Member Updates

- Members shared updates regarding Rare Disease Day events held across the state. Legislative updates were also provided, including potential creation of a Neurofibromatosis Research Grant Program, possible addition of Krabbe disease to Florida's newborn screening panel, and discussions surrounding biliary atresia screening. Members raised questions regarding communication and timing of the recent grant Letter of Intent cycle.

4. Public Comment

No public comments were received.

5. Adjournment

Chair Jordan thanked all members for their participation and noted that the use of subcommittee breakout sessions during full meetings would continue, pending feedback. Legislative updates and grant review progress will be key topics at the next meeting. The meeting was adjourned at 11:59 am.