Rare Disease Advisory Council

Meeting Minutes

Wednesday, August 27, 2025
11:00 a.m. EDT
Virtual

Welcome/Introductions:
The meeting was called to order at 11:03 a.m., EDT by Melissa Jordan, MS, MPH, Assistant Deputy Secretary for Health for the Florida Department of Health, and Chair of the Rare Disease Advisory Council (Council). Chair Melissa Jordan gave a summary of the meeting agenda.

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
Melissa Vergeson, Chief of Medicaid Quality, Agency for Health Care Administration for 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.
Anita Davis, PT, DPT, CNPT, Physical Therapist, Brooks Rehabilitation
Alexis Bakofsky, MA, Deputy Commissioner, Florida Office of Insurance Regulation
India Holroyd, MPH, Cabinet Affairs Director, Florida Department of Agriculture and Consumer Services
Mustafa Tekin, MD, University of Miami Miller School of Medicine
Barry Byrne, MD, PhD, UF Health Advanced Therapeutics and Powell Gene Therapy Center
Rajan Wadhawan, MD, Advent Health
Adam Anderson, State Representative, Florida House of Representatives
Blake Shay, PharmD, BCPS, Pharmacy Manager, BayCare Health System

Guests and Staff
Jon Conley, Strategic Initiatives Manager, Florida Department of Health
Yolanda Bonds, Rare Disease Advisory Council Staff Liaison, Florida Department of Health
Kristine Craze, Contractor, Florida Department of Health
Christina Samper, Regulatory Advocacy Manager, Advent Health
Aleska Fernandez, Corporate and Investment Banking Intern, Citi
Pradeep G. Bhide, Ph.D., Florida State University
David H. Ledbetter, Ph.D., Florida State University
Alex Young, Government Affairs Operations, Shumaker Advisors
Michelle Beekman, MSN, RN, NPD-BC, Director of Regulatory Advocacy, Advent Health
Crystal Stickle, President, Magnolia Advocacy, LLC

Business

1. **Approval of April Meeting Minutes:**
   Chair Jordan asked for a motion to approve the minutes from April 23, 2025. The meeting invitation included a copy of these minutes. Jonathan Hawayek made a motion to approve the April minutes; Rep. Anderson seconded the motion. The members approved the minutes with no objections.

2. **Discussions**
   Subcommittee Reports

   Academic Research Institutions Subcommittee – Dr. Mustafa Tekin updated the Council on subcommittee actions which include the possibility to foster collaboration with research institutions and hospitals through the Sunshine Genetics Act to increase funding for rare diseases. Dr. Tekin explained the desire for subcommittees to provide a list of centers of excellence so patients and families can receive contact information for preclinical development or clinical trials in Florida. The suggestion is also to have a centralized website that could possibly be implemented through the Sunshine Genetics Act, to increase visibility and collaboration.

Health Care Providers Subcommittee – Dr. Anita Davis updated the Council on the subcommittee discussion which included members identifying recommendations from the 2024 Annual Report that were associated with health care providers subcommittee. She identified number three in the annual report – Encourage Enhanced Health Care Services for Individuals Living with a Rare Disease, number five – Promote Provider Education and Awareness for Rare Diseases, and number six – Encourage Streamlined Rare Disease Diagnosis. The goal is to increase education, awareness and trying to find screening tools to detect rare diseases.

Dr. Anita Davis mentioned her interaction with Minnesota's RDAC's Erica Barnes, who shared with her some ideas on ways to reframe the structure to provide a format to show milestones and track and measure the approved goals. Dr. Anita Davis plans to share this information with the subcommittee and she also mentioned the desire for an accessible website.

Dr. Ledbetter asked Dr. Davis if the definition of health care providers include genetic counselors? Dr. Davis explained that the definition is broad, but it depends on the first contact with the patient that determines a referral to a geneticist. She mentioned professions that could use education on determining rare diseases, such as physical and occupational therapist.

Jon Conley shared the annual report recommendations. Chair Jordan complemented Council staff for reframing the annual report into a document that reader-friendly. This is a report that Chair Jordan would like to share with stakeholders. She encouraged Council members to share the document with their partners, distribution lists and others that were interested in RDAC's work.

State Agencies Subcommittee – Chair Jordan updated the Council on the subcommittee activities which included the discussion of the website data repository. The desire is to continue efforts to provide resources on services available with programs across the agencies to individuals and families living with rare diseases. Chair Melissa Jordan also mentioned leads on free resources such as interns that might be able to assist Department of Health with the creation of the website. Additional information will be provided in future meetings.

3. Subcommittee Structure and Participation

Chair Jordan mentioned the lack of attendance that results in not meeting quorum in the Health Care Providers subcommittee means that the members can engage in discussion without the ability to vote and make decisions. This also has halted the subcommittee in moving its work forward. Some of the suggestions to rectify this issue are as follows:

- Shift health care subcommittee members to state agencies subcommittee to focus on health care or care navigation and resources. The remaining members with clinical or research background move to the academic research subcommittee

- Create breakout sessions during full council meetings for approximately 30 minutes and reconvene to share highlights and thoughts

Chair Jordan said she thought breakout sessions would be a good way to accommodate busy schedules. Dr. Byrne, Dr. Wadhawan and Dr. Tekin agreed to the breakout sessions. Dr. Tekin approved of both suggestions 1) combining subcommittee meetings to health care providers and academic research and 2) breakout sessions during the full council meetings will begin in the next meeting.

4. Update: Sunshine Genetics Act Pilot Program

Representative Adam Anderson presented on HB 907 and provided the Council with background on the legislation which focused on rapid pediatric genetics testing and giving parents access to options for early treatment before the children become symptomatic. Representative Anderson mentioned current funding, future funding, in kind contributions and some areas where the funding will be applied. Lastly, Representative Anderson shared the savings in overall healthcare in the state of Florida.

Dr. Phadeep Bhide, Florida State University (FSU) Institute for Pediatric Rare Disease Director, presented the Council with an overview of how the Sunshine Genetics pilot program is set up to become a comprehensive support in precision medicine in Florida, and a leader in the genomic industry. Dr. Bhide explained the research master’s degree training and genetic counseling degree programs. The programs include Research, Training, Clinical Diagnostics, Genetic Engineering, Precision Medicine and Sunshine Genetics. Along with the programs, there will be a viral vector, gene editing facility and a pediatric health center in Tallahassee. The research grants program is currently offered at FSU. The program is creating trained workforce and currently recruiting positions to build the program in hopes to welcome new students in 2027.

Dr. David Ledbetter, Florida State University Institute for Pediatric Rare Disease Associate Director, shared information about steps to create the Sunshine Genetics pilot program. Early steps include creating a steering committee to develop a protocol for the healthy newborn genome sequencing project. Dr. Ledbetter included statistical information based on the number of conditions traditionally screened for versus determining the conditions Florida will screen. Dr. Ledbetter explained the types of positions within the program and consortium for the committee to determine when and how to screen patients, how to obtain permission from parents and develop a system for secure data storage and sharing identifiable data.

Dr. Tekin asked if the goal is to sequence 10,000 newborns? Dr. Ledbetter replied saying the goal is 10,000 or more. Dr. Ledbetter also explained the desire to surpass larger studies that include 100,000. Representative Anderson said the 10,000 screenings is the initial goal and then increasing it to 200,000 to 220,000 newborns yearly. Dr. Tekin raised an issue of how some of the sequencing can be hard to detect and will not be captured in the gene test. Dr. Tekin asked Dr. Bhide if the genome sequencing will be rapid or regular? Dr. Bhide said they are regular sequencing with a short turn around.

5. Member Updates

Jon Hawayek began with a reminder that Chair Jordan and Representative Anderson were invited to present best practices on different topics during the New Jersey RDAC October meeting to increase collaboration. Jon Hawayek mentioned the desire for an advocacy group called Rare and Ready to present to the Council. He said the organization represents close to 90 different rare diseases. The organization would like to present the Council and provide background information, describe projects they are currently involved with, and obstacles to access for patients with rare diseases.

Dr. Wadhawan pointed out an ongoing project at the Children’s Hospital which is part of Advent Health in Orlando, Florida. They are using rapid genome sequencing in partnership with Radi, a company that focus on analyzing data after the sequencing has been performed. Dr. Wadhawan is interested in sharing data collected from new ICU and pediatric ICU patients based on pre-established criteria with Representative Anderson and Dr. Ledbetter.

Dr. Anita Davis shared with the Council that she and her client were featured on USA Today and CBS news regarding a rare disease that affects adults and pediatric patients, known as complex regional pain syndrome. The interview was turned into print articles and as a result, Reflex Sympathetic Dystrophy (which is a disorder that causes lasting pain, typically in an arm or leg, often following an injury, stroke, or heart attack) has invited Dr. Davis to present to their audience in September 2025. Dr. Davis also mentioned Complex Regional Pain Syndrome (CRPS) Awareness Month (a chronic pain condition that is characterized by ongoing, intense pain, inflammation, swelling, and changes in skin temperature and color) with is celebrated in November. It is an international celebration to raise awareness in the health care provider field.

Dr. Tekin emphasized the need for families to receive proper genetic counseling for testing and potential outcome to avoid the consequences families must face after the results are received.

Chair Jordan mentioned the Live Like Bella Pediatric Cancer Research Symposium in Miami on September 12, 2025. She is excited to see some of the members and support pediatric Cancer Research around the state.

6. **Staff Update**

Jon Conley encouraged members to review their membership tenure to determine expiration. The Council was provided instructions on how to formally reapply based on the entity they were appointed by. Appointments are made by the Governor of Florida, the Florida House of Representatives Speaker or the Florida Senate President. Members whose terms are expiring or have expired are encouraged to use the link provided in the chat to pursue reappointment. If a member’s term has expired, the member may continue to serve until someone else has been appointed, or until they receive a letter for reappointment. Jon Conley included links in the chat.

7. **Public Comment/Open Discussion**

Dr. Ledbetter announced the recommendation from the American Academy of Pediatrics in genetic evaluation of children with global developmental delay or intellectual disability concerning pediatricians being able to order sequencing or exome (genetic testing method that focuses on sequencing the exons, or protein-coding regions, of an individual’s DNA to identify genetic variations associated with diseases) sequencing test as the first tier. This would eliminate referral to medical genetics clinic, which could result in a twelve month or longer wait time. If pediatricians initiate the testing it could have a forty percent positive diagnostic result for underlying rare genetic disease. This information was published in the Pediatrics journal (July edition).

Dr. Ledbetter said the lack of access to geneticists is the bigger problem than the infrequent misunderstanding. The person ordering the test should have good access to genetic counselors and medical geneticists to understand the positives and the variants.

8. **Adjournment**

Chair Jordan asked for a motion to adjourn. Dr. Barry Bryne offered the motion, with a second from Dr. Mustafa Tekin. The meeting concluded at 12:39 p.m., EDT.