

Rare Disease Advisory Council

October 25, 2023 Meeting Materials

The Florida Department of Health

Table of Contents

Agenda	3
May 8, 2023 RDAC Meeting Minutes for Approval.....	4
September 19, 2023 Academic Research Institutions Subcommittee Meeting Minutes for Approval.....	7
September 20, 2023 Health Care Providers Subcommittee Meeting Minutes for Approval.....	11
August 17, 2023 State Agencies Subcommittee Meeting Minutes for Approval	13
September 21, 2023 State Agencies Subcommittee Meeting Minutes for Approval.....	16
RDAC Website Draft Outline for Discussion	18
Recommendations by Subcommittee.....	19
Academic Research Institutions Subcommittee	19
Health Care Providers Subcommittee.....	20
State Agencies Subcommittee	21



Agenda

Rare Disease Advisory Council (RDAC) Meeting

Date: Wednesday, October 25, 2023

Time: 12:00 PM – 1:00 PM EST

Microsoft Teams Meeting Link: [Click here to join the meeting](#)

Or call in (audio only): 850-792-1375; Phone Conference ID: 842 202 795#

Topic	Topic Facilitator/Presenter
Call to Order and Member Roll Call (Introduction of New Members)	<p><i>Melissa Jordan, MS, MPH Chair Assistant Deputy Secretary for Health Florida Department of Health</i></p> <p><i>Kathy Hebda, M.M.Ed. Vice Chair Florida College System Chancellor Florida Department of Education</i></p>
Approval of Council and Subcommittee Meeting Minutes	<p><i>Melissa Jordan, MS, MPH Chair Assistant Deputy Secretary for Health Florida Department of Health</i></p>
Future Website Discussion	<p><i>Florida Department of Health</i></p>
Top 50 Prevalence Data Discussion	<p><i>Agency for Health Care Administration</i></p>
Rapid Whole Genome Sequencing Medicaid Coverage Discussion	<p><i>Agency for Health Care Administration</i></p>
Subcommittee Updates Discussion	<p>Academic Research Institutions Health Care Providers State Agencies</p>
Public Comment	
Adjournment	<p><i>Melissa Jordan, MS, MPH Chair Assistant Deputy Secretary for Health Florida Department of Health</i></p> <p><i>Kathy Hebda, M.M.Ed. Vice Chair Florida College System Chancellor Florida Department of Education</i></p>



Meeting Minutes

Rare Disease Advisory Council (RDAC) Meeting

Date: Monday, May 8, 2023
Time: 12:00 PM – 1:00 PM EST
Microsoft Teams Video Conference

Member Name	Member Seat	Present	Absent
Eric Biernacki	An individual who is, or was previously, a caregiver for individuals with a rare disease.	X	
Dr. Barry Byrne	A representative from an academic research institution in Florida, which receives grant funding for research regarding rare diseases.	X	
Ann Dalton	A representative of the Agency for Health Care Administration.		X
Dr. Anita Davis	A representative of organizations in this state which provide care or other support to individuals with rare diseases.	X	
Rebekah Dorr	A representative of organizations in this state which provide care or other support to individuals with rare diseases.		X
Zana Dupee	An individual who is a caregiver of an individual with a rare disease.		X
Jon Hawayek	A representative of the biotechnology industry.	X	
Kathy Hebda, Vice-Chair	A representative of the Department of Education.	X	
Melissa Jordan, Chair	A representative of the Department of Health.	X	
Dr. Scott McClelland	A pharmacist who is licensed and practicing in this state who has experience with drugs that are used in the treatment of rare diseases.	X	
Jessica O'Reilly	An individual who is 18 years of age or older who has a rare disease.		X
Dr. Divya Patel	A physician who is licensed under Ch. 458 or 459, F.S., practices in this state, and has experience in treating rare diseases.	X	
India Steinbaugh	An individual who is 18 years of age or older who have a rare disease.	X	
Jennifer Sutherland	An individual who is a caregiver of an individual with a rare disease.	X	

Dr. Mustafa Tekin	A representative from an academic research institution in this state which receives grant funding for research regarding rare diseases.		X
Dr. Rajan Wadhawan	A physician who is licensed under chapter 458 or chapter 459 and practicing in this state with experience in treating rare diseases.		X
Vacant	An individual who is, or was previously, a caregiver for individuals with a rare disease.		
Vacant	A geneticist practicing in this state.		
Vacant	A registered nurse or advanced practice registered nurse who is licensed and practicing in this state with experience in treating rare diseases.		
Vacant	A hospital administrator from a hospital in this state which provides care to individuals diagnosed with rare diseases.		
Vacant	A representative of health insurance companies.		
Vacant	A representative of the Office of Insurance Regulation.		

Guests: Danielle Uribe (Florida Department of Health), Tara Cockman (Florida Department of Health), Marci Perkins (Florida Department of Health), Christopher Cogle (in for Dr. Ann Dalton), Grace Boran, Leslie Dughi, Crystal Stickle, Katie Steigelman, Holly Murphy, Haley Tobias, and Steve Khan.

Call to Order, Member Roll Call – Melissa Jordan, Chair

The meeting was called to order at 12:02 PM by Melissa Jordan, Council Chair. Roll was taken and a quorum was established.

Approval of Council and Subcommittee Meeting Minutes – Council Members

Melissa Jordan moved for the minutes to be accepted from the April 17, 2023, council meeting. The council unanimously approved the minutes.

Review of finalized Legislative Annual Report and Recommendations – Council Members

Council members were broken up into their respective subcommittees to review their section of the annual report along with corresponding appendices while in breakout rooms. A copy of this report was included in the chat of the meeting for all to view.

Council Feedback and discussion of Legislative Annual Report and Recommendations – Council Members

All participants were returned to the main virtual meeting room. A spokesperson from each subcommittee provided a summary to the council regarding edits requested to the annual legislative report.

Legislative annual Report next Steps – Melissa Jordan, Chair

The final draft of the report will begin internal routing through the Department for approval. Once routed and approved, the Legislative Annual Report will be made available on the Department's website. The council will have a break during the month of June 2023. Council meetings from July to December will be scheduled and posted in advance on the Department website.

Public Comment – Melissa Jordan, Chair

No public comment was provided.

Adjournment – Melissa Jordan, Chair and Chancellor, Kathy Hebda, Vice-Chair

The meeting adjourned at 12:55 PM.



Meeting Minutes

Meeting of the Rare Disease Advisory Council (RDAC) Academic Research Institutions Subcommittee

Date: Tuesday, September 19, 2023
Time: 12:00 PM – 1:00 PM EST
Microsoft Teams Video Conference

Member Name	Member Seat	Present	Absent
Representative Adam Anderson	An individual who is a caregiver of an individual with a rare disease.	X	
Dr. Barry Byrne	A representative from an academic research institution in Florida, which receives grant funding for research regarding rare diseases.	X	
Dr. Divya Patel	A physician who is licensed under Ch. 458 or 459, F.S., practices in this state, and has experience in treating rare diseases.	X	
Dr. Mustafa Tekin	A representative from an academic research institution in this state which receives grant funding for research regarding rare diseases.		X
Dr. Rajan Wadhawan	A physician who is licensed under chapter 458 or chapter 459 and practicing in this state with experience in treating rare diseases.	X	

Guests: Kelly Rogers (Florida Department of Health), Tara Cockman (Florida Department of Health), Jon Conley (Florida Department of Health), Maggie Dilger (Florida Department of Health), Pradeep Bhide (Florida State University), Cynthia Vied (Florida State University College of Medicine), Crystal Stickle (Vertex Pharmaceuticals and the Florida Medical Association), Corey Reclouhe (Florida House of Representatives),

Call to Order, Member Roll Call – *Maggie Dilger, Florida Department of Health*

The meeting was called to order at 12:05 p.m., and Representative Adam Anderson was introduced.

Representative Anderson was recently appointed to the Rare Disease Advisory Council by Senate President Kathleen Passidomo, and he represents North Pinellas District 57. Roll was taken, and a quorum was established.

Approval of Meeting Minutes – *Council Members*

Dr. Rajan Wadhawan moved for the minutes to be approved from the August 15, 2023, subcommittee meeting, and Dr. Divya Patel seconded the motion. The minutes were approved.

Member Updates – Council Members

No member updates were provided.

Maggie Dilger with the Florida Department of Health asked for discussion on information the subcommittee hopes to capture from the list of Florida Geneticists collected in Year 1. Suggestions included:

- Identify specialties
- Identify sub-specialties
- Identify a list of conditions each physician specializes in
- Identify a list of special or particular interests
- If they are accepting new patients
- If they are open to research collaboration
- If any research trials are available through them
- If they have a sub-specialty, a question needs to be added to ensure they approved to have their information posted publicly. Most centers have a centralized scheduling number that could be provided instead of direct contacts if preferred.

Dr. Barry Byrne mentioned that ClinicalTrials.gov should be added to the website. He believes the organization is setting up an option for those who register to be notified regarding specific topics. The website is a database of privately and publicly funded clinical studies conducted around the world. Dr. Byrne explained there is a requirement to list public studies that have open enrollment through ClinicalTrials.gov. Private or single-subject IND studies are not required to be listed. Trials that have a commercial sponsor and are IRB-reviewed must be listed.

Representative Adam Anderson asked how the list of geneticists from Appendix F in the annual report was compiled. Dr. Divya Patel explained the list was compiled by the subcommittee of known, practicing geneticists in the state. Kelly Rogers with the Department suggested the list be cross-referenced with MQA's list of all licensed geneticists. Dr. Byrne explained most care is delivered by related sub-specialists following a diagnosis, with the exception of metabolic specialties, which would require a much broader list than just geneticists.

Jon Conley with the Florida Department of Health mentioned he works with the Physicians Workforce Advisory Council (PWAC) which administers an annual survey every two years upon re-licensure of those physicians. He offered to help with a survey and narrowing down physicians. He mentioned that MQA and the PWAC survey do not capture specialties.

Dr. Patel asked Mr. Conley if a question could be added to the Physicians Workforce Advisory Council survey regarding rare diseases. Jon explained that because it is a statutorily required survey, there is a lengthy rule-making process required, but the subcommittee could make a recommendation for any rare disease questions to be added.

Dr. Wadhawan mentioned there needs to be of a process for keeping the list updated as people are added or removed. Dr. Byrne suggested the survey be distributed to division chiefs at each academic health center or major hospital systems first. Kelly Rogers with the Department noted that cities and counties should also be captured when compiling this data. Tara Cockman with the Department added that once all details are gathered, an interactive map could be introduced to the website for ease of use.

Representative Anderson asked what the workload is for geneticists in Florida. Dr. Wadhawan explained the workload is significant as appointments are time-intensive, and patients must be prioritized. Dr. Byrne echoed this by noting there is a national shortage of those in training and in the profession. Advanced practice nurses and other sub-specialists will have to fill the gap.

Rep. Anderson inquired about what steps should be taken when building out a new college geneticist program. Dr. Byrne explained the hurdles physician providers (not genetic counselors) experience regarding limited fellowships and jobs due to the profession being one of the lowest reimbursed sub-specialties. There is also a shortage of genetic counselors which could offload some of this work from geneticists. Rep. Anderson asked if genetic counselors could be part of a workforce program through local colleges. Dr. Byrne confirmed it is a master's level program. Dr. Wadhawan added that Advent Health University, an Allied Health Sciences university, is in the process of developing a program. There is a market need and jobs should be plentiful.

Future Agenda Items/October Council Meeting Agenda Items Discussion – Council Members

Further discussion is needed regarding a Florida version of NORD's Centers of Excellence. The subcommittee has a desire to notice rare disease entities that may not have research elements to be considered a NORD Center of Excellence but have clinical abilities to care for the rare disease community. The subcommittee would like a discussion and direction on who would be responsible for overseeing and creating such a designation.

Council members have requested to hear from a Medicaid lead to present on the new law regarding Rapid Whole Genome Sequencing. Specifically, how the new law will be implemented, and funds disseminated. Rep. Anderson mentioned he has been working on this legislation and believes AHCA is still in the planning process. He is hopeful a plan will be fully executed by the October 25 full council meeting.

Rep. Anderson mentioned an appropriation in the state budget for funding a pediatric rare disease grant

program. The question was posed if the RDAC would be able to have oversight for the grant funds. Dr. Byrne mentioned there are organizations that review applicants. RDAC could possibly help establish goals, and it was suggested that someone from the Biomedical Research Program be invited to present at a future meeting to present on its process.

Public Comment – *Members of the Public*

No public comment was provided.

Adjournment – *Maggie Dilger, Florida Department of Health*

The meeting adjourned at 12:57 p.m.

DRAFT



Meeting Minutes

Meeting of the Rare Disease Advisory Council (RDAC) Health Care Providers Subcommittee

Date: Wednesday, September 20, 2023

Time: 12:00 PM – 1:00 PM EST

Microsoft Teams Video Conference

Member Name	Member Seat	Present	Absent
Dr. Anita Davis	A representative of organizations in this state which provide care or other support to individuals with rare diseases.	X	
Rebekah Dorr	A representative of organizations in this state which provide care or other support to individuals with rare diseases.		X
Zana Dupee	An individual who is a caregiver of an individual with a rare disease.	x	
Jessica O'Reilly	An individual who is 18 years of age or older who has a rare disease.		X
India Steinbaugh	An individual who is 18 years of age or older who have a rare disease.	X	

Guests: Kelly Rogers (Florida Department of Health), Tara Cockman (Florida Department of Health), Jon Conley (Florida Department of Health), Maggie Dilger (Florida Department of Health), Eric Martin (Pfizer's State Government Relations Division), Crystal Stickle (Vertex Pharmaceuticals and the Florida Medical Association)

Call to Order, Member Roll Call – Maggie Dilger, Florida Department of Health

The meeting was called to order at 12:05 p.m., and roll was taken. A quorum was established.

Approval of Meeting Minutes – Council Members

A motion was made by India Steinbaugh to approve the July 19, 2023, meeting minutes. Dr. Anita Davis seconded, and the meeting minutes were approved.

Member Updates – Council Members

Jon Conley with the Florida Department of Health updated the group that administrative responsibilities will be transitioning under the Division of Public Health Statistics and Performance Management from the Division of Community Health Promotion.

Dr. Anita Davis has been collecting information from colleges and universities on what is being taught as it relates to rare diseases. Working from a list of schools that graduate physical therapists, she has already received responses from 50 percent of the schools she has contacted. She also reached out to several

medical schools in the state to collect curriculum information. Her next step is to reach out to the Deans of Curriculum and Deans of Academic Education.

Maggie Dilger with the Florida Department of Health reminded the subcommittee there is a need to request the Agency for Health Care Administration (AHCA) to include a question on holistic care in its survey. She asked the subcommittee for questions to send to AHCA, and what data the group wishes to capture.

Maggie Dilger and Kelly Rogers with the Department provided an update from last month's joint meeting with the Academic Research Institutions Subcommittee. During that meeting members commented they were unaware of a universal list of screening tools. Genome sequencing is used but can be costly depending on whether testing is concluded in-patient/out-patient. There has been a request from the Academic Research Institutions Subcommittee to ask for a Medicaid presentation on the new genome sequencing law during the October full council meeting. Dr. Davis mentioned listing NORD's Centers of Excellence for patients to contact regarding screening and noted having genome testing information and where to direct health care providers for details on cost/coverage on the website.

An objective under Recommendation 3 is to identify current medical practices and specialists who accept both pediatric and adult individuals with rare diseases. The next action step is to coordinate with the Office of Insurance Regulation and AHCA to survey insurance plans on health care providers that accept both pediatric and adult individuals with rare diseases. A question was posed as to additional options to garner this information through other surveys being utilized. Jon Conley explained that some of the statutory surveys in place could be a more complicated venture.

Future Agenda Items Discussion – Council Members

The group was asked to provide suggestions for upcoming agenda items or subject matter experts they wished to hear from. No comment was provided, and members were encouraged to submit suggestions via email to Maggie Dilger with the Department.

October Council Meeting Agenda Items Discussion – Council Members

The group was asked to provide topics they wished to cover during the October Full Council meeting. No comment was provided, and members were encouraged to submit suggestions via email to Maggie Dilger with the Department.

Public Comment – Members of the Public

No public comment was made.

Adjournment – Maggie Dilger, Florida Department of Health

The meeting adjourned at 12:34 p.m.



Meeting Minutes

Meeting of the Rare Disease Advisory Council (RDAC) State Agencies Subcommittee

Date: Thursday, August 17, 2023

Time: 12:00 PM – 1:00 PM EST

Microsoft Teams Video Conference

Member Name	Member Seat	Present	Absent
Vacant	A representative of the Office of Insurance Regulation.		
Eric Biernacki	An individual who is, or was previously, a caregiver for individuals with a rare disease.	X	
Ann Dalton	A representative of the Agency for Health Care Administration.	X	
Jon Hawayek	A representative of the biotechnology industry.	X	
Kathy Hebda, Vice-Chair	A representative of the Department of Education.	X	
Melissa Jordan, Chair	A representative of the Department of Health.	X	
Dr. Scott McClelland	A representative of health insurance companies.	X	
Jennifer Sutherland	An individual who is a caregiver of an individual with a rare disease.	X	

Guests: Kelly Rogers (Florida Department of Health), Tara Cockman (Florida Department of Health), Maggie Dilger (Florida Department of Health), Jon Conley (Florida Department of Health), Nicole Perez (Blue Cross Blue Shield), Morgan Elaina (Florida Senate), Leslie Dughi (Metz, Husband, & Daughton, P.A.).

Call to Order and Member Roll Call – Maggie Dilger, Florida Department of Health

The meeting was called to order at 12:00 PM. Roll was taken, and a quorum was established.

Approval of Subcommittee Meeting Minutes – Council Members

Jon Hawayek moved to approve the meeting minutes from the July 20, 2023, meeting. Dr. Scott McClelland seconded the motion, and the July 20, 2023, meeting minutes were approved.

Year 2 Objective Implementation Plan – Council Members

Ann Dalton with the Agency for Health Care Administration (AHCA) provided an update regarding the Data Use Agreement (DUA) and Medicaid data. A new DUA is required to move forward with sharing AHCA's Medicaid data, and AHCA is currently working on completing that document.

AHCA did pull Medicaid claims data (single individual per year from 2018-2022) – both fee for service and managed care – for the list of top 50 rare diseases. Those findings showed total prevalence for all 50 diseases was less than one percent of the entire Florida Medicaid population. Of that one percent, thirty-three percent were diseases of the blood, and sickle cell accounted for twenty-five percent. Jon Hawayek asked if the Medicaid data mimicked the national data shared by Artia Solutions. Tara Cockman with the Florida Department of Health explained that the formatting of data from Artia Solutions needs attention in order to properly cross-walk. The Department will work with the data team and Jon, if necessary, to format the data in a way that is useable for completing the objective.

Jon Hawayek and Eric Biernaki have completed their assessment of Florida advocacy/patient groups and they plan to have a compiled spreadsheet by the next subcommittee meeting.

Kathy Hebda with the Florida Department of Education (FDOE) asked for clarification on FDOE recommendations regarding communications and if there were any suggestions.

Jennifer Sutherland suggested an educational scholarship improvement and expressed concern with funding after a person graduates high school under the Gardiner Umbrella (Step Up). Ms. Hebda explained the Gardiner scholarship is for K-12 and expansion would require new legislation and additional funds. There are other services for post-secondary students – including the Office of Vocational Rehabilitation. Ms. Sutherland suggested resources to notify parents of what is available – there is a gap in knowledge of resources as the student is aging out. Mr. Biernacki noted how difficult it is to navigate resources and mentioned listing resources on RDAC's website in the future. Kelly Rogers with the Department explained that the goal of the website is to get information out to the rare disease community, and that funding options/logistics are being researched to build the website and create communication plans to publicize once up and running. Ms. Hebda mentioned FDOE has a fairly standard plan for email blasts and asked if there is a timeline for the website and what funds are needed. Kelly explained that the Department is working with state partners to identify resources to be able to move forward since the RDAC is not funded.

FDOE shared a collection of resources for the 2022-2023 Legislative Report, and it was suggested the list be redistributed prior to the next meeting. If any additional resources should be added, the group can report back.

Tara Cockman provided an overview of what the Department is doing to review resources and identify gaps in services within the Department. Internal and collaborative meetings are being scheduled with other divisions/departments within the Department (Early Steps, Chronic Disease, Birth Defects, CMS, Brain and Spinal Injury Program, Healthy Start, School Health Programs, Medical Marijuana, WIC, County Health Systems, Office of Minority Health). The Department hopes to be able to report back in the coming months on its findings (how programs are identifying individuals with rare diseases, how they serve those persons, who qualifies, how they qualify, etc.) The Department is also researching website creation for the future. Ann Dalton recommended reaching out to the Agency for Persons with Disabilities once the Department has completed its internal review.

Public Comment – *Maggie Dilger, Florida Department of Health*

No public comment was made.

Adjournment – *Maggie Dilger, Florida Department of Health*

The meeting adjourned at 12:35 PM.

DRAFT



Meeting Minutes

Meeting of the Rare Disease Advisory Council (RDAC) State Agencies Subcommittee

Date: Thursday, September 21, 2023
Time: 12:00 PM – 1:00 PM EST
Microsoft Teams Video Conference

Member Name	Member Seat	Present	Absent
Vacant	A representative of the Office of Insurance Regulation.		
Eric Biernacki	An individual who is, or was previously, a caregiver for individuals with a rare disease.	X	
Ann Dalton	A representative of the Agency for Health Care Administration.		X
Jon Hawayek	A representative of the biotechnology industry.	X	
Kathy Hebda, Vice-Chair	A representative of the Department of Education.		X
Melissa Jordan, Chair	A representative of the Department of Health.	X	
Dr. Scott McClelland	A representative of health insurance companies.		X
Jennifer Sutherland	An individual who is a caregiver of an individual with a rare disease.	X	

Guests: Kelly Rogers (Florida Department of Health), Tara Cockman (Florida Department of Health), Jon Conley (Florida Department of Health), Maggie Dilger (Florida Department of Health), John Mattson (Agency for Health Care Administration), Eric Martin (Pfizer’s State Government Relations Division), Crystal Stickle (Vertex Pharmaceuticals and the Florida Medical Association)

Call to Order, Member Roll Call – *Maggie Dilger, Florida Department of Health*

The meeting was called to order at 12:05 p.m., and roll was taken. A quorum was not established.

Approval of Meeting Minutes – *Council Members*

Approval for the State Agencies Subcommittee’s July 19, 2023, meeting minutes will be moved to the October 18, 2023, meeting.

Member Updates – *Council Members*

Tara Cockman with the Florida Department of Health updated the group on the DUA. The Department has submitted a new application to the Agency for Health Care Administration for Medicaid data to be shared. Ms.

Cockman explained that when dealing with small data numbers that could be personal identifying, data must be suppressed in accordance with HIPPA law. John Mattson with the Agency for Health Care Administration mentioned aggregate data was just sent to the Department's data team on Tuesday. Tara confirmed the staff member is traveling and will work to obtain the information in chart form to distribute to the group in the near future.

Future Agenda Items Discussion/ October Council Meeting Agenda Items Discussion – Council Members

Melissa Jordan with the Department asked that meeting minutes and work being done by the other subcommittees be shared prior to the full council meeting to help align goals and conversation. The State Agencies subcommittee will provide an update on its progress regarding data. There should be a presentation from the IT department to discuss the future website with possible mockup ideas.

Ms. Jordan also reported she will be attending NORD's upcoming RDAC meeting in early October and reminded the group there is an open spot if a member is interested in attending.

Before the full council meeting on October 25, Maggie Dilger with the Department will send prompts along with the agenda.

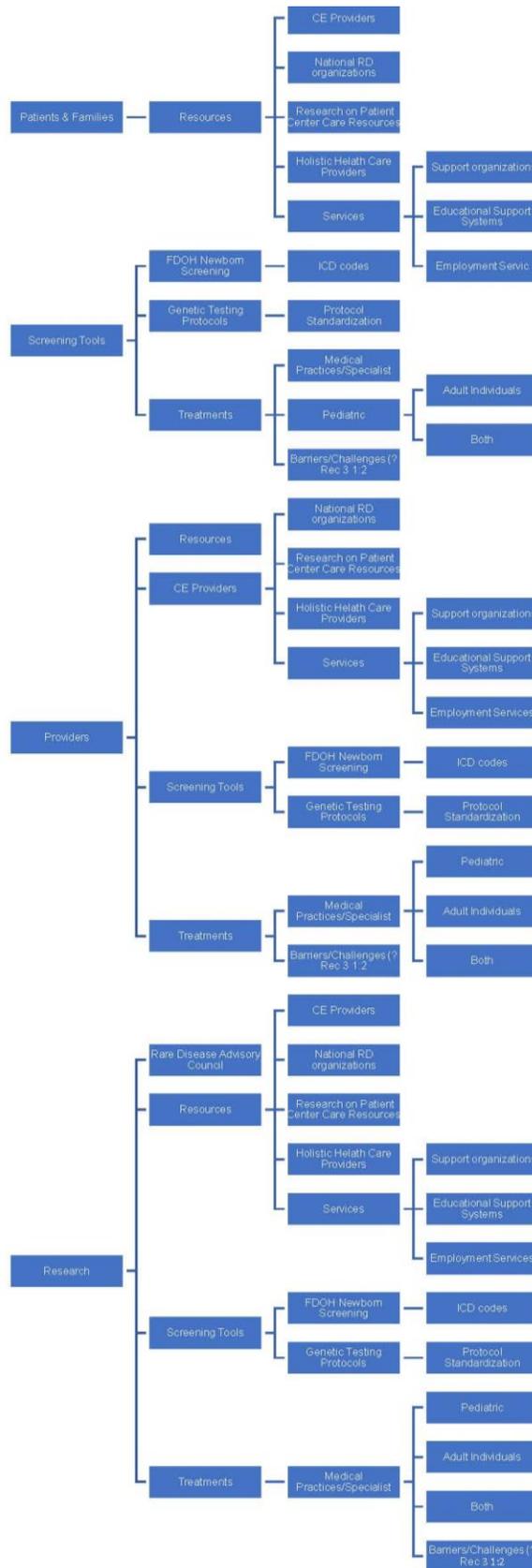
Public Comment – Members of the Public

No public comment was made.

Adjournment – Maggie Dilger, Florida Department of Health

The meeting adjourned at 12:26 p.m.

RDAC Website Draft Outline for Discussion



Recommendations by Subcommittee

ACADEMIC RESEARCH INSTITUTIONS

1

SUPPORT RESEARCH INSTITUTIONS IN FLORIDA

Latest update: The subcommittee is requesting direction in creating a recommendation for who would oversee designations for Academic Rare Disease Institutions (Academic RDRI) and Clinical Rare Disease Institutions (Clinical RDRI) within the state of Florida.

2

PROMOTE AVAILABILITY OF RESEARCH INSTITUTIONS TO INDIVIDUALS WITH A RARE DISEASE

Latest Update: Awaiting information and direction from AHCA on rWGS Medicaid Coverage that was signed into law in 2023.

3

PROMOTE EDUCATION ON RARE DISEASES TO HEALTH CARE PROVIDERS

Latest update: Subcommittee members generated a draft list of Board Certified geneticists in Florida in Year 1. These providers need to be identified based on their respective areas of expertise, and a draft survey has been discussed. The draft list from Year 1 needs to be cross-referenced with Department data to ensure it is exhaustive.

HEALTH CARE PROVIDERS

1

PROMOTE EDUCATION ON RARE DISEASES TO HEALTH CARE PROVIDERS

Latest update: Rare disease curriculum in medical programs is being evaluated. There is also a need to identify educational resources on holistic health care practices for health care providers. The subcommittee requested to discuss adding a question on holistic care on the Agency for Health Care Administration's (AHCA) questionnaire.

2

PROMOTE ADVANCEMENTS IN THE PROCESS OF ACHIEVING A DIAGNOSIS FOR RARE DISEASES.

Latest update: Objectives include identifying and compiling screening tools for health care providers. The subcommittee has identified there are currently no protocols for the diagnosis of autoimmune diseases. There are, however, protocols for genetic testing. More discussion is needed to identify centers of excellence for rare diseases instead of developing individual screening plans and options/coverage for genetic testing.

3

PROMOTE ADVANCEMENTS IN THE PROCESS OF ACHIEVING TREATMENTS FOR RARE DISEASES.

Latest update: In year 1, the committee was able to locate two providers that accept pediatric and adult individuals with rare diseases. The subcommittee plans to survey providers in year two and needs to coordinate with the Office of Insurance Regulation and AHCA to survey insurance plans on health care providers that accept both pediatric and adult individuals with rare diseases.

Another year two objective is to survey individuals with rare diseases to identify barriers in access to care for testing and treatment. Discussion is needed on how to administer such a survey.

STATE AGENCIES

1

IDENTIFY DATA NEEDS NECESSARY TO UNDERSTAND THE POPULATION WITH RARE DISEASES IN FLORIDA.

Latest update: An additional DUA is in development to allow for Medicaid data sharing between agencies. AHCA has recently shared aggregate data of top 50 rare disease. Additional data variable discussion has been requested.

2

IDENTIFY AREAS OF IMPROVEMENT FOR THE DEPARTMENT ON RARE DISEASES.

Latest update: Programs are being compiled and analyzed to identify gaps in services and to provide resources for the future website.

3

IDENTIFY AREAS OF IMPROVEMENT FOR THE AHCA ON RARE DISEASES.

Latest update: A DUA is being developed to help encompass varied needs of data sharing between agencies. Aggregate Medicaid data has been shared regarding the prevalence of top 50 diseases.

4

IDENTIFY AREAS OF IMPROVEMENT FOR THE FLORIDA DEPARTMENT OF EDUCATION (FDOE) ON RARE DISEASES.

Latest update: Programs provided in the 2023 Annual Report are being reviewed for updates and additions.

5

IDENTIFY AREAS OF IMPROVEMENT FOR THE FLORIDA OFFICE OF INSURANCE REGULATION (OIR) ON RARE DISEASES.

Latest update: Pending OIR appointment - there is a vacancy on the council

6

IDENTIFY AREAS OF IMPROVEMENT FOR DISASTER PREPAREDNESS AND PANDEMIC RESPONSE FOR INDIVIDUALS WITH RARE DISEASES IN FLORIDA.

Latest update: Meetings have been held with Division of Emergency Preparedness and Community Support and County Health Systems to identify resources and service gaps.