



Meeting Minutes

Rare Disease Advisory Council (RDAC) State Agencies Subcommittee Meeting

Date: Tuesday, February 15, 2022

Time: 11:30 AM – 12:30 PM EST

Microsoft Teams Video Conference

Member Name	Member Seat	Present	Absent
David Altmaier	A representative of the Office of Insurance Regulation.	X	
Ann Dalton	A representative of the Agency for Health Care Administration.	X	
John 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	
Jennifer Sutherland	An individual who is a caregiver of an individual with a rare disease.	X	

Guests: Vera Beloshitzkaya (Florida Department of Health), Valentina Contreras, Jennifer Coulter (Florida Department of Health), Aaron Otis (Florida Department of Health), Kelly Rogers (Florida Department of Health), Douglas Woodlief (Florida Department of Health)

Call to Order, Member Roll Call – Casey Omeke, Florida Department of Health

The meeting was called to order at 11:30 AM by Casey Omeke. Roll was taken, and a quorum was established.

Overview of Requested Rare Disease Data and ICD-10 Codes – Dr. Vera Beloshitzkaya, Florida Department of Health

Dr. Beloshitzkaya provided an update on the information obtained of the top 60 rare diseases and genetic conditions from the Genetic and Rare Disease Information Center (GARD) of the National Center for Advancing Translational Sciences (NCATS) and corresponding ICD-10 codes.

John Hawayek provided additional information on data that is being collected for the top 50 rare diseases with corresponding ICD-10 codes and any associated NDC codes by a partner organization. The data should be

prepared in the upcoming weeks.

Development of Recommendations – Council Members

Council members discussed, revised, and expanded upon the recommendations. To assist in creating recommendations on the topic of emergency preparedness and natural disasters, leadership from the Florida Department of Health Division of Emergency Management provided information on the current processes in place to assist individuals with disabilities and other special needs in an emergency situation.

Subcommittee Next Steps – Casey Omeke, Florida Department of Health

Casey shared the information on the February 17, 2022, meeting and provided the dates for the upcoming council meetings in March, April, and May.

Public Comment – Casey Omeke, Florida Department of Health

No public comment was provided.

Adjournment – Casey Omeke, Florida Department of Health

The meeting adjourned at 12:20 PM.