

Illinois Rare Disease Commission

Monday November 18, 2024

12:00-1:00 PM Virtual

Minutes

Name	Present (Y/N)	Role	Affiliation
*Maria "Ria" Pollock	X	Affected / Caregiver; Advocacy Group	(Chair) Living with rare disease
Joyce Clay	X	Affected / Caregiver; Health Professional	Daughter with rare disease
Tim Cunniff	X	Industry	(Vice Chair) Paragon Biosciences
Stacey Feuer		Affected / Caregiver; Health Professional	Living with rare disease
TaLana Hughes	X	Affected / Caregiver; Advocacy Group	Sickle Cell Disease Association of Illinois (SCDAI)
Lara Pullen	X	Affected / Caregiver; Advocacy Group; Industry	Chion Foundation / child with rare disease
Stacey Pigott		Patient Advocacy	
Maria Bellefeuille	X	Appointed	Living with rare disease
Vacant		Appointed	
Vacant		Appointed	
Vacant		Appointed	
William Hauter	X	Policymaker	Certified in Emergency Medicine
Linda Holmes		Policymaker	Living with chronic illness
Sonya Harper	p	Policymaker	By proxy, Christy Brown
Jackson Paller	X	Policymaker	

Attendants: Joan Ehrhardt, IDPH Facilitator, Catherine Counard, IDPH Medical Affairs, Emily Spangler, IDPH Governmental Affairs, Claire, staff for Representative Lindsey La Pointe, Hank Chiuppi, rare disease patient, Emily Inman, Illinois Public Health Association (IPHA), rare disease patient, Amy LaFine, Public Health Nurse, Samantha Ropski -EDS Chicago leader, and rare disease patient, John Conrad, iBIO, Steve Patterson, Acadia Pharmaceuticals, Kevin Hall, Sanofi, Greg Kitchens, Michael Welton, Associate Administrator, HFS, Melissa Black, Associate Administrator of Medical Programs, Keshonna Lones, HFS, Dani Mendez, HFS, Patrick Hostert, HFS, Andrew Wright

Welcome and Introductions: The Chair opened the meeting with introductions. There were guests at this meeting from the Illinois Department of Healthcare and Family Services (HFS). Introductions concluded about 12:17.

Late Submissions: Maria proposed that presentation from HFS be added to today's agenda (HFS), Adoption of Agenda with late submission and approval of meeting minutes from September and October meetings were approved.

Old Business: deferred for presentation from HFS.

Medicaid provided an overview of their services. This was at a high level and included the difference between Medicare and Medicaid, the role of Medicaid managed care organizations (MCOs), and the fee for service model, as well as the care coordination model and role of MCOs. HFS included information on how providers and patients may request help, elevate concerns, and file complaints. HFS also underscored their requirement to keep within the boundaries of their appropriation, which is set by policymakers.

Public Comment: There were many questions for the HFS staff. HFS remained for discussion until close of meeting.

Discussion Annual Report 2024: deferred for discussion.

Announcements: The next meeting is on Monday, December 16, 2024, noon to 1:00pm via Webex

Adjourn: Meeting adjourned at 1:00 pm

