ILLINOIS DEPARTMENT OF PUBLIC HEALTH
525-535 West Jefferson Street • Springfield, Illinois 62761-0001 • www.dph.illinois.gov

Illinois Rare Disease Commission

Wednesday March 6, 2024
10 - 11 AM In Person
(Stratton Building, Springfield Illinois)

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
Stacey Pigott		***Pending***	
Vacant		***Appointed***	
Vacant		***Appointed***	
Vacant		***Appointed***	
Vacant		***Appointed***	
William Hauter		*Policymaker*	
Linda Holmes		Policymaker	Living with chronic illness
Sonya Harper		Policymaker	By Je'Mia Irving
Vacant	-	*Policymaker*	*TBD*

Welcome and Introductions – This hybrid meeting of the Illinois Rare Disease Commission was held in person in Springfield at the Stratton Building and virtually via Webex. Tim Cuniff attended via Webex. Members Joyce Clay, TaLana Hughes, and Ria Pollock, and prior member Maria Bellefeuille were present in person with some family members. Also attending as members of the public were industry representatives and many individuals affected by sickle cell disease and their family members. William Pollock, Tiahna Hughes, Bridget Reynolds, Tammy Smith-Williams, Terrance Hill, Doneta Miller, Inessa Miller, Barry L. Barney, Sr. Linda Fioccola, Lilly Melander, Joe Hrdlicka (Genentech), John Conrad (iBio), Tanesha Seaton-Brown, KeJuan Brown, Ronisha Edwards-Elliott, Yulia Ageev, Oleg Ageev, Roman Ageev, Denis Ageev, Brandon Linten (Pepperdine University), Dennis McCullum, LiMarie Asad. Catherine Counard, IDPH attended via Webex. Lara Pullen joined via Webex at about 10:30.

Introductions and Public Comment: Ria called the meeting to order promptly at 10 am. She asked that those in attendance introduce themselves and describe their vision of utopia for individuals with rare disease. In person attendees expressed verbal permission to be photographed (by Talana).

Late Submissions: Ria announced that the IRDC was given an appointment with the House Speaker that morning, and would thus end the commission meeting at 10:40 in order to be prompt.

Adoption of Agenda & Approval of Meeting Minutes – deferred to next meeting, quorum was not reached.

Old Business/New Business/Discussion

Focus Topic: included brief discussion of challenges surrounding adequate access to genetic care and counseling, private insurance networks, and Medicaid. Highlights are that insurance networks do not always include needed specialty providers and links to out of network providers are very challenging for individuals who need them. Genetic counselors have not been recognized as providers able to be reimbursed by Illinois Medicaid. This intensifies the challenges in accessing needed genetic services. Increasing the number of disorders included on the newborn screening panel would help ease the burden of the diagnostic odyssey for individuals and families.

Announcements

Next meeting: Monday 15 April 2024 via WebEx:
Focus Topic: Access to Pharmaceuticals

Adjournment: Promptly at 10:40

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