

Illinois Rare Disease Commission

Monday October 28, 2024

12:00-1:00 PM

Via Webex

Minutes

Name	Present (Y/N)	Role	Affiliation
*Maria "Ria" Pollock	X	Affected / Caregiver; Advocacy Group	<i>(Chair)</i> Living with rare disease
Joyce Clay	X	Affected / Caregiver; Health Professional	Daughter with rare disease
Tim Cunniff	X	Industry	<i>(Vice Chair)</i> 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		<i>Pending</i>	<i>Living with rare disease</i>
Vacant		<i>Appointed</i>	
Vacant		<i>Appointed</i>	
Vacant		<i>Appointed</i>	
William Hauter		<i>Policymaker (State Representative 87th District)</i>	Certified in Emergency Medicine
Linda Holmes		Policymaker	Living with chronic illness
Sonya Harper		Policymaker	By Je' Mia Irving
Vacant		<i>Policymaker</i>	<i>TBD</i>

Attendees: Joan Ehrhardt, IDPH Facilitator, Bridget Reynolds SCDAI, Tammy Bima, Genentech, Amy LaFine, Kankakee County Health Department, Samantha Ropski, rare disease patient and EDS Chicago Leader/Admin, Emily Spangler, IDPH, legislative liaison, Erin Davis, IDPH Ethics Officer, Hank Chiuppi, person living with rare disease, Gwen Traficant, Chair, Virginia Rare Disease Advisory Council

Welcome and Introductions Maria called the meeting to order promptly with introductions. Joan explained that due to the interruption of public meetings by malicious actors, State of Illinois has

implemented greater controls of attendee participation, effective immediately. This means that attendees will be unable to unmute themselves or share content without being recognized by the Chair and will require assistance of the host (IDPH facilitator).

Late Submissions None

Adoption of Agenda & Approval of Meeting Minutes, Approval of prior meeting minutes (9/16/24) was deferred due to lack of quorum.

Old Business

There was brief information sharing and discussion with IDPH Governmental Affairs and Legal Counsel of the charge of the Illinois Rare Disease Commission and conduct of business. Allison Nickrent will present more on the topic of Boards and Commissions at a future IRDC meeting, tentatively the November meeting.

Public Comment: None

Discussion

- Report from the APHL National Newborn Screening Symposium – Joan shared some highlights of the symposium.
- Report from the RDAC and NORD Breakthrough Summit – Ria shared some highlights of the summit.

Announcements

The next meeting will be on Monday, November 18, 2024, noon to 1:00 pm via webex

Adjourn Meeting was ended at 12:56

