Illinois Rare Disease Commission

November 20, 2023
12-1 PM

MINUTES

Name	Present (Y/N)	Role	Affiliation
***Maria "Ria" Pollock**	na	Affected / Caregiver; Advocacy Group	*(Chair)* Living with rare disease, Vice chair
Joyce Clay	na	Affected / Caregiver; Health Professional	Daughter with rare disease
Tim Cunniff	X	Industry	*(Vice Chair)* Paragon Biosciences
Stacey Feuer	na	Affected / Caregiver; Health Professional	Living with rare disease
TaLana Hughes	X	Affected / Caregiver; Advocacy Group	Sickle Cell Disease Association of Illinois (SCDAI)
Vacant	-	*Provider*	
Lara Pullen	na	Affected / Caregiver; Advocacy Group; Industry	Chion Foundation
Stacey Pigott	-	***Pending***	
Vacant	**-**	***Appointed***	
Vacant	-	***Appointed***	
Vacant	**-**	***Appointed***	
William Hauter	-	*Policymaker*	
Linda Holmes	-	Policymaker	Living with chronic illness
Sonya Harper	-	Policymaker	
Vacant	-	*Policymaker*	*TBD*

Attendees: Joan Ehrhardt, IDPH facilitator, Libby Brunsvold (Vertex Pharmaceuticals), John Bullard (Pharma Alexion, AstraZenica), Hank Chiuppi, John Conrad (iBio), Alan Meizlik; Lilly Melander (iBio), Monique Naleway (iBio); Steve Patterson (Acadia Pharma, Rett syndrome product); Samantha Ropski (graduate student living with rare disease), Andrew Wright

Welcome and Introductions: Tim, acting in Maria's absence, welcomed the attendees and began introductions. The Commission membership attendance did not meet quorum during the meeting.

Late Submissions: None. Recording began at 12:08

Adoption of Agenda & Approval of Meeting Minutes: Approval of meeting minutes was tabled due to lack of quorum. (09/18/2023, 10/17/2023)

Old Business: None

Public Comment: There were no statements from the public. All commission members and member of the public participated in discussion of the **IRDC in-person meeting in Springfield for Rare Disease Day 2024** (Thursday, February 29, 2024)

There was general discussion of an in person meeting in conjunction with advocacy activities in Springfield. Awards have been proposed, including research award (Katherine Kim nominated by Maria); healthcare professional award, potential nomination of Dr. Prada to honor the first Rare Disease Center of Excellence designated by the National Organization for Rare Disorders (NORD) in Illinois; and Crystal Meyers for rare disease advocate. Tim mentioned that anyone could submit a nomination for one of these awards and that he would send information about the nominees along with bios for the members to review. Activities are tentatively scheduled for two days in early March while legislators are in session. If any need transportation or assistance with lodging let Maria and Tim know. Tim emphasized the importance of having a physical presence.

Libby asked about a resolution recognizing Rare Disease Day in Illinois. Tim said he will add that to the list. John Conrad offered to share some language and suggested that the resolution be requested soon, with the goal to pass the resolution with time to prepare awareness materials. Tim asked for volunteers from those living with rare disease to participate and tell their story. Any interested are to let Tim and Maria know. TaLana mentioned that they (Sickle Cell Disease Association of Illinois) like to bring affected individuals and caregivers. She asked to note/reserve a couple spots for SCDAI representatives. Samantha mentioned that she would be interested in going. John mentioned finding budget to provide for travel and a block of rooms. Hank asked if remote participation would be possible, for people who cannot travel. The goal will be for a virtual participation option. Any who cannot travel could provide a written statement if the situation is not optimal for virtual participation. Joan mentioned Department of Agriculture conference space is available at no cost. John mentioned that for 2023 Rare Disease Day activities their staff looked at many options and settled on the State Library. The Illinois State Library has better parking and handicap access as well as proximity to the Capital.

Tim encouraged everyone to consider nominations for the awards and to review the draft annual report.

Announcements: The next meeting will be Monday 18 December 2023 from noon to 1 pm via WebEx. Topic of discussion will be the IRDC Annual Report to the Illinois General Assembly and rare disease awards for 2023. The 2024 Meeting Calendar will need to be finalized (probably monthly, one hour).

Adjourn – meeting ended at 12:27.