IDPH
ILLINOIS DEPARTMENT OF PUBLIC HEALTH
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Illinois Rare Disease Commission

Monday December 16, 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
L. Marie Asad	**X**	Appointed (Effective 12-13-2024)	Patient advocate, living with chronic disease
Vacant		*Appointed*	
Vacant		*Appointed*	
William Hauter	**X**	Policymaker	Certified in Emergency Medicine
Linda Holmes	**na**	Policymaker	Living with chronic illness
Sonya Harper	**X**	Policymaker	By proxy, Christy Brown
Jackson Paller	**na**	Policymaker	

Attendants: Joan Ehrhardt, IDPH Facilitator, Emily Spangler, IDPH Governmental Affairs, Allison Nickrent IDPH Chief Governmental Affairs, Lewis Brien, parent of child with rare disease, Bridget Reynolds, living with sickle cell disease, SCDAI Community Engagement Coordinator for SCDAI, Catherine Counard, IDPH Medical Services, Daniel Maziarz

Welcome and Introductions Ria called the meeting to order with the question **"**What are you looking forward to in the holidays?" A quorum of members was reached by 12:02 pm.

Late Submissions – Maria proposed to include a review of rare disease dates.

Adoption of Agenda & Approval of Meeting Minutes (11/18/24) – approved with minor revisions/addition of late submission.

Old Business: HFS Relations – IRDC would like to share a standing invitation for HFS staff person to attend IRDC meetings. Meetings are by open invitation and notification. Aim is to have ongoing discussion around issues common to rare disease community and HFS program services areas. There was consensus that this would be a good idea.

Public Comment was incorporated into the topic discussion:

Discussion Annual Report 2024: Ria provided an update on the Rare Disease 2024 Annual Report draft via Webex. Lara asked if there was an update available on the outcome for the member of the public who attended an earlier meeting and requested assistance. Ria provided a brief update.

Ria mentioned that there is legislation proposed to include genetic counseling as an essential service. She proposed a recommendation to follow The Minnesota model regarding needed prior authorizations (frequency).

Lara asked for more discussion around nursing home coverage (Medicare) vs. young people's needs (Medicaid). Concerning metachromatic leukodystrophy (MLD), there was an inability to access pediatric palliative care, because it was not reimbursed, according to commentary by an Illinois family. Joyce discussed her family's challenges with coverage for her daughter. Joyce says with complex medical families, children are otherwise hospitalized long term, if family members cannot be recognized care providers. She expressed gratitude for improved reimbursement rates from HFS, Medicaid. However, she stated that it remains challenging to find licensed professionals for in home care. Joyce mentioned that it seems to be a newer track of care. There is a Medicaid omnibus waiver moving forward, 1915 state amendment is currently with HFS which allows a family member to be paid as a provider in the home (with proper training/certification). Ria mentioned the compounding financial stressors for families. Marie mentioned that it seems unusual for the health plan to be unable to find an appropriate residential care facility. Ria acknowledged the comment and suggested it could be a topic for more discussion in 2025. Ria stated that she would like to maintain focus on access to needed drugs and called out high out of pocket costs.

2025 IRDC Meeting Schedule: Maria proposed that all meetings be scheduled on the 3rd Wednesday of each month from 12-1 pm virtually. The following were approved:

- Wednesday 15 January 2025 noon – 1 pm

- Wednesday 19 February 2025 noon – 1 pm
- **Wednesday 5 March 2025 IN PERSON in Springfield, IL from 10 am to 12 am** due to House and Senate session schedule.
- Wednesday 16 April 2025 noon – 1 pm
- Wednesday 21 May 2025 noon – 1 pm
- Wednesday 18 June 2025 noon – 1 pm
- Wednesday 16 July 2025 noon – 1 pm
- Wednesday 20 August 2025 noon – 1 pm
- Wednesday 17 September 2025 noon – 1 pm
- Wednesday 15 October 2025 noon – 1 pm
- Wednesday 19 November 2025 noon – 1 pm
- Wednesday 17 December 2025 noon – 1 pm

Ria asked for additional suggestions for 2025 topics of focus. Lara shared her family's experience moving their son to a residential facility in out of state (Arizona). Her son is now approved for publicly funded coverage. The State reimbursement rate there is a bit higher than the private rate. That benefit supports the professional workforce capacity at the healthcare industry level. Care coordination is included. Lacking this solution/system, the care burden is disproportionately carried by mothers, who must leave the workforce, have fewer resources to care for siblings and other family members. Ria suggested focus on the portrayal of disability and rare disease and public awareness. Ria suggested that there should be some focus in policy developed and budgets in the new year.

L. Marie asked about Rare Disease Day being March 5th in 2025 and mentioned the national day is February 28th. Could there be a social media campaign? Maria mentioned that the National focus is in Washington DC on Feb 28th and Illinois typically recognizes the day during the following week? L. Marie asked if others could attend the events in Washington DC? Ria mentioned that the IRDC task is to make recommendations to the Illinois State general assembly (vs national policymakers). Ria encouraged all interested to participate in national events as an individual. Ria has been invited to give a workshop at University of Illinois Chicago on rare disease for medical students (3-21-25). CMEs may be available. She stated that there is no specific protocol for evaluating rare disease patients. Ria said that earlier this year she was part of a group that gave a workshop on Ehler Danlos Disease with affected individuals and received good feedback from the medical students who participated.

Announcements: Next meeting on WEDNESDAY January 15, 2025, noon to 1:00pm via Webex.

Adjourn

ILLINOIS RARE DISEASE COMMISSION