Illinois Rare Disease Commission

July 16, 2025
12:00 – 1:00 PM Virtual

Minutes

Name	Present (Y/N)	Role	Affiliation
***Maria "Ria" Pollock**	**na**	Affected / Caregiver; Advocacy Group	*(Chair)* Living with rare disease
Joyce Clay	**X**	Affected / Caregiver; Health Professional (Kristin Clay proxy)	Daughter with rare disease
Tim Cunniff	**X**	Industry	*(Vice Chair)* Paragon Biosciences
Stacey Feuer	**X**	Affected / Caregiver; Health Professional	Living with rare disease
TaLana Hughes	**X**	Affected / Caregiver; Advocacy Group (Bridget Reynolds)	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	**-**	Appointed	Living with rare disease
L. Marie Asad	**X**	Appointed (Effective 12-13-2024)	Patient advocate, living with chronic disease
EmJ Jackle-Hugh	**X**	Appointed	Living with rare disease
Vacant		*Appointed*	
William Hauter	**X**	Policymaker	Certified in Emergency Medicine
Linda Holmes	**Xp**	Policymaker (*proxy Christine Hannon*)	Living with chronic illness
Sonya Harper	**-**	Policymaker (*proxy Lance Allen*)	
Jackson Paller	**-**	Policymaker	

Attendees: Joan Ehrhardt, IDPH Facilitator, Catherine Counard, IDPH Division of Medical Services, Lydia Storm, IDPH Genetic Counseling Graduate Student Intern, Allison Nickrent, IDPH Governmental Affairs, Andrew Wright, rare disease patient and advocate, Hank Chiuppi, rare disease patient.

Welcome and Introductions -Tim Cunniff, CoChair coordinated in Ria's absence. Quorum was reached by 12:01 pm.

Late Submissions: None

Adoption of Agenda & Approval of Meeting Minutes (05/21/2025 and 06/18/2025) – Lara moved to approve, L Marie seconded**.** Minutes of recent meetings were approved without changes.

Old Business – Tim mentioned legislation around EHDI program needs that had been referenced at prior meetings. Carrie Balian, mother and advocate discussed concerns regarding lack of sustained federal funding. She reviewed some specifics regarding state grant awards past, current and concerns for future picture of federal funding priorities. Carrie shared current practice, state programming activities and needs for sustainability. She described amendment of newborn screening legislation needed and that was proposed to include funding for newborn hearing screening (EHDI). Carrie mentioned collaboration with Maria Pollock, Illinois State and Hearing Association to propose a draft bill for the fall session. They are actively gathering sponsors at this time. Tim thanked Carrie for her summary and echoed that it is very current topically, given recent federal focus and actions.

Tim asked about funding for newborn screening generally. Joan in the role of Health Assessment and Screening Section Chief, briefly described the newborn screening funding strategy in Illinois, current picture of funding and unmet needs. She added that every state newborn screening program is funded differently. Allison, IDPH Governmental Affairs, briefly described the IRDC role in making recommendations to IDPH and to Legislators through its annual report to the General Assembly. Lara said she agreed that it is important to support these efforts as best IRDC can.

Stacey informed IRDC members that she had seen some potential policy change toward having medical debt be added back to credit reporting. She observed that if that were to occur, some individuals may choose to not move forward or act on medical recommendations (e.g., not pursue recommended diagnostic evaluation and/or treatment) because of personal economic circumstances. Tim invited any other perspectives from IRDC and none was offered.

Public Comment – None was brought forth.

Announcements:
Upcoming Meeting Wednesday August 20, 12-1 pm via WebEx.

Adjournment: 12:24 pm

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