IDPH
ILLINOIS DEPARTMENT OF PUBLIC HEALTH

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Illinois Rare Disease Commission

Monday July 15, 2024
12-1 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	X	Affected / Caregiver; Health Professional	(By proxy, Chris Heredia) 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	**na**		
Maria Bellefeuille	*p*	*Pending*	*Living with rare disease*
Vacant		*Appointed*	
Vacant		*Appointed*	
Vacant		*Appointed*	
William Hauter	X	*Policymaker (State Representative 87th District)*	Certified in Emergency Medicine
Linda Holmes		Policymaker	Living with chronic illness
Sonya Harper		Policymaker	By Je'Mia Irving
Vacant		*Policymaker*	*TBD*

Attendance: Joan Ehrhardt IDPH Facilitator, Jasmine UM PharmD candidate Paragon Biosciences (with Tim), Chris Heredia (proxy for Stacey Feuer, and father of a child with Gaucher disease), Jill Pentow, Priopionic Acidemia Foundation (mother of affected person), Hank Chiuppi, Greg Kitchens, Artia Solutions

Welcome and Introductions - Ria began introductions asking what everyone did for fun in the last few weeks? Quorum was met by about 12:10.

Adoption of Agenda & Approval of Meeting Minutes: There were no late submissions. Agenda was adopted and Minutes from June 17, 2024 meeting were approved without edits

Old Business – none.

Public Comment – included in discussion.

Discussion: Joyce discussed updates from the Pitt-Hopkins Syndrome – Conference she was able to attend in Colorado in recent weeks 2024 Pitt Hopkins Conference - Denver - Pitt Hopkins Research Foundation. There are some exciting updates in management for this disorder. Ria invited Joyce to share updates with her directly by email.

Report from the Dysautonomia International Conference 28-30 June 2024 – Ria had scholarship to attend representing the EDS community and brought slides to share with IRDC today. There were about 500 participants in person, plus virtual attendees. There is interest in developing a specialty clinic for comprehensive patient care. Ria shared additional highlights regarding etiology and management.

Report from the North American Rare Disease Summit 11 July 2024 - Jill was asked to participate on a panel to provide caregiver perspective. Good discussion, good attendance. Included possible exome testing for NBS, management and treatment options for rare diseases, (Banburg Health). Ria mentioned the diversity of representation/attendants who are invested in improving access to care for are disease, providers, researchers, caregivers/families, advocates. About 80 individuals, felt very accessible. Panels explored issues and highlighted them from a variety of perspectives. Ria mentioned that Arti Barnes, IDPH CMO provided keynote/opening address. She discussed additional highlights from the Summit. Maria B asked if meetings could be communicated generally to IRDC members so that all could be aware. Joan and Ria discussed how the invitation came about.

New IRDC brochure – Ria shared the IRDC draft informational flyer virtually Maria discussed how the flyer was designed and potential uses of the flyer to bring more knowledge and awareness regarding rare disease and IRDC in Illinois. Hopefully it will be downloadable. Ria would like to include current and pending members. Joan is to share contact information for member Stacy Piggott with Ria. The members helped correct scheduled dates through the end of the year. Maria B. should be listed as a pending member. The pamphlet was approved by IRDC members with edits discussed. Ria will make the updates and post on the site (site) and send to Joan for IDPH communications approval and posting.

Ria highlighted the signing of Health Care Protection Act on July 10, 2024. She suggested all attending to schedule appointments with representatives and request they be informed of legislation in development, so that comment/input can be provided regarding needs, barriers, etc. And invite their representative(s) to attend meetings of the IRDC. Next month aim is to provide input on an Illinois Center for Rare Disease. The recently passed legislation is a step in the right direction. But more needs to be done.

Public Comment: Ria asked what it is like to have child with Gaucher. Chris discussed challenge of keeping up with needed treatment and management through life changes – e.g. infancy to early childhood, kindergarten and the ongoing struggle to maintain access, insurance approvals, etc. Ria invited Jill to talk about biologics for treatment of a rare autosomal recessive condition. Many individuals with early onset propionic acidemia (PA) require to be fed through g-tube. They must avoid fasting and so have five feeds daily and continual overnight feeding. Cognitive impairment is common with many despite all varieties of therapies. She discussed diet avoidance and balance. There is a balance that must be maintained of required protein for growth without excess to trigger metabolic problems/symptoms. In their situation they were eligible for care under two waiver, one for behavioral therapy and the other for medical care (medically fragile technology dependent (MFTD). While this was helpful, there were still challenges, for example, that nurses providing care under one waive could not provide treatments that were covered by the other waiver. Jill described her family's appeals to maintain both. She contacted residential placements in Illinois and found NOT ONE that could manage her child's care needs (he died in 2016). Jill acknowledged the huge challenge for families with children who have such broad and intensive needs. Even with waivers, they may not be able to access the staff covered by waiver (RN replacements can take a long time).

Joyce also spoke to the MFTD most families by far, if covered by one waiver cannot be covered by another. So families have to choose between medical needs and therapy/community support. Lara agreed that medical/behavioral combined care access are impossible to find and access in Illinois. The State of Illinois is unable to meet those needs.

Joyce mentioned policy in progress that may assist if passed/approved, approving parents as paid Certified Nursing Assistant (CAN) caregivers (2025). Parents must take training to access this benefit. Lara said that IRDC should provide, that being a tiny step in the right direction. Ria asked how to keep up with legislation proposed? Maria mentioned there is a site to follow, but a person must know the bill number. Ria mentioned some family support systems (state government level) dismantled under a prior administration. Ria mentioned specifics of a family moving out of country in order to afford in home caregiver. Ria stated that in a country with very high standard of living that this is unacceptable, and resources must be redistributed.

Announcements: Next meeting: Monday 19 August 2024 noon to 1 pm via WebEx

Adjournment: 12:59

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