IDPH
ILLINOIS DEPARTMENT OF PUBLIC HEALTH
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Illinois Rare Disease Commission

Monday January 22, 2024
12-1 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	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	-	Affected / Caregiver; Advocacy Group	Sickle Cell Disease Association of Illinois (SCDAI)
Vacant	-	*Provider*	
Lara Pullen	X	Affected / Caregiver; Advocacy Group; Industry	Chion Foundation
Stacey Pigott		***Pending***	
Vacant	-	***Appointed***	
Vacant	-	***Appointed***	
Vacant	-	***Appointed***	
William Hauter	X	*Policymaker*	
Linda Holmes	X	Policymaker	Living with chronic illness
Sonya Harper	X	Policymaker	By Je'Mia Irving
Vacant	-	*Policymaker*	*TBD*

Attendees: Joann Ehrhardt, IDPH Facilitator, Kevin Hall (Sanofi), Hank Chiuppi (rare disease patient), Samantha Ropski (EDS Chicago leader, graduate student and rare disease patient), Phil Lohec (Viatris), Andrew Writh, Madison Zeltwanger (Artia Solutions), Je'Mia Irving (District Director, Representative Sonya M. Harper)

Welcome and Introductions: Tim C./all at 12:07

Late Submissions: None

Adoption of Agenda & Approval of Meeting Minutes: IRDC member quorum was met at 12:17. The agenda was approved. Prior meeting minutes from December 18, 2023, meeting were approved with no edits. The 2024 IRDC meeting calendar with monthly meetings was approved, with a motion by Stacey, seconded by Joyce (none abstaining, none opposed).

Old Business/New Business:

Rare Disease Day Resolutions (Discussion & Vote): there was no feedback provided. Joan relayed that the IDPH recommendation is that IRDC members participate in rare disease activities and events as individuals, representing themselves and/or their organizations.

Approval of the 2023 Report (Discussion & Vote): the report was approved. Tim said to send any feedback to Maria and/or himself. Linda said that she read it entirely, it is a great document, and she feels they need to sit down and review the report and begin drafting legislation. Tim suggested that at the February commission meeting they can begin ranking items and working on them. IRDC needs a priority list for work throughout the year. Linda mentioned that there are policymaking deadlines also.

Public Comment: None. It was suggested that any comment on rare disease resolutions could be submitted to Maria or Tim. They can help forward comments to the right people. These will be statements of individuals.

Presentation/Discussion: Barriers to Medication Access. Linda and other members discussed several concerns impacting constituents, themselves, and their family members. This included discussion of costs, and the multiple issues that impact pricing. This is intensified for rare disease because of the smaller market. Many symptoms are nonspecific to disease. What strategies could be used on the industry side to improve access to symptomatic treatments for more individuals? Another issue is insurers making medical decisions with respect to prescribed therapies. Linda referenced pain management access challenges. She also mentioned her personal challenge. She was told mid-year she was not eligible to receive her medication, even though she has been taking it since 2014. The drug company told her she was not eligible. Her doctor submitted an appeal. The appeal was rejected. Back several years ago Linda took a different drug, but she experienced worse side effects. She was essentially told to use some different prescription until it fails her. With her condition, in cycles of remitting and relapsing – an affected person never regains 100%. Flare ups could lead to permanent impacts resulting in serious consequences for her quality of life as well as rehab costs. With her knowledge and connections, she was able to access her medication, with great difficulty. She and other policy makers are discussing proposed legislation to prevent these types of issues.

Linda and others are also looking at additional negative impacts of care networks on patient care such as restrictions limit access to essential professionals, testing, emergency transportation, and many instances leading to inflated out of pocket costs. Provider impacts are concerning. Specific examples have been shared where physicians have several employees hired to work only with appeals to insurance.

Tim mentioned during 35 years in drug development this issue has become more of a challenge in last 10 years in terms of the stepwise approach. That is, requiring a patient to take a medication until it fails them before they can access a more expensive option. Transition from childhood to adulthood can be rocky, because efficacious medications may be off label for different age groups or not covered under the existing study protocols. It is a significant issue especially for people with rare diseases. He referenced the Orphan

Drug Act 1983 which offers seven years of market exclusivity (vs 10 in Europe) for rare disease therapeutics. Prevalence threshold is also more conservative, being 200,000 patients to qualify in the US vs. 300,000 in Europe.

Stacey mentioned that pharmacies sometimes substitute for equivalents regardless of additional ingredients/different formulations/efficacy. There seems little individuals and providers can do about it. Linda said a policy has been passed on that. A policymaker had a seizure because of substitution of an antiepileptic. Patients should never be moved to the generic; "dispense as written" by providers should prevent that practice by a pharmacy. Joyce mentioned barriers to giving meds at home vs. inpatient – that may keep patients in the hospital for a long time (for example IV drugs, working with in home providers).

Lara asked about the health economics perspective. To what extent is the state picking up the bill when drugs are declined, and a patient goes on short term disability? To what extent are insurers shifting expenses to the state government? Families lose income if an earner needs to give up a job to become a caregiver. Stacey mentioned disability coverage. Families pay a certain amount. The State of Illinois will pay to cover some gaps. Joan mentioned the Illinois Department of Human Services (DHS) or Health and Family Services (HFS), and Division of Specialized Care for Children (UIC-DSCC) would need to provide specifics concerning the costs they are covering related to these impacts. Joyce says there is a lot of automatic kick back to the state (DSCC) for kids who are covered. Stacey suggested survey data may be available regarding medical incidents and the need to seek state assistance of some sort. Samantha mentioned smaller surveys with limited scope. Stacey stated that a patient survey would be most direct. Lara asked how many people on state disability have pharmacologically treatable conditions? E.g., how many people with lupus cannot access lupus medications? This group could define some conditions that may be manageable and functional with access to needed treatment. Who collects data? FMLA? Tim mentioned that these data don't appear to exist for the state of Illinois and asked who conducts such a survey?

Joan agreed to reach out within IDPH to see what might be found re: disability data. Tim thanked everyone for sharing their experience. Linda suggested items be addressed each session, e.g.: Right to medicate; Right to choose or continue with established medications, including the route of administering the meds and site (inpatient, outpatient, at home).

Announcements

- Next meeting: Wednesday 21, February 2024 noon to 1 pm via WebEx – Joan will send the meeting invite and the rest of the year as well.
- Inviting Legislators to Rare Disease Day: Wednesday 7 February 2024 10 am (Stratton Building, Springfield, IL)
- Opening Ceremony & Rare Awards: Tuesday 5 March 2024 7:30 pm Statehouse Inn, Ballroom (co-sponsored by iBio)
- Rare Disease Day Breakfast with Legislators: Wednesday 6 March 2024 7:30 am Stratton Building
- IRDC Meeting Wednesday 6 March 2024 9:30-10:30 am via WebEx / in person

Adjournment at 1 pm

ILLINOIS RARE DISEASE COMMISSION