Illinois Rare Disease Commission

Wednesday February 21, 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		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	X	Affected / Caregiver; Advocacy Group	Sickle Cell Disease Association of Illinois (SCDAI)
Lara Pullen	X	Affected / Caregiver; Advocacy Group; Industry	Chion Foundation
Stacey Pigott		***Pending***	
Vacant		***Appointed***	
Vacant		***Appointed***	
Vacant		***Appointed***	
Vacant		***Appointed***	
William Hauter		*Policymaker*	
Linda Holmes		Policymaker	Living with chronic illness
Sonya Harper		Policymaker	By Je'Mia Irving
Vacant	-	*Policymaker*	*TBD*

Attendees: Joan Ehrhardt, IDPH Facilitator, LaToya Marie Asad (living with primary biliary cholangitis, Orland Park, IL), Lewis Brien (parent of a young child with a neurodevelopmental disorder caused by a rare gene variant, Lake County, IL), Michelle Olivia (Rare Disease Nurse Navigator from Washington University, St. Louis, MO), Mary Pat Petrillo with Leigh Denny (Johnson and Johnson), Theophilus Lynn-Nguyen (pharmacy student, Ann Arbor, MI), Bridget Reynolds, (living with sickle cell - Hemoglobin SC disease, Chicago, IL metro area), Michelle Weidner (Family Justice Resource Center of Peoria, IL), Madison Zeltwanger (Artia Solutions).

Welcome and Introductions: The meeting began at 12:01 with introductions. Quorum was reached at 12:07.

Late Submissions: Maria proposed a couple of items. One was under new business, recruiting IRDC members. The other was regarding timing of the in person meeting March 6th in Springfield.

Adoption of Agenda & Approval of Meeting Minutes: The agenda was approved with late submissions. The minutes for the January meeting (1-22-24) were approved, with no changes.

Public Comment: Lewis described his family's experience in arriving at a diagnosis for his son, as well as challenges accessing resources, therapies, and providers for needed care. Commission members commented, acknowledging the many challenges for families. LaToya shared a link to her personal story, published online: https://rarerevolutionmagazine.com/digitalspotlight/learning-to-live-with-fatigue-latoya-asads-journey-with-primary-biliary-cholangitis/ in RareRevolution Magazine.

Old Business/New Business: Report on inviting Legislators to Rare Disease Day

- TaLana Hughes shared with the Commission that some individuals, including herself and Maria, gathered February 7th in Springfield to distribute fliers for rare disease day activities, including to policy makers. Maria wore a zebra costume to bring more attention to the event. They distributed many fliers, invited staffers to scan the QR code to be included in the head count for breakfast on March 6th. TaLana plans to arrive the night before for a dinner program. There will be an in person meeting for IRDC and an informative meeting with policymakers over breakfast.
- Prioritizing recommendations of the 2023 Report (Discussion & Consensus)

Prepare for rare disease day. Why is it important? Why does rare disease need to be a priority for policymakers? Maria stated that it's a magnifying glass for public health. She has attended a local town hall for denied insurance claims. Denials fall harder on rare disease families. The burdens are intensified. The individuals and families cannot find care, medications, or afford services that may be available. Some Illinois families end up moving out of state. Insurance reform and regulation is a top priority. It was stated that there are no specific laws to protect rare disease patients in Illinois. Stacey added that insurances are often employer driven, thus changes in policy choices by employer has huge consequences for rare families. Changes to insurance coverage – new care plans with new providers, new team, etc. – are very disruptive to patient care.

Lara agreed and added that the Illinois industries working on rare diseases, and Illinois institutions among the top medical communities in the world, will be part of the solution. The state can do a lot more to connect patients to the institutions they need. Many pharmaceuticals are focused on solutions for rare diseases. Investment is needed to support finding/creating solutions. Tim noted that he sees some commitment from the current administration (Governor), for example, incubators for industry. However, it is not as robust as in some other places. It takes a push to get parties talking.

Leigh (Johnson and Johnson) mentioned that they have some products in the mix with some private payor and Medicaid coverage. Coverage does not seem to be the main issue. There is a lot of fighting for coverage because there are not agreements/policies in place for specifics, for example, single gene diseases with highly targeted therapies. A broad-based solution is needed because single case solutions are not working very well for providers and families. The coverage for genetic testing is not robust so families/patients do not have access to available products.

Insurers are not covering genetic testing (for a specific disorder) because there is not a treatment on the market that targets the disorder.

Maria suggested members become familiar with the adequacy and transparency section of the Illinois insurance legal code. Adequate specialists per insured persons in a provider network is required. However, genetic medicine is not on the list of required specialists. At least one third of Illinois residents are insured by Medicaid. Illinois needs to expand the Medicaid waiver to include genetic testing and increase reimbursement rates so Medicaid coverage can be accepted.

TaLana asked a question about rare disease day events. She noted that she has been participating in planning activities for awareness. Why is it that the Illinois RDC is not more involved in the planning? Joan stated that she reviews any questions regarding activities with the IDPH Ethics Officer, Governmental Affairs, and Legal Office. Joan briefly discussed the standing of the IRDC and role of IDPH and possible concerns, using the example of the rare awards. If IRDC were to be the entity making the awards, that could be perceived as an IDPH endorsement of the winning person or entity. That is not allowable.

- Maria checked the Commission members' thoughts about whether research should be a focus of IRDC in 2024. There was strong consensus in favor. Lara stated that she likes when there is an "ask" beyond awareness. Linda announced plans for legislation going forward, e.g., to add genetic testing to adequacy coverage, and that would be a huge win for the rare disease community. Mary Pat (Johnson and Johnson) pointed out that Illinois is one of the states that does have legislation to protect biomarker testing. Legislation passed in 2021, but it is specific to cancer biomarker testing. She asked if that been amended to go beyond cancer testing? She said that members could find sponsors and learn why the mandate was limited and learn if it could be expanded. Maria stated that health care adequacy = providers (need providers for testing). She mentioned the issue of ghost networks where providers are available in name only. Maria encouraged the members to bring SMART objectives. (Specific, Measurable, Achievable, Relevant, Time-bound = SMART)
- There was consensus in favor of recruiting an IRDC member from the Lurie Children's Hospital Rare Disease Center of Excellence (designation from the National Organization for Rare Disorders (NORD))

Announcements:

- Reception & Rare Awards (co-sponsored by iBio and the rare community): Tuesday 5 March 2024, 5 pm at the Hotel Abraham Lincoln Springfield, 701 E. Adams St. Springfield, IL 62701
- Rare Disease Day Breakfast with Legislators: Wednesday 6 March 2024, 7:30 am at the Stratton Building, M1, 401 S. Spring St. Springfield, IL 62704
- IRDC Meeting Wednesday 6 March 2024 **10:00 – 11:00 am** at the Stratton Building, second floor, room M (in person and via WebEx). Topics: new SMART goal and report excerpts. (Need for home-based care. Need data to propose insurance reform.)

Adjournment: the meeting ended at 1 pm.