Illinois Rare Disease Commission

March 20, 2023
12-1 PM

Minutes

Name	Present (Y/N)	Role	Affiliation
**Vacant*	-	*Appointed*	
Joyce Clay	Y	Affected / Caregiver; Health Professional	Daughter with rare disease
Stacey Feuer		Affected / Caregiver; Health Professional	Living with rare disease
***Maria "Ria" Pollock**	Y	Affected / Caregiver; Advocacy Group	*(CHAIR)* Living with rare disease, Vice chair
Katherine Kim		Provider	Genetic Counselor Lurie Children's Hospital
Tim Cunniff	Y	Industry	Paragon Biosciences
Lara Pullen	Y	Affected / Caregiver; Advocacy Group; Industry	Chion Foundation
Jason Rothstein	Y	Affected / Caregiver; Advocacy Group	Vice Chair; Living with rare disease; Norton & Elaine Sarnoff Center for Jewish Genetics (JUF)
TaLana Hughes	Y	Affected / Caregiver; Advocacy Group	Sickle Cell Disease Association of Illinois (SCDAI)
Vacant	-	*Appointed*	
Vacant	-	*Appointed*	
Jason Barickman		Policymaker	
Linda Holmes		Policymaker	Living with chronic illness
Sonya Harper		Policymaker	
Vacant	-	*Policymaker*	

Attendees: Joan Ehrhardt (IDPH, facilitator). Public: Ann Welsh, Hank Chiuppi

Welcome and Introductions: Ria called the meeting to order at 12:08. Quorum was established soon after (about 12:12). Ria invited the members to identify a challenge they are facing.

Ria shared a current challenge of being a patient advocate for a person who could not needed care; **Talana** identified the challenge of continuously being an advocate for an "invisible" disorder. **Joyce** identified challenges around insurance coverage; there is a situation where her child's provider must order a certain medication and bill Blue Cross for reimbursement. **Hank** (*public*) described his experience with disability. **Jason** mentioned that he is advocating for a genetic counseling position in their organization to help with service delivery and is pleased about making recent progress on that front. **Tim** joined in transit, reported receiving recent approval for a drug to treat infantile spasms. There was a 2-day meeting with the Food and Drug Administration and parents to discuss. Parents whose children did not feel much benefit were still supportive of approval. Keeping up with therapeutic strategies and all the new therapies in development is a challenge. **Lara** has been successful in repurposing a drug for

Prader-Willi syndrome. She shared the challenge of a mother who reached out to Lara from another country about her child with rare disease and asking for any assistance regarding medications. That mother has found a drug that she believes could be repurposed to help her own child. **Ann** (*public*) identified challenges of learning her new role as genetic nurse at the Kankakee County Health Department. Ann attended Rare Disease Day at the Capitol.

Late Submissions: Joyce shared updated information about the IL waiver for medically fragile technology dependent children. University of Illinois Chicago Division of Specialized Care for Children (DSCC) oversees the medically fragile technology dependent waiver. This policy was extended to include adults IF enrolled before 21 yrs of age. The Department of Healthcare and Family Services and DSCC worked together on the policy. Licensed caregivers are able to continue to provide care in the home; and can bill, including overtime, within approved budget and scope of practice (the policy increases the hours that can be staffed by licensed caregiver/providers) – Joyce will send announcement. Joyce says there is a screening tool for eligibility.

Approval of Agenda – approved.

Old Business

a. Minutes approval – approved (none opposed; none abstained)
b. Bylaws adoption – tabled due to lack of 2/3 majority

Review of Bills

HB 1024, Sickle Cell Prevention (Flowers) – Talana discussed that people with sickle cell disease mostly live in Chicagoland, but there are many who reside elsewhere in state. Families who live in Kankakee County, for instance, have to travel back and forth, at minimum twice yearly for evaluation. That is without hospitalization or extra multidisciplinary care needs. This policy establishes a grant program at IDPH. The goal is to give patients more ability to contact/access needed care. Also to increase supportive services. This policy initiative was incorporated into the four pillars (for equity: criminal justice; economic access, equity, and opportunity; education and workforce development; and health care and human services). Joan added that IDPH is required to develop a biennial report on sickle cell throughout Illinois and to develop Administrative Rules to implement the program (in progress).

HB 3229, Illinois Insurance Code, Coverage Mandate (LaPointe) – an initiative to raise awareness; request appropriations (in future); policy would require that medications and therapies custom-made for specific rare diseases be covered (prior authorization would not be required). This effort is “in its infancy” and needs input. Medical food, custom medications – bring to Commission. Talana mentioned her awareness of new medications available for SCD and difficulty getting preauthorization.

SB 1774, Illinois Clinical Trial Portal (Johnson) – all trials, not limited to cancer; safety and efficacy in humans, extended to rare disease. Policy related to studies – ethical concerns; informed consent; balance with limits needed to prevent bias of results.

SB 2246, Errors of Child Abuse and Neglect Allegations (Lightford) - Parents want to know who the medical examiner is leading the investigation. This policy asks for more transparency regarding that responsibility.

Ria asked for commission members to adopt different bills/policies to follow and provide updates at future meetings.

IRDC Funding & Facilitation: Guest speaker was not available for this meeting. Ria shared the website of the Illinois Deaf and Hard of Hearing Commission (IDHHC) as an aspiration for IRDC. Lara asked if it is a good comparator and notes that the IDHHC appears to be managing complaints. Lara asked if there is a comparator? (Joan asked to check). Ria says she sees IDHHC as a good comparator because of the high numbers of individuals affected by rare diseases, as well as a mandate to provide resources. Commission questioned how to get appropriations to maintain a dedicated website, and who is the RDC sponsor. Ria mentioned that concerns can be taken to legislative liaisons, or to individual representatives. Funding can be requested in the RDC annual report to policymakers. Ria proposed to draft a budget with line-item funding needs. The RDC has never had funding allocated. There was some discussion around the challenges and strategies related to developing new policy. The need for travel stipend and coordination of activities across IRDC and rare disease communities was mentioned. Ria asked the members to provide input regarding in person meetings. She suggested two per year, with one scheduled to coincide with Rare Disease Day. Joyce suggested that DSCC might be able to provide an estimate of enrollees with rare disease, as a starting place.

Rare Disease Day 2023: Talana and Ria talked about their experiences. There was opportunity for a panel presentation. Talana, Ria, Talana's daughter, the Lt. Governor and others participated. Talana shared personal stories about SCD care access challenges during the event. She said it would be nice for all the IRDC members to be together in person at the Rare Disease Day event. There was good discussion with policymakers. The Lieutenant Governor invited IRDC members to reach out to her.

There was discussion of topics for the next meeting. These included: In-person meeting planning. Medical cannabis program eligibility; Pain management overall (meeting focus). Ria asked commission members to send resource information and/or bring it to the next meeting. Talana (SCDAI) and Ann are working together on a sickle cell awareness and outreach event.

Public Comment: None

Announcements: Joyce will share information regarding the Medicaid waiver discussed:

- HFS: MFTD Waiver
- DHS: MFTD Waiver
- DSCC: MFTD Waiver

Adjournment: the meeting ended at 12:58.

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