Illinois Rare Disease Commission

Monday April 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		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	By proxy	Affected / Caregiver; Advocacy Group; Industry	By LJ Tan
Stacey Pigott		***Pending***	
Vacant		***Appointed***	
Vacant		***Appointed***	
Vacant		***Appointed***	
Vacant		***Appointed***	
William Hauter	X	*Policymaker*	Certified in Emergency Medicine
Linda Holmes		Policymaker	Living with chronic illness
Sonya Harper	By proxy	Policymaker	By Je'Mia Irving
Vacant	-	*Policymaker*	*TBD*

Attendees: Joan Ehrhardt, IDPH Facilitator, Mary Pat Petrillo, Johnson & Johnson, John Conrad, iBio, Catherine Counard, IDPH Medical Consultant, Lewis Brian, parent of a child with a rare condition. Bridget Reynolds Communication and partner engagement at the Sickle Cell Disease Association of Illinois (sickle cell disease), Maria Bellefeuille (cystic fibrosis)

Welcome and Introductions: Maria started the meeting (color of your mood) at 12:03 and recording began. Quorum was reached during introductions.

Late Submissions – IDPH SCD Surveillance Report requested by Catherine. TaLana wants to address the opioid shortage and specific impact on SCD. A clinical nurse reached out to SCDAI with concerns.

Adoption of Agenda & Approval of Meeting Minutes – by voice roll call vote. LJ Tan abstained due to not having attended prior meetings. Approved by majority vote. None opposed. The agenda and both prior meeting minutes were approved.

I. Adoption of Agenda - approved.
II. Approval of Meeting Minutes (02/21/2024 & 03/06/2024) - approved.

Public Comment – Bridget discussed some personal challenges experienced in trying to receive needed health care for herself.

Old Business/New Business/Discussion

TaLana said at ceremony held at LaRabida, Governor J.B. Pritzker signed an Executive Order to find solutions to access to new therapies and other high-cost treatments for individuals with SCD and other diseases.

Tim said he reviewed the proposed Illinois Pre-authorization Reform Act of 2022. He felt it was very well written. The intent is to preserve patient-provider relationships. Requirements include: transparency, prior authorization requirements would be posted online, listing services requiring prior authorization and the clinical criteria required for approval. These must be consistent with national standards and updated annually. Sixty-day notice of changes is required. Insurers must further publish track record re: number requested, and number approved. The difference between urgent and non-urgent medical needs is included: Urgent is within 48 hours and non-urgent within five days. Decisions must be made by a licensed physician with experience treating the condition. The extent/length of coverage is also addressed.

Maria acknowledged that the intentions of the legislation were good. How can the patient be sure that the right type of provider is authorizing the requested medication? Tim acknowledged that even specialists may not have direct experience in managing many specific rare diseases. They may need to reach out to colleagues, other specialists in the field. Is it enforceable to the point that it protects the patients' needs? E.g. to protect them from negative impacts of brand switching, generics requirements, etc. Should the insurer be the one to determine (ultimately) if the prescription is necessary and ethical?

Stacey said there are insurers making medical decisions and patients experiencing trouble getting prior authorizations. Stacey says when that happens in rare disease, the impact is greater because there are so few additional options. Further, it's harder to access the specialist most familiar with your rare condition. Orphan Rare Status – helps communicate the needs to policymakers.

Should rare disease patients be exempt from step therapy? Bridget discussed some of the adverse effects, additional challenges related to this requirement.

Ria reiterated that medication access has been identified by the IRDC as the main focus of the IRDC work this year. Je'Mia added that there could possible be an override from doctors included to underscore their patients' needs for access to specific medicines/treatments.

Maria introduced some discussion questions for the IRDC:

- Are you taking meds?
- Has your RX dispensed on time?
- Has insurance covered?

TaLana spoke on behalf of patients and providers about concerns and frustrations related to the opioid shortage causing <u>both</u> delays in access and insufficient access. Without timely and adequate access the individual is left in pain, increasing anxiety, and increasing the intensity of their sickle crisis, increasing comorbidities, e.g. organ damage, vascular damage. It increases communication problems as patients express frustration and anger with their providers (who do not have control over this situation – undermining the provider/patient relationship).

Stacey agreed and mentioned that this impacts the Gaucher community also. However, the nuance in the Gaucher community depends on the type of Gaucher. Type 1 tends to have more treatment options. People with types 2 and 3 have fewer options and the existing treatments are more expensive. E.g., infusion therapy partially effective (vs. for Type 1) and accesses treatments approved outside of US and pays out of pocket.

LJ Tan mentioned that this also holds true for Prader Willi syndrome (PWS). There are shortages for growth hormone. Switching manufacturers changes dosages, changes prior authorizations, and creates more challenges for providers and patient/families.

Maria B mentioned that she currently is not having challenges herself. But she is aware of other patients who face similar challenges when needing to change medications, e.g., across manufacturers. Added that this issue affects heart and diabetes patients as well.

Stacey added that in the Gaucher community, insurance companies are requiring patients to change medications, changing to completely different therapeutics. Patients have to fight the insurer to continue on medications, the treatments that have been effective.

Je'Mia mentioned the experience of a constituent who had a similar experience with their insurer. Their medication (eye drops) were taken off the covered products. The patient now has to pay a high amount out of pocket (generic drops would be covered, but causes inflammation).

Bridget has not experienced delays in accessing pain medication. But mentioned that providers are very hesitant to prescribe opioids when presenting to the ER with pain crisis. So, the current climate re: opioid abuse has created another barrier to adequate pain medications.

Maria thanked those who attended in person. Ria broke a tooth. Maria got a prescription from her provider for her pain medication in February. She could not find a pharmacy to dispense it. Maria spent nearly 70 hours to find a pharmacy that could dispense the ONLY pain medication that she responds to. She tried mail order (no); tried hospital pharmacy (no); they traveled outside the country to access the needed medication. They have family in Germany and in Guatemala. Insurer denied enough meds to cover tapering: they hired a healthcare broker, found a new independent pharmacy, had to fight for another prior authorization, that prior auth was denied, they ultimately paid out of pocket. Bridget offered a contact: American Service and Product, Inc. Drugstore in Orland Park. Bridget added that her insurance has a post decision option department that allowed her to address a denial and receive a decision in 24hrs (she has a medical professional background).

When doctors are overwhelmed by required prior authorization, and insurers can at will deny prior authorization and require generics, and pharmaceuticals can have an industry directive to prevent dispensing, patient challenges are unbearable.

Announcements

- Next meeting: Monday 20 May 2024 via WebEx
- Topic continued: Access to Pharmaceuticals

Adjourn

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Appendix

Illinois Pre-authorization Act of 2022:
https://www.ilga.gov/legislation/ilcs/ilcs3.asp?ActID=4201&ChapterID=22

Cost Transparency SB 1618:
https://www.ilga.gov/legislation/billstatus.asp?DocNum=1618&GAID=17&GA=103&DocTypeID=SB&LegID=146383&SessionID=112

Clinician Administered Drugs SB1255:
https://www.ilga.gov/legislation/billstatus.asp?DocNum=1255&GAID=17&GA=103&DocTypeID=SB&LegID=145492&SessionID=112

Illinois Insurance Code 215 ILCS 5/356z.58 to 357.9 - Specific drug mandates:
https://www.ilga.gov/legislation/ilcs/ilcs4.asp?DocName=021500050HArt.+XXIV&ActID=1249&ChapterID=22&SeqStart=111500000&SeqEnd=112900000

The Illinois Rare Disease Commission was established to increase awareness of rare and orphan diseases that impact the lives of 1 in 4 people. There are more than 8,000 unique and rare disorders that affect many Illinois residents and their families. The commission is made up of representatives from health care professions; people affected with rare disorders, their parents, or caregivers; and government officials.

Pursuant to 410 ILCS 445, the commission makes recommendations to the General Assembly in the form of an annual report. Commission activities are extended through 2026, pursuant to Public Act 102-0671 (Section 75). ILCS 445 can be found here: https://casetext.com/statute/illinois-compiled-statutes/health-and-safety/chapter-410-public-health/diseases/410-ilcs-445-rare-disease-commission-act