Illinois Rare Disease Commission

Monday September 16, 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		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 / child with rare disease
Stacey Pigott	na	Patient Advocacy	
Maria Bellefeuille		*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	X (~ 12:30)	Policymaker	By Je'Mia Irving
Vacant		*Policymaker*	*TBD*

Attendance: Joan Ehrhardt, IDPH Facilitator, Samantha Ropski (EDS Chicago), Steve Patterson (Acadia Pharma), Claudia Colombo, A Meizlik (Johnson & Johnson), Sheri Dolan (Pharmacist, DHFS), John Conrad (Illinois Biotechnology Innovation Organization (iBio)), Melissa W. (Wilkinson, Chicagoland living with rare diseases myasthenia gravis, mt disease, EDS), Jon Vlasnik (AstraZenica),

Welcome and Introductions: Ria called the meeting to order at noon. Quorum was reached by 12:05.

Late Submissions - none

Adoption of Agenda & Approval of Meeting Minutes

The meeting agenda and August meeting minutes were approved with minor edits, none opposed, none abstaining.

Old Business

Public Comment – members of the public, living with rare disease, introduced themselves and briefly discussed their conditions. Melissa mentioned that her condition myasthenia gravis had better treatment approved by the FDA which she received for a time with very good results. However, she lost access nearly a year ago despite approval of insurance coverage. The pharmacies refused to provide at the approved insurance rate. This resulted in relapse, return of symptoms impacting daily function and quality of life.

Lara clarified that Melissa is covered by Medicaid, doctor prescribed the medication, and the insurance approved prior authorization promptly. Nonetheless, infusion companies refuse to provide the medication/infusion because of low reimbursement. Lara asked if there was a broad disconnect with Medicaid? Or if this may be a unique example of a disconnect between provider costs and Medicaid reimbursement rates?

Sheri Dolan, in attendance today, asked for Melissa to contact her, and said she would investigate. Sheri provided her contact information (sheri.dolan@illinois.gov). Rep Hauter mentioned that across the board Medicaid reimbursement is “atrocious”. Sheri said that managed Medicaid plans vs. fee for services plans differ in rates. Melissa mentioned that because of her individual medical needs, she requires IV infusion at home; subcutaneous administration is not a viable option for her. Maria mentioned that she experiences some similar restrictions and requirements in medication administration. Sheri briefly discussed the SPA (state plan) setting upper state maximum allowable costs. NADAC is a pricing benchmark set by federal CMS taking a survey of pharmacies in that space. Newer medication surveys may be less accurate. DHFS has a state vendor that researches the upper maximum allowable cost.

Lara asked if the challenge was related to home infusion reimbursement policy. Melissa mentioned attempting to receive approval for in-person infusion, however that was also denied (last year). Multiple companies have denied her coverage. Melissa has been told that this would also not be approved for administration in the emergency room (ER). Melissa has been sent home from the ER being told the hospital did not have the capacity to treat in the intensive care unit (ICU). Melissa was told that the hospital did not have access to the medication under discussion. Their treatment route would be limited to intubation. Lara remarked that both the personal and medical system costs must be hugely outsized in comparison to infusion costs. Access to preventative care would seem to be far more economical. Melissa has been to the ICU 30 or more times in the last 10 years. Medication name is Vyvgart by Argenx.

Maria asked if anyone on the committee could ascertain the cost of the treatment vs. the cost of ICU admission. Tim mentioned that many times it does not make sense for hospitals to carry rare drugs. It often comes from a central pharmacy and the patient must work with the hospital to provide the medication. Steve mentioned that with low volume, low history, average acquisition cost is equal to the state cost. Pharmacies therefore refuse to dispense due to cost. Sheri mentioned that Medicaid is required to cover every drug. The cost/reimbursement may vary, but it is covered. Melissa affirmed, and added that despite that fact, she is denied access to it because infusion companies refuse to provide it.

Maria asked what legislators could do? Je'Mia mentioned that legislators could have conversation with other policymakers who are on Medicare and managed care committee and healthcare availability and access committee (Rep Natalie A Manley – 98th district). Rep Harper sits on commissions and hears Bill ideas to overcome issues at the forefront. She can sponsor or be a supporting sponsor of relevant legislation. Je'Mia said to reach out with questions and provided the following information in the chat box: Health Care Availability & Accessibility Committee - Natalie A. Manley, 98th District Representative, Vice Chair. Medicaid and Managed Care Subcommittee - Dagmara Avelar, 85th District Representative, Sub-Chairperson.

Lara asked if Melissa's example is a particularly acute form of general problem? Maria and Je'Mia agreed that yes, it does seem to be the case. Lara asked if they could request of policymakers that this issue be addressed? Je'Mia said that many would not be aware of these types of challenges. She encouraged education and awareness be brought to policy makers. Lara mentioned that the avenue for remedy looks different if addressing for the individual or for a larger population of people. Lara suggested using Melissa's story to introduce this issue. Je'Mia will send some names for the IRDC to contact. Lara asked if Melissa would like to provide a version of her own story. Melissa said she would like to provide and could use assistance to summarize. Lara said that she could help shape the story and would need assistance to describe the general issue. Maria mentioned that the Medicaid reimbursement formula is different and lower than that in neighboring states. Illinois has a high percentage of people on Medicaid, approximately 4 million (1 in 3 residents). Lara underscored the need to describe the phenomena. Joyce has heard of others with mt disease and EDS with similar challenges. Joan provided her email in the chat for Melissa to reach out. Joan will send her notes from today's meeting comments and put her in touch with Maria and Lara. Ria stated the aim of an override of certain CMS rules to allow for improved reimbursement and access. Ria underscored the individual level of urgency for Melissa's health. The goal is for a letter to be drafted within a week, schedule a brief meeting for IRDC review and formal approval prior to submission to the GA; specified policy makers.

John Conrad from iBio attending today offered to reach out separately to Argenx contacts.

Joyce mentioned speaking with a hematologist last week who had asked Joyce for assistance on this issue from RDC due to frequent denials of care due to reimbursement levels.

JeMia asked if Melissa had reached out to her state rep. She suggests that would be a good action to take. Melissa mentioned that she had not because of the challenge of managing her own health care needs.

After the meeting, Tim Cuniff provided a link to The Assistance Fund, which describes itself as a charitable patient assistance organization that helps patients and families facing high medical out-of-pocket costs. (The Assistance Fund - TAF (tafcares.org)).

Announcements

Next meeting: Monday October 28, 2024 noon to 1 pm via WebEx [NOTE rescheduled from 3rd to 4th Monday due to conflicts]

Adjourn The meeting ended at 1 pm.

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