IDPH
ILLINOIS DEPARTMENT OF PUBLIC HEALTH
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Illinois Rare Disease Commission

Monday August 19, 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	X	Affected / Caregiver; Health Professional	Living with rare disease
TaLana Hughes		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**	Pending	
Maria Bellefeuille	*p*	*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	Policymaker	By Je'Mia Irving
Vacant		*Policymaker*	*TBD*

Attendance: Joan Ehrhardt, IDPH facilitator, Sophia Guo, (UM PharmD candidate and extern at Paragon Biosciences with Tim), Erica Stearns (rare disease patient and caregiver of 2 children with rare disease), southern IL Resident, Home Care Family Outreach Associate at UIC Division of Specialized Care for Children), Samantha Ropski (Chicago EDS, rare disease patient and grad student), Greg Kitchens, Artia Solutions, Lewis Brien (child with rare disease, IL resident), Brad Brekke (Regional Account Director, Argenx, left the meeting at about 12:25), Kevin Hall (SANOFI RAD, IL resident) , Phil Lohec (Viatris), Lesa Brackbill, (daughter with rare disease, state of

Pennsylvania), Dan Calloway (Intracellular Therapies, Regional Account Manager including IL), Bill (Rep Hauter)

Welcome and Introductions -Ria P. called the meeting to order at 12:01 asking *What would you go to the store for if out of?* Quorum was reached ~12:10. Meeting content began ~12:12 with approvals.

Late Submissions - None

Adoption of Agenda & Approval of Meeting Minutes: Agenda and meeting minutes (7/15/24) were approved.

Old Business - none

Public Comment – Access to genetics care and/or genetic medicine.

Discussion

Access to Mandatory Trainings – Joan discussed accessing the trainings. Contact Joan if assistance is needed.

Topic: **Mandating insurance coverage for genetic medicine and genetic counseling**

Maria discussed the challenges of lack of access related to provider practice, provider shortages, and billing complications (genetic counselors are not recognized Medicaid providers). “Genetic Care” is often being provided by non-genetic trained or certified providers.

Ria shared her genetic services fact sheet. Genetic appointments are not <10 minutes long. They are typically an hour or more, which limits numbers that can be seen (four-six per day). Genetic diagnoses save costs related to inadequate, inappropriate, care. There is one genetic residency program in Illinois. Health insurers are not required to reimburse for genetic services. Ria proposes that this needs to become an essential health benefit. In Illinois malpractice benefits have no cap, this makes Illinois les attractive for providers. Ria proposed “(DD) Genetic medicine and Genetic counseling.”

Stacey said good to look for established best practices for rare disease as a whole or individual recommendations (for individual disorders). Stacey suggested one of the centers of excellence or advocacy organization has probably developed such guidelines. Lara asked if other states have done this and what have consequences been? Lara stated that she is in support. However, what happens if coverage is mandated without providers being available? Is there a transition period? Stacey questioned if government could mandate coverage? Must be “reasonably pursued” – Lara clarified that legislation requires insurers to reimburse for genetic services, analogous to mental health parity. Stacey verbalized her understanding. Joyce mentioned a provider setting up independent practices and building large practices for private pay. Charges are somewhat reduced, but still expensive. Some national and international clients are attracted to experts in specific types of disorders. Lara mentioned virtual / telegenetic services as a possible opportunity, a method to fill this gap. Foundation funding has sometimes been used to reimburse providers for specialty care e.g., at summits and conferences. [In this model specialists in a rare disease are in attendance and schedule time to meet and evaluate people and families]. Lara stated that reimbursement is another path to rare disease awareness. Lara asked industry reps in the room if they would support such efforts. One (Sanofi) mentioned they could take that "up the ladder". Is it numbers or coverage or both? Tim asked. One of the issues may be that there are not enough and one strategy would be to encourage development of more training programs. Ria expressed that it is both that connect and reinforce each other (issue is intensified). Medical students are less likely to choose a genetic residency because of poor reimbursement. Lara clarified that both specialists are important. Stacey added that most genetic counselors are not therapists. If psychologists, for example. are not included, then genetic counselors become *de facto* therapists for family support. Ria said structures need to be created that make Illinois attractive to genetic providers (and therefore better for all rare disease individuals and families). Ria suggested looking at the Illinois health insurance commission [Illinois Department of Insurance?]. It would be possible to get an out of network exception if a network did not include a genetic provider IF genetics was considered an essential service. Stacey shared the circumstances of a certain parent of a child w/rare disease. The child is elementary school age, receiving care at a local hospital had to change care providers because of insurance. The established geneticist said they could no longer treat the child. So, the family had to fight insurance policy in order to see the prior provider. It took months of work to transfer care back. Lara asked if she should ask NORD about these policies? Ria mentioned state of MN as an example. Ria mentioned the national NORD meeting in October as an opportunity to share and learn more.

Ria discussed the transparency in network adequacy act (e.g., HIV, Pain medicine, outpatient dialysis, pediatric specialty services, were added). Stacey mentioned working cancer clinics – genetics (genetic counseling) nearly always included. Oncology, pediatrics may have some precedent, insights into getting the specialties included. Joyce suggested developmental pediatric specialists at other large medical centers out of state as having genetics on their radar. Ria said IRDC members may be asked to testify expecting in January 2025. Ria suggested to think of additional individuals to recommend/ask to testify. Ria mentioned that there may be a mitochondrial issue in addition to connective tissue disorder. These are different conditions with different treatment strategies. Ria expressed sympathy for all challenging experiences of providers as well as people and families living with rare disease. Ria thanked Representative Harper and staff for their work in this area.

Lara asked Je'Mia what barrier she may see to getting it passed. Ria mentioned the Insurance committee of Illinois and in-network provider payments and/or costs. Je'Mia suggested IRDC might build coalitions with advocates to increase support when they reach out to insurers. Candace Jones and Representative Lindsey LaPointe would likely be supportive. Lara said overcoming a cost barrier would possibly need an appropriations component. It is the geneticists' responsibility to adjust prices for patients' visit. The state would not set that cost or pay that. Lara mentioned she is not advocating for money to hire providers. Insurers must provide genetic medicine to patients. Unless patients need financial assistance to see the provider; that was not included. Ria clarified that in particular is not part of this proposed legislation. Ria says it is a quality measure. Ria says Medicaid parity in reimbursement would be a next step to address.

Stacey says it is important to differentiate and specify that the need is for BOTH geneticists AND genetic counselors. Ria stated it is the role of IDPH to determine what adequacy is, how many would be needed.

Upcoming topics:

- Collaboration with the Genetic and Metabolic Diseases Advisory Committee (aka Universal Newborn Screening Advisory Committee (UNSAC))
- NORD/RDAC Conference in Washington, D.C. 20-22 October 2024 – https://nordsummit.org/agenda/

Announcements
Next meeting: Monday 16 September 2024 noon to 1 pm via WebEx

Adjourn

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