IDPH
ILLINOIS DEPARTMENT OF PUBLIC HEALTH
525-535 West Jefferson Street • Springfield, Illinois 62761-0001 • www.dph.illinois.gov

Illinois Rare Disease Commission

July 17, 2023
12-1 PM

Focus Topic: Caregiving Challenges for Families

MINUTES

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

Attendance: Joan Ehrhardt, IDPH Facilitator, Samantha Ropski, Chicago EDS, John Bullard-Alexion-AstraZeneca Rare Disease, MaryEllen Baker, Patient Advocacy, with Vertex, Hank Chiuppi, Spastic Paraplegia Foundation, Alisha Jacob, DNP student at Bradley University (joining to learn about public health). Terri – invited by Maria (Chair) to join the meeting today – for public comment. Jon Vlasnik, PharmD, BCPS, HECON-C Alexion Pharmaceuticals.

Called to order at 12:08 by CoChair Jason; Recording started at 12:09.
Due to member schedule conflicts, there was not quorum at the start of the meeting. An unconfirmed caller "Miraj Patel" left the call at 12:15. Katherine Kim joined the meeting at about 12:30. Stacey left the call promptly at 1 pm.

Welcome and Introductions: All in attendance were welcomed and IRDC members and members of the public introduced themselves.

Late Submissions: After welcome and introductions, the meeting proceeded with a review of late submissions. Prior to the meeting, Terri was requested by Maria, Chair, to discuss her experience related to the focus topic of today's meeting: caregiving challenges for families. Terri confirmed she would share during Public Comments portion of this meeting.

Adoption of Agenda & Approval of Meeting Minutes (06/21/2023)
Adoption of Agenda
Approval of Meeting Minutes (06/21/2023) – tabled to next meeting
Amendment of Bylaws: tabled to next meeting; members were encouraged to review the proposed changes.

- i. Article I - elimination of partial terms/language
- ii. Article II - leaves the responsibility for agenda with the Chair
- iii. Article III/IV - inclusive language/pronouns

Old Business: None

Public Comment: Terri Lechter discussed her experience caring for her adult daughter (mid 30's) with multiple health problems requiring skilled care from childhood. Her daughter receives homecare services, physical therapy, and occupational therapy. With private insurance and Medicaid, early in the the year frequently expends allowable covered services. Parents tag-team to cover their daughter's care needs. <u>Most important message to community</u>: as a patient with rare disease, you must have an advocate caregiver for health care in the hospital, as an outpatient, and in home care. Emergency providers particularly were identified as being doubtful and dismissive of care needs communicated on admission to the healthcare facility. Lara asked Terri if there was any state payment available to the parent as a caregiver. Terri said she had not explored that possibility, she wasn't sure how to approach that issue. Her daughter's condition is chronic and lifelong. Her daughter is very knowledgeable of care standards and upset if providers do not follow best practices. Those experiences create mistrust of health care aids and hospital staff. Stacey asked if Terri was able to get support for herself. Terri says this is a common theme. One of the problems with chronic illness is families often break up due to the stress. Therapy is a valuable resource. Nonetheless, the stress is fulltime. Terri is a retired nurse. Terri provided examples of challenges experienced working with various providers, specialists, discounting underlying medical diagnosis as contributing to symptomatology.

Discussion: Lara shared a document that summarizes key comparisons between state performance from the perspective of individuals with disability. She added some points of interest. Investment in individuals with disability has created a workspace for higher level of care (aids, etc.) in states with a higher level of investment. Lack of investment is also a women's issue because mothers are the most likely and heavily impacted lifelong care providers. As a result, those women are frequently impoverished and exhausted; left with very little in terms of financial and emotional resources.

Katherine added that she is not an expert in resources, but she has access at her worksite (Lurie Children's Hospital) to social workers and resource specialists. Their facility has needed to increase their resource specialist staff because of the demands on families. Katherine referred to the state agencies Department of Health and Family Services (HFS) and Department of Human Services (DHS) as key providers of assistance to individuals and families with special health needs. DHS does not have a centralized bureau for navigation. Thus, individuals and families are on their own to find out what resources exist and where within the agency they lie. Additionally, Illinois has issues with funding and staffing in state government agencies. These programs are understaffed, and that makes additional barriers for families to access the services. The additional burden is placed on healthcare facilities to expand their staff to act as navigators for families. Plus, to go into the community and network. This situation exacerbates inequities in care because facilities receiving care at facilities with fewer resource specialists have less access.

Lara mentioned access through a single state hotline in Arizona; in Minnesota, there is a comprehensive website; providers know where and how to find help for patients and families. Lara said as an individual she could not figure out how to find or access services on her own. In Arizona, there is an intentional community developed for individuals with disabilities. Homeowner Association (HOA) fees go toward disability care services. This setting is like a retirement community with a disability focus.

Stacey noted how this situation contributes to the mental health burden. Providing more services is not sufficient. Added resources are needed to address the situation, reduce stress, lower the burden. There was a wait list of 3,000 for psychiatric and therapeutic services. Now that is down to a few hundred, but wait time is 6 months personally. The state is facing an economic and mental health crisis that extends well beyond the rare disease community.

Lara added that caregivers, family members, moms, do NOT have the breathing room for self-care. Katherine suggested a study of how user-friendly DHS is, and is there a better model for Illinois to follow? Illinois is falling behind expectations. Divisions within DHS need to have better collaboration and coordination. Providers need better access and understanding of DHS, the pitfalls to navigating, how to improve access.

Jason recapped that focus topics for IRDC discussion were identified to build knowledge and address the mandate.

Announcements

Next meeting: Monday 21 August 2023 from noon to 1 pm via WebEx

Meeting Adjourned at 1:02.