IDPH
ILLINOIS DEPARTMENT OF PUBLIC HEALTH

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Illinois Rare Disease Commission

Monday June 17, 2024
12-1 PM Via Webex

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 (by proxy Kristin Clay, sister w/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		*Pending*	
Maria Bellefeuille	*p*	*Pending*	*Living with rare disease*
Vacant		*Appointed*	
Vacant		*Appointed*	
Vacant		*Appointed*	
William Hauter		*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, Sheri Dolan HFS, Hank Chiuppi Spastic Paraplegia Foundation, Samantha Ropski, EDS Chicago and rare disease patient, Bridget Reynolds, Cathy Forbes primary biliary cholangitis, Madison Zeltwanger, Andrew Wright rare disease patient and advocate, Catherine Counard IDPH Medical Consultant, Julia Zylstra (until 12:14)

Welcome and Introductions ***-Ria/All***

Ria began introductions including a description of a situation when members found themselves involved in "good trouble". Quorum was met during introductions.

Late Submissions: Ria introduced publication of annual reports for 2022 and 2023.

Adoption of Agenda & Approval of Meeting Minutes: Adoption of Agenda – passed with late submissions**.** Approval of Meeting Minutes (04/15/2024 and 5/20/24) – passed with correction to May minutes.

Old Business: Tim briefly recapped May meeting's discussion.

Ria discussed the public health perspective on chronic disease and disconnect with etiology/care for rare disease. Lara discussed the great vulnerability of individuals with rare disease and greater reliance on public health protections. Ria restated her frustration, and her sense of the public health perspective is that individuals are expected to be responsible for their own health. Ria opened the discussion to public comment.

Public Comment: Ria read the following testimony which was shared with her via email: Testimony from Hank Chiuppi-

> "Imagine living with a progressive neurological disease for 21 years, constantly struggling to speak and walk. That's my reality with Primary Lateral Sclerosis or PLS. PLS affects my muscles, causing spasticity and weakness, especially in my legs. It also impacts my speech and breathing, constantly challenging daily activities. Getting diagnosed took years because PLS can mimic other neurological diseases, particularly ALS. Sadly, only around 2,500 people in the US share this rare condition so it is difficult to get the condition studied by researchers. Despite the challenges, I'm grateful for the supportive Spastic Paraplegia Foundation (SPF). I hope that raising awareness can accelerate research and improve the lives of those living with this disease. I have been volunteering my time with SPF since I retired in 2010.
> Visit the SPF's website (https://sp-foundation.org) to learn more about PLS, research initiatives, and ways to get involved." -Hank

Stacey referred to the individual vs system perspective. She says she encounters that every day. The negative impacts of common illnesses are even more pronounced for individuals with rare disease. Other therapists may not understand the impact on the emotional health and stress of coming in contact constantly with a system that doesn't understand you as well as the increased number of visits for care. There are impacts on mental health as well as a harder time accessing medical health care and treatment. Having to advocate for yourself can be 50% or more of the distress that an individual with rare disease experiences. Fighting the battle has a significant impact on the individual's wellbeing.

Dr. Counard mentioned that the individual is with the healthcare "system" that is very fragmented and that is a burden to everyone who needs care. The role of public health is to look at system level change to support all and to improve access to care. It's a continuum. To promote general health and wellness particularly for those who are more vulnerable.

Bridget mentioned that getting the public on board to protect people with rare disease seems to be an impossible task. She stated that even within her own extended family people are not on board with that or with public health. They look at things like "everyone gets a cold". It's hard to get uptick. It's not hard-heartedness, it is societal. Ria added she grew up in Europe where health care is a right. She pointed out that here it is an entitlement. She states that perhaps we would want to live in a different society where healthcare is a right vs. entitlement.

Kristin brought up how to get the public understanding of the challenges. While they may not understand rare disease. EVERYONE understands struggles with insurance, trouble getting urgent care…even though it's not daily, most people have encountered problems, have had challenges with the health care system. She suggested to frame it around the struggles that the public is aware of, and that can help connect and develop empathy.

Stacey mentioned that rare disease research benefits more common conditions as well as rare conditions. E.g., symptom overlap between Gaucher disease and Parkinson disease. Research into Gaucher treatment has benefitted people with Parkinson disease as well. Bridget mentioned that the same applies to Sickle Cell Disease.

Discussion: Comments on the Healthcare Protection Act (HB 5395) – Lara

There was some review and discussion of the proposed HB 5395. It was stated that genetic counselors should be covered. Je'Mia said she would research the issue and get back to Ria. Ria stated that she had requested that genetic counselors, genetic counseling coverage should be included.

There was discussion of a need for a definition of medical necessity for rare disease. Ria postulated that this may be very helpful for policy makers (and others). It was reported that HB 5395 passed both houses on May 25, 2024, and is currently in the Senate and has some added cosponsors. Je'Mia will find more information about the separate amendment which Ria requested, which did not make it through the most recent session. Lara asked if comments or feedback would be relevant at this point? Ria said they would only be relevant for future amendments at this point.

Legislation can be considered for the next cycle. Lara asked if the IRDC is reading proposed policies at the point where input can be given? Ria mentioned that comments are always valuable. And that she was not aware of the legislation until it was at that point. Lara clarified that her point is more to find out when should/can the IRDC review legislation/proposals at the point when it matters, when IRDC comment can be most impactful. It was clarified that typically, when policy proposal is presented in house or senate there is an opportunity to fill out witness slips and submit them and sit in on the relevant committee hearing along with the co-sponsor. The timing is often very tricky, because the policy review process is very live and there is unlikely to be more than one (1) weeks' notice.

Sheri Dolan let everyone know that she needed to leave the meeting a few minutes early and thanked the Commission for the opportunity to listen to the discussion.

Topics pending future discussion: Access to maintenance and pain medications – power map and the IRDC Flyer

Announcements: Next meeting- Monday 15 July 2024 via WebEx

Topic continued: Access to Pharmaceuticals

Adjourn: the meeting ended at 1:02 pm

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