Illinois Rare Disease Commission

November 14, 2022
12 PM -1 PM - Virtual

MINUTES

Name	Present (Y/N)	Role	Affiliation
***Maria Bellefeuille**	Y	Affected / Caregiver; Industry	Living with rare disease, Chair
Joyce Clay	na	Affected / Caregiver; Health Professional	Daughter with rare disease
Stacey Feuer	na	Affected / Caregiver; Health Professional	Living with rare disease
***Maria "Ria" Pollock**	Y	Affected / Caregiver; Advocacy Group	Living with rare disease, Vice chair
Katherine Kim	Y	Provider	Genetic Counselor Lurie Children's Hospital
Tim Cuniff	Y	Industry	Paragon Biosciences
Lara Pullen	Y	Affected / Caregiver; Advocacy Group; Industry	Chion Foundation
Jason Rothstein	Y	Affected / Caregiver; Advocacy Group	Living with rare disease; Norton & Elaine Sarnoff Center for Jewish Genetics (JUF)
TaLana Hughes	Y	Affected / Caregiver; Advocacy Group	Sickle Cell Disease Association of Illinois (SCDAI)
****Susan Axelrod**	Y	Affected/Caregiver; Advocacy Group	Daughter with rare disease; CURE Epilepsy. *Moved out of state.*
Vacant	-	*Appointed*	
Jason Barickman	na	Policymaker	
Linda Holmes	na	Policymaker	Living with chronic illness
Sonya Harper	Y	Policymaker	
Vacant	-	*Policymaker*	

**Cochair, ** Vice Chair, ***Withdrawn*

Attendees: Karen Mancera-Cuevas (IDPH), Joan Ehrhardt (IDPH, Facilitator)

The meeting agenda was reviewed by Maria. Handouts were distributed by Joan Ehrhardt on the morning of the meeting. The meeting was called to order by Maria Bellefeuille and began with introductions.

- **Maria Bellefeuille** mentioned her experience living with cystic fibrosis (CF) a rare disease that affects the lungs, referred to the commonality of struggles for all those living with a rare disease, and her advocacy for the rare disease community.
- **Jason Rothstein** mentioned his work with the Norton & Elaine Sarnoff Center for Jewish Genetics and his personal experience living with a non-genetic rare disorder.
- **Katherine Kim** mentioned her career working as a genetic counselor at Lurie Children's Hospital.
- **Lara Pullen** mentioned her science background (microbiology/immunology) and personal experience as a parent of a child with a rare disorder. Lara established Chion Foundation to support pharmaceutical solutions for rare diseases. This has included the repurposing of a drug to help treat her son. The medication is currently in Phase II clinical trials and moving toward Phase III trials.
- **Talana Hughes** mentioned her work as Executive Director of Sickle Cell Disease Association of Illinois, and experience as a parent of a young adult with sickle cell disease. Talana looks forward to increasing awareness of rare genetic disorders generally, as well as sickle cell disease, through advocacy and her participation on the Rare Disease Commission.
- **Tim Cunniff** discussed his professional career and current role as head of research and development for Paragon Biosciences. He has been involved in the incubation of five companies with a focus on unmet need, much of that involves rare diseases. He has experience with development of new drugs for rare disorders, and the related FDA approval process.
- **Susan Axelrod** discussed her experiences founding CURE Epilepsy in order to support discovery and access to better treatments – disease modifying therapies - for her daughter's condition of intractable epilepsy. Susan referenced the need to understand the mechanisms, the underlying causes of seizures, in order to develop effective treatments. A tremendous number of genes have been discovered that are associated with epilepsy. She identifies epilepsy as a public health problem with many different genetic causes.
- **Sonya Harper** mentioned her work toward passage of the bill to establish the commission. She stated that she is glad to see that the Rare Disease Commission is still working on behalf of all people that suffer from rare diseases throughout the state and thanked the members for their involvement.
- **Maria "Ria" Pollock** mentioned her personal experience living with a rare condition and her advocacy work as well as her current graduate studies focused on the connections between disease and homelessness. She would like to work with the Rare Disease Commission to lessen the struggles of individuals and families living with rare diseases.

Maria again thanked Representative Harper and all the members for their attendance. She communicated the importance of meeting quorum in order to conduct commission business. Maria checked that members had received meeting materials and proceeded to review bylaws and minor revisions proposed previously. Lara asked about the meeting schedule, and whether meeting quarterly is an expectation or required? Maria and Joan explained that there had been delays in filling vacancies, as well as challenges with administrative support, due to multiple competing priorities and limited staff resources. Maria also underscored the need to follow the Open Meetings Act in regard to member communications and conducting commission business. Members were encouraged to contact Maria or Joan to suggest agenda items and if unable to attend a meeting. Joan called attention to the provision in the bylaws (approval draft) for members to be able to designate an alternate representative in writing to the Chair prior to a meeting, and subject to approval by the Chair. Meeting quarterly is anticipated in 2023. Maria "Ria" Pollock asked about the minutes. Joan explained that she takes minutes. Commission minutes have typically not been posted on the department website. Draft minutes for approval were distributed with other handouts. It was confirmed for Susan that eligibility for commission membership depends on Illinois residency. Interested persons may participate in commission activities or workgroups and attend open meetings.

Approval of bylaws and meeting minutes:

- **Bylaws**: Katherine Kim made a motion to approve the bylaws. Lara seconded. Ria abstained. All other members present voted in favor. Ria pointed out that amendment of bylaws requires a 2/3 majority vote for approval (7 is too few). Therefore, bylaws approval was tabled to next meeting.
- **Minutes**: Maria briefly reviewed the prior meeting minutes. Ria made a motion to approve prior meeting minutes. Jason seconded. Maria state that members may vote to approve prior meeting minutes if they have no concerns. Minutes passed with none abstaining and none opposing.

Selection of Chair and Vice Chair: Maria is the current Chair. The previous Vice Chair had to resign from the commission, leaving that position vacant. Lara asked for clarification of the roles. Maria described duties of meeting facilitator, working with IDPH staff to set meeting agenda, attending all meetings (as far as possible), and responding to policymaker and other inquiries about the commission work. The Vice Chair provides support to the Chair and covers functions as necessary. Lara asked for additional clarification about meeting schedules and more specifically about the lack of meetings earlier in 2022. Maria provided some background. Joan added some details about current pressures on staff resources at IDPH. Maria confirmed interest in resuming her role as Chair. Ria expressed interest in serving as Vice Chair. Talana made a motion to accept the nomination and approve Maria and Ria for Chair and Vice Chair respectively. Katherine seconded. The candidates were approved with no members abstaining and none opposing.

Review of Open Meetings Act and Annual Trainings: Legislative Affairs staff were unable to attend this meeting. Joan will invite them to attend next meeting. Joan will send required annual trainings (Ethics and Harassment) to the members.

Priorities for 2023: Maria opened the discussion of commission priorities. Items of interest were recommended by commission members. These include:

- Telehealth – supports greater access to health care services.
- Provider availability and provider networks – limited providers and limitations for patients to see providers out of network present a challenge to accessing needed health care. Providers may not have a full care team. Some residents must cross state lines to get adequate care.
- Insurance coverage and networks – similarly, lack of health care coverage and network requirements present a barrier to accessing special care.
- Health equity – addressing factors that intensify challenges to accessing special care for certain populations
- Education and Outreach – guests can be invited to speak to the commission to share information and increase participation and representation in discussion.

Lara pointed out that these broad issues were introduced at the prior meeting. She asked if there were answers to questions that were asked at that meeting, and how commission members would learn of updates. She added that this would help the commission move forward and address specifics. Maria stated that she believes that some progress has been made on telehealth, not particularly with the Rare Disease Commission, but with other Illinois Boards and with patients and caregivers across the board with rare disease. Maria also mentioned that member turnout was less than optimal to set priorities. Maria asked Joan to discuss how to reach out within state government to obtain updates and how the commission can work with government to set policy. Joan expressed concern about lack of resources and knowledge of other agencies to research topics on behalf of the commission. Joan asked the commission members if any had the ability to tap into their networks to bring information forward to share. Maria asked if Representative Harper or other policymakers may be able to assign staff to assist and provide updates on current policy work of interest to the commission. Lara agreed that could be helpful and that she would like to identify some concrete activity or strategy.

Maria asked member to email their top two to three priorities so working groups can be assigned to promote work between commission meetings, identify policy needs and data needs that support specific recommendations to the Illinois House and Senate. And so that members feel they are involved in work that is important to them. Ria suggested polling the members during the meeting. Maria agreed that would be a good idea. Jason suggested that Joan could help identify some examples of policy, e.g., from other states, and identify resources and contact from other State of Illinois Government Agencies, and involve an intern in the commission's work. Jason also suggested that Joan might seek out and help apply for grant funding to help support the commission's work. Joan informed the commission that the IDPH internship program is on hold and that due to a relatively short work experience in Illinois, that very specific resources or programs are needed to determine those contacts.

The commission agreed to return the discussion of priorities at next meeting. Maria said that she and Ria would work with Joan to draft the agenda. Ria suggested emailing an inquiry to the members to determine individual priorities. Maria agreed. Talana asked if there was a website where members could find current and prior work, and share with their respective disease communities. Joan said she would check into that. There was some additional discussion and clarification of public-facing vs. internal member work spaces, and potential to update the IDPH website.

Next meeting – Maria stated that she would check legislative schedules and then the members will be polled regarding meeting dates.

Publiс Comment- None.

The meeting ended at 1:10.