IDPH
ILLINOIS DEPARTMENT OF PUBLIC HEALTH

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Illinois Rare Disease Commission

June 21, 2023
12-1 PM

MINUTES

Name	Present (Y/N)	Role	Affiliation
***Maria "Ria" Pollock**	X	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	na	Affected / Caregiver; Health Professional	Daughter with rare disease
Tim Cunniff	X	Industry	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)
Katherine Kim	X	Provider	Genetic Counselor Lurie Children's Hospital
Lara Pullen	X	Affected / Caregiver; Advocacy Group; Industry	Chion Foundation
Stacey Pigott	***na***	***Pending***	
Vacant	**-**	***Appointed***	
Vacant	**-**	***Appointed***	
Vacant	-	*Policymaker*	(*TBD, Tom Bennet*)
Linda Holmes	X	Policymaker	Living with chronic illness
Sonya Harper	X	Policymaker	
Vacant	-	*Policymaker*	

Attendance: Joan Ehrhardt, facilitator IDPH Office of Health Promotion. Samantha Ropski, EDS Chicago, Karin Pritikin, Orphan Disease and Independent Public Health Policy Analyst, John Conrad, Illinois Biotechnology Innovation Organization (iBIO), Kiara Leonard, EDS, Julie Boyd (Ultragenyx), Alyssa Valentine, Cook County Health and Illinois Society of Genetics Professionals (ISGP), Marc Rosenbaum- (Rush University Medical Center and ISGP), Dana Clemmans (Xeris Pharmaceuticals), Hank Chiuppi (member of the public living with rare disease, Spastic Paraplegia Foundation), Julia (State Rep. Lindsey LaPointe) Outreach Director for the Representative.

The meeting was called to order at 12:01 by the Chair.

Welcome and Introductions: Maria began with an introduction and asked everyone to mention a favorite site to visit in Illinois.

Late Submissions: Under old business, the IRDC Annual Report for 2022 has been previously approved; this item was removed from agenda with board approval (none objecting; none abstaining). This report needs to be posted on the website.

Adoption of Agenda & Approval of Meeting Minutes (04/17/2023 and 05/15/23)
The agenda was approved as noted. April minutes' approval motion to approve by Lara; Tim seconded. April's meeting minute were approved (none opposed, none abstaining). May minutes' approval motion to approve by Tim; Jason seconded. May's meeting minutes were approved (none opposed, none abstaining).

Old Business: Adoption/Amendment of Bylaws (revisions proposed previously): Motion to approve by Maria; Commission Bylaws were passed with none opposed and none abstaining. Additional changes to the IRD Bylaws were proposed and shared by Maria with members for review and later approval.

Public Comment: Kiara Leonard discussed her personal experiences living with rare disease, chronic pain, and challenges with pain management, particularly access to ketamine. Problems experienced include medical access to controlled substances, availability on site, expense, lack of insurance coverage, and more. IRDC members acknowledged her experience and thanked her for sharing them with the Commission today. Lara asked what IRDC would be able to do to help address this issue. Lara expressed the desire to target one issue for the Commission's focus. In response, Maria moved to discussion of IRDC work. Maria stated that in future meetings that public comment would be requested to align with areas of Commission focus.

Discussion: Maria added a link to the chat box to a Google Docs site with proposed focus areas, with discussion following on the proposed topics:

- **Best Practices** to care in the context of Rare Disease - access to care when there is not a specific diagnosis.
- **MAY - False Allegations** of child abuse and neglect). Refer to the May IRDC meeting discussion.
- **JULY - Caregiving Challenges** for families - how to support families (all families). Lara was asked if she and Joyce would accept leadership on this topic, with Lara to identify challenges and Joyce to help identify resources. Discussion included that there is no

centralized location to find resources. The Commission can suggest that an easily accessible, searchable, and public site be developed as an identified need. Katherine shared that she relies on her site's social work team and Google to find resources. Resources available are also dependent on the individual and family's health care coverage, specific insurer. There is limited access to the Division of Specialized Care for Children (DSCC) for 'extra' coverage. To her knowledge, there is no one site to find the information. Perhaps state agencies such as the Department of Healthcare and Family Services (HFS) and/or the Department of Human Services (DHS) develop such a resource. Katherine agreed to lead the discussion for this focus area in July.

- **AUGUST - Access to Genetic Care and Research** – Tim has some knowledge of various trials going on. This topic area will be the August focus of discussion, to include clinical trials, expanded access to participate in trials (the various avenues). Katherine mentioned that reimbursement is an issue for individuals on public-funded insurance (managed Medicaid). Care access can be limited to a few institutions due to facilities' policies for providing care to people who have state assisted medical plans. Jason and Katherine agreed to co-lead this discussion. The members discussed tapping into knowledge of stakeholders (e.g., Illinois Society of Genetic Professionals (ISGP)).
- **SEPTEMBER - Pain Care** for patients with rare diseases – Discussion of challenges included inadequate coverage; portrayal of patients as medication seeking re: controlled substance. Tim identified issues of off-label use impacting access to ketamine. Cures within Reach is an entity that helps fund research for off-patent drugs. Tim said he with the Commission may have opportunity to give input, direction, roadmaps to help make progress to better availability. TaLana agreed to co-lead this topic area for a September discussion focus.
- **OCTOBER - Telehealth/Telemedicine Access.** Katherine suggested this topic area to be brought forward for discussion. Proposed as the October focus for discussion, the scope should include best practices in telehealth and access across state lines.

Announcements

- National Organization for Rare Disorders (NORD) update: State Advocacy Coordinator Anissa Reed is leaving the organization. Maria will attend the meeting in July.
- Next meeting: Monday 17 July 2023 from noon to 1 pm via WebEx
    - Maria asked for IRDC members to name an alternate if they cannot attend.

Adjourn

The Illinois Rare Disease Commission was established to increase awareness of rare and orphan diseases that impact the lives of 1 in 4 people. There are more than 8,000 unique and rare disorders that affect many Illinois residents and their families. The commission is made up of representatives from health care professions; people affected with rare disorders, their parents, or caregivers; and government officials.
Pursuant to 410 ILCS 445, the commission makes recommendations to the General Assembly in the form of an annual report. Commission activities are extended through 2026, pursuant to Public Act 102-0671 (Section 75). ILCS 445 can be found here: https://casetext.com/statute/illinois-compiled-statutes/health-and-safety/chapter-410-public-health/diseases/410-ilcs-445-rare-disease-commission-act

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A. Proposed Amendments to the Bylaws:

Illinois Rare Disease Commission

B. BYLAWS

1. NAME

The name of the Commission shall be the Illinois Rare Disease Commission, hereafter called "the Commission."

2. PURPOSE

The purpose of the Illinois Rare Disease Commission is to advise the State on issues pertaining to the care and treatment of individuals with rare diseases. The Rare Disease Commission shall perform all of the following duties and responsibilities set forth in the Rare Disease Commission Act [410 ILCS 445]:

1) Make recommendations to the General Assembly, in the form of an annual report, regarding:

a. The use of prescription drugs and innovative therapies for children and adults with rare diseases, and specific subpopulations; as appropriate, as well as

b. Recommendations on the ways this information about rare diseases should be used in specific State programs that: i. provide assistance or health care coverage to persons with rare diseases or broader populations that include individuals with rare diseases; or ii. have responsibilities associated with promoting the quality of care for individuals with rare diseases or broader populations that include individuals with rare diseases;

c. Legislation which could improve the care and treatment of children and adults with rare diseases;

d. In coordination with the Genetic and Metabolic Diseases Advisory Committee (aka, the Universal Newborn Screening Advisory Committee or "UNSAC"), newborn screening for genetic disorders; and

e. Other issues which the Commission considers appropriate.

2) The Commission shall submit its annual report to the General assembly by December 31st each year.

3) The Commission shall comply with the Open Meetings Act in all respects where applicable.

3. ARTICLE I

Membership: Section 1-1. The Commission will consist of 15 members. Eleven (11) members shall be appointed by the Governor from residents of the State whose position, knowledge, or experience enables them to represent the needs, concerns, and recommendations of those with rare diseases. Members shall include, among others, physicians or health care providers who treat patients with rare diseases. At minimum, 5 members of the Commission shall be persons who either have a rare disease or are a family member of a person living with a rare disease, additionally, appointments shall be considered for members of advocacy groups for rare diseases and community-based organizations.

Other members shall be appointed as follows: One member of the Senate appointed by the President of the Senate; One member of the Senate appointed by the Minority Leader of the Senate; One member of the House of Representatives appointed by the Speaker of the House of Representatives; and One member of the House of Representatives appointed by the Minority Leader of the House of Representatives

Section 1-2. Members shall serve for terms of 3 years and no member may serve for more than two consecutive terms. A member shall serve until a successor is appointed and qualified.

Section 1-3. Vacancies shall be filled in the same manner as initial appointments. ~~Appointments to fill vacancies occurring before the expiration of a term shall be for the remainder of the unexpired term.~~

Section 1-4. Members shall be legal residents of the State of Illinois.

Section 1-5. Commission members who are unable to attend may appoint an alternate ~~An alternate designee may be appointed by the member~~ to attend and vote on ~~behalf of absent Commission members who are unable to attend~~ their behalf. The alternate may be appointed in writing (e.g., email) to the Chairperson and pending approval by the Chair

Section 1-6. A member is expected to attend all regularly scheduled, special, and emergency Commission Board meetings unless excused by the Chairperson. An excused absence includes, but is not limited to, emergencies or pre-planned vacations. Members may attend in-person meetings virtually if they meet the criteria of the Open Meetings Act.

Section 1-7. Total membership consists of the number of members currently serving on the Commision, not including any vacant positions.

4. ARTICLE II

Meetings: Section 2-1. The Commission shall meet at least quarterly.

Section 2-2. All Commission meetings shall be open to the public unless a meeting or portion thereof qualifies for a closed session in accordance with the Open Meetings Act.

Section 2-3. The Illinois Department of Public Health, Office of Health Promotion shall assist the Chairperson in the preparation of ~~an Agenda prior to~~ each meeting. The approval of Minutes from the previous meeting shall be included on each Agenda.

5. ARTICLE III

Officers: Section 3-1. The Chairperson shall be elected from the Commission's membership by a simple majority vote of the total membership of the Commission and selected on an annual basis.

Section 3-2. The Vice-Chairperson shall be elected from the Commission's membership by a simple majority vote of the total membership of the Commission and selected on an annual basis. The Vice-Chairperson shall have the duties and responsibilities described in these Bylaws.

Section 3-3. If the Chairperson's membership on the Commission is vacated for any reason, or the Chairperson resigns from that office, the Vice-Chairperson shall serve in his/her/their place until the next regularly scheduled election.

6. ARTICLE IV

Conducting Business: Section 4-1. A quorum shall be present in order to convene the Commission and conduct business. A quorum shall consist of a simple majority of the appointed members, not including any vacant positions (Art I, Sec ~~7-1~~1-7). A Commission member is present to conduct business if attending a meeting in person, by audio or video conference. A member will also be considered present if his/her/their appointed designee is attending the meeting in person, by audio or video conference.

Section 4-2. All business shall be conducted in accordance with the current edition of Robert's Rules of Order, unless otherwise specified in these Bylaws.

Section 4-3. The Chairperson shall preside at all Commission meetings. In the Chairperson's absence, the Vice-chairperson shall preside over that meeting and assume the Chairperson's duties related to that meeting.

7. ARTICLE V

Remuneration: Section 5-1. Each Commission member, while serving on the Illinois Rare Disease Commission, shall serve without compensation.

8. ARTICLE VI

Bylaws: Section 6-1. Adoption or amendment of these Bylaws requires a 2/3 majority vote of the Commission. Amendments shall be proposed at a meeting of the Commission and voted upon during the next subsequent meeting.