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

Illinois Rare Disease Commission

September 18, 2023
12-1 PM
Focus Topic: Access to Pain Management

MINUTES

Name	Present (Y/N)	Role	Affiliation
***Maria "Ria" Pollock**	X	Affected / Caregiver; Advocacy Group	*(Chair)* Living with rare disease
Vacant	-	***Appointed***	
Joyce Clay	X	Affected / Caregiver; Health Professional	Daughter with rare disease
Tim Cunniff	X	Industry	*(Vice Chair)* 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 (vacant)**~~	**(resigned)**	Provider – Katherine Kim	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*
Linda Holmes	X	Policymaker (at 12:08)	Living with chronic illness
Sonya Harper		Policymaker	
Vacant	-	*Policymaker*	*TBD*

Attendees: Joan Ehrhardt, IDPH facilitator; Samantha Ropski, Hank Chiuppi, Spastic Paraplegia Foundation, Rebecca Fleming (US Pain Foundation, have Chiari, EDS, syringomyelia), Meredith Harris (NORD Center for Excellence at Lurie Children's Hospital)

Meeting called to order by the Chair at 12:00 (with color that describes mood). Recording started at 12:00 followed by introductions. Quorum was reached at 12:08.

Late Submissions
Maria discussed the invitation for 2 IRDC members to attend the national NORD meeting. Maria shared her personal Padlet site where she keeps resources and notes.

Adoption of Agenda and Approval of Meeting Minutes
- Adoption of Agenda – approved by voice vote with none opposed and none abstaining.
- Approval of Meeting Minutes (08/21/2023) - approved by voice vote with none opposed and none abstaining, see below.

Old Business
- Approval of Meeting Minutes (06/21/2023, 07/17/2023) – Maria proposed and moved that the meeting minutes for June, July, and August be approved with one nomination. The minutes were approved by voice vote with none opposed and none abstaining.
- Amendment of Bylaws: Maria discussed the changes proposed, noted below and moved to approve. Proposed changes were approved by voice vote with none opposed and none abstaining.
    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

New Business
Nominations for Vice-Chair of the IRDC / Elections – Tim Cuniff accepted the nomination for Vice-Chair. He was elected by voice vote with none opposed and none abstaining.

Public Comment and Discussion (Access to Pain Management)
Talana Hughes began discussion with a description of challenges experienced by individuals in the sickle cell community. Access to ketamine can be a challenge, particularly for children. Some institutions, some providers do not have experience administering it. Similarly for lidocaine. Joyce seconded that injectables at home are often disallowed by insurance. Insurers often will require providers to order them, and that adds another barrier.

Becky Fleming, a member of the public, added her experience with challenges accessing medication. If the identified pain provider or pain center is uncomfortable offering certain treatments, the individual patient is viewed as “provider shopping and medication seeking” when they need to change providers to access additional or different therapies. Form changes have made it more challenging also. Some providers are not comfortable submitting information needed to authorize treatment, e.g., medical marijuana. There are many hoops, including quarterly preauthorization.

Meredith echoed that many patients seeking care at their institution voice similar concerns about the challenges of obtaining insurance coverage and prior authorizations. She added that people experience pain differently and respond to medications individually. Their center has begun to focus on individual profiles that include some pharmacogenomic information as well as educating emergency room providers about the condition(s). They are beginning to use more than the pain scale to gage, monitor, manage pain.

Tim spoke about the factors that impact the supply of prescription medications. For example, generic medications are not seen as money makers. Due to low overhead, manufacturers here in the US do not provide "oversupply" the market. Because of quality concerns regarding medications manufactured overseas, there is some return of manufacturing to the US. There is a chronic shortage of IV drugs. (See also www.fda.drugs – shortages). Margins are higher for non-generic prescription drugs.

Linda (living with MS) shared that at the end of July she was denied coverage of her medication by insurance. She was told she did not qualify to take her (longstanding) medication (for her chronic medical condition) because she had not taken the steps required to demonstrate need. Her provider wrote in and it was still denied. She had to appeal the decision. She was within a couple of days out of supply. She was able to work behind the scenes to access her medication. She has taken this medication for nearly ten (10) years. She has meetings set up with providers to discuss the scope of these issues. The burden put on providers to fight insurance denials is too great.

Lara observed that this is yet another layer of barriers: payor level obstacles are not pharmaceutical company obstacles. Maria mentioned that her provider needs to submit three (3) approvals each year for Maria to maintain her access to needed medications. Linda mentioned this is a potential focus for a legislative solution to protect patients and providers. Lara agreed and discussed maintenance medication as a particularly rational point of focus. The Commission discussed potential patient related costs of losing access to maintenance meds. These may include: increased cost to patient (symptoms acute and chronic), family (increased care, loss of productivity), state agencies (coverage of potentially avoidable or under supported disabilities, coverage of medical care for acute and increased chronic symptoms), providers (increased patients with increased symptoms; productivity loss to administrative concerns)

Samantha discussed the long-term impact she has felt from a gap in medication access, resulting in her being unable to regain her prior baseline of health/ability despite care and therapy. Lara mentioned that additionally this limits the access to providers because of the increased amount of time taken to manage rare disease and all chronic conditions.

Maria mentioned that there are not best practices taught to providers. Maria read her own testimony. Maria had shoulder surgery and spent three months without adequate pain management. She was accused of self-medicating, becoming tolerant to opioids. Through intense personal research she learned she carries a gene variant that results in higher metabolism/inactivation of many pain medications. Maria participated in a pilot trial with her pain clinic/provider; she requires much slower infusions, due to being a rapid metabolizer. Maria has to pay up front for treatments. Ketamine is not an opioid. Ketamine is a narcotic. It is on the WHO list of essential medications. So how can it not be routine to stock it here? If ketamine and lidocaine injections are not known to providers, then provider education needs to be a focus.

Meredith suggested that primary targets for provider education would be emergency medicine, pain management providers, family medicine, internal medicine, anesthesiologists, for example. This would help increase familiarity and remove stigma.

Maria stated that it should not be a privilege to have adequate pain management.

TaLana said that any opportunity for education for the prescriber, staff who perform infusions, and others could be helpful. Patients can be seen and portrayed as medication seeking. Removing stigma and increasing empathy among all staff may help people needing care. Maria also discussed her need for an advocate at appointments because she will often break down due to heightened anxiety around past experiences.

Maria has created a Rare Disease Bulletin Board online using Padlet.

Announcements

a. Next meeting: Monday 16 October 2023 from noon to 1 pm via WebEx
b. Focus Topic: Maria and TaLana will attend the national NORD meeting.

Adjourn: 1 pm

ILLINOIS RARE DISEASE COMMISSION

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

---

Proposed Amendments to the Bylaws:

Illinois Rare Disease Commission

BYLAWS

NAME

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

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.

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 Commission, not including any vacant positions.

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.

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/<u>their</u> place until the next regularly scheduled election.

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 ~~7-11~~-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/<u>their</u> 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.

ARTICLE V

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

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.