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Illinois Rare Disease Commission

June 21, 2023

12-1 PM

Via Webex

<https://illinois.webex.com/illinois/j.php?MTID=m1e0cd36085a821f83fe8f1857b37ed75>

Agenda

- 1) Welcome and Introductions - *Ria P./all*
- 2) Late Submissions
- 3) Adoption of Agenda & Approval of Meeting Minutes (04/17/2023 and 05/15/23)
- 4) Old Business
 - a. Adoption/Amendment of Bylaws
 - b. Approval of the IRDC Annual Report of 2022
- 5) Public Comment
- 6) Discussion
 - a. Work Proposal for the Remainder of 2023
Collect commentary from constituents on focus areas:
 - i. Best practices in the context of Rare Disease
 - ii. Caregiving challenges for families
 - iii. Pain care for patients with rare diseases
 - iv. Access to genetic care/research
- 7) Announcements
 - a. Update from NORD: State Advocacy Coordinator Anissa Reed leaves
 - b. Next meeting: Monday 17 July 2023 from noon to 1 pm via WebEx
- 8) 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>

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 Commission, 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 ~~7-11~~-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/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.

