IDPH
ILLINOIS DEPARTMENT OF PUBLIC HEALTH

525-535 West Jefferson Street • Springfield, Illinois 62761-0001 • www.dph.illinois.gov

Illinois Rare Disease Commission

Monday July 15, 2024
12-1 PM
Via Webex
https://illinois.webex.com/illinois/j.php?MTID=m6175acd91d7060ca71c4b0d5239b61b0

Agenda

I. **Welcome and Introductions** *-Ria P/All*

II. **Late Submissions**

III. **Adoption of Agenda & Approval of Meeting Minutes**
   a. **Adoption of Agenda**
   b. **Approval of Meeting Minutes (6/17/24)**

IV. **Old Business**

V. **Public Comment**

VI. **Discussion**
   a. **New IRDC brochure**
   b. **Report from the Dysautonomia International Conference 28-30 June 2024**
   c. **Report from the North American Rare Disease Summit 11 July 2024**

VII. **Announcements**
Next meeting: Monday 19 August 2024 noon to 1 pm via WebEx

VIII. **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

Section 410 ILCS 445/15 - [Section scheduled to be repealed 1/1/2027] Study; recommendations

The Commission shall make recommendations to the General Assembly, in the form of an annual report through 2026, regarding:

(1) the use of prescription drugs and innovative therapies for children and adults with rare diseases, and specific subpopulations of children or adults with rare diseases, as appropriate, together with recommendations on the ways in which this information should be used in specific State programs that (A) provide assistance or health care coverage to individuals with rare diseases or broader populations that include individuals with rare diseases, or (B) have responsibilities associated with promoting the quality of care for individuals with rare diseases or broader populations that include individuals with rare diseases;

(2) legislation that could improve the care and treatment of adults or children with rare diseases;

(3) in coordination with the Genetic and Metabolic Diseases Advisory Committee, the screening of newborn children for the presence of genetic disorders; and

(4) any other issues the Commission considers appropriate.

The Commission shall submit its annual report to the General Assembly no later than December 31 of each year.

The Illinois Rare Disease Commission is a non-partisan committee to increase awareness of rare disease and orphan disease that affect the lives of 1 in 10 people. There are more than 8,000 named rare disorders and many unnamed.

The commission strives to build a triangle that moves mountains: **People, government and science.**

ABOUT US

The governor appoints the members of the IRDC.

Joyce Clay (Rare Disease Representative, Health Professional)

Tim Cunniff, Vice-Chair (Bioscience Industry Representative)

Stacey Feuer (Rare Disease Representative, Health Professional)

Talana Hughes (Rare Disease Representative, Rare Disease NPO)

Maria “Ria” Pollock, Chair (Rare Disease Representative)

Lara Pullen (Rare Disease Representative)

Sonya Harper (House Majority)

Bill Hauter (House Minority)

Linda Holmes (Senate)

JOIN THE COMMISSION

Submit your application for the Illinois Rare Disease Commission (board) along with a current resume at https://govappointments.illinois.gov/submit-an-application/

JOIN A PUBLIC MEETING

The commission meets monthly via WebEx to hear public comment, evaluate policy, and issue qualified commentary on rare disease issues.

Mo 17 July 2024 noon to 1 pm CST

Mo 21 August 2024 noon to 1 pm CST

Mo 17 September 2024 noon to 1 pm CST

Mo 16 October 2024 noon to 1 pm CST

Mo 20 November 2024 noon to 1 pm CST

Mo 18 December 2024 noon to 1 pm CST

CONTACT

To view upcoming meetings and agendas, visit: https://dph.illinois.gov/resource-center/advisory-boards/illinois-rare-diseases-commission.html

For more information, contact the IDPH facilitator, Joan V. Ehrhardt at joan.ehrhardt@illinois.gov, or the IRDC Chair Maria G. Pollock at mariapollock67@gmail.com.

ILLINOIS RARE DISEASE COMMISSION

DRAFT for REVIEW

The Illinois Rare Disease Commission purpose is to increase awareness of the more than 10,000 unique and rare disorders that impact the lives of over 1.5 million Illinois residents and their families.

“I was unable to regain my prior baseline of health and function despite care and therapy.” (Patient testimony, Samantha R., Minutes, September 2023)

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.” (Hank C., living with primary lateral sclerosis)”

“Nobody believed us,”
Ria Pollock,
September 2023.

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.” (TaLana Hughes, Minutes, September 2023)

See the full 2023 report …

https://tinyurl.com/RareReport2023

“Mothers are the most likely and heavily impacted lifelong care providers. As a result, those women are frequently impoverished and exhausted; left with very little in terms of financial and emotional resources … caregivers, family members, moms, do NOT have the breathing room for self-