IDPH
ILLINOIS DEPARTMENT OF PUBLIC HEALTH

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# Illinois Rare Disease Commission

**May 15, 2023**
**12-1 PM**
**Via Webex**
https://illinois.webex.com/illinois/j.php?MTID=m1e0cd36085a821f83fe8f1857b37ed75

## Agenda

In compliance with the Open Meetings Act, this virtual meeting serves as information gathering and discussion only.

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

II. **Late Submissions**

III. **Review of Agenda & Meeting Minutes (04/17/2023)**

IV. **Old Business**

V. **IRDC Semiannual In-person Meetings –** ***Jason R./All***
   a. Chicago (May/June 2023, October 2024)
   b. Springfield (February/March 2024) to coincide with Rare Disease Day 2024

VI. **Legislation Updates –** ***Katherine K/All***
   a. **SB0067** Newborn screening (NBS) expansion: metachromatic leukodystrophy (MLD)
   b. **SB 0376-SFA2**: Disclosing investigation to alleged child abusers

VII. **Public Comment**

VIII. **Announcements**
   a. **Next meeting: WEDNESDAY June 21, 2023 TBD**

IX. **Adjourn**

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 10 people. There are more than 7,000 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Section 410 ILCS 445/15 - [Section scheduled to be repealed 1/1/2027] Study; recommendations

> (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;
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> (2) legislation that could improve the care and treatment of adults or children with rare diseases;
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> (3) in coordination with the Genetic and Metabolic Diseases Advisory Committee, the screening of newborn children for the presence of genetic disorders; and
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> (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.

**410 ILCS 445/15**
Amended by P.A. 102-0671,§ 75, eff. 11/30/2021.
Amended by P.A. 101-0606,§ 5, eff. 12/13/2019.
Added by P.A. 099-0773,§ 15, eff. 1/1/2017.