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

Illinois Rare Disease Commission

April 17, 2023
12-1 PM
Via Webex
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Agenda

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

II. **Late Submissions**

III. **Approval of Agenda & Meeting Minutes (03/20/2023)**

IV. **Old Business**
   a. Adoption of bylaws
   b. Adoption of IRDC 2022 Annual Report

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** – *Katherine K/All*
   a. SB0067 Newborn screening (NBS) expansion: metachromatic leukodystrophy (MLD)

VII. **IRDC Flyer** - *All*

VIII. **Public Comment**

IX. **Announcements**
   a. Next meeting: Monday May 15, 2023 12-1 pm

X. **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).