

Illinois Rare Disease Commission

December 18, 2023

12-1 PM

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

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 (11/20/2023)
- IV. **Old Business**
 - a. Approval of Meeting Minutes (09/18/2023, 10/17/2023)
- V. **New Business**
 - a. IRDC 2023 Report
- VI. **Public Comment**
- VII. **Discussion** – *Ria P. /all*
 - a. Recap of 2023 Commission Members report
- VIII. **IRDC in-person meeting in Springfield for Rare Disease Day 2024**
(Thursday, February 29, 2024)
- IX. **Announcements**
 - a. Next meeting: TBD (Monday 15 January 2023 is Martin Luther King Jr State Holiday)
 - b. Illinois Rare Disease Day Monday 6-7 March 2024 is co-sponsored by iBio.
 - i. Opening Ceremony Monday 6 March 2024
 - c. IRDC In-person meeting Tuesday 7 March 2024 10 am to noon.
 - d. 2024 Meeting Calendar
- X. **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>
