

Illinois Rare Disease Commission

November 20, 2023

12-1 PM

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

Agenda

- I. **Welcome and Introductions** – *Tim C./all*
- II. **Late Submissions**
- III. **Adoption of Agenda & Approval of Meeting Minutes**
 - a. Adoption of Agenda
 - b. Approval of Meeting Minutes (09/18/2023, 10/17/2023)
- IV. **Old Business**
- V. **Public Comment**
- VI. **Discussion** – *Tim C. /all*
- VII. **IRDC in-person meeting in Springfield for Rare Disease Day 2024**
(Thursday, February 29, 2024)
- VIII. **Announcements**
 - a. Next meeting: Monday 18 December 2023 from noon to 1 pm via WebEx
 - b. Discussion: IRDC Annual Report to the Illinois General Assembly (What goes into the report?)
 - c. 2024 Meeting Calendar
- IX. **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>
