

Illinois Rare Disease Commission

Monday June 17, 2024

12-1 PM

Via Webex

<https://illinois.webex.com/illinois/j.php?MTID=m6175acd91d7060ca71c4b0d5239b61b0>

Agenda

- I. Welcome and Introductions *-Maria/All*
- II. Late Submissions
- III. Adoption of Agenda & Approval of Meeting Minutes
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 - b. Approval of Meeting Minutes (04/15/2024 and 5/20/24)
- IV. Old Business
 - a. Illinois Drugs and Therapeutics Advisory Board
- V. Public Comment
- VI. Discussion
 - a. Comments on the Healthcare Protection Act ([HB 5395](#))
 - b. Access to maintenance and pain medications – power map
 - c. IRDC Flyer *-All* [[IRDC Flyer 2023 - Google Docs](#)]
- VII. Announcements

Next meeting: Monday 15 July 2024 via WebEx
Topic continued: Access to Pharmaceuticals
- 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>
