

## Illinois Rare Disease Commission

Wednesday February 21, 2024

12-1 PM

Via Webex

<https://illinois.webex.com/illinois/j.php?MTID=maf5bc7c67c4c0ce29d330959d57bd782>

### Agenda

- I. Welcome and Introductions *-Maria/Commission Members*
- II. Late Submissions
- III. Adoption of Agenda & Approval of Meeting Minutes
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  - b. Approval of Meeting Minutes (1/22/2024)
- IV. Public Comment
- V. Old Business/New Business
  - a. Report: Inviting Legislators to Rare Disease Day *-TaLana Hughes*
  - b. Prioritizing recommendations of the 2023 Report (Discussion & Consensus)
  - c. Focus Topics for 2024 (Discussion & Vote)
- VI. Announcements
  - a. Reception & Rare Awards (co-sponsored by iBio and the rare community):  
Tuesday 5 March 2024, 5 pm at the Hotel Abraham Lincoln Springfield, 701 E. Adams St. Springfield, IL 62701
  - b. Rare Disease Day Breakfast with Legislators:  
Wednesday 6 March 2024, 7:30 am at the Stratton Building, M1, 401 S. Spring St. Springfield, IL 62704
  - c. IRDC Meeting Wednesday 6 March 2024 10:30 – 12:30 am at the Stratton Building, second floor, room M (in person and via WebEx)
- VII. Adjournment



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>

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