

Illinois Rare Disease Commission

October 23, 2023

12-1 PM

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

Agenda

Focus Topic: Best Practices and Standards of Care in the Context of Rare Disease



- 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 (09/18/2023)
- IV. Old Business - None
- V. New Business
 - a. Report from the NORD RDLA Summit – TaLana Hughes / Ria Pollock
- VI. Public Comment
- VII. Discussion: Best Practices and Standards of Care in the Context of Rare Disease
 - o Topic Leader: TBA
 - o Standards of Care / Best Practices: accountability mandate for health insurers, protecting the rights of patients and medical providers
 - o Best Practices for Research: the mandatory case study as a best practice to document rare patient's account and family history
 - o Best Practices for Illinois Policymakers: persons over policies pleading for an Illinois Rare Disease Act
- VIII. Announcements
 - a. Next meeting: Monday 20 November 2023 from noon to 1 pm via WebEx
 - b. Discussion topic: IRDC Annual Report to the Illinois General Assembly (What goes into the report?)
- 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>
