

Illinois Rare Disease Commission

January 15, 2025

12:00 – 1:00 PM Via Webex

<https://illinois.webex.com/illinois/j.php?MTID=m5b7d2f112d218f39852b2ca3d9ceb7df>

Draft Agenda

- I. Welcome and Introductions -*Maria/All***
- II. Late Submissions**
- III. Adoption of Agenda & Approval of Meeting Minutes (12/16/2024)**
- IV. Old Business: Approval of Annual Report 2024**
- V. Public Comment**
- VI. Discussion: 2025 Focus on State Programs Improvement for Rare Disease Patients and Researchers**
Creation of IRDC Workgroups (2 IRDC members)
 - a. Legislation: Watching for bill proposals from Illinois General Assembly that affect the rare disease community**
 - b. Research, data & statistics: In support or concern of policy and bills**
 - c. Community & Communication: Solicit public comment, notify community of IRDC and other events**
- VII. Announcements:**
 - a. Upcoming Meeting Wednesday February 19, noon to 1 pm via WebEx**
- VIII. 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>

Section 410 ILCS 445/15 - [Section scheduled to be repealed 1/1/2027] Study; recommendations

The Commission shall make recommendations to the General Assembly, in the form of an annual report through 2026, regarding:

- (1) the use of prescription drugs and innovative therapies for children and adults with rare diseases, and specific subpopulations of children or adults with rare diseases, as appropriate, together with recommendations on the ways in which this information should be used in specific State programs that (A) provide assistance or health care coverage to individuals with rare diseases or broader populations that include individuals with rare diseases, or (B) have responsibilities associated with promoting the quality of care for individuals with rare diseases or broader populations that include individuals with rare diseases;
- (2) legislation that could improve the care and treatment of adults or children with rare diseases;
- (3) in coordination with the Genetic and Metabolic Diseases Advisory Committee, the screening of newborn children for the presence of genetic disorders; and
- (4) any other issues the Commission considers appropriate.

The Commission shall submit its annual report to the General Assembly no later than December 31 of each year.
