

Illinois Rare Disease Commission

September 17, 2025

12:00 – 1:00 PM Via Webex

<https://illinois.webex.com/illinois/j.php?MTID=m3b95d597bb2c95c7045413a48769a7e5>

Draft Agenda

- I. Welcome and Call to Order - *Ria Pollock*
- II. Late Submissions -*Commission members*
- III. Adoption of Agenda & Approval of Meeting Minutes (8/20/25)
- IV. Old Business
- V. Public Comment
- VI. Discussion
 - a. Patient Registry Policy and Awareness
 - b. Overcoming Health Information Portability and Accountability Act (HIPAA) hurdles for positive Newborn Screenings
 - c. Provider education in Illinois: Developing CMEs about Rare Disease (example)
 - d. 2025 IRDC Draft Report (pick four focus topics): Newborn hearing screening fees, paratransit service oversight (secret shopper reports?), certified nursing assistants' compensation (HFS, DSCC), Prader-Willi syndrome (PWS) as a qualifying disability (HB2541/SB1651), Medicaid reimbursement rates (HB1786), coverage of new or custom-made medications, medical foods and garments (HB1770), supporting local infrastructure for Illinois Centers for Rare Disease network
- VII. Announcements
 - a. Upcoming Meeting Wednesday October 15, 12-1 pm via WebEx.
- VIII. Adjournment



ILLINOIS
**RARE
DISEASE**
COMMISSION

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Section 410 ILCS 445/15 - [Section scheduled to be repealed 1/1/2027] Study; recommendations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