IDPH
ILLINOIS DEPARTMENT OF PUBLIC HEALTH
525-535 West Jefferson Street • Springfield, Illinois 62761-0001 • www.dph.illinois.gov

Illinois Rare Disease Commission

Monday November 18, 2024
12:00-1:00 PM
Via Webex
https://illinois.webex.com/illinois/j.php?MTID=m6175acd91d7060ca71c4b0d5239b61b0

Agenda

I. Welcome and Introductions

II. Late Submissions

III. Adoption of Agenda & Approval of Meeting Minutes
  a. Adoption of Agenda
  b. Approval of Meeting Minutes (10/28/24)

IV. Old Business

V. Public Comment

VI. Discussion Annual Report 2024: Policy Recommendations
  In accordance with the Charge of the Illinois Rare Disease Commission Act of 2017
  a. Drug Coverage and Innovative Therapies
    i. State Programs: Assistance/Healthcare Coverage
    ii. State Programs: Promoting Quality of Care
  b. Legislation to Improve Care and Treatment
  c. Newborn Screening Recommendations
  d. Other Issues

VII. Announcements
The next meeting will be on Monday, December 16, 2024, noon to 1:00pm via Webex

VIII. Adjourn

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Section 410 ILCS 445/15 - [Section scheduled to be repealed 1/1/2027] Study; recommendations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