

Illinois Rare Disease Commission

**Wednesday March 6, 2024
10 - 11 AM**

IN PERSON:

**Stratton Building
401 S. Spring Street, Room 200-6S (M-1)
Springfield, Illinois 62706**

And Virtual Via Webex:

<https://illinois.webex.com/illinois/j.php?MTID=m06eb801607ddb34b00fabe600e133f90>

Agenda

- I. Welcome and Introductions -*Ria Pollock/Commission Members***
- II. Late Submissions**
- III. Adoption of Agenda & Approval of Meeting Minutes**
 - a. Adoption of Agenda**
 - b. Approval of Meeting Minutes (2/21/2024)**
- IV. Public Comment**
- V. Old Business/New Business/Discussion**
 - a. Focus Topic: Adequate Access to Genetic Care and Counseling**
 - b. Private Insurance Networks**
 - c. Medicaid**
- VI. Announcements**
 - a. Next meeting: Monday 15 April 2024 via WebEx: Access to Pharmaceuticals**
- VII. Adjournment**



The information shared is not necessarily reflective of the position of IDPH and is for informational purposes only.

Proposed Amendment to the Illinois Insurance Code
(215 ILCS 124) Sec. 10. Network adequacy

(c) The network plan shall demonstrate to the Director a minimum ratio of providers to plan beneficiaries as required by the Department.

(1) The ratio of physicians or other providers to plan beneficiaries shall be established annually by the Department in consultation with the Department of Public Health based upon the guidance from the federal Centers for Medicare and Medicaid Services ...

The Department shall consider establishing ratios for the following physicians or other providers:

(A) Primary Care;

(B) Pediatrics;

(C) Cardiology; ...(BB) Outpatient Dialysis;

~~and (CC) HIV;~~

and (DD) Genetic Medicine

and Genetic Counseling.

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>
