

Illinois Rare Disease Commission

Monday May 20, 2024

12-1 PM

Via Webex

<https://illinois.webex.com/illinois/j.php?MTID=m6175acd91d7060ca71c4b0d5239b61b0>

Agenda

- I. **Welcome and Introductions -*Maria/Commission Members***
- II. **Late Submissions**
- III. **Adoption of Agenda & Approval of Meeting Minutes**
 - a. **Adoption of Agenda**
 - b. **Approval of Meeting Minutes (04/15/2024)**
- IV. **Public Comment**
- V. **Old Business/New Business/Discussion**
 - a. **Access to Pharmaceuticals – Strategies for Access**
 - i. **Off-label uses**
 - ii. **Overcoming insurance denials**
- VI. **Announcements**

Next meeting: Monday 17 June 2024 via WebEx
Topic continued: Access to Pharmaceuticals
- VII. **Adjourn**



Appendix

Illinois Pre-authorization Act of 2022:

<https://www.ilga.gov/legislation/ilcs/ilcs3.asp?ActID=4201&ChapterID=22>

Cost Transparency SB 1618:

<https://www.ilga.gov/legislation/billstatus.asp?DocNum=1618&GAID=17&GA=103&DocTypeID=SB&LegID=146383&SessionID=112>

Clinician Administered Drugs SB1255:

<https://www.ilga.gov/legislation/billstatus.asp?DocNum=1255&GAID=17&GA=103&DocTypeID=SB&LegID=145492&SessionID=112>

Illinois Insurance Code 215 ILCS 5/356z.58 to 357.9 - Specific drug mandates:

<https://www.ilga.gov/legislation/ilcs/ilcs4.asp?DocName=021500050HArt.+XXIV&ActID=1249&ChapterID=22&SeqStart=111500000&SeqEnd=112900000>

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>
