IDPH
ILLINOIS DEPARTMENT OF PUBLIC HEALTH

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Illinois Rare Disease Commission

March 20, 2023

12-1 PM
Via Webex
https://illinois.webex.com/illinois/j.php?MTID=m1e0cd36085a821f83fe8f1857b37ed75

Agenda

I. **Welcome and Introductions** *- Ria P./All*

II. **Late Submissions** *- All*

III. **Approval of Agenda**

IV. **Old Business** *- Ria P./All*
   a. Minutes approval
   b. Bylaws adoption

V. **Review of Bills**
   a. HB 1024, Sickle Cell Prevention (Flowers)
   b. HB 3229, Illinois Insurance Code, Coverage Mandate (LaPointe)
   c. SB 1774, Illinois Clinical Trial Portal (Johnson)
   d. SB 2246, Errors of Child Abuse and Neglect Allegations (Lightfoot)

VI. **IRDC: Funding & Facilitation**
   a. Guest speaker (TBA)
   b. Discussion

VII. **Public Comment**

VIII. **Announcements**

IX. **Adjournment**

The **Illinois Rare Disease Commission** was established to increase awareness of rare and orphan diseases that impact the lives of 1 in 10 people. There are more than 7,000 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).