



ANNUAL REPORT 2022

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ILLINOIS RARE DISEASE COMMISSION

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INTRODUCTION

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.

OVERVIEW AND ACTIVITIES

LEGISLATIVE MANDATE

The Illinois Rare Disease Commission was established by the Rare Disease Commission Act (410 ILCS 445) to advise the state on issues pertaining to the care and treatment of individuals with rare diseases. Pursuant to 410 ILCS 445, the commission makes recommendations to the General Assembly in the form of an annual report. Commission activities extend through 2026, pursuant to Public Act 102-0671 (Section 75).

MEMBERSHIP

The commission is composed of 15 members:

Eleven members are appointed by the governor, are residents of the state, and are familiar with the concerns, needs, and recommendations of people with rare diseases based on their knowledge, experience, or position. A minimum of five such appointees are people who either are themselves affected with a rare disease or who have a family member living with a rare disease.

The final four members are policymakers:

- Two are from the Senate (one each appointed by the president and the minority leader)
- Two are from the House of Representatives (one each appointed by the speaker and the minority leader)

Members

Commission bylaws provide for meeting and conducting business with current active members. There were thirteen active governor-appointed members at the time of meeting, with additional prospective applicants pending approval. One active member resigned following the meeting (due to a change in residence outside of Illinois).

Governor Appointees

- Susan Axelrod (Rare Disease and Bioscience Industry Representative) - *resigned*
- Maria Bellefeuille, Cochair (Rare Disease Representative)
- Joyce Clay (Rare Disease Representative, Health Professional)
- Tim Cunniff (Bioscience Industry Representative)
- Stacey Feuer (Rare Disease Representative, Health Professional)
- Talana Hughes (Rare Disease Representative, Rare Disease NPO)
- Katherine Kim (Health Professional)
- Maria "Ria" Pollock, Cochair (Rare Disease Representative)
- Lara Pullen (Rare Disease Representative)
- Jason Rothstein (Rare Disease NPO)

Policymakers

- Jason Barickman
- Sonya Harper
- Linda Holmes

ACTIVITIES

The commission met November 14, 2022 under the leadership of Maria Bellefeuille, Chair. There were several new members and IDPH staff in attendance. Bylaw revisions were discussed. Approval was tabled due to less than two-thirds majority needed to amend bylaws. Maria Bellefeuille and Maria "Ria" Pollock were elected 2023 Commission Chair and Vice Chair respectively.

Prospective Priorities for 2023:

- Telehealth
- Provider availability and provider networks
- Insurance coverage and networks
- Health equity
- Education and outreach

Members are eager to meet in 2023.

NEXT STEPS

Next steps are to:

- Finalize the 2023 meeting schedule.
- Identify and approve members for empty seats.
- Determine priority topics and strategies.