



ANNUAL REPORT 2021

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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.

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).

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. The commission held its first meeting in December 2017, elected cochairs, and approved bylaws. The commission met regularly in 2018, but it subsequently fell dormant until being recently reestablished.

MEMBERSHIP

The commission is to be made up 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 seven active governor-appointed members at the time of the first 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

- Maria Bellefeuille, Chair (Rare Disease Representative)
- Joyce Clay (Rare Disease Representative, Health Professional)
- Stacey Feuer (Health Professional)
- Katherine Kim (Health Professional)
- Lara Pullen (Rare Disease Representative)
- Jason Rothstein (Rare Disease NPO)
- Allison Weisman (Health Professional) - *resigned*

Policymakers

- Jason Barickman
- Sonya Harper
- Linda Holmes

ACTIVITIES

The commission met December 15, 2021 for the first time since 2018 under the leadership of Maria Bellefeuille, one of the original cochairs. There were several new members and interested members of the public in attendance. The original bylaws were reviewed and revisions suggested to bring the bylaws into greater alignment with the act.

The current membership is eager to identify priorities for further discussion and action in 2022.

NEXT STEPS

Essential next steps to be completed for the commission to make progress are to:

- Finalize the 2022 meeting schedule.
- Identify and approve members for empty seats.
- Determine priority topics and strategies.

