Illinois Rare Disease Commission

ABOUT US

The Illinois Rare Disease Commission is a non-partisan committee to increase awareness of rare disease and orphan disease that affect the lives of 1 in 10 people. There are more than 7,000 different rare disorders that affect many Americans and their families. The Commission is made up of representatives from healthcare providers, patients and government officials.

CO-CHAIRS

Maria Bellefeuille
Christine Presta, RRT NPS

MEMBERS

Senator Jason Barrickman
Maria Bellefeuille- Cystic Fibrosis patient
Barbara Burton, M.D.
Jennifer Hammer, Illinois Department of Insurance
Representative Sonya Harper
Amy Leverenz- Parent representative
Felicia Norwood, Illinois Department of Health and Family Services
Representative David S. Olsen
Christine Presta, RRT NPS
Nirav Shah, M.D., Illinois Department of Public Health
Michael Tarantino, M.D.
Ann Weaver – Parent representative

OBJECTIVES

- Safety in the community
- Care in schools
- Insurance
- Geographical access to care
- Adding diseases to Newborn Screening
- Report submitted yearly on progress

CONTACT US

Interested persons may contact the Office of Health Promotion
at 217-785-4093 for information.

To view upcoming meetings and agendas please visit:
http://dph.illinois.gov/

2018 meetings:

Tuesday, March 27th at 10AM
Tuesday, May 15th at 10AM
Tuesday, August 14th at 10AM
Tuesday, October 30th at 10AM
Tuesday, December 18th at 10AM

All meetings abide by the Open Meetings Act.

Dial-in 1-888-494-4032; Access Code: 6749670741