

# 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

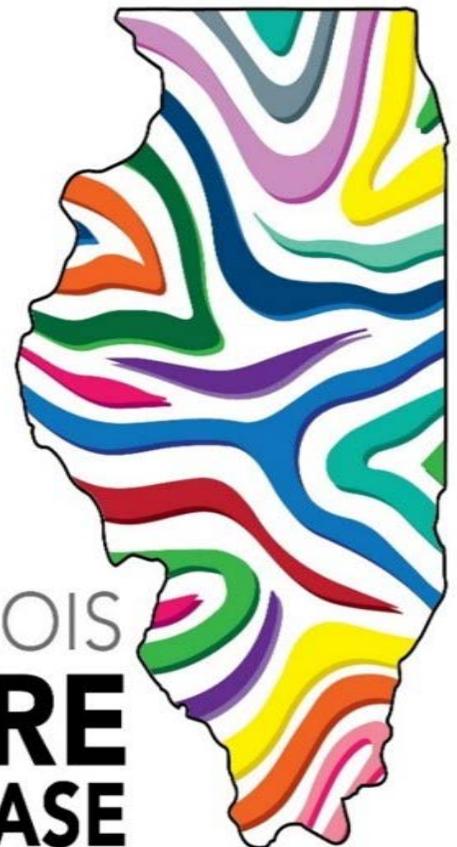
Maria Bellefeuille  
Christine Presta, RRT NPS

## 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



ILLINOIS  
**RARE  
DISEASE**  
COMMISSION  
COMMISSION  
DISEASE  
RAKE

## 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 27<sup>th</sup> at 10AM  
Tuesday, May 15<sup>th</sup> at 10AM  
Tuesday, August 14<sup>th</sup> at 10AM  
Tuesday, October 30<sup>th</sup> at 10AM  
Tuesday, December 18<sup>th</sup> at 10AM

All meetings abide by the Open Meetings Act.

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