

# **Illinois Rare Disease Commission**

## **Meeting Minutes - draft**

December 19, 2017

10:00 AM

69 West Washington St., 35th Floor, Chicago  
535 West Jefferson St., 5th Floor, Springfield

### 1. Welcome and Introductions

Call to order at 10:00 a.m.

Members present: Senator Barrickman; Maria Bellefeuille; Representative Harper; Amy Leverenz; Felicia Norwood; Representative Olsen; Christine Presta; Nirav Shah; Michael Tarantino; Ann Weaver

Others present: Nicole Niwa, Conny Mueller Moody

### 2. Election of Chairperson and Vice-Chairperson

- a. Motion by Director Shah to elect Maria Bellefeuille and Christine Presta, Co-Chairs
- b. 2<sup>nd</sup> by Director Norwood
- c. Motion Passed

### 3. Review and Approval of By-Laws

- a. Motion to approve the by-laws as presented by Rep. Olsen
- b. 2<sup>nd</sup> by Maria Bellefeuille
- c. Motion Passed

### 4. Selection of Meeting Dates and Times for 2018

- a. Upcoming meeting dates
  - January 16<sup>th</sup> at 10 a.m.
  - February 27<sup>th</sup> at 10 a.m.
  - March 20<sup>th</sup> at 10 a.m.

### 5. Discussion

- a. Topics of Discussion for future meetings
  - i. Concerns in the Communities
    1. Safety in the community
    2. Care in Schools
    3. ER procedures already in place

- ii. Insurance Coverage and Waivers, also Managed Care and Medicaid
- iii. Geographical Access to Care, therapies and treatments
- iv. Adding diseases to the newborn screenings
  1. Conny Moody of IDPH volunteered to present the department procedure of how to add a screening
- v. How to bridge with the Disability committee for invisible diseases
- vi. Create a white paper for rare diseases to explain the state of affairs and goals of the commission
- vii. Reach out to other commissions to see what they have accomplished and are working on
  1. North Carolina
  2. Ohio
  - 3.

6. Adjournment

- a. Motion to Adjourn by Rep. Olson
- b. 2<sup>nd</sup> Maria Bellefeuille
- c. Motion Passed

The meeting adjourned at 10:20 a.m.

Members:

Senator Barrickman

Maria Bellefeuille

Barbara Burton

Jennifer Hammer

Representative Harper

Amy Leverenz

Felicia Norwood

Representative Olsen

Christine Presta

Nirav Shah

Michael Tarantino

Ann Weaver