IDPH
ILLINOIS DEPARTMENT OF PUBLIC HEALTH

525-535 West Jefferson Street • Springfield, Illinois 62761-0001 • www.dph.illinois.gov

Illinois Rare Disease Commission

October 23, 2023
12-1 PM

Focus Topic: Best Practices and Standards of Care in the Context of Rare Disease

MINUTES

Name	Present (Y/N)	Role	Affiliation
***Maria "Ria" Pollock**	X	Affected / Caregiver; Advocacy Group	*(Chair)* Living with rare disease
Vacant	-	***Appointed***	
Joyce Clay		Affected / Caregiver; Health Professional	Daughter with rare disease
Tim Cunniff		Industry	*(Vice Chair)* Paragon Biosciences
Stacey Feuer	X	Affected / Caregiver; Health Professional	Living with rare disease
TaLana Hughes	X	Affected / Caregiver; Advocacy Group	Sickle Cell Disease Association of Illinois (SCDAI)
Vacant	-	*Provider*	
Lara Pullen	X	Affected / Caregiver; Advocacy Group; Industry	Chion Foundation
Stacey Pigott		***Pending***	
Vacant	**-**	***Appointed***	
Vacant	**-**	***Appointed***	
William Hauter	X	*Policymaker*	
Linda Holmes		Policymaker	Living with chronic illness
Sonya Harper	X	Policymaker	
Vacant	-	*Policymaker*	*TBD*

Attendees: Joan Ehrhardt, IDPH facilitator; Andrew Wright (Myotonic Dystrophy Type I), Karin Pritikin (health policy analyst living with rare disease), Lindsey Viscarra (State Policy Manager, NORD), Samantha Ropski (graduate student living with rare disease), Mary Ellen Baker (Vertex Pharmaceuticals), Matthew Botos, John Conrad (iBIO), Jon Vlasnik (Pharma Alexion, AstraZenica), The meeting was called to order by the Chair at 12:00 (with costume planning for Halloween and decor). Seconded by TaLana Hughes. Recording started at 12:00

Welcome and Introductions – Quorum reached at 12:04

Late Submissions – NBS Symposium 2023 update. Maria moved. Lara seconded. Approved by voice vote with none opposed, none abstaining. Karin asked if there were policies and channels for appeal for denials of care.

Adoption of Agenda & Approval of Meeting Minutes

- Adoption of Agenda - approved
- Approval of Meeting Minutes (09/18/2023) - deferred.

Old Business – None

New Business

- Report from the NORD RDLA Summit

Public Comment

Discussion Topic: Best Practices and Standards of Care in the Context of Rare Disease

Joan provided a brief overview of the Association of Public Health Laboratories Newborn Screening Symposium 2023.

Lindsey (state policy for western region) provided an overview of the national NORD meeting and on-site concurrent meeting of the Rare Disease Advocacy Council Summit state representatives.

TaLana shared her experience attending NORD and the Rare Disease Advisory Council Summit. TaLana felt that IRDC activities and achievements were in the middle, ahead of a few and looking to leadership from others.

Regarding best practices, Maria brought a statement from a member of the public. A mother received a medical order for palliative care for their child. They are having trouble finding a qualified provider to give palliative nursing care at home. Maria does not have a lot of details of their situation.

It was mentioned that it is difficult to “qualify” patients for palliative care. Lara also observed that practice guidelines are best crafted by the relevant professional organizations.

Stacey said patients and providers frequently confuse hospice care with palliative care. Palliative care is comfort care. Stacey added that education is needed. A campaign perhaps targeted at both health professionals and the lay public. Palliative care can be offered to anyone at any time. People must know to ask for it. Providers need to know to offer it. Lara suggested that families be informed to request a Palliative Care provider to be part of the multidisciplinary health care team. A directory of providers may help facilitate access. What is meant by palliative home care?

Karin (member of the public) said palliative care is not available to her because her condition, chronic pain, is not recognized or treated by the system. For her, comfort care = pain management.

Lara said she thinks of Palliative Care often as hospital based. TaLana asked if palliative care is an option at every institution, or are there access issues? Stacey said it may depend on insurance. There is an outpatient palliative medicine department at her organization. Home based care would require insurance approval, community based/outpatient care might be a better in between option vs. inpatient/in hospital care. Traveling to get to care is another barrier, e.g., for individuals too sick to travel. Lara asked what the solution would be, if wanting to spread/establish outpatient palliative care across communities statewide. Some states surveyed individuals in the rare disease community about unmet needs. That strategy could provide more information to inform models and activities to improve access.

Karin asked if the entryway into the system was also part of the problem? For example, triage from the ER waiting area into a patient room. Can rare disease patients be fast-tracked, such as through flagging in the medical record?

Stacey said she thought a survey would be a good next step. She said she was not sure if the committee or a subcommittee would work on that. Lara suggested using NORD resources to assist with survey templates and contacts. TaLana agreed with this suggestion. She said that she would like to share with her organization to help raise awareness and knowledge about palliative care. Templates and examples from NORD were mentioned at the national NORD RDAC meeting TaLana and Maria attended.

Announcements

- Next meeting: Monday 20 November 2023 from noon to 1 pm via WebEx
- Discussion topic: IRDC Annual Report to the Illinois General Assembly
  Ria asked members to review minutes and identify essential elements for the report.

The meeting adjourned at 12:58.

The **Illinois Rare Disease Commission** was established to increase awareness of rare and orphan diseases that impact the lives of 1 in 4 people. There are more than 8,000 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). ILCS 445 can be found here: https://casetext.com/statute/illinois-compiled-statutes/health-and-safety/chapter-410-public-health/diseases/410-ilcs-445-rare-disease-commission-act