

**SUMMARY**  
**Approved May 15, 2014**

**ILLINOIS DEPARTMENT OF PUBLIC HEALTH  
MULTIPLE SCLEROSIS (MS) TASK FORCE MEETING**

**Thursday, March 27, 2014  
11:00 a.m. to 1:00 p.m.**

**Present:** Nancy Arndt, Jeremy Barewin, John Blazek, Melanie Dumlao, Maureen Linehan Howard, Todd Marvel, Meghan Melone, Tarin Lorenz, Catherine O'Connell, Kathy Preissner, Jacob Sosnoff. IDPH Representatives: Conny Moody, Rhonda Clancy

**Absent:** Matthew McCoyd, Matthew Petry

- *Welcome and Introductions*  
Conny Moody, Assistant Deputy Director, Office of Health Promotion, Illinois Department of Public Health, welcomed members and asked for introductions.  
  
John Blazek, President, National MS Society, Chicago Chapter also welcomed members and stated his support of task force efforts.
- *Adoption of Agenda*  
The task force unanimously adopted the agenda.
- *Update on MS Task Force Members*  
Rhonda Clancy, Task Force Coordinator, Office of Health Promotion, Illinois Department of Public Health, thanked members for timely submission of nomination forms. Rhonda explained nomination packets are undergoing internal approval and that once finalized each member will receive a letter officially welcoming them to the task force. Members are being recruited for four remaining designations.
- *Development of Illinois' Legislation/Senate Bill 1640 and Overview of New Jersey's Task Force Efforts (model for Illinois legislation)*  
Maureen Linehan Howard, National MS Society, Chicago Chapter shared how the Illinois legislation was developed using New Jersey's legislation as a model. She suggested using national data to focus Illinois' efforts to develop recommendations.
- *Task Force Recommendations—Process to Complete and Timelines*  
Conny stated the purpose of the task force is to develop and report findings and recommendations to the Governor and the General Assembly, along with any legislative proposal recommendations, no later than December 31, 2015. The task force is abolished on January 1, 2016.

The suggestion was made to inquire what other states are doing (successes and challenges) related to development of MS recommendations and/or initiatives.

Attention will be placed on care and treatment environment because of the changes to access

to care, types of care, research resulting from the Affordable Care Act.

NMSS support groups could be a good place to gather “real life” stories and needs of constituents and major issues.

IDPH will consider developing a website/page to raise awareness of MS and to solicit public and professional comments to draft recommendations; and IDPH will explore the feasibility of offering a mailbox for public questions, posting MS Task Force meeting summaries, and other resources and tools. MS Society staff offered to help link people with MS and professionals to the site for comment submission. Research centers, local MS chapter offices, and support efforts could be on site as well. Rural and urban needs, resources and access to care will be assessed for potential inclusion.

One potential recommendation discussed was to track MS cluster(s) in Illinois; and perhaps pursue diagnostic tracking and resource tracking (Neuro, partners in MS Care). NMSS has a national team creating a map of resources in Illinois.

It was suggested to use SB 1640 cited strategies (i.e. identify and address unmet needs, provide greater access to various treatments and therapeutic options, and improve education and awareness) as a starting point to identify task force recommendation priorities. Members urged inclusion of the public and health care professionals (neurologists, PTs, OTs, MS specialty physicians, etc.) in addressing these issues. Also, recommendations should be a “wish list” of what could be achieved in Illinois, should funding become available.

The group discussed a preference to meet in person for the first few meetings and potential for conference calls or video-conferencing for consecutive meetings. Members will explore the need for subcommittees to address specific topic areas.

Conny shared travel reimbursement provisions for “actual and necessary travel expenses associated with meetings of the Task Force” (By-laws, Section 6-1), which must be at state rate costs and accompanied by a receipt. Rhonda will send an expense form to members.

- *Status of Task Force By-laws*

A motion was made by Jacob Sosnoff and seconded by Todd Marvel to amend Section 1-4 to read: **Members shall be legal residents and/or licensed and currently practicing in their profession in the state of Illinois.**

A motion was made by Todd and seconded by Maureen to finalize the By-laws at the next Task Force meeting.

- *Selection of Officers—Chair and Vice-chair*

Maureen offered to serve as Task Force Chair; a motion was made by Jacob and seconded by Nancy Arndt. Maureen was unanimously voted Chair.

Jacob Sosnoff offered to serve as Vice-Chair; a motion was made by Nancy and seconded by Todd. Jacob was unanimously voted Vice-Chair.

Rhonda will serve as secretary and meeting coordinator.

- *Future Meeting Dates/Locations*

The next meeting was scheduled for Thursday, May 15 from 1:00 to 3:00 p.m. at the MS Society office (Monroe and Canal Streets) in Chicago. An agenda and directions will be sent to members.

- *Adjourn*

The meeting adjourned at 1:00 p.m. Motion made by Maureen, seconded by Kathy Preissner.