

## SUMMARY

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

**Thursday, May 15, 2014**

**1:00 to 3:00 p.m.**

*National MS Society, Greater Illinois Chapter  
525 W. Monroe, Suite 900  
Chicago, Illinois 60661*

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

**Absent:** None

- 1:00 p.m.     *Welcome*  
Conny Moody, Assistant Deputy Director, Office of Health Promotion, Illinois Department of Public Health, welcomed members and asked for introductions.
- 1:10     *Approval of March 27 Meeting Summary*  
Kathy Preissner motioned to approve March 27 minutes; Todd Marvel seconded.
- Approval of By-laws Revisions*  
Nancy Arndt motioned to approve By-laws; Meghan Melone seconded.
- 1:15     *Task Force Recommendations Based on Legislation*  
Maureen Linehan Howard, Chair, MS Task Force; Group Discussion
- Categories and Topic Areas-Draft  
The TF discussed categories and topics in detail. Rhonda developed a list of categories and TF member volunteers to develop first draft of categories for final report. This list is attached.
  - Timeline-Draft  
After this meeting, Maureen, Jacob and Rhonda discussed:
    - ✓ **June 17<sup>th</sup>** – MSTF members review and confirm the list of MS report framework recommendations re: who volunteered to assist in writing particular sections by.
    - ✓ **June 25** – “meeting” a conference call to brainstorm detailed content for each section of the report (from attached list).
    - ✓ **July 17** – Request that MSTF individuals/groups complete a first draft on their area(s) (Rhonda offered to facilitate conference calls to do so) by. Drafts will be forwarded to the full MSTF for review prior to next in-person meeting.
    - ✓ Schedule our next in-person meeting in Chicago (MSS office?). MSTF members will present their drafts to the full TF and solicit group input.

- ✓ **July 23 – August 8** - Writers will update/revise drafts and submit to Rhonda by August 8.
- ✓ **October 1** – Maureen, Jake and Rhonda will compile all sections into a report for MSTF review and comment by. The final draft will be submitted to IDPH approval process.

2:00

*MS Webpage Development- Conny Moody and Group Discussion*

Conny explained that the information on the MS Task Force and multiple sclerosis should be accessible to the public. Conny confirmed that the Department will be able to post a page on the Department of Public Health site. The page cannot include recommendations for health care providers and services. There can be a public comment section for persons to provide input on the final draft of the report. The information will be separated for patients, researches, and providers.

Meghan suggested inclusion of the National MS Society, Greater Illinois Chapter link. ([www.msillinois.org](http://www.msillinois.org)) Dr. Bernard recommended [www.danaweb.org](http://www.danaweb.org), which provides information about different neurologic disorders and has a section for children.

Dr. Bernard inquired if the site could be bilingual. Conny explained the Department does not have specific bilingual pages but provides information in different languages via reports and brochures. The Department's Disability and Health staff can assist to make the site compatible and accessible for people with disabilities. Tarin suggested providing links to the sites' bilingual landing pages and said that she will send links to Rhonda.

Todd recommended that the site link to "NARCOMS", and in parentheses cite "Multiple Sclerosis Patient Registry." Todd also suggested including a link for the Rocky Mountain MS Center, which includes information on complementary therapies.

Tarin asked Dr. Bernard if [www.danaweb.org](http://www.danaweb.org) has information on pediatric MS. Dr. Bernard thought it was more educational activities for children about neurological disorders. Meghan said that she would look up links on neurology for pediatric patients and send to Rhonda or suggested a link from the National MS Society page on pediatric MS.

Maureen asked the MSTF members if they were in favor of starting the page; members agreed.

2:30

*New Jersey's Task Force Report (model for Illinois legislation)*

The report was not accessed at the time of this meeting and will be discussed at a future meeting.

3:00

*Next Meeting and Adjournment*

June 25 via conference call (changed from an in-person meeting)

## **Recommendation Framework for MS Task Force (MSTF) Report**

The following categories, and topics related to each category, are the framework for the MSTF to develop recommendations to address Multiple Sclerosis, and are based on the current legislation.

As a result of our May 15<sup>th</sup> meeting, names of MSTF members and colleagues to assist in writing the first draft report are included. Please contact Rhonda Clancy at [Rhonda.clancy@illinois.gov](mailto:Rhonda.clancy@illinois.gov) if corrections are needed to the list. Thank you

### **Recommendation Categories**

### **MSTF Members/Colleagues as Writers**

- 1) Identify and Address Unmet Needs .....Jacob Sosnoff
  - Data Collection
    - IDPH
    - Advanced MS morbidity/mortality rate
- 2) Access to Treatments.....Kathy Preissner
  - Physical access to medical care
    - Exam tables, diagnostic equipment
  - Financial access.....Kathy Preissner, Nancy Arndt
    - Caps and co-pays
    - Rehab
  - Geographic Access.....Todd Marvel, Melanie Dumlao
    - Rural areas- south eastern area
  - Knowledgeable Providers.....Matt McCoyd, Nancy Arndt,
    - Hospitalist
    - Discrimination Issues
    - Healthcare disparities.....Dr. Jacqueline Bernard
  - Financial Obstacles to Home and Community-Based Services.....Tarin Lorenz, Cathy O’Connell
    - Eligibility
    - Home mod
    - Cost of care
  - Pharmacologic costs.....Nancy Arndt
  - Research.....Jacob Sosnoff
  - Advanced MS – mortality.....Dr. Jacqueline Bernard (guest)
- 3) Education and Awareness
  - Public Awareness.....Meghan Melone, Jeremy Barewin
  - Professional Education .....Matt McCoyd
    - Healthcare disparities
- 4) Financial Burden for Persons with High Level of Disability.....Tarin Lorenz, Nancy Arndt
  - Maximize quality of life