National
Multiple Sclerosis
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News Sheets

CHAPTER PRESIDENTS

December 2, 2011	CC:
Chapter Manual Revised	

Significant changes to the Chapter Manual have been made during the past year, which were approved by the Chapter Relations Committee at its November 2011 meeting.

Most of the changes are due to structural changes that have been made and previously communicated (National Program Expense [NPE] allocation process, development of regions, Core Values, Conflict of Interest, Society Employee Handbook [to be issued by calendar year end], etc.). There also have been limited changes to many other sections of the Chapter Manual.

The Chapter Manual, (Revised November 2011) is posted on Share Point under Chapter Management Information.

Also posted on SharePoint in the same location is an Executive Summary of the approved changes and a Chapter Manual Users Guide, which provides a brief summary of common policy and operational questions that are most frequently asked by chapter boards.

From: Craig Weber
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PROGRAMS & SERVICES

December 2, 2011	**CC:** All
Treatment Decision Webinars	

As therapies to manage MS become more effective, they will also carry increased risks – and the ability to think clearly about these relative benefits and risks will be essential for everyone affected by MS. Helping our clients feel better equipped to make comfortable, informed treatment decisions in the days ahead will be a high priority for all of us.

In early December, we will be offering a Webinar entitled Helping Our Clients Make Comfortable Treatment Decisions: Tips for Thinking Clearly about Benefits and Risks. Based on very positive feedback about the workshop on this topic at our National Conference, we decided to make it available nationwide. Our goal is to help chapter staff and our IRC specialists feel prepared to discuss these issues with people living with MS and their family members.

For those who are unable to attend either one of the scheduled programs, the presentation will be recorded and archived on SharePoint. In addition, a slide deck with talking points will be made available so that chapters can use the program locally with their clients.

Please join one of the following two calls – and invite other staff members who might benefit from this presentation to join as well.

Topic: Treatment Decisions - Presented By Roz Kalb
Date: Wednesday, December 7, 2011
Time: 1:30 pm, Mountain Standard Time (Denver, GMT-07:00)
Meeting Number: 764 251 070
Meeting Password: (This meeting does not require a password.)

To start or join the online meeting
Go to
https://nmss.webex.com/nmss/j.php?ED=158733132&UID=481562102&RT=MiM2

Topic: Treatment Decisions - Presented By Roz Kalb
Date: Friday, December 9, 2011
Time: 11:00 am, Mountain Standard Time (Denver, GMT-07:00)
Meeting Number: 760 139 085
Meeting Password: (This meeting does not require a password.)

To start or join the online meeting
Go to
https://nmss.webex.com/nmss/j.php?ED=158733217&UID=481562102&RT=MiM2

Teleconference information for both calls:
1-800-910-3597
ID: 15122898#

If you have any questions about this program, please contact:

Rosalind Kalb
rosalind.kalb@nmss.org
212-476-0479

Debra Frankel
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RESEARCH/CLINICAL UPDATE

December 2, 2011

New & Free Health Professional Resource: MS Diagnosis and Management Healthcare Professional Pocketcard Set & App

The Society's Professional Resource Center (PRC) partners with health care professionals to enhance quality of care and increase access to care for people living with MS. We are pleased to announce a new tool and resource to assist healthcare professionals with important information on the diagnosis and management of MS.

The "MS Diagnosis and Management Healthcare Professional Pocketcard Set and App" is a concise collection of important and easy-to reference information on the diagnosis and management of MS and is available as a FREE downloadable Apple and Droid "App" and/or printed plastic pocketcard set.

Highlights of this resource include:
• Signs and symptoms characteristic of MS
• The four MS disease courses
• 2010 Revised McDonald Diagnostic Criteria for MS
• Differential diagnoses
• Elements of the diagnostic workup, including typical findings on brain and spinal MRI, and cerebrospinal fluid analysis
• Common clinically-isolated syndrome presentations
• Treatment strategies including disease-modifying medications and relapse and symptom management
• Assessment scales including the Kurtzke Functional Systems Scores, Kurtzke Expanded Disability Status Scale, Bladder Control Scale, and Two-Question Screening Tool for Depression
• National MS Society resources for clinicians and their patients

(Below is an example of the first 2 of the 6 sections of the pocketcard set/App.)

Multiple Sclerosis

Diagnosing Multiple Sclerosis

A diagnosis of MS requires evidence of

1) Signs and symptoms that are consistent with inflammatory demyelinating disease
2) Dissemination in time
3) Dissemination in space
4) No other explanation for the clinical and paraclinical findings

Diagnostic Algorithm (Miller et al., 2008)

Symptoms Consistent with Inflammatory Demyelinating Disease
↓
Exclude Non-Demyelinating Syndrome → Determine Dx of Non-IDD
↓
Not MS ← Classify IDD → Consistent with MS
↓
2010 Revised McDonald Criteria for Dissemination in Time and Space
↓ ↓
MS established | MS not yet established

Signs and Symptoms Consistent with Inflammatory Demyelinating Disease

Visual	Blurred vision, unilateral loss of vision, oscillopsia, diplopia
Motor	Limb weakness, spasticity, hyperreflexia
Sensory	Numbness, paresthesias, dysesthesias, Lhermitte's sign, "MS hug", trigeminal neuralgia, allodynia, hyperpathia
Cerebellar	Tremor, ataxia, incoordination
Genitourinary	Urgency/frequency/retention, incontinence, frequent UTI, constipation, impotence, anorgasmia, dyspareunia
Neuropsychiatric	Impairment of memory, attention, and/or processing speed, depression, irritability
Prominent, intractable fatigue with no other explanation	

Differential Diagnoses

Common Differentials (Manhall and Mayer, 2001)

V	Vascular	Multiple lacunar infarcts, CADASIL, spinal arteriovenous malformation
I	Infectious	Lyme disease, syphilis, HIV myelopathy, PML, HTLV-I myelopathy
T	Traumatic	Spondylitic myelopathy
A	Autoimmune	NMO, acute disseminated encephalomyelitis, CNS vasculitis, Behcet syndrome, sarcoidosis, SLE
M	Metabolic/toxic	Central pontine myelinolysis, vitamin B12 deficiency, vitamin B6 deficiency, radiation, hypoxia
I	Idiopathic/ genetic	Spinocerebellar degeneration, Friedreich ataxia, Arnold-Chiari malformation, adrenoleukodystrophy, metachromatic dystrophy
N	Neoplastic	CNS lymphoma, glioma, paraneoplastic encephalomyelitis, metastatic cord compress.
S	Psychiatric	Conversion disorder

Neuroinflammatory Disorders

Acute disseminated encephalo-myelitis (ADEM)	Features	• Isolated postinfectious or postvaccinal autoimmune attack on the CNS • Diffuse demyelination, occasionally with fulminant hemorrhagic component (acute hemorrhagic encephalomyelitis or leukoencephalitis)
	Symptoms	• Encephalopathy: confusion, irritability, AMS (somnolence to coma) • Multifocal deficits, fever, meningismus (headache, photophobia, stiff neck)
	Imaging	• Large (> 1 to 2 cm) multifocal, hyperintense, bilateral, asymmetric lesions in the supra-/infratentorial white matter on T2-weighted or MRI FLAIR images • Gray matter, especially basal ganglia and thalamus, may be involved
Optic neuritis	Features	Usually a clinically isolated syndrome (CIS) caused by an inflammatory condition or idiopathic, but may be associated with MS or ADEM
	Symptoms	• Headache and painful eye movements followed by vision loss, pupillary defect (Marcus Gunn pupil), or visual field defects • Usually unilateral in adults but may be bilateral in children < 12 yo
	Imaging	Gadolinium MRI shows acute demyelination confined to optic nerve
Transverse myelitis	Features	• Spinal cord dysfunction typically owing to inflammatory lesion • Usually presents as a CIS, but may be associated with MS or ADEM
	Symptoms	Unilateral or bilateral motor or sensory deficits such as paresthesias, weakness, sphincter dysfunction; can occasionally be more severe, including paraplegia and urinary retention
	Imaging	Gadolinium-enhancing lesions on MRI spreading over 1 or more segments
Neuromyelitis optica	Features	• Dx requires ON, myelitis, and 2 out of the following 3: longitudinally extensive spinal cord lesion ≥ 3 segments in length; brain MRI nondiagnostic for MS; NMO-IgG seropositivity (Wingerchuk et al, 2007). • More common in non-Caucasians, especially Asians • Rule out sarcoid, SLE, Sjogren's or other vasculitis
	Symptoms	Combination of concurrent or sequential bilateral optic neuropathy and transverse myelitis

S. v. Stuckrad-Barre

www.nationalMSsociety.org – 1-800-344-4867

Features Suggestive of MS	Red Flags for Other Diagnoses
• Relapses and remissions • Onset between ages 15 and 50 • Optic neuritis • Lhermitte sign • Internuclear ophthalmoplegia • Fatigue • Uhthoff phenomenon	• Steady progression • Rigidity, sustained dystonia • Seizures • Early dementia • Onset before age 10 or after age 50 • Absence of sensory or genitourinary symptoms • Deficit developing within minutes • Cortical deficits (aphasia, apraxia, alexia, neglect)

2010 Revised McDonald Diagnostic Criteria for MS

2010 Revised McDonald MS Diagnostic Criteria[1]

Diagnosis of MS requires elimination of more likely diagnoses and demonstration of dissemination of lesions in space (DIS) and time (DIT)*

CLINICAL (ATTACKS)	LESIONS	ADDITIONAL CRITERIA TO MAKE DX
2 or more	Objective clinical evidence of ≥ 2 lesions or objective clinical evidence of 1 lesion with reasonable historical evidence of a prior attack	None. Clinical evidence alone will suffice; additional evidence desirable but must be consistent with MS
2 or more	Objective clinical evidence of 1 lesion	DIS; OR await further clinical attack implicating a different CNS site
1	Objective clinical evidence of ≥2 lesions	DIT; OR await a second clinical attack
1	Objective clinical evidence of 1 lesion	DIS OR await further clinical attack implicating a different CNS site AND DIT; OR await a second clinical attack
0 (progression from onset)		One year of disease progression (retrospective or prospective) AND at least two of: DIS in the brain based on ≥1 T2 lesion in periventricular, juxtacortical or infratentorial regions; DIS in the spinal cord based on ≥2 T2 lesions; or positive CSF

[1] Polman et al. Diagnostic criteria for multiple sclerosis: 2010 revisions to the McDonald Criteria. Ann Neurol 2011;69:292-302. *Time course for DIS and DIT

Paraclinical Evidence in MS Diagnosis

Evidence for Dissemination of Lesions in Space (DIS)[2]	Evidence for Dissemination of Lesions in Time (DIT)[2]
≥ 1 T2 lesion in at least two out of four areas of the CNS: periventricular, juxtacortical, infratentorial, or spinal cord • Gadolinium enhancement of lesions is not required for DIS • If a subject has a brain stem or spinal cord syndrome, the symptomatic lesions are excluded and do not contribute to lesion count	• A new T2 and/or gadolinium-enhancing lesion(s) on follow-up MRI, with reference to a baseline scan, irrespective of the timing of the baseline MRI or • Simultaneous presence of asymptomatic gadolinium-enhancing and non-enhancing lesions at any time
Evidence for Positive CSF Oligoclonal IgG bands in CSF (and not serum) or elevated IgG index	• Swanton KL et al. Lancet Neurology 2007;6:677-686 (Swanton KL et al. J Neurol Neurosurg Psychiatry 2006;77:830-833 • Montalban X, et al. Neurology 2010;74:427-434

These diagnostic criteria were developed through the consensus of the International Panel on the Diagnosis of MS. See cited articles for details. Funding through National Multiple Sclerosis Society (USA) and European Committee for Treatment and Research in MS; additional support from the Multiple Sclerosis International Federation and MS Ireland

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http://www.nationalMSsociety.org/PRC, MD_Info@nmss.org

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Healthcare Professional Outreach:

- On December 8, an email will go to approximately 95,000 healthcare professionals, including neurologists, general/family practitioners, OB/Gyns, Society Clinical Fellows, etc. with information and an invitation to download this free App. (This email will also go out every few months over the next 18 months.)
- This resource will also be promoted at events such as the Academy of Neurology and at the 2012 Consortium of MS Centers Conference.
- The link to download the free app can be found on the "For Professionals" section of the Society's website at http://www.nationalmssociety.org/prc.
- In addition, **The Professional Resource Center will be providing 20 printed pocketcards and 40 color promotional flyers to each chapter (at no expense to the chapter). Chapters can also request up to an additional 30 more pocketcard sets and 40 more color flyers.** (We anticipate that more card sets will be available later in the year as well.) While the cards and flyers will remain free, chapters will be asked to pay shipping costs for these additional resources. To request additional pocketcards and flyers, please send your request to chapterorders@nmss.org.
- Chapters are encouraged to reach out to local health care professionals and distribute the pocketcard set and color promotional flyers as well.

-- Questions? Roz Kalb, Rosalind.kalb@nmss.org , Vice President, Professional Resource Center

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RESEARCH/CLINICAL UPDATE

	cc: Chapter President, Programs, Development

December 2, 2011

Sign Up to Receive Emails Relating to MS Research Promotion

Based on requests we have received from staff, we are inviting chapter staff to sign up to receive emails relating to promoting awareness of research, such as the following items, which are already being received by chapter staff who act as liaisons to their volunteer Research Advocates:

- News items about research that are posted on the web site and included in news sheets
- Notices of upcoming events relating to research, such as national donor calls or webcasts
- The bi-monthly Research Promotion Update, which highlights events and resources relating to promoting awareness of Society research efforts.

If you are interested in receiving these emails, please contact Sara Bernstein at sara.bernstein@nmss.org.

Please visit the Research Promotion section of SharePoint for research promotion resources, including past issues of the Research Promotion Update: http://intranet.nmss.org/Topics/cr/Pages/ResearchPromotion.aspx.

For information about the Research Advocates Program, feel free to contact me and/or view information about the Program on SharePoint: http://intranet.nmss.org/Topics/cr/Pages/ResearchAdvocatesProgram.aspx

-- Sara Bernstein, Research Information Manager, Research Programs
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RESEARCH/CLINICAL UPDATE

	cc: Chapter President, Programs, Development

December 2, 2011

Tovaxin® (T cell vaccination) granted fast-track designation by FDA

The company Opexa Therapeutics (The Woodlands, TX) announced that the experimental therapy Tovaxin® has been designated by the U.S. Food and Drug Administration as a "Fast Track Product" for the treatment of secondary-progressive MS (http://www.nationalmssociety.org/about-multiple-sclerosis/progressive-ms/secondary-progressive-ms/index.aspx). Tovaxin is a personalized vaccine that aims to induce immunity against T cells that attack the brain and spinal cord in MS. It uses a person's own immune cells, which are removed, manipulated, and then reintroduced by under the skin injections.
The Fast Track designation may expedite its future review by the FDA after the company submits results of future phase III trials. The company is planning to begin a Phase IIb clinical trial of Tovaxin in secondary-progressive MS "subject to securing the necessary resources," according to a November 8, 2011 press release.

Results so far: A one-year, multi-center trial of Tovaxin was conducted in 140 people with relapsing-remitting MS and 10 people who had experienced a neurological episode that put them at possible risk for being diagnosed with MS. The TERMS study found Tovaxin to be safe, but did not achieve statistical significance in the primary endpoint evaluating the cumulative number of active MRI lesions in those on active therapy versus those on placebo (*Multiple Sclerosis*, published online November 6, http://msj.sagepub.com/content/early/2011/11/07/1352458511428462.long). Analyzing a subset of participants after the study, investigators found that Tovaxin stabilized or reduced disability as measured by the EDSS scale, and the average number of relapses in a year.

Tovaxin is a trademark of Opexa Pharmaceutics.

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RESEARCH/CLINICAL UPDATE

	cc: Chapter President, Programs, Development

December 2, 2011

Researchers Recruiting African Americans with MS and Family Members Across the U.S. for Genetics Studies – *Key to finding cause of MS and better treatments*

Investigators at the University of California, San Francisco, are recruiting African Americans with MS and their family members across the country for genetic studies. For one study, the team is looking for an African American family that has three generations of family members with MS, or a family with multiple people with MS within one generation. There is no cost to people who agree to participate.

Rationale: Genes are known to play a role in who is susceptible to developing multiple sclerosis, and may also influence the course of the disease. People living with MS and their family members can make a difference in studies searching for these genes by donating their DNA from blood samples. Identifying the exact location of MS genes could help determine who is at risk for developing the disease, and may provide clues to its cause, prevention and better treatment. Focusing on ethnic groups with lower susceptibility to MS (such as African-Americans) and higher susceptibility (such as individuals of Northern European descent), and searching for what is common and what is different in their genes may help pinpoint regions that contain MS genes. Large number of participants and their families are needed to accelerate this research.

Details: It is not necessary to travel to San Francisco to participate in this study. Once an individual has gone through the initial phone screening and has agreed to participate, they are sent a kit via express mail. The kit includes a consent form, a health information privacy form, and a medical records release form (only for participants with MS). The kit also includes everything necessary for the blood draw, which can be taken to a local lab or clinic, where the blood can be drawn and then returned in a prepaid envelope to the UCSF MS Genetics Lab. There is no cost to the study participants.

At all times, records and other information that is shared with investigators are handled in a confidential manner. There is no charge for participation.

Contact: If you are interested in participating in this study please click on the following link and fill out the UCSF Electronic Intake form:
https://redcap.ucsfopenresearch.org/surveys/?s=RPKGc4.

If you would like more information about this study, please contact the research coordinator:
Cuquita Gomez
Phone: (415) 502-4567
Toll Free Phone: 1 (866) MS-GENES or 1 (866) 674-3637
E-mail: refujia.gomez@ucsf.edu
Study Web site: http://neurology.ucsf.edu/msdb/