

## WEBINAR & TELELEARNING SERIES



# Your Whole Health, Your Whole Team: Decision-Making and Multiple Sclerosis

March 8, 2016

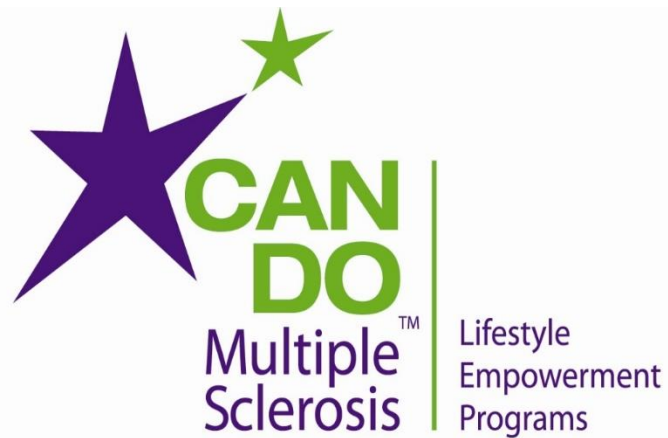
*Presented by:*



EMD Serono | Teva Pharmaceuticals | Acorda Therapeutics

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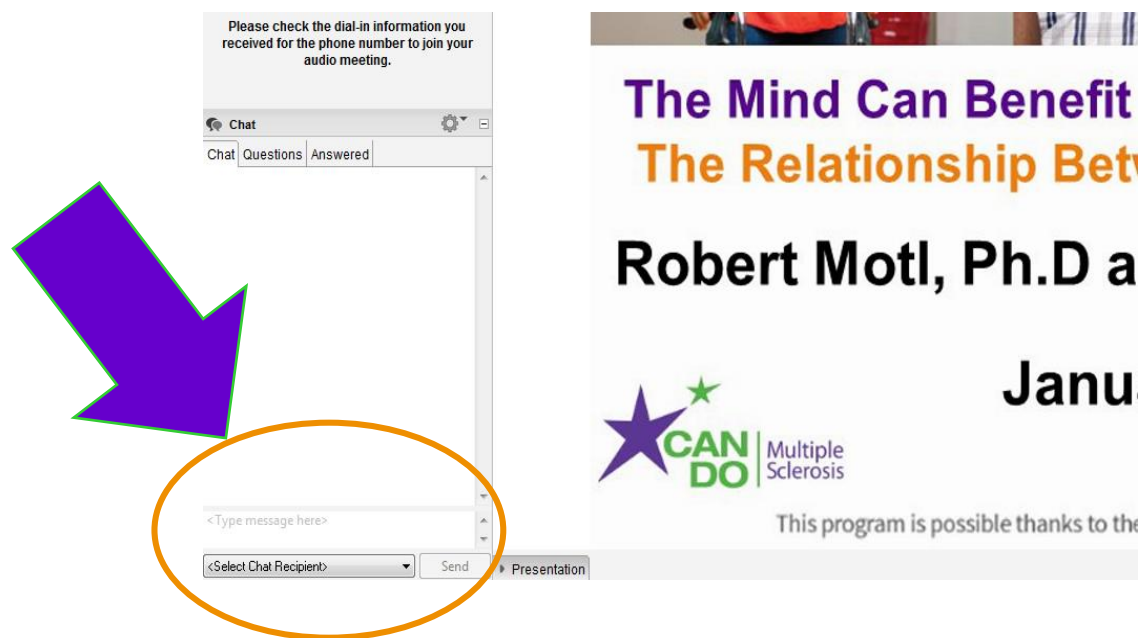


THE **POWER** TO BE MORE THAN YOUR MS  
[www.msando.org](http://www.msando.org) | 800-367-3101



# How to Ask Questions During the Webinar:

- **Chat Feature** – Type in your questions using the chat box on the lower left hand side of your screen.



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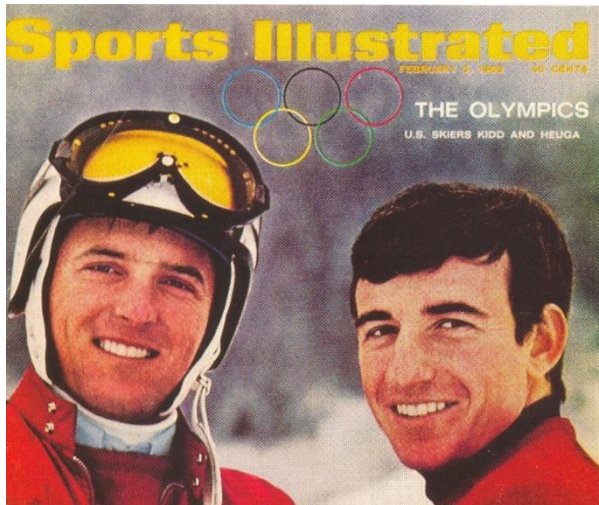


# Objectives

- **Identify key members of your health care team and understand their roles in helping you manage your symptoms**
- **Learn tips for making the best use of the time with your health care team**
- **Establish a framework for making decisions regarding symptom management strategies**



# Multiple Sclerosis “March Madness”



[www.realvail.com](http://www.realvail.com)



[www.mynewnormals.com](http://www.mynewnormals.com)



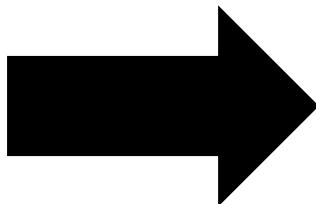
[www.patients.aan.com](http://www.patients.aan.com)



# NCAA March Madness and MS

- **NCAA Tournament**

- 68 teams
- Sweet 16
- Elite 8
- Final 4
- Championship Game



- **Multiple Sclerosis**

- Seems like 68 symptoms...
- Nearly 16 (actually 13) DMTs to choose from...
- 8 medical appointments/wk. ...
- 4 differing opinions...
- How to make it to the finals?  
Achieve Success?

# Your MS Team/Your Basketball Team

- Team Captain/"Most Valuable Player" (MVP) – Person with MS
- Co Captain – Primary Care Partner
- Coach – Neurologist
- Assistant Coach – Nurse
- Other Team Members/Players:
  - Mental Health: Psychologist, Social Worker
  - Rehabilitation: Physical Therapist, Occupational Therapist, Speech Pathologist
  - Nutritionist/Registered Dietician
  - Other Physicians: Primary Care; Urologist; Physiatrist
  - Vocational Rehabilitation

# Polling Question #1

- Who are the members of your health care team? (Question to gather a sense of what providers participants are currently accessing)
- Neurologist  
Nurse  
Psychologist  
Social worker  
Rehabilitation specialist (PT, OT, Speech)  
Dietitian  
Urologist
- Other

# Many symptoms.....many decisions.....

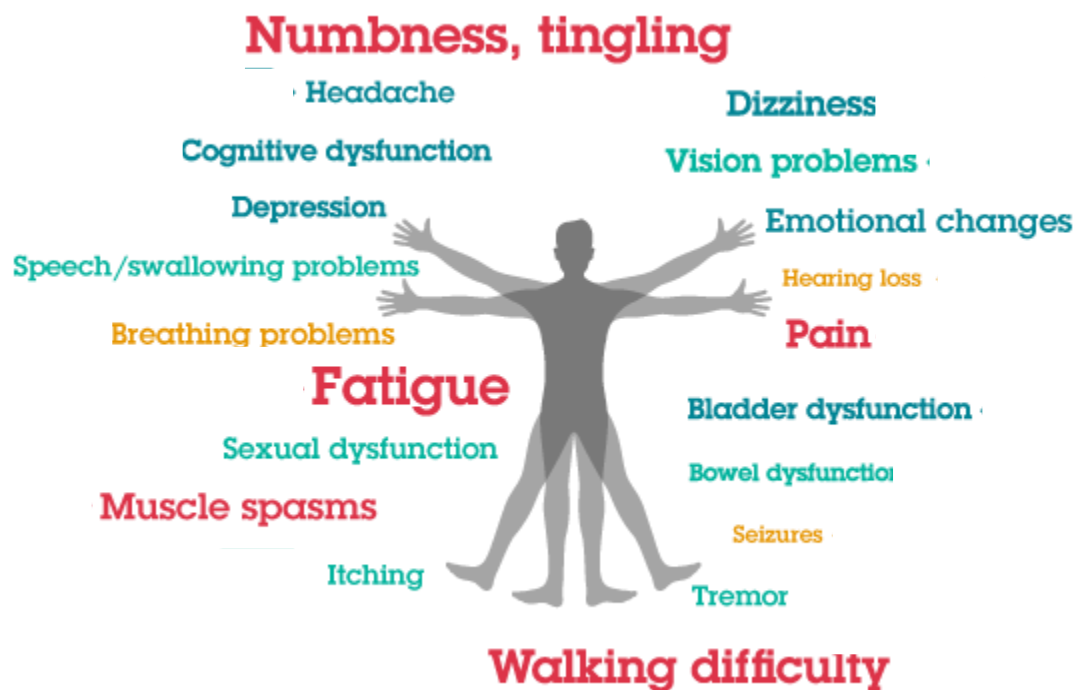


[www.employerlawreport.com](http://www.employerlawreport.com)

How do you make the call?

Whom do you call?

# My MS can cause all this?!?!



[www.blog.mymsaa.org](http://www.blog.mymsaa.org)

When trying to explain  
your Multiple Sclerosis  
symptom becomes  
more annoying than  
the symptom  
itself...



som<sup>ee</sup>cards  
user card

<http://hisworkingprogress2.com/ms-awareness-types-symptoms/>



National  
Multiple Sclerosis  
Society



# Communicating with the “Coach,” a.k.a MD

- Your relationship with your doctor requires teamwork
- Your game plan will be built around:
  - Your doctor’s knowledge and expertise
  - Your goals, priorities and preferences
- Treatment decisions will be built around:
  - Your report of symptoms that have appeared, changed, disappeared
  - The doctor’s assessment of your symptoms, neurologic findings on exam, test results
  - Your ability to prioritize the symptoms that are having the greatest impact
- Open communication is essential
  - Even the best clinician cannot read your mind
  - Be prepared with a prioritized list of issues and questions – advocate for yourself!

**There’s no room for don’t ask/don’t tell in this partnership!**  
**To help find the right “coach” for you, call the**  
**National MS Society at 1-800-344-4867**



# Meet the Captain and Co-Captain



- Sally and Stan
  - Sally, age 45, has had MS for 15 years
  - She and her husband, Stan, have 2 teenage daughters
  - Recent severe relapse with new symptoms: fatigue, spasticity, difficulty walking, increased numbness, bladder urgency/frequency, and “brain fog” that are affecting activities at home and work
  - Dr. Jones prescribed steroids, which seem to have provided some relief, and discussed treatment options
  - Sally and Stan are concerned with the new symptoms that are impacting Sally’s work and their family life
  - Stan is especially worried and just wants his “wife back”

## Polling Question #2

- Which team members would be the most appropriate for Sally and Stan to consult?

Neurologist

Nurse

Psychologist

Social worker

Rehabilitation specialist (PT, OT, Speech)

Nutritionist/Dietitian

Urologist

# First Half: Physician Visit

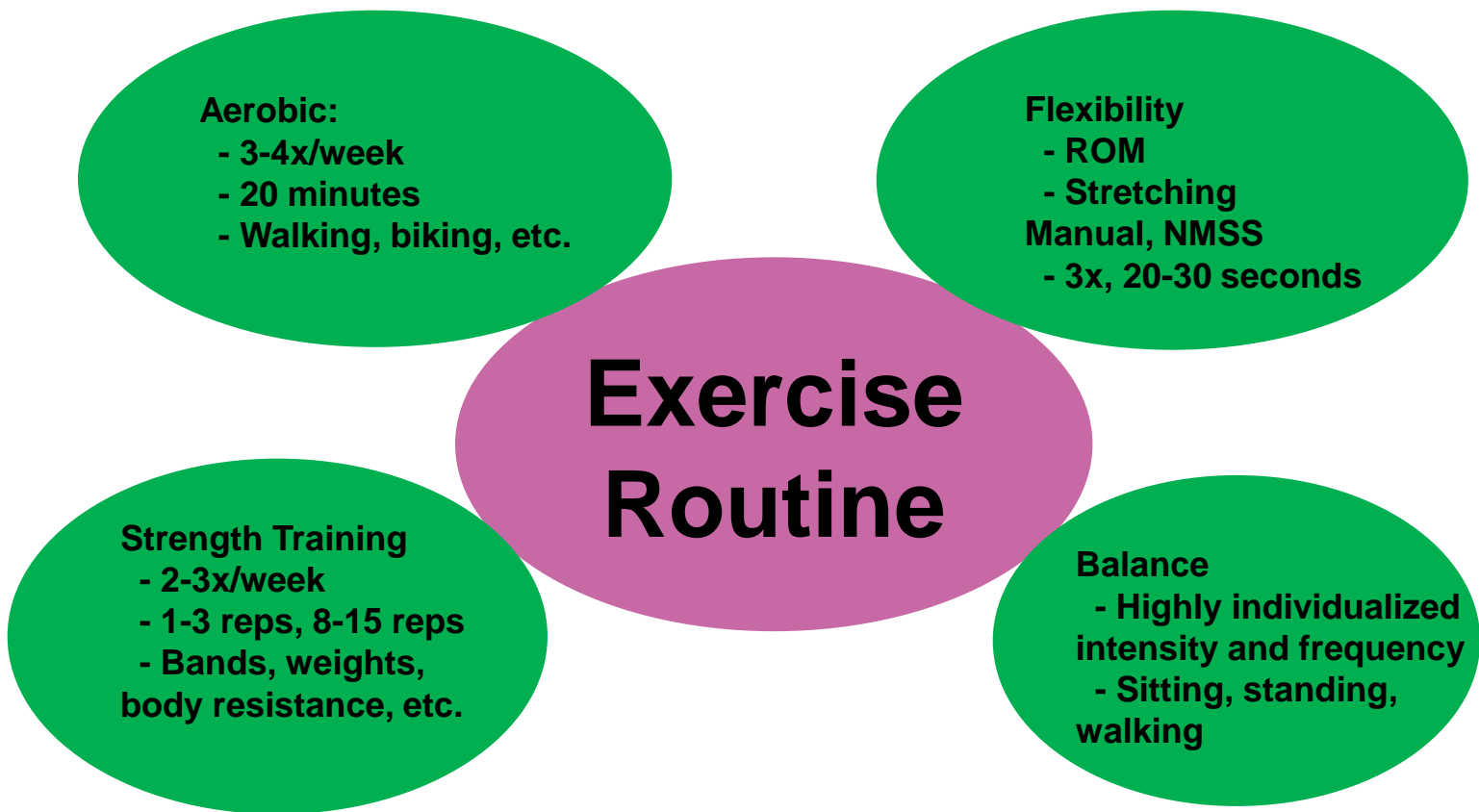
- **Discuss Disease Modifying Therapy**
  - Don't let this dominate the discussion
    - Potential “ball hog”
- **Prioritize symptoms**
  - Fatigue
  - Spasticity
  - Mood/depression and cognition
- **Wellness priorities – physical, emotional, intellectual, spiritual**
  - Data supports the value of wellness and exercise in MS



Which play should they execute?

Which team “players” can best help Sally and Stan?

# General Exercise Guidelines



# First Half: Physical Therapy

- **Fatigue**
  - 4 Ps play: Planning, Prioritizing, Positioning and Pacing
  - Body temperature – staying cool
  - Appropriate exercise
  - Collaborate with MDs: confounding medical issues, medications
- **Spasticity**
  - Stretching, positioning, bracing, strengthening, etc.
  - Collaborate with MDs: Botox, Baclofen, etc.
- **Walking**
  - Safety
  - Exercise
  - Assistive devices
  - Bracing, if appropriate
  - Strategy: Fit for function!
- At the end of PT, Stan mentions that Sally seems really down.....



[www.polarproducts.com](http://www.polarproducts.com)

# First Half: Psychologist

## •Mood Changes

- Depression, anxiety and moodiness are common
- While not surprising with a chronic unpredictable illness, mood changes in MS are:
  - More common than in other chronic illnesses
  - Caused by changes in the brain and immune system, as well as daily challenges
- Impact quality of life and make other symptoms (i.e. fatigue, cognition and pain) feel worse
- Deserve the same careful diagnosis and treatment as other MS symptoms (psychologist, psychiatrist, social worker, counselor)
- Are treatable (talk therapy, medication, exercise, stress management)

# Timeout Tip #1: Working on Weight Gain



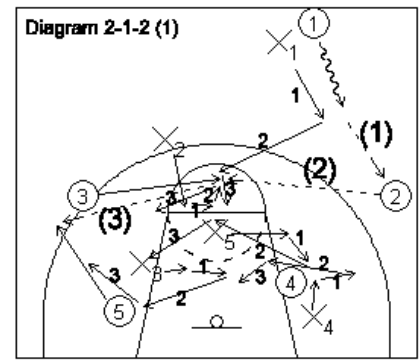
[www.123rf.com](http://www.123rf.com)

**Reduced activity, mood changes and fatigue can all contribute to weight gain**

**Call Your Team!**

- Nutritionist/registered dietician
- Rehabilitation for exercise program
- Emotional/cognitive support

# Halftime – Pause/Reflect



- Sally and Stan Update: 3 years later
- Transitioning to secondary progressive MS
- No additional relapses, but gradual worsening
- Sally is concerned with her ability to get to work and function effectively as an insurance agent.
- Bladder challenges causing more isolation and challenges with intimacy

What players from the team should execute the play?

What play should they execute?

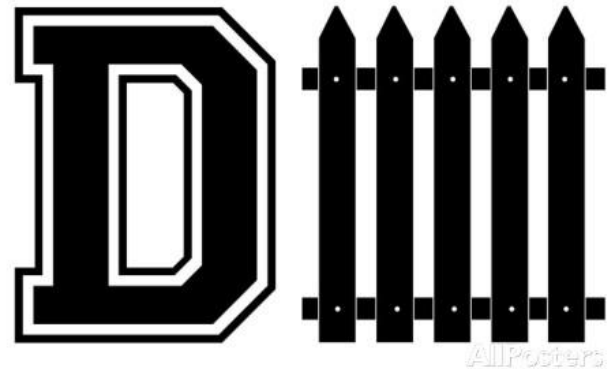


## Polling question #3

- What would be the most appropriate SMART goal for Sally and Stan?
  - A. Sally and Stan will complete home modifications, including a stair glide, to better allow Sally to access the family room in the basement, 8 weeks.
  - B. Sally and Stan will implement 2 organization strategies to help Sally improve her ability to manage family schedules, 8 weeks.
  - C. Sally and Stan will exercise together a minimum of 2 days per week to address weight challenges, mental health and wellness, as well as mobility, 8 weeks.
  - D. ALL are SMART goals!

# Second Half: Challenges of Secondary Progressive MS (a really tough defense)

- MS management goals
- Rehabilitation goals
- Mood and cognition goals
- Wellness goals



[www.thefranchiseok.com](http://www.thefranchiseok.com)

Other team members to recruit?

# Second Half: Occupational and Speech Therapists

- **Cognitive changes**

- Are common, affecting up to 65% of people with MS
- Primary reason for early departure from the workforce
- Can impact self-esteem, communication, relationships, daily activities and self-care
- Include slowing of information processing, learning and memory, visual/spatial skills, etc.
- Deserve careful assessment and management with compensatory tools and strategies (neuropsychology, OT, speech/language)
- Can generally be managed in ways that reduce impact at home and at work

# Second Half: Nursing +/- Urologist

- **Bladder dysfunction**

- Is common, affecting up to 85% of people with MS
- Embarrassing to discuss, can lead to social isolation
- Can coexist with sexual dysfunction
- Can involve failure to store urine (urgency) or failure to empty (hesitancy) or a combination
- Behavioral strategies: timed or double voids, Kegel exercises, intermittent self-catheterization, avoidance of bladder irritants
- Medications

**Fluid restriction may cause constipation and worsen fatigue**

# Timeout Tip #2



[www.123rf.com](http://www.123rf.com)



## Keep mobile!

- Team members to help
  - Physician/nurse
  - Physical Therapist
  - Exercise physiologist
- Weight control
- Safety is of paramount importance
- Adaptive equipment

# Overtime.....Overwhelmed.....Exhausted..... “Too Many Balls in the Air”

- What do you do in those times when it is feeling overwhelming?
- Now is the time to pull together as a team more!!!
- End of game and you are exhausted = when you need your team the most
- Advocate more for yourself and your needs!



[www.observer-reporter.com](http://www.observer-reporter.com)

# Your MS Decision Making Playbook

- **Speak up/communicate**
- **Prioritize**
- **Teamwork**
- **“Huddle up” with team during the “hard” times**

For referrals to healthcare professionals in your community,  
contact the National MS Society: **1-800-344-4867**



[www.mybasketballblackmamba.weebly.com](http://www.mybasketballblackmamba.weebly.com)

# Your MS Decision Making Playbook

- **Ask your healthcare providers for recommendations**
- **Consult other professional organizations**
  - Can Do MS
  - Consortium of MS Centers
  - American Physical Therapy Assoc.
  - American Occupational Therapy Assoc.
- **Consider alternative modes of communication/access**
  - Email
  - Telehealth



[www.mybasketballblackmamba.weebly.com](http://www.mybasketballblackmamba.weebly.com)



## Polling question #4

- What "player"/discipline will you add to your team?

Neurologist

Nurse

Psychologist

Social worker

Rehabilitation specialist (PT, OT, Speech)

Dietitian

Urologist

Other

# Thank You!

**Questions?**  
**Comments?**

# Can Do MS Resources

**e | NEWS**  
your best life update

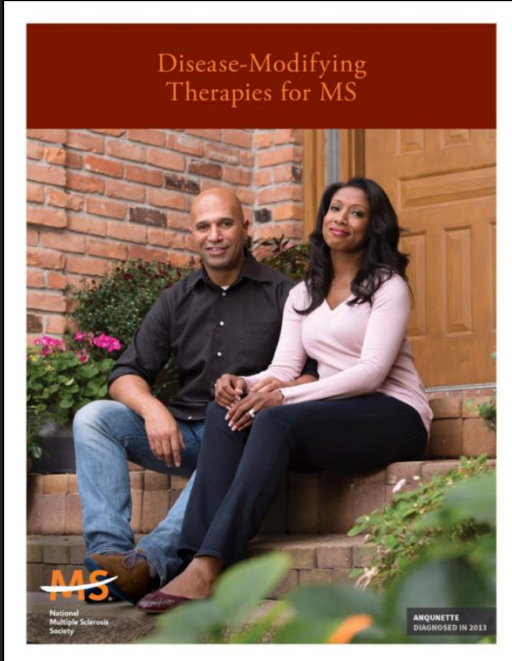
**Q&A**

*Can Do Library*

Find these resources at [www.MSCanDo.org](http://www.MSCanDo.org).

# National MS Society Resources

<http://www.nationalmssociety.org/>  
Treating-MS/Comprehensive-Care



**Making Treatment & Lifestyle Decisions:**  
Thinking About Benefits & Risks



## WEBINAR & TELELEARNING SERIES



# The Complete Guide to Social Security Disability Employment Series: Part III

March 15, 2016

*Presented by:*



EMD Serono | Teva Pharmaceuticals | Acorda Therapeutics

Mallinckrodt Pharmaceuticals Autoimmune and Rare Diseases | US Bank

