#### Relapse and MS Series





# Relapse and MS

January 22, 2019

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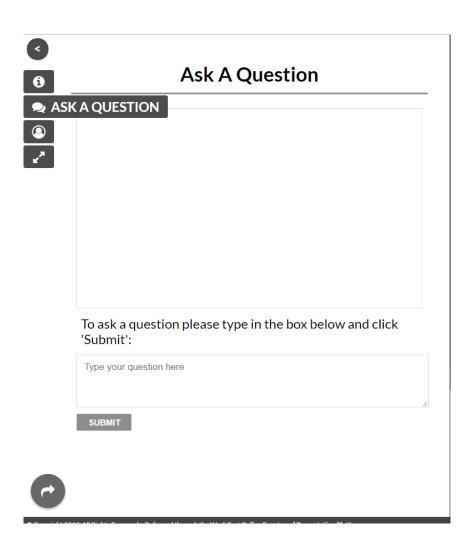




# How to Ask Questions During the Webinar:

- Type in your question in the "Ask A Question" Box.
- This can be found by expanding the second box in your control panel on the left side of your screen.







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# Polling Question:

Have you experienced, or do you think you've experienced a relapse in the last year?

- A. Yes
- B. No



#### **Objectives**

- Review historical and current classifications of MS
- Learn what a relapse is and how it differs from a pseudorelapse
- Understand the treatment options for both
- Describe the role played by the interdisciplinary team in symptom management of these episodes
- Have realistic expectations for relapse outcomes



#### What's the bottom line?

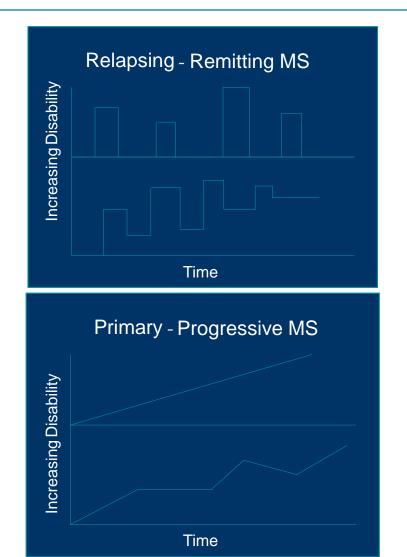
- When this discussion is over, you should be able to...
  - Communicate effectively with your support partners and healthcare team about relapse
  - Know what to expect and who to call

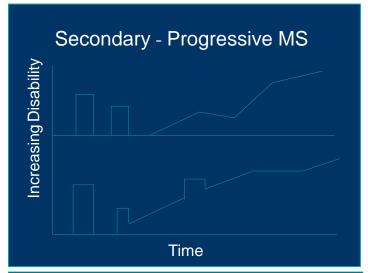
#### AND...

Have a plan should one occur



# Classical Types of MS (1996)

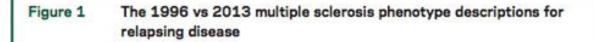


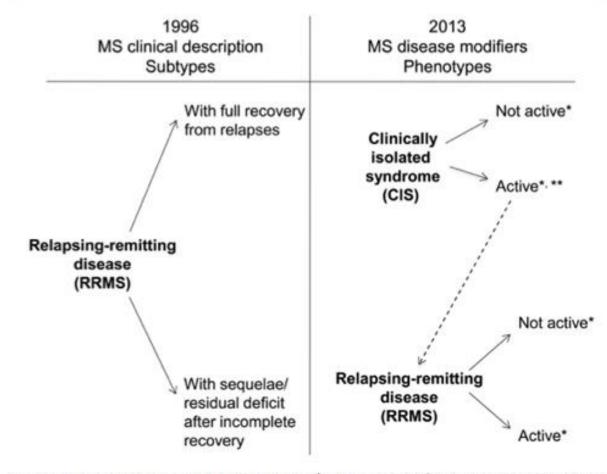






# 2013: Defining the Clinical Course of MS





<sup>\*</sup>Activity determined by clinical relapses and/or MRI activity (contrast-enhancing lesions; new or unequivocally enlarging T2 lesions assessed at least annually); if assessments are not available, activity is "indeterminate." \*\*CIS, if subsequently clinically active and fulfilling current multiple sclerosis (MS) diagnostic criteria, becomes relapsing-remitting MS (RRMS).



#### **MS Basics**

#### MS affects....

- More than 1 million in the US
- Women 3-4 times more than men
- People living with MS and their families/friends
- Lifestyle, dreams, goals





#### **MS Basics**

#### MS is...

- An autoimmune disease
- A chronic disease without known cause, but thought to be related to a complex interplay of environmental and genetic factors
- The most common non-traumatic cause of neurological disability in people of working age
- Associated with smoking, high sodium intake, low Vitamin D, and exposure to Epstein Barr virus
- Treated depending on type of MS; treating relapses and symptoms are also important parts of the treatment paradigm



# **MS Symptoms**

VISIBLE	INVISIBLE
Walking problems	Pain
Coordination problems	Fatigue
Balance problems	Sexual Dysfunction
Sensory problems	Bladder and/or bowel problems
Vision issues	Vision issues
Mood changes	Cognitive problems
	Mood changes



# **Navigating Symptoms**

- Do a daily survey or daily body check
- Is it a...
  - Good day
  - Mediocre day
  - Bad day
  - Holy &\*%\*\*^@ what is happening to me day











#### Relapse

- A new neurologic symptom or increased severity of old neurologic symptom
- Lasts longer than 24 hours
- Occurs more than 30 days from the last relapse
- Cannot be explained by another cause
  - Pseudorelapse
  - Other medical problem



#### Relapse Example

- John is a 40 year old male living with relapsing MS for 5 years
- When he is tired or overheated, he usually experiences decreased color vision in his right eye, where he had an optic neuritis years ago
- One night, he went to bed with some tingling in his right arm, that he had never had before
- As the next day progressed, his right arm and leg became numb, new symptoms for him
- He called his neurologist the next day





#### Pseudorelapse

- An increase in severity of an old/recurring neurologic symptom
- Caused by infection, fever, exposure to heat (less commonly cold), increased stress, fatigue
- The most common infection to cause pseudorelapse is Urinary Tract Infection (UTI)
  - UTI can cause increase in MS symptoms even without traditional UTI symptoms



#### Pseudorelapse Example



- Mary is a 55 year old who has been living with MS for 20 years
- When she is tired, overheated, sick, or under a lot of stress, her leg spasms get worse and her legs tingle
- She notices frequency of urination lately, and those "old friend" symptoms start
- She worries that she is having a relapse, and calls her doctor
- He orders a urinalysis, which is + for UTI
- She is treated with antibiotics, and her symptoms resolve



# Relapse Treatment

The foundation of relapse treatment for relapsing MS is starting on disease modifying therapy early, assessing how that therapy is working for you and your MS on a regular basis, and staying adherent to the treatment plan; maintaining health with exercise, healthy eating habits, and regular preventive care; and addressing emotional health.

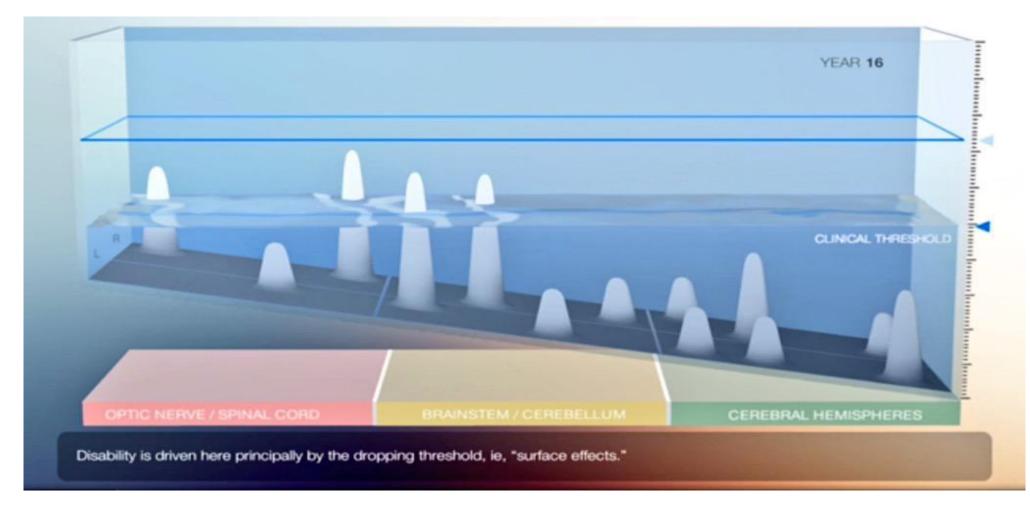


#### In other words...

# Do your best to prevent them from happening!



#### **A New Perspective**





# Relapse Treatment

<u>Intravenous steroids</u> (methylprednisolone) given 3-5 days

Challenge: access

High dose oral steroids

Challenge: tolerability

<u>ACTH</u> (adrenocorticotropin hormone, Acthar gel) given SC or IM, schedule varies

Challenge: cost

Plasma exchange for severe relapses

IVIg infrequently used



# Relapse Treatment

- Steroidogenic treatments are usually well-tolerated
  - But do have side effects, adverse events (usually associated with long-term use), and reasons not to use them
  - It is important that your MS provider knows your entire medical history as well as all of your medications and supplements before prescribing steroid treatment



#### Pseudorelapse Treatment

- Treatment of underlying condition
  - Infection: antibiotics
  - Heat exposure: cooling, rest
  - Fatigue: rest
  - Stress: mental rest



#### **Symptom Management**

- Both Relapses and Pseudorelapses are associated with an increase in symptoms
- Symptom management occurs best with an interdisciplinary team
  - Medicine: pharmaceuticals, referrals
  - Nursing: counseling, navigating, prioritizing, referrals
  - Rehabilitation: PT, OT, Speech Therapy
  - Mental Health



#### **Rehab Team**

- Physical Therapy
  - Develops plan to improve strength, movement, pain, balance that may have been affected; use bracing, assistive devices if needed
- Occupational Therapy
  - Develops plan to make activities of daily living easier, use adaptive equipment, and improve energy conservation
- Speech Therapy
  - Develops plan for speech and swallowing



# **Relapse Outcomes**

- Relapses suggest active MS
- They indicate new areas of inflammation in the brain or spinal cord
- Most people have complete recovery of relapses, especially early in relapsing MS





# What if my relapse symptoms stay?

- Incomplete recovery of relapse early in disease is a poor prognostic sign
- Relapse symptoms may take a few months to completely resolve
- As MS progresses, your level of disability may increase after a relapse



# **Your Relapse Toolkit**

- Have you had a relapse before?
  - Did your treatment help? Did you tolerate it?
  - If not, talk to your provider about other options BEFORE you have another relapse
- If you are currently working, do you have the appropriate securities in place in case of relapse?
- Do you see your MS provider regularly for appointments to assess relapse rate, MRI, and disability progression?



#### Your Relapse Toolkit

- If you are currently working...
  - Have your MS provider complete FMLA paperwork so that you can use it IF you need it, not frantically have to get it when you are already anxious!
  - Talk to your employer about short and long-term disability plans and decide if they are right for you (cost v need)
  - It's important to plan...think of it as an investment that can decrease anxiety if you face the adversity of needing time off for relapse or pseudorelapse



#### Your Post-relapse Plan

- A relapse is a sign…
  - For you & your MS provider
    - That your disease modifying therapy is not controlling your MS
  - For you & your support partners
    - That you should look at lifestyle factors and selfcare practices that could improve your life with MS
      - Wellbeing and mental health
      - Nutrition
      - Exercise





#### Your Post-relapse Plan

- Make a follow up appointment with your MS provider
- Review your relapse history, last MRI, and disability progression with your MS provider
- Discuss whether or not you both feel you are on the appropriate disease modifying therapy
- Make an appointment with your primary care provider to discuss other medical issues that may have been affected by relapse or relapse treatment
- Develop a plan together that is one you are willing to follow



#### **Your MS Team**

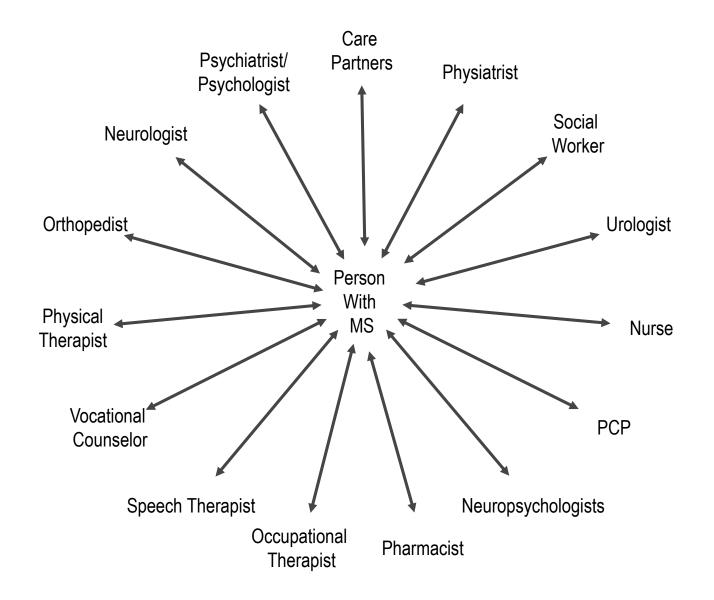
#### MS care requires an interdependent team:

No significant task can be accomplished without the help and coordination of every team member.

Members typically specialize in different tasks.

The success of every individual is ultimately bound to the success of the whole team. No team member has ever won alone.







#### **Your MS Team**

- It looks overwhelming, but...
  - You don't need all the Special Teams all the time!
  - It's better to have them trained when you need them!





# Be Ready...not worried!







Mind Full, or Mindful?











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