

# Multiple Sclerosis Nurse Leadership Program



## THE LIVED EXPERIENCE OF MULTIPLE SCLEROSIS

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Provided by Academy for Continued Healthcare Learning and  
Annenberg Center for Health Sciences at Eisenhower



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# Beginning With the Diagnosis

- What do you think is wrong?
- Feelings of fear: What will happen to me?
- Grief: Who am I now?
- Anxiety: Can I have children?
- Support from family and friends



# MS Is...

- Unpredictable
- Part of life, not all of it
- Manageable



Courtesy of Michelle Keating, RN, MSCN

# The Early Years

- 1981–1986: “5-year prognosis”
- 1986–1989: only complete remission
- 1986–1993: one to two relapses/year

# Disease-Modifying Treatment As the Years Continue

- Living through relapses and steroid treatments
- 1993: I am a “pioneer” in treatment with interferon beta-1b as a patient and nurse educator
- First hospitalization in 1999 for injection site cellulitis/panniculitis
- The “difficult” years: hospitalization 1999, 2000, 2003, 2005, 2007, 2009 and treatment changes
- With treatment experience of interferon  $\beta$ -1b and 1a, mitoxantrone, dalfampridine, and dimethyl fumarate





“Whether you think  
you can or think you  
can’t, you’re right.”

Henry Ford



# Vacationing on the Beach With MS

**2000**



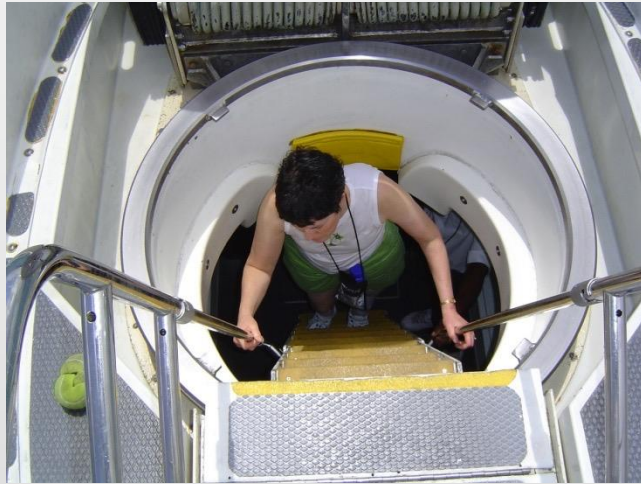
**2013**



Images courtesy of Michelle Keating, RN, MSCN



# Experiencing the Caribbean “Out of” and “In” the Water



Images courtesy of Michelle Keating, RN, MSCN



# What Has Kept Me Going on My Journey With MS?

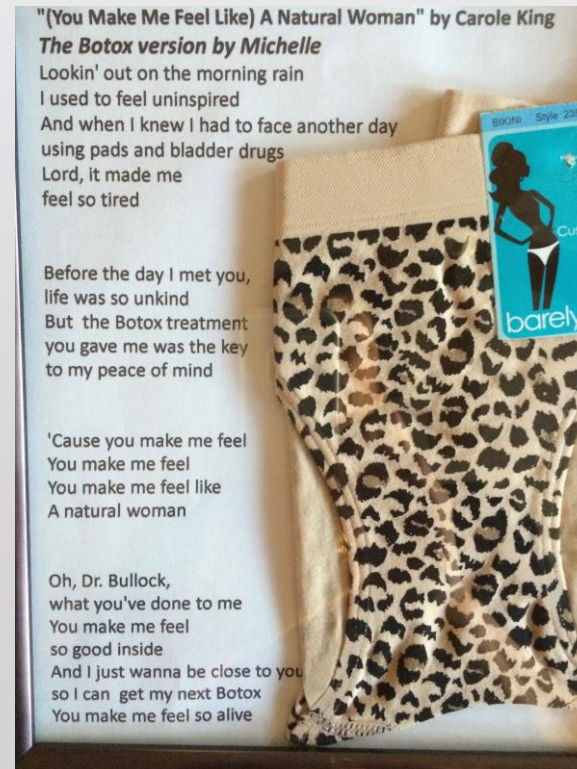
- Being positive
- Exercise!
- Accepting change and readjusting life schedule
- Having faith and humor
- Asking for and accepting help



Image courtesy of Michelle Keating, RN, MSCN

# Managing My Symptoms

- Dealing with the silent symptoms: “You look so good”
- Difficulty walking (spasticity, weakness, balance)
- Bowel and bladder
- Fatigue
- Heat



Images courtesy of Michelle Keating, RN, MSCN

# Hope with MS: Comes From My Career as a Nurse

- Oncology Nurse Navigator for 29 years at Mercy and 13 years at another hospital
- Educating as an MSCN
- Pharmaceutical Support Nurse



Images courtesy of Michelle Keating, RN, MSCN



# HOPE: Comes From My Family



Images courtesy of Michelle Keating, RN, MSCN



# HOPE: Comes From Accepting and Giving Support

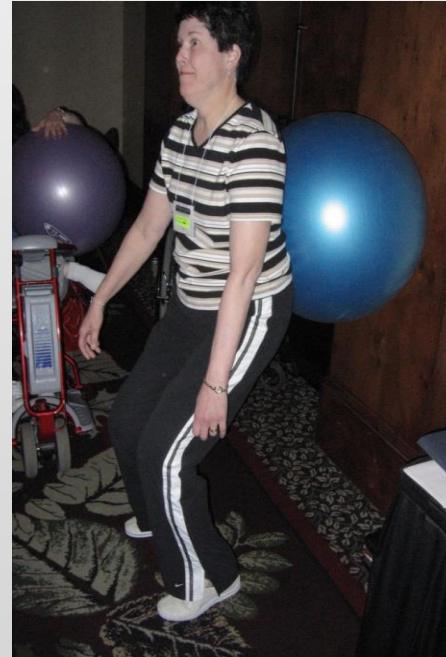
- Friends
- Coworkers
- MS community
- Faith community



Images courtesy of Michelle Keating, RN, MSCN

# HOPE: Comes From Health Professionals

- Mercy co-workers:
  - Mary, Carol, Elissa
- My “MS team”
- CanDoMS



Images courtesy of Michelle Keating, RN, MSCN



# Later Years Living with MS

- No relapses
- Focus on wellness
- Better walking



# Supporting the MS Community

- National MS Society volunteer roles as patient and nurse
- Relentless MS fundraising “Star” with MS Walk and MS bracelets and my 50th birthday bash with Teri Garr
- Quilt projects



Images courtesy of Michelle Keating, RN, MSCN



# HOPE in My Life

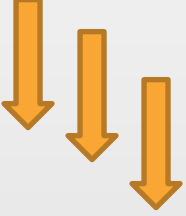
- Imagine the best
- Is the cup half full or half empty?
- A happy and healthy life is possible



Images courtesy of Michelle Keating, RN, MSCN



# HOPE: It Continues for the Future: Recent Years

- PDSS 
- Significantly improved mobility, upper body function, bowel and bladder control



PDSS – Patient-Derived Multiple Sclerosis  
Severity Score

Images courtesy of Michelle Keating, RN, MSCN

# MS Bright Spots of Hope: Created May 2016

- Mission: educate, empower, spark creativity, and enhance wellness for the MS community
- Programs: MS Evening of Hope, Many Steps Toward Hope, MS Creative Arts with MS Cruisers, Many Steps Fitness Fun, and MORE

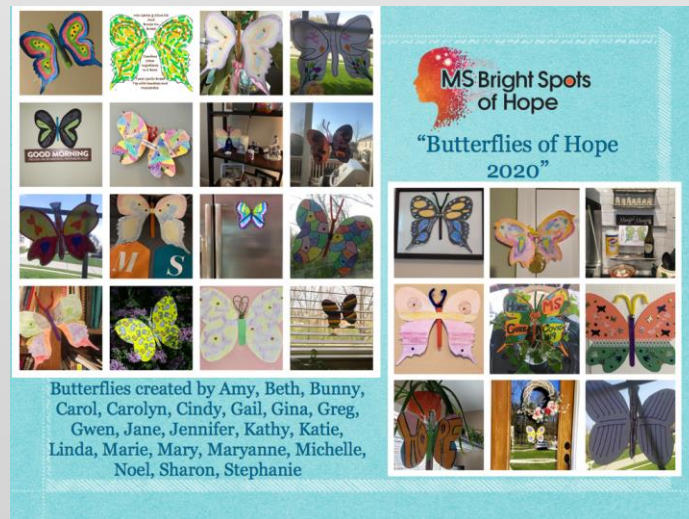


Images courtesy of Michelle Keating, RN, MSCN



# MS Bright Spots of Hope

- [https://www.youtube.com/channel/UCCm2bmlacARjkU\\_Zom2fsZg](https://www.youtube.com/channel/UCCm2bmlacARjkU_Zom2fsZg)
- And then there was 2020...





# New Programs in 2021

- <https://www.youtube.com/watch?v=oogUMcFOYHY&t=24s>
- [https://www.youtube.com/watch?v=Todeo\\_OMnAW](https://www.youtube.com/watch?v=Todeo_OMnAW)

