

SEVERE ME/CFS: CARE, RIGHTS & RESEARCH

Caregiving: Navigating Support, Advocacy & Daily Challenges with Severe ME



Galen Warden



Amy Mooney, MS
OTR/L



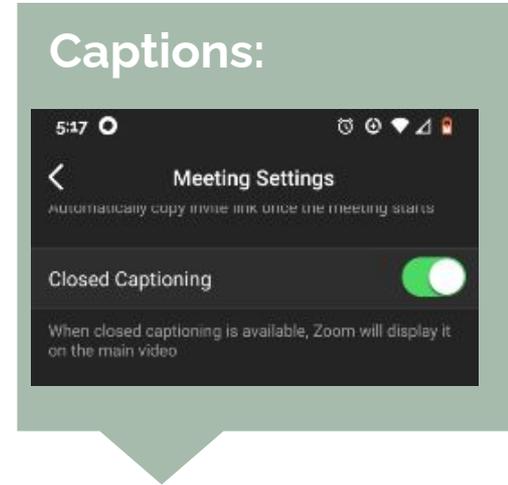
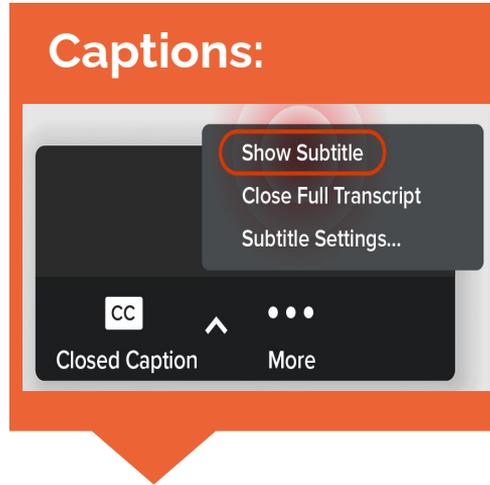
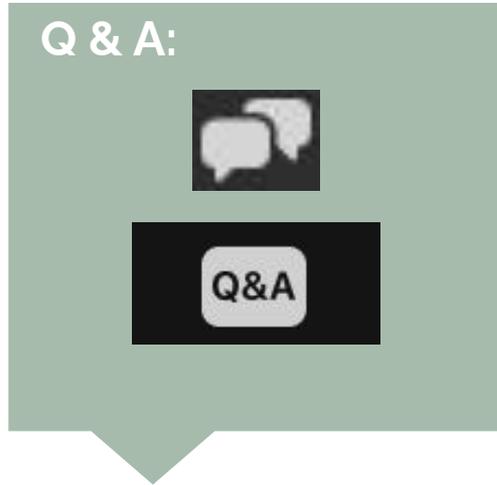
Kyle Kitzmiller



Kim Moy

Wednesday, October 9
10 am PT, 11 am MT,
12 pm CT, 1 pm ET

About Our Webinars



- If time permits, a Q&A session will follow the presentation
- Enter your questions in the box at the bottom of the screen (not in the chat) and **upvote your favorite questions**
- Closed captioning is available on the zoom control settings as shown above

About Our Webinars

- Webinars are recorded and will be available on our YouTube channels: youtube.com/@SolveME and youtube.com/@BatemanHorneCenter
- The content provided by Solve M.E. and the Bateman Horne Center in this webinar is for informational purposes only and does not constitute legal or medical advice. Viewers are encouraged to consult with qualified legal or medical professionals for specific advice tailored to their individual circumstances.



SEVERE ME/CFS: CARE, RIGHTS & RESEARCH

Caregiving: Navigating Support, Advocacy & Daily Challenges with Severe ME



Galen Warden



Amy Mooney, MS
OTR/L



Kyle Kitzmiller



Kim Moy

Wednesday, October 9
10 am PT, 11 am MT,
12 pm CT, 1 pm ET

Kyle Kitzmiller

Kyle Kitzmiller is a mechanical engineer, entrepreneur, surfer and outdoorsman. Before stopping work to care full-time for his wife Dianna Cowern, he was a producer for her YouTube channel Physics Girl. He is also the co-founder of ShredLights, where he made lights and accessories for electric skateboards. Since being thrust into the world of chronic illness, Kyle now focuses on caring for his wife, engaging in Long Covid advocacy efforts, and figuring out how to make an impact on a deeply biased and broken system.



Amy Mooney, MS OTR/L

Amy is a private practice occupational therapist (OT) who specializes in providing therapeutic care to individuals with chronic conditions involving post-exertional malaise/post exertion symptom exacerbation (PEM/PESE). Amy's "Pacing for PEM" guidelines and therapeutic strategies have been featured presentations at national and international conferences, continuing education programs for medical professionals, and patient advocacy webinars. As caregiver for a loved one with ME/CFS, Amy understands first-hand the challenges individuals and families experience seeking appropriate care.

Amy has a bachelor's degree from Loyola University Chicago, a master's degree in occupational therapy from Rush University Chicago and is a returned Peace Corp volunteer. Amy calls Chicago home.

amymooneyOT@gmail.com

www.linkedin.com/in/amy-mooney-otr



Kim Moy

Kim Moy is a coach and caregiver support group leader with nearly 20 years of experience caring for her husband, who is currently disabled with ME/CFS, POTS, and related illnesses, and her elderly parents.



She leads the ME/Long COVID partner caregiver support group affiliated with #MEAAction and founded Caregiver Wisdom, which offers coaching, community, and resources for chronic illness caregivers. Caregiver Wisdom includes the free monthly support group, "Thrive as a Caregiver" group course, 1-on-1 coaching, an online community, and a blog.

Learn more at caregiverwisdom.net.



Galen Warden

Galen Warden is a force of nature – a patient empowerment advocate, caregiver, and marketing expert with more than thirty years of experience. A natural cheerleader, Galen has inspired thousands through her instinctive ability to motivate and encourage.

Since her son James became bedridden with severe Myalgic Encephalomyelitis, she has harnessed her talents and made it her mission to advocate for the many people who are not believed by the medical establishment, especially those with ME (ME/CFS), and those who have developed ME following a COVID infection.



Kyle: Daily Care and Relationship Maintenance

- **Daily Care and Activities of Daily Living (ADLs):** Kyle, can you share practical strategies that have helped you manage daily care tasks and ADLs for your wife? What advice would you give to caregivers working on consistency and efficiency in these routines?
- **Maintaining a Relationship:** How have you and your wife managed to maintain your relationship despite the challenges of severe Long Covid? What tips can you offer to other caregivers on preserving intimacy and connection?
- **Psychology and Practicality of Self-Care:** Can you discuss the psychological aspects of self-care that have been most impactful for you? What practical steps do you take to ensure your mental and emotional well-being?

Amy: Navigating Systems and Trusting Instincts

- **Navigating Systems:** Amy, with your experience as a mother navigating healthcare, education, and home care for your daughter, how do you trust your instincts in advocating for your daughter's needs?
 - **Trusting Your Instincts as a Caregiver:** How can caregivers learn to trust their instincts and advocate effectively, especially when medical professionals or school administrators may lack specific ME/CFS expertise?
- **Balancing Health and Education for Children with ME:** What practical advice do you have for parents prioritizing health and daily living over academic progress for children with ME?
- **Recognizing the Lived Experience:** How can caregivers validate their own and their loved one's experiences, and ensure their voices are heard in healthcare settings?

Kim: Self-Care and Relationship Navigation

- **Self-Care and Resilience:** Kim, can you share strategies from your self-care course that have helped caregivers build resilience and prevent burnout? How do you suggest balancing self-care with caregiving demands?
- **Navigating Ambiguous Loss and Change:** How can caregivers acknowledge and cope with ambiguous loss while supporting their loved ones? Could you share how you address this in your support groups?
- **Navigating Relationships and Decision-Making:** What advice do you have for caregivers to maintain healthy communication and ensure that the person with the illness remains central in decision-making?

Galen: Caregiver Mental Health

- **Mental Health Journey:** Galen, your journey through the stages of grief and loss for your life and that of our sons is inspiring. Can you share the key turning points or tools that have helped you sustain your caregiving role?
- **Caregiver's Coping Toolkit:** What would you include in a "Caregiver's Coping Toolkit"? Are there specific strategies or resources that were invaluable to you?
- **Beyond Self-Care:** What other mental health aspects are crucial for caregivers to focus on, beyond preventing burnout, and how can they integrate these into their routines?

SEVERE ME/CFS: CARE, RIGHTS & RESEARCH

NAVIGATING THE SPECTRUM OF ILLNESS

4-PART WEBINAR SERIES

- Wednesday, Oct 9, Caregiving
- Wednesday, Nov 13, Legal
- Wednesday, Dec 4, Medical
- Wednesday, Jan 15, Research

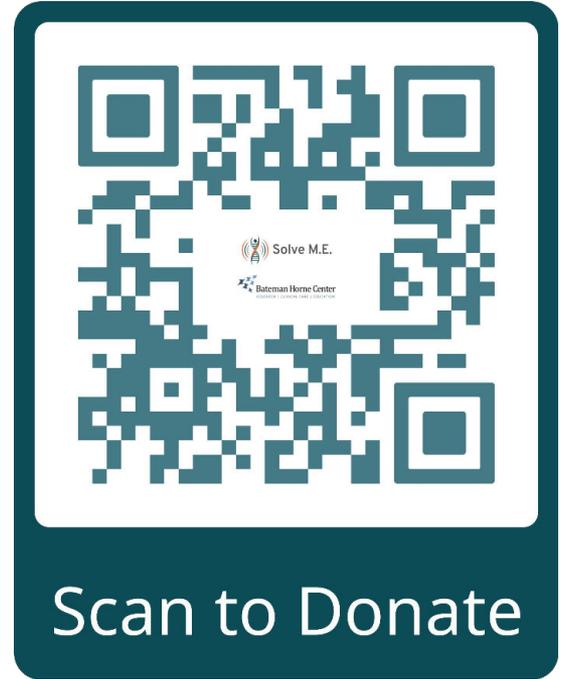
10 a.m. PT, 11 a.m. MT, 12 p.m. CT, 1 p.m. ET

REGISTRATION OPEN

Support our free educational webinars!

If you obtained helpful information and resources from a Solve M.E. or Bateman Horne Center webinar, you're not alone! Thousands have registered for or viewed one of our free informational videos about ME/CFS, Long Covid, and other infection-associated chronic conditions (IACCs). Our webinars contain timely research updates and targeted educational content valuable to patients, researchers, and healthcare providers.

Please consider supporting our free educational webinars by making a gift to Solve and Bateman Horne today. (The donation will be shared with the two non-profit organizations.) Whether you give \$10, \$25, \$50, or more, your donation helps us share this valuable information with those who need it most.



Thank you!



Solve M.E.



Bateman Horne Center

RESEARCH | CLINICAL CARE | EDUCATION