MYOCONNECT Summit

Date: 29 August 2026

Time: 11:00 am - 4:30 pm ET

Location: Virtual - Zoom

JOIN US

Join this free community gathering to talk about the issues that mean most to myositis patients and caregivers. Led by patients, the Summit will provide you with the information and tools you need to navigate your myositis journey with confidence and hope.

TIME	AGENDA	PRESENTER
11:00 AM	**Welcome & Community Opening** • Leadership team introductions • Key announcements	MSU Leadership
11:15 AM	**Living with Myositis: Real Conversations, Real Experiences** • Diagnosis journeys and daily life adaptations • Mental health and purpose after diagnosis	Megan M. Jason Hopfauf Marlene Jansen
12:05 PM	**Advocacy in Action: Using Your Voice to Create Change** • Self-advocacy and legislative advocacy • Social media advocacy and storytelling	Krystle Irby Ali Gutierrez
12:50 PM	**Midday Break** • Resource slides and sponsor spotlight reel	MyoConnect Team
1:20 PM	**Wellness Beyond the Diagnosis** • Fatigue management and mobility • Work/school and practical wellness strategies	Joe Sanchez, Kaniah Gunter, Marcus Owens, Kyanna W Johnson
2:15 PM	**Research & Hope: Emerging Therapies** • Cell therapies and clinical trials, patient experiences • Emerging treatments for DM, IMNM, research participation	Dr. Prateek Gandiga, Lindsay Guentzel
3:10 PM	**Advocating for the Care you Deserve** • Appointments and insurance barriers • Communication strategies and second opinions	argenX - Gwen Valencia, Dr. Elena Schiopu Kyanna W Johnson
4:30 PM	**Closing Remarks** • Final remarks	MSU Leadership

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Meet Our Panelists

Session 1: Living with Myositis

Marlene Jansen

Neuropsychologist & Care Partner

Marlene Jansen, a Neuropsychologist and Care Partner to her husband, Rod Jansen, who stands by his side through both the personal and professional challenges they face together.

For more on Rod's story, watch his inspiring interview with Stephen Moore (link below), where he and Marlene discuss their experiences with IBM and the impact it has had on their lives.

https://www.youtube.com/watch?v=_MMNcQzeHWU

Jason Hopfauf

Associate Director of Volunteer & Support Operations at MSU

Jason Hopfauf lives in Everett, Washington, and has been living with Necrotizing Autoimmune Myopathy for ten years as of this month. He has been volunteering with MSU for 9 years and is the Associate Director of Volunteer & Support Operations at MSU. He enjoys helping others in the myositis community. He loves spending most of his days with family and friends, playing video games, listening to music, and watching movies. The best thing to remember throughout your myositis journey is that you're NEVER alone, which is an amazing thing.

Megan M.

Writer, Legal Professional, & Myositis Advocate

Megan is a writer and legal professional with a background in litigation, environmental policy, science communications, advocacy, and research. She is passionate about living and working in communities that share their stories and life experiences to support and uplift other people, locally and abroad. She feels most connected to others through her work and faith, and in her free time through sharing food, cultural traditions, language, and music. Megan joined the Myositis community in 2023.

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Session 2: Advocacy in Action: Using Your Voice to Create Change

Krystle Irby
Myositis Advocate & Content Creator
Diagnosed with Necrotizing Myopathy

Krystle Irby is a myositis advocate and content creator living with anti-SRP necrotizing autoimmune myopathy, diagnosed in February 2022. Through authentic storytelling, she raises awareness about myositis and empowers others navigating life with chronic illness and disability.

Ali Gutierrez
Caregiver & Myositis Advocate

Ali Gutierrez believes the most powerful force in healthcare isn't a textbook — it's a story. As a nurse, PhD student, and creator of Look Mom! Advocacy, Ali turned the loss of her mother to Dermatomyositis into a mission to humanize medicine. Grounded in clinical experience and personal loss, her work focuses on raising awareness of myositis by sharing her mother's journey and the lessons it revealed about listening, advocacy, and compassionate care. Through public speaking, research, and community engagement, she strives to strengthen the connection between patients and healthcare professionals beyond the chart.

Learn more here: http://lookmomadvocacy.org/

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Session 3:
Wellness Beyond the Diagnosis

Joe Sanchez
Myositis Advocate
Diagnosed with IBM

Better known as - Myositis Joe
Diagnosed (IBM) - Oct. 2013
USTTA Table Tennis PARA Athlete - Dec. 2019
KOURAGE HEALTH member - June 2019

Recognized for his ability to improve his grip, balance, standup from a seated position, climb stairs, and walk during his Myositis Journey.Recognized for his positive daily Myositis posts on Facebook's "Myositis Warriors" support group site. Huge promoter of KOURAGE HEALTH's "Power of Movement" exercise program.

Kaniah Gunter
Myositis Advocate
Diagnosed with Dermatomyositis

Kaniah Gunter is a Certified Integrative Nutrition Health Coach, Mental Health First Aider, Community Health Worker, and founder of Unique Guidance Nutritional Health Coaching in Norfolk, Virginia. She is also a motivational speaker, Amazon Bestselling author, and powerful autoimmune disease advocate living with dermatomyositis since 2007. As a Myositis Ambassador and Women of Color Leader for The Myositis Association, she works to elevate awareness, strengthen patient voices, and expand education and support within the autoimmune community.

Her advocacy includes collaborations with MSU Adult Dermatomyositis, externally-Led Patient-Focused Drug Development Meeting (EL-PFDD), Johns Hopkins University, the National Institute of Health, Autoimmune Association, Norfolk State University Community of Practice, Priovant Therapeutics, Octapharma, Alexion Pharmaceuticals' Patient Advisory Board, The Journal of Rheumatology, Prime Education, and CSI Pharmaceutical, helping advance research and patient-centered care. Through holistic nutrition, lifestyle change, and faith-driven resilience, Kaniah empowers others to take control of their health, restore hope, and live with purpose despite chronic illness. Her impactful work and personal story have been featured on Channel 13 ABC News Now, Empowered Magazine, The Health Journal, The Final Call, and various media platforms. She loves spending time with family, volunteering, traveling, and drinking her favorite green smoothies.

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Session 3:
Wellness Beyond the Diagnosis

Marcus Owens
Myositis Advocate
Diagnosed with Necrotizing Myopathy

Marcus was misdiagnosed with muscular dystrophy in 2018 and correctly with necrotizing myopathy in June of 2023. He lives in Cleveland OH with his family. They have two dogs named Scotty and Crash. He loves history, jokes, and loud music.

Kyanna W. Johnson, MPH
Director of Public Health & Policy
Diagnosed with Dermatomyositis

Kyanna Johnson is a medical student, an experienced Public Health Consultant, and the Director of Public Health and Policy at Myositis Support and Understanding (MSU). With a strong background in grant writing and community health program coordination, Kyanna has demonstrated a deep commitment to advancing health equity. Her work focuses on improving care for underserved populations through research, education, and advocacy. Kyanna holds a Master of Public Health (MPH) in Behavioral and Community Health Sciences from the University of Pittsburgh, as well as a secondary master's degree in Biomedical Studies from Chatham University. In addition to her professional accomplishments, as someone living with Dermatomyositis and diagnosed in 2025, Kyanna brings a unique perspective that bridges clinical knowledge and lived experience, helping to highlight the challenges patients face and the importance of patient-centered, inclusive care. Her journey enhances her perspective as a leader and drives her ongoing commitment to advancing health and wellness within communities

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Session 4: Research & Hope

Dr. Prateek Gandiga
M.D. FACP

Prateek Gandiga, M.D. FACP is committed to the ideal that compassionate, collaborative, patient-centered care is the core of rheumatology. While he enjoys helping patients with a variety of rheumatologic conditions, he has a special interest in autoimmune muscle diseases and Myositis (including Dermatomyositis, Polymyositis, Anti-Synthetase Syndrome, and Immune-Mediated Necrotizing Myositis). In addition to patient care activities, he serves in multiple national and local professional societies and medical education efforts. He has also completed clinical research training through the competitive National Institutes of Health CRTP and educator training through the selective Measey Medical Educators' Training Program. In his free time, he enjoys being outdoors, discovering good things to eat, and making up silly songs to sing to his family and their gooberhead rescue dog.

Lindsay Guentzel
Recipient of CAR T-cell Therapy
Diagnosed with Dermatomyositis associated
with Antisynthetase Syndrome

Lindsay Guentzel is an award-winning journalist, writer, producer, and podcast host who was diagnosed with Dermatomyositis associated with Antisynthetase Syndrome in March 2023. Her treatment journey began immediately with high-dose steroids, Rituximab infusions, and monthly IVIG infusions, and her body was responding well to the treatments. In an effort to help her mechanic's hands, her rheumatologist suggested she try mycophenolate. Unfortunately, after two weeks, Lindsay's disease activity skyrocketed — her CK levels soared from 1100 to 21,000, and she was admitted to the hospital in September 2023. Unbeknownst to Lindsay or her medical team, she was having a rare reaction to mycophenolate called paradoxical acute inflammatory syndrome that sent her immune system into an aggressive, uncoordinated attack. By October 2023, the atrophy to Lindsay's muscles left her unable to care for herself, and her partner John had to quit his job to stay home with her. These difficult months were the catalyst for Lindsay pursuing the clinical trial for CAR T-Cell therapy. In September 2024, she connected with a trial site, and after fulfilling the pre-screening criteria, she worked with the trial site coordinator over the next six months to schedule a screening visit. In March 2025, she traveled from her home in Minnesota to Denver for her final screening and then — if she qualified — she would also undergo the necessary cell retrieval. With her cells off at the laboratory, Lindsay returned home to Minnesota to wait for confirmation that her cells were ready and it was time for her to return to Denver. On April 21, 2025, Lindsay received her CAR T-cells through an infusion. Her symptoms related to Dermatomyositis have been in remission since November,
and she's been off of all disease-related medication since before the transplant.

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Session 5: Advocating for the Care You Deserve

Dr. Elena Schiopu

Rheumatology Expert at ArgenX

Dr. Schiopu is a board-certified rheumatologist and serves as argenx's Rheumatology expert within the MAEG body. She completed her rheumatology fellowship at Wayne State University in Detroit before joining the University of Michigan, where she founded the Myositis Program. She later became Director of Clinical Trials at the Medical College of Georgia at Augusta University. Her clinical and research interests include outcome measures and disease subtypes in myositis, scleroderma, and Sjögren's disease.

Gwen Valencia

Associate Director of U.S. Patient Advocacy at ArgenX

Guinevere Valencia serves as Associate Director of U.S. Patient Advocacy at argenx. She is passionate about building meaningful partnerships with patient communities and advancing programs that support, educate, and empower people living with rare diseases.

Kyanna W. Johnson, MPH,

Director of Public Health & Policy
Diagnosed with Dermatomyositis

Kyanna Johnson is a medical student, an experienced Public Health Consultant, and the Director of Public Health and Policy at Myositis Support and Understanding (MSU). With a strong background in grant writing and community health program coordination, Kyanna has demonstrated a deep commitment to advancing health equity. Her work focuses on improving care for underserved populations through research, education, and advocacy. Kyanna holds a Master of Public Health (MPH) in Behavioral and Community Health Sciences from the University of Pittsburgh, as well as a secondary master's degree in Biomedical Studies from Chatham University. In addition to her professional accomplishments, as someone living with Dermatomyositis and diagnosed in 2025, Kyanna brings a unique perspective that bridges clinical knowledge and lived experience, helping to highlight the challenges patients face and the importance of patient-centered, inclusive care. Her journey enhances her perspective as a leader and drives her ongoing commitment to advancing health and wellness within communities