



Cure JM Family Day-Seattle

Join other Cure JM families and some of the world's leading JM doctors for a spirited day of sharing and connecting with families, physicians, and researchers. Families will learn about the latest juvenile myositis research and treatments while, while connecting with others.

Brought to you by the Cure JM Clinical Care Network

Saturday
April 20, 2024

12:00PM - 3:00PM PDT

Seattle Children's Sand Point Learning Center
5801 Sand Point Way NE
Seattle, WA 98105

For more Information contact:
lauren.alvord@curejm.org



Bring the Whole Family!

The whole family is invited! Supervised activities for children and teens, including siblings, will take place in separate rooms. Children will enjoy supervised art activities and games in adjoining rooms. Teens are invited to enjoy fun social time with other teens and young adults and are invited to attend any educational sessions they would like. We recommend that teens attend the sessions on exercise, nutrition, and transitioning to independent management of their care.





Family Day Agenda

11:45 a.m.

Doors open

12:00 p.m.

Complimentary buffet lunch served while families socialize and meet the presenters

12:30 p.m.

Welcome

Susan Sheno, MD, MS, Director, Cure JM Center of Excellence in JM Care and Research, Seattle Children's Hospital
Suzanne Edison, MA, MFA, Mental Health Coordinator, Cure JM Foundation, Former Chair of Cure JM's Research Committee

12:35 p.m.

How to Get the Most Out of Your Doctor Visits

Aviya Lanis, MD, Fellow, Cure JM Center of Excellence in JM Care and Research, Seattle Children's Hospital

In this session, parents and teens will gain useful skills for getting the most out of medical appointments by learning how to share medical histories and organizing important information. The focus extends to building confidence in interacting with healthcare professionals, expressing concerns, and actively engaging in decision-making.

1:00 p.m.

The importance of Exercise as a Treatment and Tips & Tricks to Exercise at Home

Chris Wong, PT, Sports Physical Therapist, Seattle Children's Hospital

Alex Carpenter, PT, DPT, Physical Therapist, Ambulatory Rehabilitation, Seattle Children's Hospital

In this session, parents and teens will gain new scientific insight into the benefits of exercise, including movement as a therapy, boosts energy, and fights chronic health conditions. This session guides incorporating home workouts and provides equipment-free routines for all fitness levels, providing tips for your fitness journey.

Agenda Continued

1:20 p.m.

Nutrition and Auto-Immune Conditions: Real-world tips for real-world Families

Julie Shevlin, RD, Pediatric Nutrition Registered.

This session addresses common concerns related to juvenile myositis, including the best foods, managing steroid cravings, and maintaining a healthy diet despite medication side effects. This interactive session aims to discuss practical ways to apply healthcare providers' nutrition recommendations in the real world.

1:40 p.m.

Second Line Treatments and New Treatments on the Horizon

Susan Shenoj, MD, MS, Director, Cure JM Center of Excellence in JM Care and Research, Seattle Children's Hospital

Dr. Shenoj will share her knowledge of the treatments available to JM patients and their side effects. She will also update families on new treatments on the horizon.

2:00 p.m.

Calcinosis: What Parents & Patients Need to Know

Christian Lood, PhD, Associate Professor, Division of Rheumatology, University of Washington

Calcinosis is a condition that some patients experience. Calcinosis appears as hard, irregular lumps in or under the skin or in any area of the body. Much is being learned about why these nodules develop and how to treat them. Dr. Lood will present the latest information about calcinosis and will answer audience questions.

2:20 p.m.

Transitioning to Independent Management of Your Own Care: A Panel Discussion

Natalie Rosenwasser, MD, Pediatric Rheumatologist, Seattle Children's Hospital

Jenna Thomason, MD, MPH, Rheumatologist, UW Medicine

Suzanne Edison, MA, MFA, Parent to a young adult living with juvenile myositis

Caregivers, teens, and young adults are invited to a panel addressing strategies for the transition from Pediatric to Adult Care. The session will cover establishing policies, tracking progress, readiness assessments, planning for adult care, and facilitating a seamless transition into adult practice.

Agenda Continued

2:40 p.m.

Real-World Coping Tips for Families and Patients

Suzanne Edison, MA, MFA, Mental Health Coordinator, Cure JM Foundation, Former Chair of Cure JM's Research Committee

This session addresses supporting children with chronic illness, addressing topics like coping with appearance changes, managing low energy, and dealing with potential feelings of depression. The session focuses on emotional issues at different developmental stages, open family communication, guiding coping strategies for children, and providing tips for caregivers' self-care.

3:00 p.m.

Closing Susan Shenoj, MD, MS and Suzanne Edison

3:00 p.m. - 4:00 p.m.

Optional Family Social Time after the event.

Families who wish to stay are invited to stay and continue social time. Complimentary snacks, tea, and coffee will be served.

Presenting Experts



**Suzanne Edison,
MA, MFA**



Dr. Susan Shenoj



Dr. Chris Wong



Dr. Natalie Rosenwasser



Dr. Christian Lood



Dr. Aviya Lanis



Dr. Jenna Thomason



RSVP to attend

<https://www.curejmsattleeventbrite.com>

or scan the QR code



Brought to you by the generosity of:



The Bertsch
Family Charitable
Foundation

For more Information contact:
lauren.alvord@curejm.org
(916) 872 - 7883

