

* All times are ET

FRIDAY, DECEMBER 4, 2026

10 a.m.

Check-in and Networking

Kick off the day with coffee and a chance to connect with fellow rare disease patients, families and caregivers.

10:30 a.m.

Keynote Address

- Firdaus S. Dhabhar, PhD, Professor and Director, Flourishing Healers Program; Director, Scholarly Concentration in Advancing Mind-Body Medicine, Department of Psychiatry and Behavioral Sciences, Department of Microbiology and Immunology, Sylvester Comprehensive Cancer Center, Miller School of Medicine, University of Miami

11:10 a.m.

Creating Space for Life Beyond Appointments

Living with a rare disease or caring for someone with a rare disease can impact every part of life. For many, there are no breaks, days off, or respite. Appointments, treatments, symptoms, and uncertainty affect relationships, family routines, work, school, and the ability to plan for the future. This panel will explore how patients and caregivers navigate daily realities while staying connected to people, activities, and moments that matter most.

Moderator: Ashley Williams, LCSW, CCTP-II, CBHP, Licensed Clinical Social Worker and Desmoid Tumor Patient

Speakers:

- Shannon Bajwa, BS, CCLS, Director of Child Life and Creative Arts, Certified Child Life Specialist, Joe DiMaggio Children's Hospital
- Angela Fero, LCSW, BCD, Castleman Disease Patient; Licensed Clinical Social Worker; Founder, Rare Find Pilates & Wellness
- Jesus Loreto, Rare Disease Caregiver, Patient Community Liaison, Patient Health Alliance

11:55 a.m.

Networking & Exhibiting

Enjoy the opportunity to connect with others, navigating similar journeys and explore our exhibitor section.

12:20 p.m.

Finding the Right Fit: Navigating Rare Disease Research Opportunities

Research is essential to understanding rare diseases, improving care, and developing new treatments, yet it can be challenging for patients and families to find research opportunities that are a good fit for them. During this session, panelists will provide education on different types of research, how patients and caregivers can identify meaningful research opportunities, and how to evaluate whether a research opportunity is a good fit for your needs and goals.

Speakers:

- Irman Forghani, MD, FACMG, Director of Clinical Genetics and Genomics, Chief of RAD Center for Precision Medicine, Mount Sinai Medical Center, Braman Comprehensive Cancer Center
- Pamela Gavin, MBA, President & CEO, National Organization for Rare Disorders (NORD)
- Carson Smith, MS, CGC, Certified Genetic Counselor, University of Miami Miller School of Medicine, Department of Human Genetics

1:05 p.m.

Closing Remarks

1:15 p.m.

Lunch & Conclude

We hope you've enjoyed today's program! Grab some lunch and feel free to continue networking.

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