



FOUNDATION FOR
SARCOIDOSIS RESEARCH

Summit Agenda 2025

** All highlighted sessions indicate that they overlap with other sessions. All times are in Central Time Zone.

	Start	End	Session Title	Session Description	Speaker
SATURDAY 6/28					
	8:00AM	9:00AM	Exhibit Hall & Networking	From the home page, click on 'Exhibitors' and then click any booth that you are interested in visiting. Once on the booth, you will also see a chat window where you can chat with booth staff (if the staff is available). Click here to download tips for meeting with exhibitors. Visit the summit partner booths to view and download the educational and support resources available to you! Whether you are living with sarcoidosis or know someone impacted by sarcoidosis, there are many tools to help you or your loved one navigate the journey.	
	9:30AM	9:45AM	United for Progress: Propelling Us Towards a Brighter Future Together	Join Mary McGowan, CEO of the Foundation for Sarcoidosis Research, as she kicks off the 2025 FSR Summit, United for Progress: A New Chapter in Sarcoidosis. In this inspiring opening session, Mary will reflect on 25 years of FSR-led progress, celebrate milestones achieved through community and collaboration, and unveil exciting initiatives that are shaping the future of sarcoidosis research, care, and advocacy. This is the moment to come together, honor how far we've come, and look ahead—united—for what's next.	Mary McGowan, FSR President and CEO
	10:00AM	10:50AM	Turning the Page: Resilience and Hope in the Face of Sarcoidosis	Join actress, advocate, and sarcoidosis warrior Jeryl Prescott Gallien for an inspiring keynote session that celebrates the strength, resilience, and hope within the sarcoidosis community. In Turning the Page, Jeryl	Jeryl Prescott Gallien, actress and patient



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				reflects on the power of honoring what we've already survived, tapping into the resources we carry with us, and transforming pain into purpose. With an extended Q&A following personal insight, this session invites real conversation, shared strength, and a renewed sense of connection as we move forward—together	
Coffee Break opens 11:00AM Pause to recharge, network and process the information you have learned.	11:00 AM	11:50AM	Sarcoidosis 101: Pulmonary	During this session, we will delve into the basics of pulmonary sarcoidosis, including its definition, symptoms, diagnosis, and treatment options.	Dr. Parijat Sen, University of Kentucky Dr. Zeenat Safdar, Houston Methodist
Coffee break closes 11:50AM	11:00AM	11:50AM	Legislative Advocacy: FSR's Priorities and How to Join In	Join us for an in-depth session exploring FSR's pivotal role in federal advocacy and its legislative priorities aimed at improving the lives of those affected by sarcoidosis. As the leading international organization dedicated to finding a cure and enhancing patient care, FSR leverages the collective power of patients, caregivers, and medical professionals to drive change at the federal level.	Dane Christiansen, Health and Medicine Counsel
	12:00PM	12:50PM	Lunch		
	12:00PM	12:50 PM	Exhibit Hall & Networking		
	12:00PM	12:50PM	Poster Sessions: Advancing Knowledge in Sarcoidosis Research	Explore the latest findings in sarcoidosis research during our poster sessions. These informal, interactive displays offer a chance to dive into emerging science, connect with researchers, and gain a deeper understanding of what we've learned—and where we're headed.	



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	12:30PM	12:50PM	Affinity Group - Caregiver	This informal affinity session is a dedicated space for caregivers of individuals with sarcoidosis to come together, share their experiences, and find support. It's a relaxed, welcoming environment designed to foster connection, understanding, and community through open and compassionate conversation.	
	12:30PM	12:50PM	Affinity Group - Neurosarc	This informal affinity session is a dedicated space for individuals living with neurosarcoidosis to connect, share experiences, and find support. It's a relaxed, welcoming environment that encourages open conversation, understanding, and community.	
	12:30PM	12:50PM	Affinity Group - Cardiac	This informal affinity session is a dedicated space for individuals living with cardiac sarcoidosis to connect, share experiences, and find support. It's a relaxed, welcoming environment that encourages open conversation, understanding, and community.	
	1:00PM	1:50PM	Shared Decisions, Stronger Voices: Understanding Sarcoidosis and Advocating for Your Care	When it comes to sarcoidosis, there's no one-size-fits-all approach to treatment—and that makes your voice more important than ever. This session will explore how shared decision-making can transform the patient-provider relationship, helping you feel more confident, informed, and respected in your care journey. Learn how to communicate your goals, ask the right questions, and become an empowered partner in your treatment—without feeling like you're challenging your doctor. Because the best decisions are made together.	Dr. Joseph Barney, University of Alabama at Birmingham Scarlette Washlock, Patient Kelly Washlock, Parent and caregiver of patient
Coffee Break opens 11:00AM	2:00PM	2:50PM	Sarcoidosis 101: Cardiac	During this session, we will delve into the basics of cardiac sarcoidosis, including its definition, symptoms, diagnosis, and treatment options.	Dr. Jordana Kron, Virginia Commonwealth University Dr. Mahwash Kassi, Houston Methodist
	2:00PM	2:50PM	Intimacy and Sarcoidosis	Sarcoidosis can affect more than just the body—it can challenge emotional closeness, intimacy, and self-	Zoë Kors, Sex and Intimacy Coach



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				connection. In this session, sexologist and trauma therapist Zoë Kors shares supportive strategies inspired by her book <i>Radical Intimacy</i> to help patients and partners reconnect with each other—and themselves—with compassion, clarity, and confidence.	
	2:00PM	2:50PM	Genetics & Familial Connections	We often hear from the community wanting to better understand if sarcoidosis can be passed on to loved ones or why others in the family are impacted. During this educational session you will obtain a better understanding of the genetic underpinnings of sarcoidosis, new and emerging research on how genetics can help us understand flairs, and progression of the disease and the role that genetics can play precision medicine for future therapies.	Dr. Natalia Rivera, Karolinksa University Dr. Courtney Montgomery, Oklahoma Medical Research Foundation
	3:00PM	3:50PM	What's in the Air? Exploring Environmental Triggers in Sarcoidosis	From dust and mold to pollution and climate, what surrounds us might be shaping our sarcoidosis journey. Join this panel of experts as they dive into environmental exposures—like occupational risks, geographic patterns, and seasonal trends—and how these factors may influence sarcoidosis. We'll also explore what the latest research says, what we still don't know, and where future studies are headed. Whether you're curious about triggers or looking for ways to reduce risk, this session brings science and lived experience together to clear the air.	Dr. Mohamed Seedahmed, VA Dr. Albert Levin, Henry Ford Health
Coffee Break closes	3:00PM	3:50PM	Navigating Insurance and Access to Care	Insurance shouldn't be a barrier to getting the care you need—but too often, it is. In this panel, we'll break down how the insurance claims system works, what to do when your medication or procedure is denied, and how to advocate for yourself effectively. With real-life examples, expert tips, and trusted resources, you'll walk away better equipped to fight for the coverage you deserve and navigate the system with confidence.	Janet Mockovciak, Patient Erin Bradshaw, Patient Advocate Foundation



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	3:50PM	4:30PM	Break		
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SUNDAY 6/29					
	8:00AM	9:20AM	Exhibit Hall & Networking	From the home page, click on 'Exhibitors' and then click any booth that you are interested in visiting. Once on the booth, you will also see a chat window where you can chat with booth staff (if the staff is available). Click here to download tips for meeting with exhibitors. Visit the summit partner booths to view and download the educational and support resources available to you! Whether you are living with sarcoidosis or know someone impacted by sarcoidosis, there are many tools to help you, or your loved one navigate the journey.	
	9:30AM	9:45AM	Opening Session- Reflections from Mary Cobb, FSR Board President	Join the Foundation for Sarcoidosis Research (FSR) Board President, Mary Cobb, as she reflects on the highlights from Day 1 and offers a look ahead at today's exciting sessions and opportunities	Mary Cobb, FSR Board President
	10:00AM	10:50AM	Patient Panel: Let's Get Moving: A Talk on Exercise	Starting to exercise while living with sarcoidosis—and dealing with fatigue—can be hard. In this panel, you'll hear from patients and a healthcare provider about how to get moving safely and in a way that works for you. Learn how others found the right types of exercise, talked with their doctors, and built confidence over time. Whether you're just starting out or looking to make changes, this session offers support, advice, and real-life experiences.	Marion Paetznick, Cathleen Terrano, Patient Royce Robertson, Patient John Carlin, Moderator
Coffee Break opens 11:00AM	11:00AM	11:50AM	Sarcoidosis 101: Steroids and Sarcoidosis	During this session, we will delve into the basic challenges of leveraging steroids as a first line defense for treating sarcoidosis, including the enhanced risk for	Dr. Lucian Marts, Emory Dr. Logan Harper, Cleveland Clinic



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Pause to recharge, network and process the information you have learned.				co-morbidities such as osteoporosis and diabetes and how to manage long-term use.	
	11:00AM	11:50AM	Mindful Moments: Managing Stress and Finding Calm	Join mindfulness meditation coach and FSR Virtual Support Group Leader Susan D'Agostino for an engaging session on the mind-body connection. Explore how stress affects the body and learn practical techniques to manage it, including a guided breathing awareness and meditation exercise. This session offers both valuable insight and a restorative pause to support your well-being during the summit.	Susan D'Agostino, FSR Virtual Support Group Leader
Coffee Break closes 11:50AM	11:00AM	11:50AM	The future of Sarcoidosis Research: What's next?	This forward-looking session will explore the most pressing and promising questions in sarcoidosis research today. Expert speakers will highlight 2–3 key research priorities that are poised for breakthrough in the next five years. The session will also spotlight the Foundation for Sarcoidosis Research (FSR) Patient Registry as a vital tool driving discovery. Attendees will gain a deeper understanding of how patient participation in research efforts, especially registries, is essential to accelerating progress and shaping the future of sarcoidosis care.	Elise Hoover, FSR VP of Research Maneesh Bhargava, Ohio State
	12:00PM	12:50PM	Lunch		
	12:00PM	12:50PM	Exhibit Hall & Networking		
	12:00PM	12:50PM	Poster Sessions: Advancing Knowledge in Sarcoidosis Research	Explore the latest findings in sarcoidosis research during our optional poster sessions. These informal, interactive displays offer a chance to dive into emerging science, connect with researchers, and gain a deeper	



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				understanding of what we've learned—and where we're headed.	
	12:30PM	12:50PM	Affinity Group – Black Patient	This informal affinity session offers Black individuals living with sarcoidosis a space to connect, share their experiences, and discuss the unique challenges they may face. It's a supportive and welcoming environment where open dialogue fosters community, understanding, and empowerment.	
	12:30PM	12:50PM	Affinity Group – International	A welcoming space for individuals across the globe impacted by sarcoidosis to connect, share experiences and discuss the challenges of living with sarcoidosis in different health care systems and cultural contexts. This session fosters global community support and knowledge sharing.	
	1:00PM	1:50PM	Ask the Experts	Join us for this extraordinary session where leading sarcoidosis experts come together to answer questions directly from you. This panel brings together experts from numerous specialties and focus areas to ensure you are provided with the most up-to-date and relevant research and clinical best practices. Come armed with your questions and a pen and paper, we are sure you will be taking notes throughout this important session.	Dr. Barney Stern, Johns Hopkins Dr. Viiabhav Patel, The Ohio State University Dr. Debabrata Bandyopadhyay, Tampa General Dr. Elizabeth Frame, Cedars Sinai
Coffee Break opens 2:00pm Pause to recharge, network and process the information you have learned.	2:00PM	2:50PM	What's Sarcoidosis and What's Not? Understanding Organ Involvement, Monitoring, and Shared Decisions	Sarcoidosis can affect many parts of the body—but how do you know which symptoms are part of the disease and which aren't? This session will explore how sarcoidosis manifests across different organs, how clinicians decide when to investigate new symptoms, and when it's time to bring concerns to your healthcare team. We'll also highlight the most important topics for shared decision-making between patients and providers, so you feel confident navigating your care.	Dr. Craig Smuda, University of Chicago Dr. Clara Restrepo, National Jewish



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	2:00PM	2:50PM	Sarcoidosis 101: Neurosarcoidosis	During this session, we will delve into the basics of neurosarcoidosis, including its definition, symptoms, diagnosis, and treatment options.	Dr. Brandon Moss, Cleveland Clinic Dr. Amanda Piquet, University of Colorado Health
	2:00PM	2:50PM	Creating a Roadmap for Your Sarcoidosis Journey: Workshop	THIS WORKSHOP IS LIMITED TO 50 PARTICIPANTS Join Dr. Bobak Akhavan as he shares practical tools and strategies he uses to support patients in his clinical practice. During the session, you'll have the opportunity to provide feedback, offer suggestions, and share insights on the types of resources and information that would be most valuable to you in your clinical journey.	Dr. Bobak Akhavan, Cedars Sinai
	3:00PM	3:50PM	Emerging Therapies for Sarcoidosis: What's Changing and Why It Matters	In the past five years, doctors have changed how they treat sarcoidosis. They now try to use fewer steroids because of their side effects. Instead, they might use other medicines, including some that were first made for different diseases called "repurposed drugs". Learn about the therapies that clinicians are using to treat sarcoidosis and how these decisions should include not only clinical evidence but conversations about patient values and quality of life.	Dr. Mridu Gulati, Yale Dr. William Damsky, Yale Dr. Vivienne Kahlmann, University Medical Center, Netherlands
Coffee break closes 3:50PM	3:00PM	3:50PM	Managing the Invisible: Fatigue, brain fog and dizziness in Sarcoidosis	Chronic symptoms like fatigue, brain fog, and dizziness can significantly impact quality of life for people living with sarcoidosis, yet they are often underrecognized and undertreated. In this session, speakers will explore holistic approaches to managing these invisible symptoms—including strategies for energy conservation, the role of spirituality in healing, and practical guidance for navigating daily activities with greater ease and intention	Dr. Jinny Tavee, National Jewish



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	3:50PM	4:30PM	Break		
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	4:30PM	5:20PM	United for Progress: A Fireside Chat on Confidence, Connection, and Moving Forward	To close out the summit, join Mary McGowan, the CEO of the Foundation for Sarcoidosis Research and [TBA] for an open, uplifting fireside chat. Together, they'll reflect on how we're turning the page to a new chapter in sarcoidosis—one grounded in shared decision-making, stronger partnerships between patients and providers, and confidence in what comes next. This session is about connection, collaboration, and feeling empowered to take the next step—united, informed, and inspired.	Mary McGowan, FSR President and CEO