

AGENDA - DAY ONE: Saturday, May 4, 2024

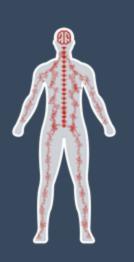
Check-In opens at 8 AM | Program runs from 9 AM-5 PM | IN PERSON & VIRTUAL Sheraton Hartford Hotel at Bradley Airport, Windsor Locks, CT

Time		Location
8am-5pm	Registration	Lobby
·	Sponsor Exhibits Open	
	Networking	
8am-9am	Breakfast Provided	Lobby
9am-9:15am	Opening Remarks & Overview	Ballroom
	David Axelrod, 2024 SPS Symposium Committee Chair	
9:15am-10:45am	From Invisible to Invincible	Ballroom
	Stiff Person Syndrome Patient Registry Panel Discussion	
	Tara Zier, DDS, Founder & CEO, The Stiff Person Syndrome	
	Research Foundation	
	Jacqueline Kraska, Registry Manager	
	Registry Steering Committee Members: Shannon Gibbons,	
	Scott Newsome, Moira Scully Papp, Amanda Piquet, Lara	
	Vujovic	
10:45am-11:15am	Break, Networking, Sponsor Exhibits	Lobby & Ballroom
11:15am-12:30pm	Research in SPS: Past, Present, and Future	Ballroom
'	Scott Newsome, DO, MSCS, FAAN, FANA	
	Professor of Neurology	
	Director, Johns Hopkins Stiff Person Syndrome Center	
	Director, Johns Hopkins Neuroimmunology and Neurological	
	Infectious Disease Fellowship Program	
12:30pm-1:45pm	Lunch Buffet	Lobby & Ballroom
	Networking, Sponsor Exhibits Open	
1:45pm-2pm	Guest Speaker	Ballroom
	Mollie Baumer	
2pm-3:15pm	Hematopoietic Stem Cell Transplant in SPS	Ballroom
	Amanda Piquet, MD	
	Associate Professor of Neurology	
	Director, Autoimmune Neurology, University of Colorado	
	Neuroimmunology, Neuroinfectious Disease &	
	Neurohospitalist Sections	
	University of Colorado School of Medicine	
3:15pm-3:45pm	Break, Networking, Sponsor Exhibits	Lobby & Ballroom
3:45pm-4:15pm	Exploring the Fundamentals of SPS	Ballroom
	Duarte Machado, MD	
	Director of Program Excellence and Recognition, Chase	
	Family Movement Disorders Center, Hartford HealthCare	
4:15pm-5pm	Panel Discussion and Q&A	Ballroom
5pm	Closing Remarks	Ballroom
•	David Axelrod, 2024 SPS Symposium Committee Chair	
	Day One Concludes: Dinner on your own	



WHAT IS STIFF PERSON SYNDROME?

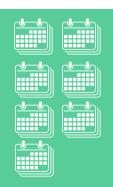
Stiff Person Syndrome (SPS) is a rare neurological disease with autoimmune features. Symptoms include muscle spasms, hyper-rigidity, debilitating pain, and chronic anxiety. Muscle spasms can be so violent they can dislocate joints and even break bones.



SPS AFFECTS

A few in a 1,000,000

PEOPLE PEOPLE



OFTEN MISDIAGNOSED, ON AVERAGE, SPS TAKES

7 years

TO BE IDENTIFIED IN PATIENTS.



SPS IS OFTEN MISTAKEN AS:

- Multiple Sclerosis,
- Parkinson's,
- Fibromyalgia,
- Psychosomatic Illness,
- Anxiety,
- Phobia,
- Other autoimmune diseases

RESULTING IN DELAYED TREATMENT PLANS

OCCURRENCES OF SPS:

- Females are affected twice as often as males.
- Patients most commonly develop symptoms between the ages of 30-50.
- 5% of cases of SPS are reported in children.



TODAY, THERE IS NO CURE FOR SPS.





MOST TREATMENTS DON'T WORK WELL.

PATIENTS CAN BE DISABLED, UNABLE TO WORK, OR CARE FOR THEMSELVES.





Take-Away: Ways to Get Involved

Join Our Quest for A Treatment for Stiff Person Syndrome

Together, we are a force for change. Let's amplify our voices, bolster our strength, and define our invincibility. Your actions propel us towards treatment—because SPS doesn't define us!

STAY CONNECTED

Sign up for our emails & newsletter, follow us on social media.

ENGAGE

Sign up for the Patient Registry, attend SPSRF events (like this Symposium!) or other programs.

DONATE

Host an event, share a Facebook Fundraiser, or participate in fundraiser activities.









REACH OUT

Reach out with questions or ideas to advance our mission (info@stiffperson.org).



SHARE YOUR STORY

Share your story and SPS experiences with our community and the world.



DO WHATEVER IT TAKES!

Dress up your dog!

Ideas to Explore:		



Now What?

All material highlighted below will be available on our social media pages, through email, and online at: stiffperson.org/sps-symposium.html

Social Media:

Follow us on social media.

- Facebook.com/TheSPSRF
- •Instagram.com/stiff_person_syndrome
- •linkedin.com/company/SPSRF

Email:

Join our mailing list to receive updates. Sign up here stiffperson.org/news/ newsletter.html: Or, scan this code to sign up.





This Week:

Stay engaged and shape our future events by **sharing your valuable feedback** through our surveys.



Later This Month:

Revisit the moments of today's symposium with our **curated video recaps and summaries**—keeping the conversation alive and the momentum going!



Next Month:

The following month, we'll provide **comprehensive summary documents** detailing the insights from today's presentations and tomorrow's interactive breakout groups.



Expect an upcoming invitation to a Zoom call focused on the SPS International Patient Registry & Natural History Study to learn more about this critical initiative.



Finally, we'll soon schedule a webinar to share more about **The SPSRF's core research initiatives** and **review our 2023 financial impact**, all to keep you informed and involved