

# 2024 STIFF PERSON SYNDROME SYMPOSIUM



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

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## 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



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**

**TODAY, THERE  
IS NO CURE FOR  
SPS.**



**MOST  
TREATMENTS  
DON'T WORK  
WELL.**

### 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.



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



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## 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](mailto: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:

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## Now What?

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

### Social Media:

Follow us on social media.

- [Facebook.com/TheSPSRF](https://Facebook.com/TheSPSRF)
- [Instagram.com/stiff\\_person\\_syndrome](https://Instagram.com/stiff_person_syndrome)
- [linkedin.com/company/SPSRF](https://linkedin.com/company/SPSRF)

### Email:

Join our mailing list to receive updates.

Sign up here [stiffperson.org/news/newsletter.html](https://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.