

# 2024 STIFF PERSON SYNDROME SYMPOSIUM



Take-Away: The SPS International Patient Registry & Natural History Study (Panel Discussion)

## WHAT IS THE SPS INTERNATIONAL PATIENT REGISTRY & NATURAL HISTORY STUDY



The Registry provides researchers with valuable **data** from SPS patients. It is led by The SPSRF with **input from global experts, researchers, statisticians, and data analysts.**

## WHY IS IT IMPORTANT?

The International Patient Registry and Natural History Study will **provide a more thorough understanding of SPS** based on a **more diverse patient population**, accelerating clinical trials for better treatments.

## WHAT IS IT NOT

It is NOT a map of people with SPS.



It is NOT a collection of SPS patient stories.



## STEPS TO DEVELOP THE SPS INTERNATIONAL PATIENT REGISTRY & NATURAL HISTORY STUDY

- 1 Develop Protocol
- 2 Develop Registry Patient Surveys
- 3 Develop Informed Consent Form
- 4 Develop Participant Recruitment Material
- 5 Inform SPS Community and promote

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- 6 Launch Registry

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- 7 Recruit Participants
- 8 Support patient engagement and retention
- 9 Secure long-term funding

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- 10 Conduct data analysis and produce outcomes reports
- 11 Share data and collaborate with experts

*Phase 1  
Development*

*Launch*

*Phase 2  
Recruit & Retain*

*Phase 3  
Research & Collaborate*