

The Spastic Paraplegia Foundation

YouTube conferences, talks and podcasts from 2020

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Note: Use “Ctrl + Click” on the title of a presentation to go to the corresponding video or audio material on our YouTube channel.

SPF Annual Conferences

2025 SPF Annual Conference

1. Craig Blackstone, MD, PhD – [Therapeutic approaches for the HSPs.](#)
2. Collin Hovinga, PharmD, MS – [Drug development in rare diseases.](#)
3. Greg Pruitt – [A patient voice in action.](#)
4. Javier Tuel – [Movements and exercises in HSP.](#)
5. Darius Ebrahimi-Fakhari, MD, PhD – [Spastic Paraplegia Centre of Excellence Research Network: Transforming collaboration to coordinated global research.](#)
6. Lindsay Perlman – [The Paralyzed Veterans of America.](#)
7. Collin Hovinga, PharmD, MS – [Pre-consortium-HSP/PLS.](#)
8. Mukesh Gautum, MD, PhD – [Investigating upper motor neuron health in HSP and PLS.](#)
9. [Leigh Ann Fairley, Health Legislative Assistant for U.S. Congressman Gus M. Bilirakis, Florida.](#)
10. [Zack Settle, Legislative Assistant for US Congressman James Comer, Kentucky.](#)
11. Jon Audhya, PhD – [Gene therapies strategies for HSP.](#)
12. John Fink, MD – [Towards in-home testing and novel rehabilitation strategies for subjects with PLS and HSP: Ideas, progress, and imagination.](#)
13. Peter W. Baas, PhD – [Developing a therapeutic regimen for SPG4-HSP.](#)
14. Javier Tuel – [Exercise period.](#)
15. P. Hande Ozdinler, PhD – [From understanding to treatment: why upper motor neurons degenerate and how can we repair them.](#)
16. Liang Oscar Qiang, MD, PhD – [From human stem cell based motor cortical organoids to preclinical therapeutic testing for HSP.](#)
17. Richard Silverman, PhD – [Inhibition of protein aggregation and the development of NU-9 \(AKV9\) for amyotrophic lateral sclerosis and other degenerative diseases.](#)
18. Richard Novak, PhD – [Predictable medicine: How patient-driven drug discovery is accelerating a path to treatment for multiple spastic paraplegia.](#)
19. Rahul Sachdeva, PhD – [Neurological recovery with spinal cord neuromodulation. Insights from spinal cord injury and cerebral palsy.](#)
20. [Senator Chuck Grassley](#)
21. [Senator Amy Klobuchar](#)

2024 SPF Annual Conference

1. P. Hande Ozdinler, PhD – [Developing effective treatments for UMN diseases: the future is now.](#)
2. Darius Ebrahimi-Fakhari, MD, PhD – [The dawn of translational research in hereditary spastic paraplegia.](#)
3. Lauren Leiva, DPT – [Inspiration and movement, including a mini-stretch.](#)
4. Thomas J. Hart, JD – [Fast tracking HSP and PLS.](#)
5. Natalie Downs, MSc, CGC – [Delivering novel therapies to patients impacted by genetic disease.](#)
6. Craig Blackstone, MD, PhD – [New therapeutic approaches for the HSPs.](#)
7. Hiroshi Mitsumoto, MD, DSc – [PLS natural history study and PLS International Meeting.](#)
8. Peter W. Baas, PhD – [Development of an M1-spastin antibody for diagnosis, study and treatment for SPG4 hereditary spastic paraplegia.](#)
9. Emanuella Piermarini, PhD – [Beyond gene therapy, can we promote functional recovery of SPG4-patients?](#)
10. Liang Oscar Qiang, MD, PhD – [Advancing hereditary spastic paraplegia research: insights from human stem cell models.](#)
11. Linda LaFontaine – [The HSP cohort within C-BIG at the NEURO at McGill University in Montreal, Canada.](#)
12. Stephan Züchner, MD, PhD – [Updates on spastic paraplegia genetics and opportunities ahead.](#)
13. Daniel Calame, MD, PhD – [Genetic mechanism underlying undiagnosed pediatric HSP.](#)
14. Luca Schierbaum, PhD – [HSP sequencing initiative: closing the diagnostic gap for childhood-onset HSP.](#)
15. Kim Sanchez – [Podcasts and social media.](#)
16. John R. Fink, MD – [Questions and answers.](#)
17. After the 2024 SPF Conference, James H. McClaren provides a down-to-earth explanation of the speaker's presentations – [Breaking down the science.](#)

2023 SPF Annual Conference

1. Chris Lorek, Katie Gregg, Bridget Lassig and Ece Filiz – [Diagnostic to hope: life as a parent caregiver.](#)
2. Chrissy Smith – [Duo dogs.](#)
3. Darius Ebrahimi-Fakhari, MD, PhD – [Clinical trial readiness for children with HSP.](#)
4. Stephan Züchner, MD, PhD – [Opportunities in HSP genomic and therapy: Centers of Excellence Research Network \(HSP-CERN\).](#)
5. Craig Blackstone, MD, PhD – [Hereditary spastic paraplegia: biology.](#)
6. Darius Ebrahimi-Fakhari, MD, PhD – [Clinical trial readiness for hereditary spastic paraplegia: lessons learned from translational research in rare diseases.](#)
7. Hiroshi Mitsumoto, MD, DSc – [PLS natural history study \(PLS NHS\) update.](#)
8. P. Hande Ozdinler, PhD – [Developing clinical trials.](#)
9. Mukesh Gautam, PhD – [Potential role of cardiolipin in improving upper motor neuron health.](#)
10. Emanuela Piermarini, PhD – [Gene therapy approach for SPG4-based hereditary spastic paraplegia: a preclinical study.](#)
11. D Liang Oscar Quiang, MD, PhD – [Unveiling HDAC6: a promising therapeutic target for SPG4 – insights from human and animal models.](#)
12. [Open forum with doctors.](#)
13. John R. Fink, MD – [Questions and answers.](#)

2022 SPF Annual Conference

1. John K. Fink, MD – [Let's dance. Emerging strategies towards neuro-rehabilitation in primary lateral sclerosis and hereditary spastic paraplegia.](#)
2. Peter W. Baas, PhD – [Mechanistic route to therapy for SPG4 hereditary spastic paraplegia.](#)
3. Hiroshi Mitsumoto, MD, DSc – [PLS natural history study \(PLS NHS\) update.](#)
4. Angie & Jeremy McCord – [Movement matters.](#)
5. Chelsea Burton, PA-C – [Symptomatic management of spasticity.](#)
6. P. Hande Ozdinler, PhD – [Building effective and long-term treatments for UMN diseases: time is NOW.](#)

7. Darius Ebrahimi-Fakhari, MD, PhD – [Childhood-onset hereditary spastic paraplegia: lessons learned from a translational approach to ultra-rare diseases.](#)
8. John K. Fink, MD – [Post discussion.](#)
9. [Questions and answers panel discussion with doctors.](#)

2021 SPF Virtual Annual Conference

1. P. Hande Ozdinler, PhD – [Building effective treatment strategies for UMN \(upper motor neuron\) disease.](#)
2. Sabrina Paganoni, MD, PhD – [What's new in PLS?](#)
3. John K. Fink, MD – [Spasticity and spastic gait in HSP and PLS treatment targets and approaches.](#)
4. Corey Braastad, PhD – [Basic genetics, cell and gene therapy update, and virtual conference talk review.](#)
5. Marcondes Franca, MD, PhD – [Anti-spastic therapies in hereditary spastic paraplegia.](#)
6. Hiroshi Mitsumoto, MD, DSc – [We are making a steady progress in clinical front of PLS.](#)
7. Wladimir Bocca Vieira de Rezende Pinto, MD, PhD – [Hereditary spastic paraplegia in Brazil: recent achievements and current challenges.](#)

2020 SPF Virtual Annual Conference

1. Corey Braastad, PhD – [Basic genetics and therapy update.](#)
2. John K. Fink, MD – [Primary lateral sclerosis, hereditary spastic paraplegia: paths towards therapy.](#)
3. Peter W. Baas, PhD – [HSP: understanding what's wrong so that we can fix it.](#)
4. P. Hande Ozdinler, PhD – [Path to improve upper motor neuron health.](#)
5. Stephan Züchner, MD, PhD – [Genetic topics in HSP & related diseases.](#)
6. Hiroshi Mitsumoto, MD, DSc – [We have made steady progress on the clinical front of PLS.](#)
7. Craig Blackstone, MD, PhD – [Research advances in the HSPs.](#)
8. Darius Ebrahimi-Fakhari, MD, PhD – [AP-4-associated hereditary spastic paraplegia \(SPG47, SPG50, SPG51 & SPG52\) - A multimodal strategy to finding a cure for an ultra-rare disease.](#)

PLS Conference

2024 International PLS Conference

PANEL 1 - TAKING PLS DIAGNOSIS TO THE NEXT LEVEL

1. John Fink, MD – [How to clinically distinguish PLS from HSP.](#)
2. Matthew Kiernan, PhD – [Cognitive and behavioral dysfunction in PLS.](#)
3. Matthew Harms, MD – [Do we need genetic testing in PLS?](#)
4. Albert C. Ludolph, MD – [Validation of the new PLS diagnostic criteria.](#)
5. Eric Sorenson, MD – [EMG is crucial for diagnostic criteria.](#)
6. Lauren Elman, MD – [PLS NHS diagnostic criteria.](#)

PANEL 2 - PLS REGISTRIES AND BIOREPOSITORIES: THINKING GLOBAL

7. Orla Hardiman, MD – [The Irish registry.](#)
8. Osamu Kano, MD, PhD – [Japanese registry.](#)
9. Leonard Van den Berg, MD – [ENCALS PLS.](#)
10. Alexander Sherman, MS – [International expansion PLS registry.](#)
11. Paul Mehta, MD – [USA CDC National ALS/PLS registry.](#)
12. Hiroshi Mitsumoto, MD, DSC – [PLS NHS - Harmonised system of collecting data in PLS.](#)

KEYNOTE SPEAKER

13. Peter Bede, MD, PhD – [What is neuroimaging teaching us about PLS?](#)

PLS BIOMARKERS TO WATCH

14. Sandra Banack, PhD – [MicroRNA in PLS.](#)
15. Ikjae Lee, MD – [Lipidomics in PLS.](#)
16. Paride Schito, MD – [NFL in PLS.](#)
17. P. Hande Ozdinler, PhD – [UMN marker biomarkers for PLS trials?](#)
18. Kourosch Rezaei, MD – [Intermuscular coherence in PLS.](#)

PANEL 3 - PERFORMANCE OF THE PLSFRS AND OTHER OUTCOMES TO SUPPORT CLINICAL TRIAL READINESS

19. Ken Cheung, MD – [PLSFRS performance](#).
20. Grace Jang – [Other outcomes for NHS](#).
21. Daragh Heitzman, MD – [EMG can be outcome](#).
22. Ken Cheung, MD – [How to conduct effective clinical trials in rare disease. How does magnitude of change fare in relation to variability of the measure, and what can be learned from clinical trial/sample size simulations based on these data.](#)

PANEL 4 - CRITICAL PATH TO CLINICAL TRIALS

23. Senda Ajroud-Driss, MD – [Eligibility criteria](#).
24. Osamu Kano, MD, PhD – [Can we make PLSFRS universal?](#)
25. Michael Benatar, MD, PhD – [What outcome would have a clinically meaningful impact on PLS?](#)
26. Martin Turner, MD, PhD – [Do we need to revise the current Diagnostic Criteria?](#)
27. Philippe Corcia, MD – [Any other critical issues?](#)
28. Vincenzo Silani, MD, PhD – [What else do we suggest before the next clinical trial?](#)
29. [Questions and answers](#).
30. [Wrap up- Are we ready for clinical trials?](#)

This session is without slides. Panelists: Jinsy Andrews, Mamede de Carvalho, Angela Genge, Orla Hardiman, Matthew Kiernan, Martin Turner and Leonard van den Berg.

SPF Talks

2026 SPF Talks

1. Nancy Carlson, PhD, OTR/L CAPS – [Living Your Best Life. Navigating your HSP/PLS with purpose and confidence](#).
2. Sabrina Paganoni, MD, PhD & Erica Scirocco, MD – [PLS Research Updates](#).
3. Kent Keyser and Bill Nixon / SecureRide Coalition – [Advocating Wheelchair Securement Standards](#).
4. Ikjae Lee, MD – [PLS Natural History Study](#).

2025 SPF Talks

1. Jon Bockelmann-Evans – [How to use the Joy Formula.](#)
2. Marcondes Franca Jr, MD, PhD – [Biomarcadores : neuroimagem e neuromodulação podem ajudar a entender o tratamento de pacientes comPEH.](#)
3. Marcondes Franca Jr, MD, PhD – [Biomarkers: neuroimaging and neuromodulation can help understand and treat HSP patients.](#)
4. Annie Streit and Steve Lieberman, United Spinal Association – [Advocacy.](#)
5. SPF team – [Fundraising ideas.](#)
6. Rahul Sachdeva, PhD – [Neurostimulation: spinal cord stimulation for neurological recovery.](#)
7. Sabrina Paganoni, MD, PhD – [Connecting PLS patients](#) (March 28th, 2025).
8. Anne Cameron, MD – [UTI causes, treatment and prevention.](#)
9. E. Guterriez – [5K Run, Walk, and Roll 2025.](#)
10. Ikjae Lee, MD – [Natural history study for PLS.](#)
11. Sabrina Paganoni, MD, PhD – [Connecting with PLS Patients](#) (June 5th, 2025).
12. Sherry Brady – [Dnsys X1 exoskeleton](#)
13. Sabrina Paganoni, MD, PhD – [Connecting with PLS patients](#) (August 18th, 2025).
14. Ruth Dismuke-Blakely, MS – [Hippotherapy](#)
15. Jason Karamchandani, MD, & Linda Lafontaine – [HSP cohort within the NEURO at McGill University.](#)
16. Javier Tuel – [Transforming Your Strength.](#)

2024 SPF Talks

1. Bianca Martinez, MD – [Spasticity management.](#)
2. Lori Renna Linton – ["Potato Pants" revised.](#)
3. Mike Marsh – [Parking mobility.](#)
4. Paul Freda, MD – [Mental help part 1.](#)
5. Paul Freda, MD – [Mental help part 2.](#)
6. Roberta La Piana MD, PhD and Ruwan Bedeir – [On the hunt for genetic diseases: white matter abnormalities as diagnostic clues.](#)

7. Senda-Ajorud Driss, MD – [Connecting with PLS patients.](#)
8. Zachary Lipson – [Adaptive training.](#)

2023 SPF Talks

1. Angela Girardier, PT – [Incontinence.](#)

2022 SPF Talks

1. Brittany Kasaba – [Disability life-hacks, tips and tricks, part 1.](#)
2. Brittany Kasaba – [Disability life-hacks, tips and tricks, part 2.](#)
3. Chris Pace, MSW – [Self-care and chronic illness-disability.](#)
4. Christine Patrick Hendrickson, ARNP – [Three mobility assistive devices.](#)
5. Crissy Smith – [Duo dogs.](#)
6. David Ball – [Social security disability benefits.](#)
7. Kevin Gallagher – [BOTOX.](#)
8. Melissa Sheorn – [Caregiving.](#)
9. Yolanda Heath, ND – [Vitamins and supplements.](#)

SPF Podcasts

2024 SPF Podcasts

1. [Anne Gridley with Kim Sanchez.](#)
2. [Cece Russell with Kim Sanchez.](#)
3. [Celyna Káritas Rackov.](#)
4. [Gary Goad with Kim Sanchez.](#)
5. [Kristen Cordrey with Kim Sanchez.](#)
6. [Ray White speaks about HSP.](#)
7. [Tina Croghan's Story.](#)