



The  
Ehlers  
Danlos  
Society

GLOBAL LEARNING  
CONFERENCE 2024

EDS & HSD

FROM  
HEAD  
TO  
TOE



# MAIN CONFERENCE AGENDA

JULY 17-20, 2024

# WEDNESDAY JULY 17

| TIME (EST):  | SESSION & PRESENTATION:  | SPEAKER(S):   |
|--|--|---|
| 8:00 AM  | In-person attendees: Badge collection & Shop opens                                       |   |
| 12:00 - 12:20 PM   | Mindful Movement Snacks: Somatics with Mel   | Melissa Williams  |
| 12:30 - 1:45 PM  | Welcome lunch  |   |
| 1:45 PM  | Ballroom opens   |   |
| 2:00 - 2:15 PM   | Welcome orientation, housekeeping and overview of conference theme                       | Sarah Hamilton, Scarlett Eagle, Danielle Hohlier  |
| 2:15 - 2:30 PM   | Updates on The Society: An Overview  | Lara Bloom  |
| 2:30 - 2:40 PM   | Updates on The Society: EDS ECHO   | EDS ECHO Team   |
| 2:40 - 2:50 PM   | Updates on The Society: Research   | EDS Research Team   |
| 2:50 - 3:20 PM   | Keynote Panel: Equitable Care: Empowering Marginalized Voices in EDS and HSD             | Lara Bloom, Akilah Cadet, Michelle Jalali, Sabra Thomas, Mars Lombardi, Danielle Medina |
| 3:20 - 3:50 PM   | Break  |   |
| SESSION 1: Everyday management strategies for patients and providers   Chair: Dr. Alan Hakim |  |   |
| 3:50 - 4:20 PM   | Keynote: Prioritizing symptoms of EDS and HSD: what needs to be evaluated first?         | Dr. Dacre Knight  |
| 4:20 - 4:40 PM   | Bringing EDS & HSD Clinical Tools to Primary Care in a Major Academic Health System      | Dr. Nathan Rudin  |
| 4:40 - 5:00 PM   | Coping with Chronic Pain and Fatigue While Living with HSD or EDS                        | Aviva Gaskill, PhD  |
| 5:00 - 5:20 PM   | Establishing a Positive physician/patient relationship with Skeptical EDS & HSD Patients | Dr. Dennis Hart   |
| 5:20 - 5:40 PM   | How to engage in activities with modification  | Aiko Callahan   |
| 5:40 - 6:00 PM   | Panel Q&A  |   |
| 6:05 PM  | Close  |   |
|  |  |   |
| 6:30 - 7:30 PM   | Your Voice Matters! Shaping the Future for Kids & Teens Living with EDS & HSD            | Sarah Hamilton, Janae Davis   |
| 6:30 - 7:30 PM   | Young Adults Meet-Up   | Scarlett Eagle, Nina Fernandez  |



**SESSION**



**BREAK**



**Q&A**

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# THURSDAY JULY 18

| TIME (EST):  | SESSION & PRESENTATION:   | SPEAKER(S):                                    |
|--|---|--|
| 7:30 - 8:30 AM   | Pre event: Fascial Breath   | Jeannie Di Bon & Tina Wang                     |
| 8:00 AM  | In-person attendees: Badge collection & Shop opens  |  |
| 8:35 AM  | Ballroom opens  |  |
| 8:50 - 9:00 AM   | Welcome, housekeeping and overview of todays theme  |  |
| <b>SESSION 2: Neurodivergence and Mental Wellbeing   Chair: Francie Fitzgerald</b> |   |  |
| 9:00 - 9:20 AM   | Definitively Different: Embracing Neurodivergence and Mental Wellbeing in Ehlers-Danlos Syndrome and Hypermobility Spectrum Disorders | Dr. Camille Schrier, PharmD, Miss America 2020 |
| 9:20 - 9:40 AM   | Thriving and Flourishing with Chronic Pain  | Dr. Sarah Wenger & Dr. Valerie Iovine-Rogers   |
| 9:40 - 10:00 AM  | Autism, ADHD, and EDS...Oh My!  | Kathleen Johnson                               |
| 10:00 - 10:20 AM   | Enhancing Wellbeing with Hypermobility, Neurodivergence, and Disability   | Lisa Belvy                                     |
| 10:20 - 10:40 AM   | How Dialectical Behavior Therapy Can Help in EDS & HSD Care and Management  | Francie Fitzgerald                             |
| 10:40 - 11:00 AM   | Panel Q&A   |  |
| 11:00 - 11:30 AM   | Break   |  |
| <b>SESSION 3: The Orofacial Region   Chair: Dr. Clair Francomano</b>               |   |  |
| 11:30 - 11:50 AM   | Vision Matters: Eye Conditions in EDS & HSD   | Dr. Jefferson Doyle                            |
| 11:50 - 12:10 PM   | EDS/MCAS Problems and Therapies for Nasal/Sinus Issues  | Dr. Subinoy Das                                |
| 12:10 - 12:30 PM   | Oral Health: Navigating Dental and Jaw Issues in EDS & HSD  | Dr. Rebecca Schaffer                           |
| 12:30 - 12:50 PM   | EDS, HSD, & the orofacial region: chewing, swallowing, and tongue posture   | Christina Semonick                             |
| 12:50 - 1:10 PM  | Panel Q&A   |  |
| 1:10 - 1:30 PM   | Mindful Movement Snacks: Pilates with Jeannie   | Jeannie Di Bon                                 |
| 1:30 - 2:30 PM   | Lunch   |  |
| <b>SESSION 4: The Head and Neck   Chair: Dr. Fraser Henderson</b>                  |   |  |
| 2:30 - 2:50 PM   | It's Not All In Your Head: Unraveling Neurological Complications in EDS & HSD   | Dr. Clair Francomano                           |
| 2:50 - 3:20 PM   | Upper Cervical Instability - Presentation and Non-surgical Treatment Methods  | Patricia Stott & Susan Chalela                 |
| 3:20 - 3:40 PM   | CranioSacral Therapy: An avenue for pain management in EDS & HSD  | Eloise Stager                                  |
| 3:40 - 4:10 PM   | Demographics, Comorbidities, and Surgical Outcomes of the Neuro-EDS Population  | Dr. John Biggins                               |
| 4:10 - 4:30 PM   | Panel Q&A   |  |
| 4:30 - 5:00 PM   | Break   |  |



**SESSION**



**BREAK**



**Q&A**

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|---|---|----------------------|
| SESSION 5: Breathing and Respiratory Wellness   Chair: Jeannie Di Bon |   |                      |
| 5:00 - 5:20 PM  | Prescriptive Breathing and Related Corrective Exercises:<br>An Approach for Systemic EDS & HSD Management | Robyn Fog            |
| 5:20 - 5:40 PM  | Respiratory Health in Ehlers-Danlos Syndrome and Generalized Hypermobility Spectrum Disorders             | Dr. Dmitry Rozenberg |
| 5:40 - 6:00 PM  | Breath - it's role in posture   | Jeannie Di Bon       |
| 6:00 - 6:20 PM  | Panel Q&A   |                      |
| 6:20 PM   | Close   |                      |
|   |   |                      |
| 7:30 - 9:30 PM  | Golden Zebra Reception  |                      |

# FRIDAY JULY 19

| TIME (EST):  | SESSION & PRESENTATION:  | SPEAKER(S):                |
|--|--|----------------------------|
| 7:30 - 8:30 AM   | Pre event: Fascia Movement   | Jeannie Di Bon & Tina Wang |
| 8:00 AM  | In-person attendees: Badge collection & Shop opens   |                            |
| 8:35 AM  | Ballroom opens   |                            |
| 8:50 - 9:00 AM   | Welcome, housekeeping and overview of todays theme   |                            |
| SESSION 6: Elbows, Wrists, Hands, and Shoulders   Chair: Leslie Russek |  |                            |
| 9:00 - 9:20 AM   | Shoulder, Elbow, and Wrist Instability: Strengthening and Support  | Dr. Leslie Russek          |
| 9:20 - 9:40 AM   | Hand Function and Fine Motor Skills: Enhancing Dexterity in EDS & HSD                                      | Amanda Lazo                |
| 9:40 - 10:00 AM  | The Role of Upper Extremity Surgery in Patients with Joint Hypermobility, Including Ehlers-Danlos Syndrome | Dr. William Ericson        |
| 10:00 - 10:20 AM   | Panel Q&A  |                            |
| 10:20 - 10:50 AM   | Break  |                            |



**SESSION**



**BREAK**



**Q&A**

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# FRIDAY JULY 19

| TIME (EST):  | SESSION & PRESENTATION:  | SPEAKER(S):                  |
|--|--|------------------------------|
| SESSION 7: Gastrointestinal Considerations   Chair: Dr. Alan Hakim |  |                              |
| 10:50 - 11:10 AM   | MCAD Manifestations of GU and GI disease   | Dr. Anne Maitland            |
| 11:10 - 11:30 AM   | Fueling the Gut: Optimizing Diet, Nutrition, and Digestive Health in EDS and HSD   | Laurie Bilyeu                |
| 11:30 - 11:50 AM   | Panel Q&A  |                              |
| SESSION 8: Urogynecological Concerns   Chair: Dr. Alan Hakim       |  |                              |
| 11:50 - 12:20 PM   | Managing Urogynecological Challenges in EDS and HSD: Strategies for Pelvic Pain, Bladder Dysfunction, and Prolapse       | Dr. Shilpa Gajarawala        |
| 12:20 - 12:40 PM   | Beyond Joints: Living with Urogynecological Symptoms in EDS and HSD: Diagnosis, Treatment, and Improving Quality of Life | Lauren Brown                 |
| 12:40 - 1:00 PM  | Panel Q&A  |                              |
| 1:00 - 1:20 PM   | Mindful Movement Snacks: Hatha Yoga with Mel   | Melissa Williams             |
| 1:20 - 2:20 PM   | Lunch  |                              |
| SESSION 9: The Pelvis and Hips   Chair: Dr. Clair Francomano       |  |                              |
| 2:20 - 2:40 PM   | The Pelvis is the Center of the Universe   | Cynthia Neville              |
| 2:40 - 3:00 PM   | Hip Microinstability in EDS & HSD  | Dr. Luke Spencer Gardner     |
| 3:00 - 3:20 PM   | Pelvic Venous Disease in Patients with EDS & HSD   | Dr. Elizabeth Brooke Spencer |
| 3:20 - 3:40 PM   | Panel Q&A  |                              |
| 3:40 - 4:10 PM   | Break  |                              |
| SESSION 10: Musculoskeletal Management   Chair: Dr. Alan Hakim     |  |                              |
| 4:10 - 4:30 PM   | Physical Therapy Techniques for the Hypermobile Patient  | Dr. Valerie Iovine-Rogers    |
| 4:30 - 4:50 PM   | Corrective and Functional exercise for Hypermobility   | Andrea Julian                |
| 4:50 - 5:10 PM   | Injury Prevention in EDS & HSD   | Dr. Alissa Zingman           |
| 5:10 - 5:30 PM   | Panel Q&A  |                              |
| 5:30 PM  | Close  |                              |
|  |  |                              |
| 7:00 PM  | Gala Dinner - Celebrating 5 Years of EDS ECHO  |                              |



**SESSION**



**BREAK**



**Q&A**

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# SATURDAY JULY 20

| TIME (EST):  | SESSION & PRESENTATION:  | SPEAKER(S):                 |
|--|--|-----------------------------|
| 7:30 - 8:30 AM   | Pre event: Fascial Embodiment  | Jeannie Di Bon & Tina Wang  |
| 8:00 AM  | In person attendees: Badge collection & Shop opens   |                             |
| 8:35 AM  | Ballroom opens   |                             |
| 8:50 - 9:00 AM   | Welcome, housekeeping and overview of todays theme   |                             |
| <b>SESSION 11:</b> Knees, Ankles, Feet, & Mobility   Chair: Valerie Iovine                           |  |                             |
| 9:00 - 9:20 AM   | They Knead it: Strength Promotion in the Hypermobile Patient   | David Shirey                |
| 9:20 - 9:40 AM   | Foot and Ankle Issues and Management   | Dr. Patrick Agnew           |
| 9:40 - 10:00 AM  | From the Ground Up: The Importance of Foot Posture, Footwear, and Seemingly Unrelated Joints in EDS & HSD                            | Valerie Iovine-Rogers       |
| 10:00 - 10:20 AM   | Keeping Realistically Active: Adaptive Exercise when living with EDS and HSD   | Marcia Perretto             |
| 10:20 - 10:40 AM   | Panel Q&A  |                             |
| 10:40 - 11:10 AM   | Break  |                             |
| <b>SESSION 12:</b> Building Strength, Stability, & Supporting Immunity   Chair: Dr. Clair Francomano |  |                             |
| 11:10 - 11:30 AM   | Whole Body Rehabilitation with Exergaming  | Nathan Mayberry             |
| 11:30 - 11:50 AM   | Lymphatic Wellness for EDS & HSD   | Kimby Maxson                |
| 11:50 - 12:10 PM   | Managing Hypermobility in children: Advice and practical solutions with a lifestyle focus to reduce risk and improve quality of life | Jennifer Penston            |
| 12:10 - 12:30 PM   | Panel Q&A  |                             |
| 12:30 - 12:50 PM   | Mindful Movement Snacks: Strength with Jeannie   | Jeannie Di Bon              |
| 12:50 - 1:50 PM  | Lunch  |                             |
| <b>SESSION 13:</b> Research and Therapies   Chair: Dr. Alan Hakim                                    |  |                             |
| 1:50 - 2:10 PM   | Peripheral Nerve Compression in the EDS Patient  | Dr. Shar Hashemi            |
| 2:10 - 2:30 PM   | Non-pharmacologic Management Approaches for EDS and HSD: Virtual Reality, Friend or Foe  | Dr. Shilpa Gajarawala       |
| 2:30 - 2:50 PM   | Non-surgical treatment for MALS (Median Arcuate Ligament Syndrome) in EDS & HSD  | Patricia Stott & Amy Morris |
| 2:50 - 3:10 PM   | Brain Based Therapies for EDS Comorbidities  | Dr. Kevin Lasko             |
| 3:10 - 3:30 PM   | Panel Q&A  |                             |
| 3:30 - 4:00 PM   | Break  |                             |



**SESSION**



**BREAK**



**Q&A**

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# SATURDAY JULY 20

| TIME (EST):  | SESSION & PRESENTATION:  | SPEAKER(S):          |
|--|--|----------------------|
| <b>SESSION 14:</b> Fascia from Head to Toe: A Fascia Perspective on EDS & HSD   Chair: Leslie Russek |  |                      |
| 4:00 - 4:20 PM   | Fascia Science: Its Relation to EDS & HSD                                | Dr. Tina Wang        |
| 4:20 - 4:40 PM   | Prolotherapy: Exploring its Role   | Dr. Fraser Burling   |
| 4:40 - 5:00 PM   | Fascia Movement and Exercise   | Jeannie Di Bon       |
| 5:00 - 5:20 PM   | Fascial Counterstrain: A Novel Manual Therapy with Multi-System Benefits | Dr. Brianna Cardenas |
| 5:20 - 5:40 PM   | A Physical Therapists Approach to Managing TMJ Pain                      | Leslie Russek        |
| 5:40 - 6:00 PM   | Panel Q&A  |                      |
| 6:00 - 6:10 PM   | Celebrating 4 years of Lara Blooms Professor of Practice Appointment     | Madlyn Hanes         |
| 6:10 - 6:20 PM   | Close of event   | Prof. Lara Bloom     |



**SESSION**



**BREAK**



**Q&A**

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In support of improving patient care, this activity has been planned and implemented by the Ehlers-Danlos Society and Project ECHO. Project ECHO® is jointly accredited by the Accreditation Council for Continuing Medical Education (ACCME), the Accreditation Council for Pharmacy Education (ACPE), and the American Nurses Credentialing Center (ANCC), to provide continuing education for the healthcare team.



### AMA Designation Statement

Project ECHO® designates this live activity for a maximum of 29.25 AMA PRA Category 1 Credits™. Physicians should claim only the credit commensurate with the extent of their participation in the activity.

### Disclosure Statement

Project ECHO®, in compliance with the ACCME Standards for Integrity and Independence in Accredited Continuing Education, requires that anyone who is in a position to control the content of an educational activity disclose all relevant financial relationships they have had within the last 24 months with an ineligible company.

None of the planners and presenters for this educational activity have relevant financial relationship(s) to disclose with ineligible companies whose primary business is producing, marketing, selling, re-selling, or distributing healthcare products used by or on patients.

Prof. Lara Bloom, Dr. Alan Hakim, Stacey Simmonds, Faye Moran, Aiko Callahan, Dr. Akilah Cadet, Amanda Lazo, Alissa Zingman, Amy Morris, Andrea Julian, Anne Barlow, Dr. Anne-Marie Malfait Aviva Gaskill, Dr. Brianna Cardenas, Camille Schrier, Chris Bland, Christina Semonick, Dr. Clair Francomano, Dr. Dacre Knight, Dr. Dennis Hart, Dr. Dmitry Rozenberg, Eloise Stager, Enid Neptune, Francie Fitzgerald, Prof. Fransiska Malfait, Jeannie Di Bon, Jennifer Penston, Katie Wright, Kayla Scott, Kimby Maxson, Kristi Posival, Lauren Brown, Laurie Bilyeu, Leanne Barrett, Dr. Leslie Russek, Madlyn Hanes, Marcia Peretto, Mars Lombardi, Melissa Williams, Nathan Mayberry, Nathan Rudin, Paolo Bolognese, Patricia Stott, Dr. Patrick Agnew, Dr. Rebecca Schaffer, Robyn Fog, Sabra Thomas, Sarah Wegner, Dr. Serwet Demirdas, Shar Hashemi, Dr. Shilpa Gajarawala, Siddharth Parakash, Dr. Tina Wang, Dr. Tomoki Kosho, Dr. Valerie Iovine, Wanda Barlow, Dr. William Ericson.

The following planners/presenters listed below have disclosed that they have a relevant financial relationship with an ineligible company.

| Name                         | Nature of Relationship                             | Name of Ineligible Company                               |
|------------------------------|--|--|
| Dr. Elizabeth Brooke Spencer | Researcher, Consultant, Speaker, Advisor, Syntheon | Medtronic, Boston Scientific, Philips Medical, Surmodics |
| Dr. Cynthia Neville          | Consultant   | Atlantic Therapeutics                                    |
| Dr. Fraser Burling           | Researcher   | The International Consortium on EDS and HSD              |
| Dr. Kevin Lasko              | Other  | Gladiator Therapeutics                                   |
| Dr. Subinoy Das              | Speaker, Executive Role                            | Optinose, Inc., Zotarix, LLC, Soundtrace, LLC            |
| Dr. Kathleen Johnson         | Other  | LS Pro, Fullscript                                       |

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# RARER TYPES DAY AGENDA

JULY 21, 2024

# SUNDAY JULY 21

| TIME (EST):   | SESSION & PRESENTATION:  | SPEAKER(S):            |
|---|--|------------------------|
| 8:00 AM   | Badge collection & shop opens  |                        |
| 8:35 AM   | Ballroom opens   |                        |
| 8:50 - 9:00 AM  | Welcome, housekeeping and overview of todays theme                                     | Lara Bloom             |
| <b>SESSION 15:</b> Living with a Rarer Type of EDS - Coping and Resilience Part 1   Chair: Dr. Clair Francomano |  |                        |
| 9:00 - 9:20 AM  | Emergency preparedness when living with a rare condition                               | Katie Wright           |
| 9:20 - 9:40 AM  | Prioritizing Mental Health: Resiliency & Seeking Support                               | Valerie Iovine-Rogers  |
| 9:40 - 10:00 AM   | Aging with a Rarer Type of EDS   | Dr. Clair Francomano   |
| 10:00 - 10:20 AM  | Living and Loving Life with Vascular EDS   | Kristi Posival         |
| 10:20 - 10:40 AM  | Panel Q&A  |                        |
| 10:40 - 11:10 AM  | Break  |                        |
| <b>SESSION 16:</b> Living with a Rarer Type of EDS - Coping and Resilience Part 2   Chair: Dr. Clair Francomano |  |                        |
| 11:10 - 11:30 AM  | Body Image and Acceptance with vEDS  | Anne Barlow            |
| 11:30 - 11:50 AM  | Coping with the unexpected when living with a rare disease                             | Leanne Barrett         |
| 11:50 - 12:10 PM  | The Challenges of Being a Caregiver for my vEDS Family                                 | Wanda Barlow           |
| 12:10 - 12:30 PM  | Embracing Resilience: Healing from Trauma and Loss when Living with a Rare Condition   | Kayla Scott            |
| 12:30 - 12:50 PM  | Panel Q&A  |                        |
| 12:50 - 1:50 PM   | Lunch  |                        |
| <b>SESSION 17:</b> Insights and Management Strategies in Rare Disease   Chair: Prof. Fransiska Malfait          |  |                        |
| 1:50 - 2:10 PM  | vEDS 101   | Dr. Peter Byers        |
| 2:10 - 2:30 PM  | Living With Heritable Vascular Disease: Exercise and Physical Activity Recommendations | Dr. Siddharth Parakash |
| 2:30 - 2:50 PM  | Periodontal EDS - The Key to Hypermobile EDS?  | Dr. Anne Maitland      |
| 2:50 - 3:10 PM  | Managing lung complications in EDS   | Dr. Enid Neptune       |



**SESSION**



**BREAK**



**Q&A**

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# SUNDAY JULY 21

| TIME (EST):  | SESSION & PRESENTATION:  | SPEAKER(S):                 |
|--|--|-----------------------------|
| 3:10 - 3:30 PM   | Living with Skin Injuries and Classical EDS  | Dominique McGinn            |
| 3:30 - 3:50 PM   | Panel Q&A  |                             |
| 3:50 - 4:20 PM   | Break  |                             |
| <b>SESSION 18:</b> Scientific Research and Updates on the Rarer Types of EDS   Chair: Prof.Fransiska Malfait |  |                             |
| 4:20 - 4:40 PM   | The Road to 2026   | Prof. Fransiska Malfait     |
| 4:40 - 5:00 PM   | Recent Advances in Musculocontractural Ehlers-Danlos Syndrome (mcEDS)                              | Dr. Tomoki Kosho            |
| 5:00 - 5:20 PM   | Variants of Unknown Significance for the Rarer Types of EDS  | Dr. Roberto Mendoza-Londono |
| 5:20 - 5:40 PM   | Pain studies   | Anne-Marie Malfait          |
| 5:40 - 6:00 PM   | Research for All: Finding and Supporting Participation of Marginalised Individuals and Communities | Dr. Serwet Demirdas         |
| 6:00 - 6:20 PM   | Panel Q&A  |                             |
| 6:20 - 6:30 PM   | Close  |                             |



**SESSION**



**BREAK**



**Q&A**

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# WORKSHOPS AGENDA

JULY 21, 2024

# P.R.I.S.M. Physiolign Primer:

Immersive Education, Skills, and Support for the  
EDS & HSD patient, family member, and care team.

## SUNDAY JULY 21

| TIME (EST):      | WORKSHOP, PRESENTER(S) & DESCRIPTION/INFORMATION  |
|------------------|---|
| 10:40 - 11:10 AM | Pre-workshop refreshments and snacks  |
| 11:30 - 12:45 PM | <b>WORKSHOP 1</b><br>P.R.I.S.M. Physiolign Immersive Education Part 1: Spine and Joints Framework and Evaluation<br><br><b>PRESENTER(S):</b><br>Dr. Alissa Zingman MD MPH with Dr. Amanda Isen DPT and Ann Behrends MPT<br><br><b>DESCRIPTION:</b><br>Come learn with us in the only way that makes sense: by doing! We will teach you more than just skills - you will learn how to think about your spine and joints so that you can continue to expand your skills far beyond this workshop. Gain knowledge on self-assessment, "red flag" symptoms, specific techniques and interventions including self-care, and how it all ties together. Then join us in part 2 "on the mat" for even more experiential education!  |
| 12:50 - 1:45 PM  | Lunch   |
| 1:50 - 2:50 PM   | <b>WORKSHOP 2</b><br>P.R.I.S.M. Physiolign Immersive Education Part 2: Alignment, Stability, and Movement<br><br><b>PRESENTER(S):</b><br>Dr. Alissa Zingman MD MPH with Dr. Amanda Isen DPT, Ann Behrends MPT, and Ashley Shepherd ATC<br><br><b>DESCRIPTION:</b><br>This "on the mat" session is all about understanding and improving alignment, biomechanics, proprioception, and movement. Learn by doing as we bring you a paradigm/philosophy and teach specific techniques that you can bring home with you. Spine and joint health is critical to cardiovascular, respiratory and digestive health. Expand upon over a century of progress by leveraging the lessons of Pilates, dance, elite athletic training, breathwork, Alexander Technique, and more. Create a game plan that feels safe, nurturing, and hopeful. |
| 2:50 - 3:05 PM   | Comfort break   |



**BREAK**



**Q&A**

### PLEASE NOTE:

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IF YOU MISS ANYTHING LIVE, YOU CAN CATCH UP BY WATCHING THE RECORDINGS BACK.

# SUNDAY JULY 21

| TIME (EST):    | WORKSHOP, PRESENTER(S) & DESCRIPTION/INFORMATION   |
|----------------|--|
| 3:10 - 4:10 PM | <p><b>WORKSHOP 3</b><br/>Strategy Session: Optimizing Mindset, Relationships, and Clinical Care</p> <p><b>PRESENTER(S):</b><br/>Drs. Alissa Zingman MD MPH and Dr. Amanda Isen DPT</p> <p><b>DESCRIPTION:</b><br/>From specific communication strategies for patients and their families to getting the most out of your doctor's appointments and insurance plan, this session aims to empower. Learn about ring theory, the power of a meaningful narrative around identity in the context of chronic illness and pain, and how to approach tough conversations at work and at home. This session aims to provide both intellectual frameworks and practical advice. Our team of P.R.I.S.M. providers, all of whom have hEDS, MCAS, POTS and various sites of spine or joint instability, will share personal and professional insights.</p> |
| 4:10 - 4:30 PM | Break  |
| 4:40 - 5:45 PM | <p><b>WORKSHOP 4</b><br/>Discovery Session: POTS, MCAS, and Evidence Based Ayurvedic Strategies</p> <p><b>PRESENTER(S):</b><br/>P.R.I.S.M. Staff</p> <p><b>DESCRIPTION:</b><br/>East meets West as we explore techniques derived from ancient eastern medicine traditions which have known efficacy based on modern research. Discover the Ayurvedic approach to treating inflammation, itching, digestive tract dysfunction, and cardiovascular regulation. In India, Ayurvedic medical school is four years - just like allopathic (M.D. in the west) medical training! Ayurvedic medicine offers simple, easy to implement strategies with the potential to enhance your well-being and navigate the complexities of life with EDS.</p>   |
| 5:45 - 6:00 PM | <p><b>Q&amp;A</b></p> <p><b>PRESENTER(S):</b><br/>P.R.I.S.M. Staff</p> <p><b>NOTE:</b><br/>Our staff mostly specialize in spine and joint care, pain management, and primary POTS and MCAS care. For complex or refractory POTS/MCAS cases, we collaborate with specialists. We will do our best to answer all of your questions!</p>  |
| 6:00 PM        | End - Thank you!   |



**BREAK**



**Q&A**

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The  
Ehlers  
Danlos  
Society

GLOBAL LEARNING  
CONFERENCE 2024

EDS & HSD

FROM  
HEAD  
TO  
TOE







GLOBAL LEARNING  
CONFERENCE 2024

EDS & HSD

FROM  
HEAD  
TO  
TOE



**JUNIOR  
ZEBRAS KIDS**



The Ehlers-Danlos Society



**JUNIOR  
ZEBRAS TEENS**



The Ehlers-Danlos Society

**AGENDA**

**JULY 18 – 20, 2024**

# THURSDAY JULY 18

| TIME (EST):      | KIDS   | TEENS  |
|------------------|--|--|
| 8:35 - 9:00 AM   | <b>WELCOME: NAME TAGS, CHECK IN, AND ICE BREAKERS</b>  |  |
|                  | Wood cookies, brain games (sudoku), word searches, coloring  | Wood cookies, puzzles, word games  |
| 9:00 - 11:00 AM  | <b>OPENING ACTIVITIES</b>  |  |
|                  | <p>Big group welcome, Simon says</p> <p>Opening "fire": rules, songs, skits, Camp Joy Beat</p> <p>Goal setting</p> <p>Introduce to groups</p> <p>Cabin Mesh</p> <p>Name games: splat, fruit salad, animal master</p> <p>Small groups to complete scavenger hunts around room</p>   | <p>Big group welcome, Simon Says</p> <p>Mini campfire, "rules"</p> <p>Share what we want to get out of conference (bonding, friends, chance to be silly, etc)</p> <p>Card Team Activities, chaos-ish</p> |
| 11:00 - 11:30 AM | <b>BREAK</b>   |  |
| 11:30 - 1:30 AM  | <b>ACTIVITIES</b>  |  |
|                  | <p>Gold Rush kids vs teens, long hair vs short hair, counselors vs kids</p> <p>EDS Holiday Card Art Contest!</p> <p>Group banner/flag, chant, bucket list</p> <p>Bandana/Zebra name suggestions</p> <p>Back to Back Change</p> <p>About Me flags, share in small groups</p> <p>Poison dart frog</p> <p>Pictionary relay</p> <p>4 corners</p> | <p>Collaborative mural, how it feels to live with EDS/HSD or how you want people to see you</p> <p>Flags and sharing</p> <p>Mafia</p> <p>Hand Cup Game</p>   |



ACTIVITIES



BREAK




SESSION

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# THURSDAY JULY 18

| TIME (EST):    | KIDS  | TEENS  |
|----------------|---|--|
| 1:30 - 2:30 PM | LUNCH   |  |
| 2:10 - 2:40 PM | EHLERS-DANLOS SOCIETY SESSIONS  |  |
|                | Aiko Callahan - Beyond the Bend: Nurturing Strength in Kids with EDS and HSD  | Lisa Belvy - Navigating the Teenage Years with EDS & HSD: Self-Care, Relationships, and Empowerment                          |
| 2:50 - 3:20 PM | EHLERS-DANLOS SOCIETY SESSIONS  |  |
|                | Kathleen Johnson - Unlocking Superpowers: Guiding Kids with EDS & HSD through navigating their exceptional minds and bodies               | Aiko Callahan - Bend, Don't Break: Navigating Hypermobility in Teens with EDS and HSD  |
| 3:20 - 4:30 PM | ACTIVITIES  |  |
|                | Water Bottle Game<br>Cup Stacking Challenge<br>Free Art<br>Cards<br>Hand Cup Game<br>Ships and Sailors<br>Night at museum, sleeping lions | Free art<br>Cards<br>Bracelets<br>Chat time<br>Lip Sync Battle<br>Afternoon Rotations (30 minutes)<br>Cabin Talent Show Prep |
| 4:30 - 5:00 PM | BREAK   |  |
| 5:00 - 6:20 PM | CLOSING ACTIVITIES  |  |
|                | 2 songs, Black Magic riddle<br>Popsicle, Poopsicle<br>Camp Joy Beat<br>Smores<br>Cabin 'Campfire'<br>Group Clean Up                       | Energizer<br>Teambuilding Game - Ship Wreck or Joy Auction<br>Rose, bud, thorn<br>Stick riddle<br>Open games<br>Group clean  |

|   |            |   |       |   |         |
|---|------------|---|-------|---|---------|
|  | ACTIVITIES |  | BREAK |  | SESSION |
|---|------------|---|-------|---|---------|

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# FRIDAY JULY 19

| TIME (EST):      | KIDS   | TEENS  |
|------------------|--|--|
| 8:45 - 9:00 AM   | ARRIVAL  |  |
| 9:00 - 10:20 AM  | Morning Stretch<br>Song, skit, fun fact<br>Energizer<br>Evolution Rock Paper Scissors<br>Morning rotations (30 mins)<br>Silent line-up<br>Arts<br>Science activity<br>Talent Show Prep |  |
| 10:20 - 10:50 AM | BREAK  |  |
| 11:00 - 11:30 AM | EHLERS-DANLOS SOCIETY SESSIONS   |  |
|                  | <b>EDS Educational Session:</b><br>Jeannie Di Bon - My Mindfulness Superpower  | <b>EDS Educational Session:</b> Valerie Iovine-Rogers<br>- Advocacy Avengers: Teens Transforming<br>the Narrative of EDS and HSD |
| 11:40 - 12:10 PM | EHLERS-DANLOS SOCIETY SESSIONS   |  |
|                  | <b>Valerie Iovine - Little Leaders:</b> Finding Our Voices and<br>Learning About the Power of Self-Advocacy  | <b>Jeannie Di Bon - Mindfulness Everyday</b>   |
| 12:10 - 1:20 PM  | IMPROV GAMES   |  |
|                  | Creative story telling<br>Grab bag skits<br>ABC acting<br>Questions only   | Story telling<br>Grab bag skits<br>Impromptu interviews  |



ACTIVITIES



BREAK



SESSION

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# FRIDAY JULY 19

| TIME (EST):    | KIDS  | TEENS  |
|----------------|---|--|
| 1:20 - 2:20 PM | LUNCH   |  |
| 2:20 - 3:40 PM | ACTIVITIES  |  |
|                | Cabin talent Show Prep<br>Energizer<br>Seize the Adventure<br>3 activities (rotations)  |  |
|                | DIY treasure hunt   | Free Time (art, cards, chat, chills)   |
| 3:40 - 4:10 PM | BREAK   |  |
| 4:10 - 4:40 PM | <b>EDS Educational Session: [KIDS] Creative Adventures:</b><br>Exploring Artistic Expression with Music, Art, and Theater and Fun! - Michael Bihovsky | Campfire<br>Rose, bud, thorn<br>Wind down<br>Mafia<br>Joy auction<br>Clean   |
| 4:40 - 5:30 PM | Campfire<br>High, low<br>Wind down<br>Poison dart frog<br>Clean   | <b>EDS Educational Session: [TEENS] Artistry Unleashed:</b><br>Empowering Teens through Creative Expression - Michael Bihovsky |



ACTIVITIES



BREAK






SESSION

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# SATURDAY JULY 20

| TIME (EST):      | KIDS   | TEENS                         |
|------------------|--|-------------------------------|
| 8:45 - 9:15 AM   | ARRIVAL  |                               |
|                  | Morning Stretch<br>Song, skit, fun fact<br>Energizer<br>Giants, Wizards, Elves<br>Morning rotations (30 mins)<br>Gaga ball<br>Arts<br>Puzzle it out<br>Art<br>Tabletop Games |                               |
| 9:15 - 10:00 AM  | ACTIVITIES   |                               |
|                  | 21<br>Zip Zap Zop<br>Werewolf  | 21<br>Zip Zap Zop<br>Werewolf |
| 10:00 - 10:20 AM | Watercolour Art  | Free Choice Activities        |
| 10:20 - 10:40 AM |  | Emoji Charades                |
| 10:40 - 11:10 AM | BREAK  |                               |
| 11:10 - 11:40 AM | ACTIVITIES   |                               |
|                  | Activity Time<br>Balloon volleyball<br>Real life battleship<br>Ultimate sock basketball<br>Hot potato  | Watercolor Art                |
| 11:50 - 12:50 PM |  | Trivia, Pictionary Relay      |

|   |            |   |       |   |         |
|---|------------|---|-------|---|---------|
|  | ACTIVITIES |  | BREAK |  | SESSION |
|---|------------|---|-------|---|---------|

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# SATURDAY JULY 20

| TIME (EST):     | KIDS   | TEENS   |
|-----------------|--|---|
| 12:50 - 1:50 PM | LUNCH  |   |
| 1:50 - 2:30 PM  | <b>EDS EDUCATIONAL SESSION [JZ PARENTS &amp; CARERS]</b><br>FAMILY MATTERS: EMPOWERING INSIGHTS AND PRACTICAL STRATEGIES FOR PARENTING WITH EDS/<br>HSD - DR. COHEN-SOLOMON & DR. ALISSA ZINGMAN |   |
|                 | Calm Activities, cards, art, etc.  |   |
| 2:50 - 3:30 PM  | <b>EDS Educational Session: Ask the Experts: Family, Friendship, and Confidence for Kids with EDS &amp; HSD</b><br>- Drs. Sarah Cohen Solomon MD, Alissa Zingman MD MPH, and Amanda Isen DPT     | <b>Olympics</b><br>- Popsicle Stick Bridge<br>- Packing Peanut Tower<br>- Tissue Paper Prom Dress<br>- Balloon Volleyball   |
| 3:30 - 4:00 PM  | BREAK  |   |
| 4:00 - 4:40 PM  | Final Campfire!  | <b>EDS Educational Session: Ask the Experts: Navigating Milestones, Independence, and Relationships with your EDS &amp; HSD</b> - Drs. Sarah Cohen Solomon MD, Alissa Zingman MD MPH, and Amanda Isen DPT |
| 4:40 - 5:00 PM  | BREAK  |   |
| 5:00 - 6:30 PM  | Circle Tag<br>Closing Campfire<br>Songs & reflection<br>Camper Pick Up   |   |



ACTIVITIES



BREAK



SESSION

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