

EXTERNALLY LED PATIENT-FOCUSED DRUG DEVELOPMENT MEETING

31 OCTOBER 2023

PRESENTATION

Treatment: Pain, an Integrated Approach

SPEAKER

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Postdoctoral Scholar

Norris Lab, Medical University of South Carolina



About Me:

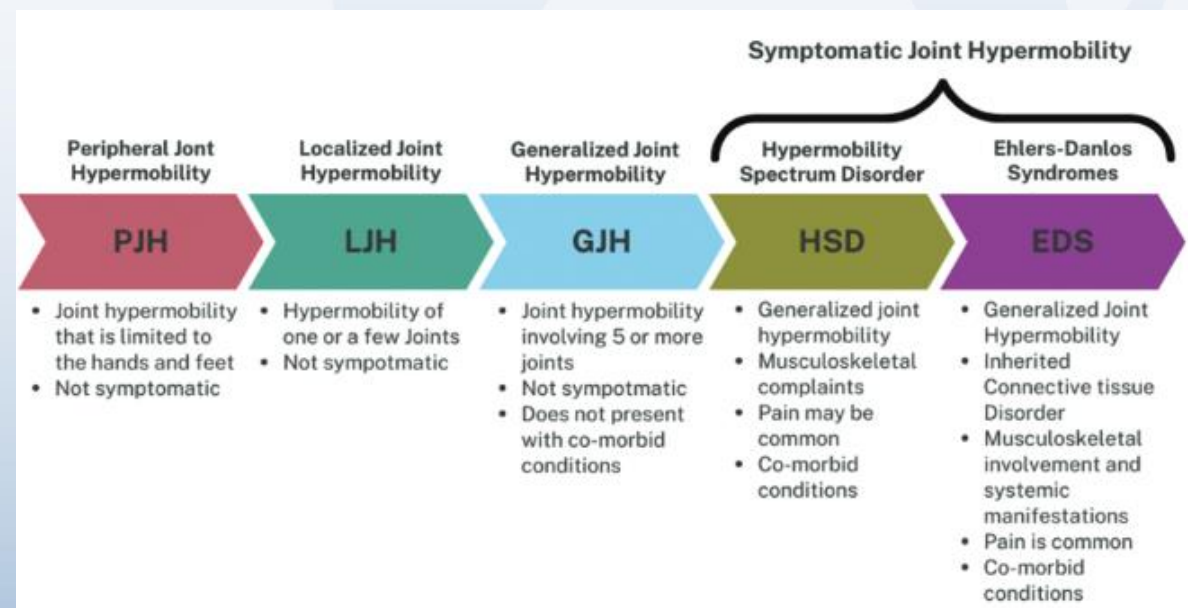
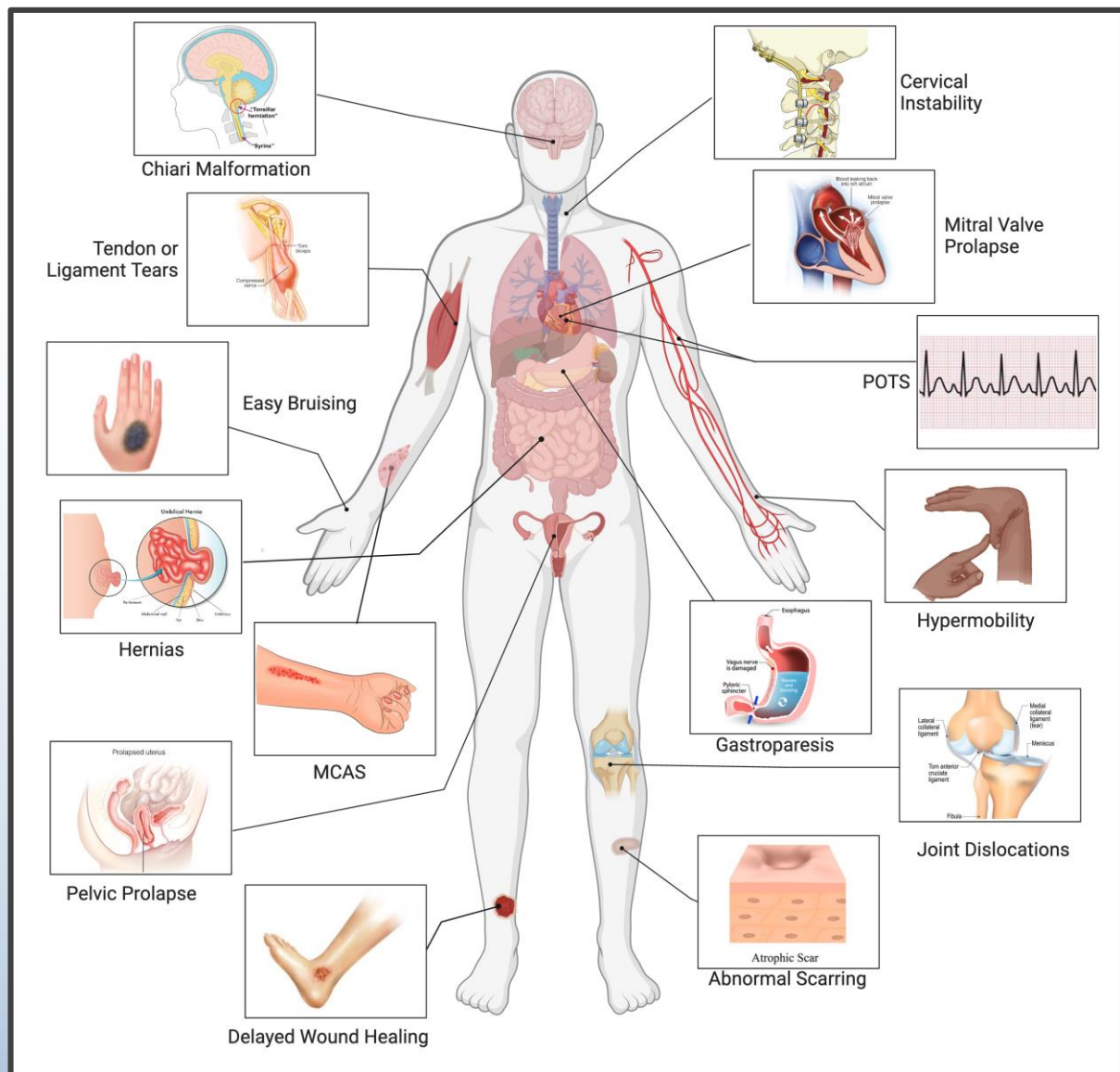
- Completed my PhD at MUSC in 2022 in biomedical sciences
- Currently a postdoctoral scholar in the Norris Lab studying genetic and molecular mechanisms of EDS & comorbidities
- Passionate about science communication
- Advocate for patient representation in research
 - EDS Intern program



The Ehlers Danlos Syndromes (EDS) and Hypermobility Spectrum Disorders (HSD)

can present with a variety of manifestations and comorbidities contributing to acute and chronic pain

- challenging to diagnose and manage



How Common is it for Patients to Experience Pain?

- Pain can affect anywhere between 11-40% of the general population and as many as 90% of people with symptomatic joint hypermobility
- EDS/HSD is not often considered by healthcare professionals as a factor contributing to pain
 - Hypermobility can be associated with chronic pain and frequent injury
- Pain can extend beyond the joints to include comorbidities of EDS
- Occurs on a spectrum of severity and presentation, and is *dynamic*



CONTINUING EDUCATION ACTIVITY

Hope for Hypermobility: Part 1—An Integrative Approach to Treating Symptomatic Joint Hypermobility

Victoria Daylor, BFA, Cortney Gensemer, PhD, Russell A. Norris, PhD, and Linda Bluestein, MD

Learning Objectives: After participating in this continuing professional development activity, the provider should be better able to:

1. Describe symptomatic joint hypermobility and associated comorbid conditions.
2. Explain the physiological basis of pain associated with joint hypermobility.
3. Examine the range of diagnostic testing available to identify the source of pain in individuals with joint hypermobility.

Key Words: Comorbid conditions, Ehlers-Danlos syndrome, Hypermobility, Pain types

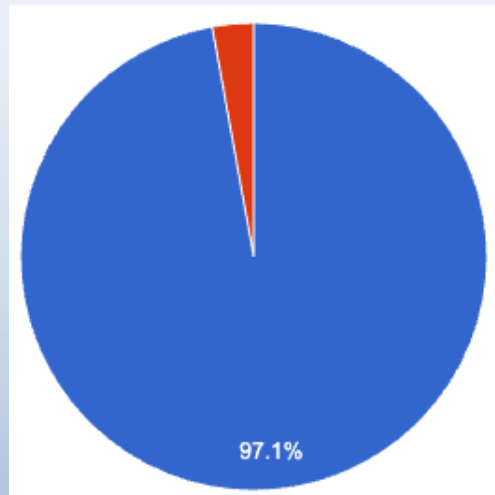
Goal: 10,000 people with all types of EDS and HSD

Comprehensive survey: includes all things associated with EDS and comorbidities, medications, hurdles to accessing care

Preliminary Results from 2,768 people

Do you have chronic pain? (Pain that lasts for longer than 3 months)

Yes (2689, 97.1%),
No (79, 2.9%)



Participants Needed

Are you at least 18 years old and diagnosed with Ehlers-Danlos Syndrome (EDS) or a Hypermobility Spectrum Disorder (HSD)?



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If so, you may be eligible to participate in a voluntary research study.
Participation includes the completion of a 20-30 minute survey related to demographics, medical history, and patient experience.

If eligible, use the link below to participate:
<https://redcap.link/EDSHSDsurvey>

IRB number & date

If you have questions or concerns, please contact:

Victoria Daylor
EDSHSDsurvey@musc.edu
Clinical Research Coordinator at the Norris Lab
Department of Regenerative Medicine and Cell Biology





Treating Pain: An Integrated Approach



What we want treatment to look like:



What it actually looks like:



There is no 'one size fits all' approach to managing pain in EDS & HSD

So what does treatment look like?

Managing Pain requires an integrative approach that can include:

- **Physical Activity: Movement and Exercise**
 - For some, this may include participating in weight lifting and sports
 - Can include occupational therapy, physical therapy, specialized PT (pelvic floor or neuro PT)
 - Tailored exercise programs designed for hypermobility
 - Some are online: Taylor Goldberg, DC (@TheHypermobilityChiro), Jeannie Di Bon (Zebra Club), Katie Goss (Whealth), Emily Rich, OT, Kate Bacigalupo, DPT (@thehyperphysio_kate)
- **Education:** Educated patients understand their bodies and are empowered!
- **Diet and Nutrition:** consider working with a gastroenterologist and registered dietician for managing GI symptoms and any diet concerns influencing symptoms (no healthy diet or supplements will 'cure' EDS)
- **Sleep:** Sleep disorders can contribute to pain and should be evaluated when suspected
- **Psychosocial:** trauma, anxiety, depression, and neurodivergence



Figure 1. MENS PMMS treatment strategy for managing SJH.

Linda Bluestein, MD

So what does treatment look like?



- **Medications:**
 - Pain Medications: Opioids, low dose naltrexone, ketamine, gabapentin, pregabalin, SSRIs, SNRIs, tricyclic antidepressants, cannabinoids, muscle relaxers, anti-inflammatory (steroidal and nonsteroidal)
 - Medications for comorbidities: dysautonomia, MCAD and other comorbidities can be managed through medications, managing comorbidities can reduce pain
 - Compounding pharmacies
- **Diagnostic Testing:** While pain alone cannot be detected on any tests, imaging and lab work may be necessary for accurate diagnosis of specific causes of pain
- **Other considerations:** massage, acupuncture, dry needling, vagus nerve stimulation, bracing, mobility aids, compression garments, nerve blocks, surgical intervention

The goal is to find what works for you to improve your quality of life. What works for one person may not work for another, and what works for you now might not work in the future.

But how do I find a doctor who will address these issues?

“How do I find an EDS specialist near me?”

What IS an EDS specialist?

My advice: Find a compassionate doctor willing to try different approaches to address your symptoms and pain. Someone who is willing to learn more – and educate you in the process.

While certain injuries, diagnoses and comorbidities may require an expert in treating them, you do not need need a world leading expert to manage pain. You will need a team of supportive providers that will listen and learn.

Be an advocate. Share resources with your providers. If they are not receptive, they might not be the best person to help you.



Topics in
PAIN MANAGEMENT

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CONTINUING EDUCATION ACTIVITY

Hope for Hypermobility: Part 2—An Integrative Approach to Treating Symptomatic Joint Hypermobility

Victoria Daylor, BFA, Cortney Gensemer, PhD, Russell A. Norris, PhD, and Linda Bluestein, MD

Learning Objectives: After participating in this continuing professional development activity, the provider should be better able to:

1. Describe the components of multimodal pain management for individuals with joint hypermobility.
2. Examine the anticipated outcomes of specific treatment recommendations for improving pain, function, and quality of life for patients with symptomatic joint hypermobility.
3. Explain the importance of sequence of treatments to determine which are effective for each patient.

Key Words: Hypermobility, Movement, Nutrition, Specific management



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Be cautious of those promising:

- Instant results
- Magic cures
- Anything that sounds “too good to be true”
- Complex chronic illness communities can be targeted by those who only care about making money \$\$\$



We Still have a long way to go: Gaps in Research and Patient Care



When it comes to Clinical Care we desperately need more:

- Education
- Awareness
- Support

In Research, We need to understand:

- Genetic causes and biological pathways involved in EDS and HSD
- Relationships among comorbid conditions
- Why pain is such a big issue in EDS and HSD (seems to be more than just hypermobility)?
- What pain pathways can we target therapeutically?



As a Patient, What Can I do to Help?

- Participate in research studies and surveys
- Awareness: Talk about EDS
- Share resources with others

As Researchers or Clinicians, What Can we do to Help?

- Listen to patients
- Make sure they are represented in the work you are doing (Patient-Scientists)
- Talk about EDS to your colleagues
- Work together with one another
- Apply for grants, get funding and make research progress!

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TheNorrisLab.com



**Thank you for
your attention**