



A Summit Connecting Patients, Physicians & Researchers



# 2025 Summit Agenda

**3 Days of Action** | Sat-Mon, Jun 28-30, 2025



# Summit Program

## At-A-Glance

### Day 1 | Understanding the Basics

-  **11:00 am** *Lunch*
- 12:00 pm** **Paths Forward for hEDS Research** | Russell “Chip” Norris, PhD
- 12:25pm** **Immune Dysregulation in hEDS** | Cortney Gensemer, PhD
- 12:50 pm** **Neuroinflammation in EDS** | Anne Maitland, MD
- 1:15 pm** **Spine and Neurosurgery in EDS** | Sunil Patel, MD
- 1:40 pm** **Prenatal Genetic Counseling** | Paige Babb, MGC
-  **2:05 pm** *Break - 25 mins*
- 2:30 pm** **Clinical Aspects of Physical Therapy** | Susan Chalela, MPT
- 2:55 pm** **EDS Rehabilitation** | Michelle Nichols, PhD, RN
- 3:20 pm** **Comprehensive Pain Management Options** | Sarah Merritt, MD
-  **3:45pm** **Biomechanics & the Craniocervical Junction** | Alissa Zingman, MD
-  **6:00 pm** *\*Optional\* Patient Outing*

### Day 2 | Proactivity in Research, Wellness & Advocacy

- 9:30 am** **Patient Science Panel**
-  **10:10 am** **Movement for Quality of Life** | Beth Marks, MPT
-  **10:35 am** **Hands-On Physical Therapy Movement** | Chalela & Marks
-  **11:00 am** *Lunch*
- 12:00 pm** **Integrative Health Care in Connective Tissue Disorders** | Linda Bluestein, MD
- 12:25 pm** **Social Connection in Chronic Illness** | Christie Cox
- 12:50 pm** **Parenting with Chronic Illness** | Molly Griggs
- 1:15 pm** **Chronic Illness & Psychological Distress** | Varsha Radhakrishnan, MD
- 1:40 pm** **Trauma-Informed Approach to Complex Illness** | Elizabeth McRae, PhD
-  **2:05 pm** *Break - 25 mins*
-  **2:30 pm** **Advocacy Workshop: Crafting Your Story** | Julie Rauch, RN, BCPA
-  **3:15 pm** **Advocacy Workshop: Prepping for Your Meeting** | Rauch & Kaitlyn Esposito
- 7:00 pm** **Private Screening** of “Complicated” + Q&A Session with Filmmakers

### Day 3 | Meetings with Congressional Reps



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# Summit Program



## DAY 1

### SESSION I: Understanding the Basics – Part 1



11:00 am – 12:00 pm

**Lunch**

12:00 pm – 12:25 pm

#### **The Path Forward for hEDS Research**

**Russell “Chip” Norris, PhD**

Professor, Regenerative Medicine & Cell Biology  
Medical University of South Carolina

12:25 pm – 12:50 pm

#### **Exploring Immune Dysregulation in hEDS: Insights from Serum Biomarkers**

**Cortney Gensemer, PhD**

Post-doctoral Fellow, Regenerative Medicine & Cell Biology  
Medical University of South Carolina

12:50 pm – 1:15 pm

#### **Neuroinflammation in EDS**

**Anne Maitland, MD**

Associate Professor, Rheumatology & Immunology  
Medical University of South Carolina

1:15 pm – 1:40 pm

#### **Spinal and Neurosurgical Manifestations of EDS**

**Sunil Patel, MD**

Professor, Neurological Surgery  
Medical University of South Carolina

1:40 pm – 2:05 pm

#### **Genetics & Gestation: Prenatal Genetic Counseling and Pregnancy Care in EDS**

**Paige Babb, MGC**

Certified Genetic Counselor  
Medical University of South Carolina

**Day 1 | Saturday, June 28, 2025**

# DAY 1

## SESSION II: Understanding the Basics – Part 2



Recharge

2:05 pm – 2:30 pm

Break (25 mins)

2:30 pm – 2:55 pm

### Clinical aspects of physical therapy in EDS/UCI

**Susan Chalela, MPT**

Founder & Clinician

The Chalela Physical Therapy Institute for EDS & Cervical Instabilities

2:55 pm – 3:20 pm

### Adopting a Whole-Person Approach Towards EDS Rehabilitation

**Michelle Nichols, PhD, RN**

Associate Professor, College of Health Professions

Medical University of South Carolina

3:20 pm – 3:45 pm

### Empowering Your Well-being: A Comprehensive Pain Management Approach for EDS

**Sarah Merritt, MD**

Clinician, Anesthesiology & Pain Management

University of Maryland / Lifestream Health



Hands-On

3:45 pm – 4:15 pm

### Hands-On Session: Biomechanics & the Craniocervical Junction

**Alissa Zingman, MD**

Clinician, Orthopedics & Preventive Medicine

PRISM Spine & Joint



Connect

6:00 pm – 8:00 pm

### *\*Optional\** Patient Outing

Boardwalk Bar & Arcade at The Wharf  
715 Wharf St SW  
Washington, DC 20024



# DAY 2

## SESSION I: Proactivity in Research & Wellness

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9:30 am - 10:10 am

### **Patient Science Panel: Being A Part of Research**

**Moderator:** Molly Griggs

**Panelists:** Cortney Gensemer, Roman Fenner, Victoria Daylor

10:10 am - 10:35 am

### **Improving Your Quality of Life with Movement**

**Beth Marks, MPT**

Clinician, Physical Therapy

The Chalela Physical Therapy Institute for EDS & Cervical Instabilities



10:35 am - 11:00 am

### **Hands-On Session: Lengthening Muscles & Mindfulness of Alignment**

**Susan Chalela, MPT & Beth Marks, MPT**

Clinician, Anesthesiology & Pain Management

The Chalela Physical Therapy Institute for EDS & Cervical Instabilities



11:00 am - 12:00 pm

**Lunch**

12:00 pm - 12:25 pm

### **Targeting Complexity: Integrative Clinical Pathways for Connective Tissue Disorders**

**Linda Bluestein, MD**

Clinician, Anesthesiology & Integrative Pain

Hypermobility MD

12:25 pm - 12:50 pm

### **Connection Rx: The Social Health Prescription for Chronic Illness**

**Christie Cox**

Advisor, Author and Advocate

12:50 pm - 1:15 pm

### **No Manual for This: Raising Kids with Illness While Managing Your Own**

**Molly Griggs**

Operations & Patient-Science Coordinator

The Norris Lab at Medical University of South Carolina

# DAY 2

## SESSION I: Proactivity in Research & Wellness



1:15 pm – 1:40 pm

### Unraveling the Mind-Body Connection: Navigating Chronic Illness & Psychological Distress

**Varsha Radhakrishnan, MD**

Consultation-Liaison, Transplant, Emergency Psychiatrist  
Tufts Medical Center

1:40 pm – 2:05 pm

### A Trauma-Informed Approach to Navigating Medical Complexity

**Elizabeth M. McRae, PhD**

Pediatric Psychologist  
University of Alabama at Birmingham



Recharge

2:05 pm – 2:30 pm

Break (25 mins)

## SESSION II: Proactivity in Policy & Advocacy

2:30 pm – 3:15 pm

### Advocacy Workshop I: Crafting Your Story

**Julie Rauch, RN, BCPA**



Advocate

3:15 pm – 4:00 pm

### Advocacy Workshop II: Preparing for Your Meeting

**Julie Rauch, RN, BCPA** and **Kaitlyn M. Esposito, MPH**



Connect

7:00 pm

### Private Screening

“Complicated” + Filmmaker Q&A

**Andrew Abrahams**

Open Eye Pictures

**Donna Sullivan**

Pathways to Trust



# DAY 3

## ADVOCACY DAY: Meetings with Representatives



9:00 am

**Group Photo Outside the Capitol Building**

9:30 am – 3:00 pm

**Scheduled Meetings on The Hill**

\*Contact staff for your meeting times

## important Notes



### **Honor Your Body**

Remember! This conference involves 3 *full* days of learning, connection, and advocacy... Listen to your body! If you need to, make sure you take breaks as needed.

### **The Social Outing is Optional**

You are welcome to join us for fun and games on Saturday evening! The social event and games are free, but food and drinks are *not* included in your Summit registration. As such, this event is optional.

### **Thank You!**

On behalf of The Norris Lab and the Bobby Jones Chiari & Syringomyelia Foundation, thank you for participating in this Summit and advocating on behalf of the millions of patients and families who live with Ehlers Danlos syndrome, Chiari, syringomyelia and many other invisible illnesses! You are making a huge difference just by being here!



**The Norris Lab**

**Day 3 | Monday, June 30, 2025**