



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	<b>EDS Underlying Biology</b>   Russell “Chip” Norris, PhD
12:50 pm	<b>Immune Dysregulation in hEDS</b>   Cortney Gensemer, PhD
1:15 pm	<b>Neuroinflammation in EDS</b>   Anne Maitland, MD
1:40 pm	Topic TBD
2:05 pm	<b>Spine and Neurosurgery in EDS</b>   Sunil Patel, MD
2:30 pm	Break - 25 mins
2:55 pm	<b>Clinical Aspects of Physical Therapy</b>   Susan Chalela, MPT
3:20 pm	<b>EDS Rehabilitation</b>   Michelle Nichols, PhD, RN
3:45 pm	<b>Comprehensive Pain Management Options</b>   Sarah Merritt, MD
6:00 pm	*Optional* Patient Outing

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

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

**Title TBD**

**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

**Title TBD**

**Speaker TBD**

1:40 pm - 2:05 pm

**Spinal and Neurosurgical Manifestations of EDS**

**Sunil Patel, MD**

Professor, Neurological Surgery  
Medical University of South Carolina

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

# DAY 1

## SESSION II: Understanding the Basics – Part 2

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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 Ehlers-Danlos Syndrome

**Sarah Merritt, MD**

Clinician, Anesthesiology & Pain Management

University of Maryland / Lifestream Health

6:00 – 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

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1:15 pm - 1:40 pm

### **Title TBD**

**Varsha Radhakrishnan, MD**

Psychiatrist

Tufts University

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

2:05 pm - 2:30 pm

Break (25 mins)

## SESSION II: Proactivity in Policy & Advocacy

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2:30 pm - 3:15 pm

### **Advocacy Workshop I: Crafting Your Story**

**Julie Rauch, RN, BCPA**

3:15 pm - 4:00 pm

### **Advocacy Workshop II: Preparing for Your Meeting**

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

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**