



# Ehlers-Danlos Society

## EHLERS-DANLOS INDIA CONFERENCE 2017

Conference: February 3–4, 2017 // Workshops: February 5, 2017

RECOUP Hospital Auditorium, Anjanapura Layout,  
Bangalore, India

Ehlers-Danlos syndrome (EDS) is a collection of heritable connective tissue disorders. Either directly or indirectly, EDS is known or thought to alter the biology of collagen in the body (the most abundant protein), which can lead to multi-systemic symptoms.

Each type has certain physical traits and with notable exception to the most common form, the hypermobile type of EDS, most types have a known disease-causing gene. There are physical characteristics that are common to all types of EDS, including hypermobile joints (joints that move in greater amounts than expected) and skin involvement, such as any of the following: soft, stretchy, saggy, too thin, easy bruising, easy wounding, poor wound healing and/or atrophic scarring.

The prevalence of EDS is considered as 1 in 2,500 to 1 in 5,000 people. EDS is known to affect both males and females of all racial and ethnic backgrounds.

There can be a wide or narrow range of severity within a family, but each person's case of EDS will be unique. While there is no cure for EDS, there is treatment for symptoms, and there are preventative measures that are helpful for most.

This is the first conference on EDS in Asia and the multidisciplinary faculty includes the who's who of International EDS research and authors of almost all landmark textbooks on the subject.

### Organising chairs

Dr. Deepak Sharan, Consultant in Orthopaedics and  
Rehabilitation, RECOUP, Bangalore, India

Lara Bloom, Co-Executive Director, The Ehlers-Danlos Society

### Organised by



Supporting organisation



## Who should attend?

Rehabilitation Physicians · Orthopaedic Surgeons · Rheumatologists · Pain Physicians  
Paediatricians · Neurologists · Physiotherapists · Occupational Therapists  
Patients and Caregivers

## FACULTY

**Prof. Rodney Grahame**

Honorary Professor at University College London in the Division of Medicine and Consultant Rheumatologist to the Hypermobility Unit, Hospital of St John & St Elizabeth, London

**Dr. Brad T. Tinkle**

Paediatrician and Clinical Geneticist, Advocate Children's Hospital in Chicagoland, USA

**Prof. Suranjith Seneviratne**

Consultant in Clinical Immunology and Allergy, the Royal Free Hospital and University College, London, UK

**Dr. Adam D. Farmer**

Consultant Gastroenterologist, Keele University, UK

**Prof. Fransiska Malfait**

Clinical Geneticist and Rheumatologist, University of Ghent, Belgium

**Dr. Marco Castori**

Geneticist, San Camillo-Forlanini Hospital, Rome, Italy

**Prof. Raoul Engelbert**

Professor of Physiotherapy, University of Amsterdam, Netherlands

**Prof. Birgit Juul-Kristensen**

Professor of Physiotherapy, Institute of Sports Science and Clinical Biomechanics, University of Southern Denmark, Odense, Denmark, and University College of Bergen, Norway

**Dr. Helen Cohen**

Consultant in Rheumatology and Pain Management, Royal National Orthopaedic Hospital, Stanmore, UK - Head of Rehab at Stanmore EDS inpatient clinic

**Lara Bloom**

Co-Executive Director, The Ehlers-Danlos Society

**Dr. Alan J. Hakim, MA FRCP**

Consultant in Rheumatology and Acute Medicine, The Hospital of St. John and St Elizabeth, London, UK

**Dr. Emily O'Dell**

Asst. Professor of English and Literature (Oman), professional writer, EDS patient and disability advocate

## PROGRAM OUTLINE

### February 3, 2017

TIME	TOPIC	SPEAKER
09:00-09:15	Introduction to EDS	Lara Bloom
09:15-10:00	Natural history of Hypermobile EDS	Rodney Grahame
10:00-10:45	Aetiology, pathophysiology, epidemiology, common co-morbidities	Marco Castori
10:45-11:15	Diagnostic criteria and approach to diagnosis	Brad Tinkle
11:15-11:30	Coffee break	
11:30-12:00	How to diagnose generalised joint hypermobility	Birgit Juul-Kristensen
12:00-13:00	Diagnosis and management of Classical EDS	Fransiska Malfait
13:00-13:45	Lunch	
13:45-14:30	Manifestations and prognosis of EDS in children	Brad Tinkle
14:30-15:15	Manifestations and prognosis of EDS in adults	Marco Castori
15:15-16:00	Diagnosis and manifestations of Rarer EDS Subtypes	Fransiska Malfait
16:00-16:15	Coffee break	
16:15-16:45	Brain mechanisms contributing to severe chronic pain: a possible role in EDS	Helen Cohen
16:45-17:30	Autonomic dysfunction and chronic fatigue in EDS	Alan Hakim
17:30-18:00	Mast cell and allergy in EDS	Suranjith Seneviratne
18:00-18:30	EDS from the patient's perspective	Lara Bloom

### February 4, 2017

TIME	TOPIC	SPEAKER
09:00-09:30	Outcome measures	Marco Castori
09:30-10:00	Genetics of EDS	Fransiska Malfait
10:00-10:45	Mechanisms and management of functional abdominal pain	Adam D Farmer
10:45-11:15	Pregnancy in EDS	Rodney Grahame
11:15-11:30	Coffee break	
11:30-12:15	Management of Rarer EDS Subtypes	Fransiska Malfait
12:15-13:00	Management of postural orthostatic tachycardia syndrome (POTS)	Alan Hakim
13:00-13:45	Lunch	
13:45-14:45	Medical rehabilitation and pain control in EDS	Helen Cohen
14:45-15:30	Management of chronic visceral pain in EDS	Adam D Farmer
15:30-16:00	Immunologic dysfunction in EDS: a field for future research	Suranjith Seneviratne
16:00-16:15	Coffee break	
16:15-17:15	The international physiotherapy guidelines for EDS	Raoul Engelbert, Birgit Juul-Kristensen
17:15-18:00	Joint hypermobility, work-related musculoskeletal disorders and performing arts	Birgit Juul-Kristensen
18:00-18:30	Activities of The Ehlers-Danlos Society	Lara Bloom

**February 5, 2017 • Hypermobility Rehabilitation Workshop**

TIME	TOPIC	SPEAKER
09:00-09:30	Principles of management of hEDS	Rodney Grahame
09:30-10:15	Rehabilitation in child with EDS	Raoul Engelbert
10:15-11:00	Rehabilitation in adolescent with EDS	Raoul Engelbert
11:00-11:15	Coffee break	
11:15-12:00	Rehabilitation in adult with EDS	Birgit Juul-Kristensen
12:00-13:00	Management of fibromyalgia and complex regional pain syndrome in EDS	Helen Cohen
13:00-13:45	Lunch	
13:45-14:15	Management of Fatigue	Alan Hakim
14:15-15:00	The Stanmore Hypermobility Rehabilitation Programme	Helen Cohen
15:00-15:30	Management of craniofacial pain in EDS	Brad Tinkle
15:30-15:45	Coffee break	
15:45-16:15	Management of sleep and psychological comorbidities	Alan Hakim
16:15-16:45	Proprioceptive dysfunction in EDS and its management	Raoul Engelbert
16:45-17:15	Wrap-up	Lara Bloom

**February 5, 2017 • Workshop for Patients and Caregivers**

TIME	TOPIC	SPEAKER
09:00-10:00	Overview of EDS in plain speak	Brad Tinkle, Fransiska Malfait
10:00-10:30	Role of nutrition	Suranjith Seneviratne
10:30-11:00	Self-management of pain	Helen Cohen
11:00-11:15	Coffee break	
11:15-11:45	Coping with pregnancy	Rodney Grahame
11:45-12:15	Psychological approaches and sleep management	Alan Hakim
12:15-12:45	Exercises, sports, activities and injury prevention	Raoul Engelbert
12:45-13:15	Home and school adaptations, workplace accommodations	Birgit Juul-Kristensen
13:15-13:40	How to deal with professionals? What to expect from support groups and rehabilitation programmes?	Emily O'Dell Lara Bloom
13:40-14:00	Q&A and wrap-up	Lara Bloom

**REGISTRATION FEES**

- Conference for Professionals .....INR 6000
- Conference for Patients and Caregivers .....INR 5000
- Hypermobility Rehabilitation Workshop.....INR 5000
- Workshop for Patients and Caregivers .....INR 2500



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## REGISTRATION FORM

Name: \_\_\_\_\_

Job Designation/Profession: \_\_\_\_\_

Hospital/Organisation: \_\_\_\_\_

Phone: Mobile: \_\_\_\_\_ Landline: \_\_\_\_\_

Email: \_\_\_\_\_

Address (Office): \_\_\_\_\_

City/State: \_\_\_\_\_ Country/Postal Code: \_\_\_\_\_

### Terms and Conditions of Registration

1. Registration to the course will be confirmed once the total course fees has been received. This fees is transferable but not refundable, barring cancellation of course due to unavoidable reasons.
2. All successful registrations will be confirmed by email.
3. Places in a course will be allocated on a first come first served basis.
4. Course fees include instruction, beverages, light lunch, certificate of participation signed by the chief faculty and the course director.
5. Please send copy of professional qualification and certification with the application form.

### For NEFT Transfer

Name of the Account: Sharanam Charitable Trust  
Bank Branch: Axis Bank Ltd, Konanakunte Branch, Bangalore, India  
Nature of the Account: SBTRS  
Account Number: 916010011296798  
MICR Number: 560211029  
IFSC Code: UTIB0001185

### Payment Details

Demand Draft/Local Cheque No.: \_\_\_\_\_ Worth INR: \_\_\_\_\_

Drawn On: \_\_\_\_\_ Bank: \_\_\_\_\_ Branch: \_\_\_\_\_

Dated: \_\_\_\_\_

**Please make the DD/Local Cheque in favour of Sharanam Charitable Trust, payable at Bangalore.**

### FOR FURTHER DETAILS, PLEASE CONTACT:

Mr. Joshua Samuel R., Course Coordinator

RECOUP Neuromusculoskeletal Rehabilitation Centre  
#312, 10th Block, Further Extension of Anjanapura Layout,  
80 Feet Road, Bangalore 560108, India

For accommodation information, and online registration  
and payment, please visit [www.recoup.in](http://www.recoup.in)

Facebook: [www.fb.com/recoup](http://www.fb.com/recoup)



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