



## December 2021- March 2022 Topic #3: Ehlers-Danlos Syndrome

We are all done with topic #2! We hoped you enjoyed the Developmental Delays and Genetics Topic area.

If you have not yet had a chance to provide feedback on topic #2 through the **evaluation/survey**, please take about 10-15 minutes to share your honest feedback with us so we can continue to improve Time 4 Genetics.



This month, we kick off Topic #3:  
**Ehlers-Danlos Syndrome**

For the next 4 months we will explore the topic of Ehlers-Danlos Syndrome in various ways:

**December:** Newsletter (you are reading that now!)

**January:** Webinar (see details below- **coming up on January 6th!**)

**February:** Check your Snail Mailbox!

**March:** Family Centered Perspectives

Please take an hour (or more!) to review the resources in this newsletter. Also, please feel free to forward this newsletter on to a colleague and invite them to **APPLY** (click button below) to be part of cohort #2 of Time 4 Genetics clinics (the deadline has been EXTENDED to January 11th. Cohort #2 starts March 2022).

We thank you for taking TIME 4 GENETICS!

**Time 4 Genetics Application for Cohort #2 EXTENDED due date  
1/10/22**

**Survey Link to Provide Feedback for Time 4 Genetics and Topic  
#2: Developmental Delays and Genetics**

**Time 4 Genetics Library (Archive of Topics #1 & #2)**

**Register NOW!**  
**January 6, 2022**  
(at 11am PT, noon MT, 1pm CT, and 2pm ET)

## **Webinar:** What to do when you suspect Ehlers- Danlos syndrome: a practical guide

*CME and CEU is available*

Mountain States  
REGIONAL GENETICS NETWORK

Time 4  
Genetics

JOIN US FOR THE TIME 4 GENETICS WEBINAR:

**WHAT TO DO WHEN YOU  
SUSPECT  
EHLERS-DANLOS  
SYNDROME:  
A PRACTICAL GUIDE**

**January 6, 2022**  
(at 11am PT, noon MT, 1pm CT, and 2pm ET)

**Guest Presenter:**  
Dr. Abdallah (Abe) Elias  
Clinical Geneticist, Medical Director of the Department  
of Medical Genetics at Shodair Children's Hospital.

This program is supported by the Health Resources and Services Administration (HRSA) of the U.S. Department of Health and Human Services (HHS) as part of an award totaling \$610,000 to assist in various activities related to genetic research and clinical genetics. The contents are those of the author(s) and do not necessarily represent the official views of HRSA, HHS, or the U.S. Government. For more information, please visit [www.hrsa.gov](http://www.hrsa.gov). In support of ongoing research and clinical genetics, the Mountain States Regional Genetics Network and Program Management Project is gratefully and humbly acknowledged 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.

**Our guest presenter is:**

Dr. Abdallah (Abe) Elias  
Clinical Geneticist,  
Medical Director of the Department of  
Medical Genetics at:  
Shodair Children's Hospital

To register please click: [HERE](#)

For a clickable and ready to share PDF  
version of this flyer please download: [HERE](#)

**Register for the Webinar Here**

**Resources for TOPIC #3:  
Ehlers Danlos Syndrome**



### **2017 International Classification of Ehlers-Danlos Syndromes**

The Ehlers-Danlos syndromes (EDS) are a clinically and genetically heterogeneous group of heritable connective tissue disorders (HCTDs) characterized by joint hypermobility, skin hyperextensibility, and tissue fragility.

Read more [HERE](#).



### **MSRGN's Ehlers-Danlos Syndrome (EDS) Algorithm**

In 2019, MSRGN convened a workgroup to develop this **EDS Algorithm** for Primary Care Physicians in our region. The algorithm, completed in 2020 and all related resources can be found [HERE](#).



### **Recorded Webinar: "Ehlers-Danlos Syndromes – more than just skin and joints"**

Virtual Education Series Recording MSRGN and Colorado Children's Hospital Watch [HERE](#).

Guest Presenter:  
Ellen Roy Elias, MD  
Recorded: 11/10/20



### **Ehlers-Danlos Syndrome (EDS) CHECKLIST**

Printable Version [HERE](#)  
PDF e-fillable version [HERE](#)

These checklists from Ehlers-Danlos Society is highlighted in the MSRGN Algorithm. Print a few and see the challenge below!

**Topic #3: Challenge:  
3 EDS Checklists by March 2022**

For each topic area we will issue a challenge for you to try over the next few months:

## Topic #3 for 3 EDS Checklist Challenge\*\*



Print a few checklists below and when you suspect Hypermobile EDS, fill out one of the checklists with a family to determine your next steps.



Challenge: since this is topic #3, we are challenging our Genetics Champions to fill out 3 checklists for 3 pediatric patients in the next 4 months! Go!

### Ehlers-Danlos Syndrome (EDS) CHECKLIST

Printable Version [HERE](#)  
PDF e-fillable version [HERE](#)



\*\*Please note participation in this challenge is not a required activity of the Time 4 Genetics Initiative but rather a challenge to bring your attention to this topic over the next 4 months. We would love your input if you choose to participate!

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### Don't Forget! Data from Topic #2 is DUE NOW!

Please **email Kristi** any zip codes (**download tool here**) of those patients with whom you utilize any of the Time 4 Genetics information, resources, and tools! You can also include any zip code of patients you used Topic #1 (Red Flags) info for as well!

[Download the Zip Code  
Collection Tool Here](#)

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THANK  
*you*

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Mountain States Regional Genetics Network  
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