

December 2021March 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)

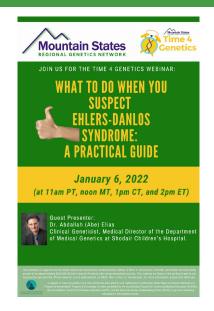
Register NOW! January 6, 2022

(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



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: <u>HERE</u>

Register for the Webinar Here

Resources for TOPIC #3: Ehlers Danlos Syndrome





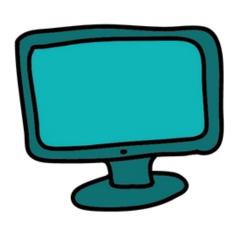
2017 International Classification of Ehlers-Danlos Syndromes

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 <u>HERE</u> PDF e-fillable version **HERE**

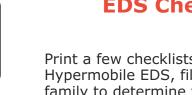
These checklists from Ehlers-Danlos Society is highlighted in the MSRGN Algorithm. Print a few and see the challenge below!

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 <u>HERE</u>
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!

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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Mountain States Regional Genetics Network **www.MountainStatesGenetics.org**







Time 4 Genetics Projects Manager: Kristi Wees kwees@mountainstatesgenetics.org