

November 2021

MSRGN Project Directors' Message



We are Giving Thanks

From All of us At

Mountain States Regional Genetics Network



We are Thankful for You!

The MSRGN management team would like to thank each and every one of you who is reading this message today. We are grateful for you. In a world that has been filled with uncertainty, loss, fear and the challenges of a worldwide pandemic, we appreciate each and every one of your contributions to our region and to improving access to genetics services in the Mountain States.

This November, MSRGN reached a few new milestones. We held our first 100% virtual Genetics Summit with the highest registration and attendance numbers to date! Thanks to each and every one of you who joined us for the 12 dynamic presentations about genetics in our region and beyond. If you missed a session or would like to share, the recordings are available on the MSRGN website

(enduring continuing education is available for up to the next 2 years!).

Thankful and Grateful for all of you!



We need your help to spread the word!

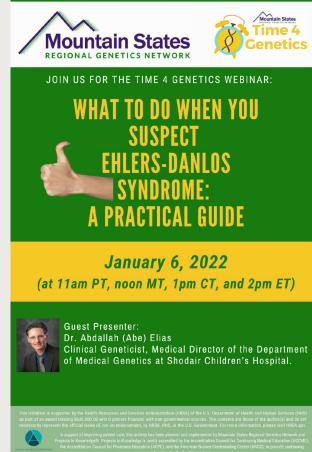
Genetics Pop-Up Promoters Application is OPEN

Rare Disease Day is less than 100 days away!

The Genetics Pop-Ups in our region have been a HUGE success over the last 3 years, as we have adapted to the changing world we live in. This year we are tweaking things again and are excited to share a sneak peak and ask for your help in getting the word out!

We will be holding a few Virtual Genetics Pop-Ups in winter 2022 that will be open to ALL STATES in our REGION (versus state specific pop-ups). The theme of this year's pop-ups will be: "Ask a Genetic Navigator".

In order to help spread the word, in each of our 8-states, we are recruiting 8 **Genetics Pop-Up Promoters.** A \$100 stipend will be



Time 4 Genetics Webinar in January:

What to do when you suspect Ehlers-Danlos Syndrome (EDS): A Practical Guide

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

Guest Speker:

Dr. Abdallah (Abe) Elias

Clinical Geneticist, Medical Director of

paid for those selected to represent their state upon completing (and documenting) 8 promotional activities, to spread the word about the pop-ups.

There are 8 open pop-up promoter spots available one for each of our eight states-

AZ, CO, MT, NV, NM, TX, UT, WY.

Does this sound like something you would like to help with?

Apply HERE!

Application deadline: 1/10/22

Apply to be a Genetics Pop-Up

Promoter



Meet our MSRGN Texas Genetic Navigator

Lourdes Torres email: <u>Texasgenetic@gmail.com</u>

Lourdes Torres is the proud mother of 3 beautiful girls and has been married for over 20 years. She has a career as a computer systems engineer, which she practiced for several years until the arrival of her third daughter, who, when born with an ultra-rare genetic condition (HNRNPH2 mutation), caused a 180-degree turn in her family and professional life. She is currently a parent educator for the Children's Disabilities Information Coalition-Community Parent Resource Center where she happily engages in

the Department of Medical Genetics at Shodair Children's Hospital

Register for Webinar Here



Recordings
Now Available
as well as
Enduring Continuing
Education
Genetics Summit 2021

- Did you miss a presentation at our Genetics Summit?
- Do you want to share your favorite session with your friends or colleagues?
- Did you miss the entire LIVE summit but would like to go back and listen?
- Are you short a few CEU credits and need to catch up?
- Do you want to share a link to a talk with your child's genetic care team?
- Would your PCP like to learn more about genetics and enjoy a link to one of the "Outreach" presentations?

Click here or the button below to do all of the above with the Genetics Summit recordings.

> Genetics Summit 2021 Recordings

informing and training other parents in the difficult process of raising a child with a disability, helping them to be effective advocates and provide a better future for their children. She likes to spend time with her family cooking and traveling at any opportunity; she loves to paint pottery and create foil art.

En Espanol:

Lourdes Torres es orgullosa madre de 3 hermosas niñas y está casada desde hace más de 20 años. Tiene una carrera en ingeniería en Sistemas Computacionales, misma que ejerció por varios años hasta la llegada de su tercera hija, la cual al nacer con una condición genética ultra rara (mutación HNRNPH2), ocasionó un giro de 180 grados a su vida familiar y profesional. Actualmente es educadora de padres para la Coalición de Información sobre Discapacidades de los Niños donde se dedica felizmente a informar y entrenar a otros padres en el difícil proceso de criar a un hijo con discapacidad, ayudándoles a ser defensores eficaces y brindarles un mejor futuro a sus hijos. Le gusta pasar tiempo en familia cocinando y viajando en cualquier oportunidad; le encanta pintar cerámica y crear arte en aluminio (foil art).



Time 4 Genetics Applications for Cohort #2 EXTENDED to 1/10/22

Do you know a pediatrician or family medicine provider in our region who would like to learn more about genetics? Please ask them to apply here to become a Genetics Champion in your state as part of our Time 4 Genetics initiative! The application deadline has been extended to 1/10/22.

Apply for Time 4 Genetics
Cohort #2 Here

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