

July 2021

MSRGN Project Directors' Message

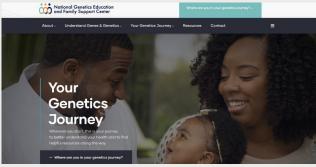


In July 2021, MSRGN kicked off Year 5 with our state teams resuming their monthly meetings and a special recording from Kristi and Cody highlighting the "State of the States" address (like the State of the Union but with an MSRGN flair!). If you missed this video or would like to review some of the dates that were highlighted, you can replay the video here are a few highlights and dates to save:

- Connect with our new 8 Genetic Navigators<u>here!</u> Their emails are up and running and they began navigating with families in July. Send them an email to connect, they would love the encouragement as they embark on this journey with families in our region.
- November 15, 2021: Due date for Application for Cohort #2 of our Time 4 Genetics Initiative for genetics education for primary care

- providers in our region. Goal: 2 new clinics from each state, see more details below! Application link <u>here.</u>
- November 15, 2021: Due date for Applications for ROUND 1 of the State Team Funding. Application link <u>here.</u>
- February 15, 2021: Due date for Application for ROUND 2 of any Remaining State Team Funding.
- 2021 MSRGN Genetics Summit: Save the dates: November 9-10th. Registration coming in August... stay tuned!





Time 4 Genetics Application Open Now Until 11/15/21

Our first cohort, of seven Time 4 Genetics clinics across our region, is in full swing. We are excited to announce the call for applications for cohort #2 primary care clinics for our Time 4 Genetics Initiative. This short (5 min) application is open from now until November 15, 2021 and is open to any and all primary care providers in our 8-state-region. Sixteen cohort #2 clinics will be selected and notified in December 2021 and begin the Time 4 Genetics educational program in March of 2022. We are asking all state team members and individuals connected to MSRGN to share this application with Pediatric and PCP practices in your state to help us get the word out!

To learn more about Time 4 Genetics you can watch this short video <u>here.</u>

Time 4 Genetics
Application

NEW Website for NGEFSC National Genetic Education

National Genetic Educatior Family Support Center aka: "The Family Center"

Recently, the National Genetics
Education and Family Support
Center or "The Family Center" (for
short) has launched their new
website for families about genetics!
Check it out here
or at the button below!
If you have any feedback about
the website, please contact Kristi
and she can pass it along to
NGEFSC.

Visit Their New Website





Meet our MSRGN Wyoming Genetic Navigator

Melody Rupple email: wyominggenetic@gmail.com

Melody Rupple stepped into rare disease and genetic advocacy following the genetic diagnosis of her second born child. Being a wife and mother of 4 youngsters, daily life is now intertwined with educating those who surround them in their beautiful community of Lander, Wyoming. With a background in teaching, her love for learning has spurred her to educate herself in the importance and impact of Newborn Screening, early intervention and access to appropriate medical care. She has also been actively engaged in organizations such as the National MPS Society (Mucopolysaccharidos), National Organization for Rare Disorders, and now MSRGN. She hopes her role as Genetic Navigator will provide her with the tools to better support and encourage other families impacted by genetic conditions in the state of Wyoming. Melody has established a **Wyoming Genetics Connections** Facebook page as part of her outreach to families. Please contact her for more information.

The MSRGN Genetics Summit 2021: Connecting the Dots

November 9-10, 2021

8:30 PT, 9:30 MT, 10:30 CT, 11:30 ET to

1:30 PT, 2:30 MT, 3:30 CT, 4:30 ET

Registration Opening in AUGUST!
Stay Tuned

In case you missed it last month...

Red Flags For Genetics Handout

for Families and Providers



Download the Red Flags 4
Genetics PDF here!

Did You Know?

Where did the word "gene" come from?

Gregor Mendel is often referred to as the "father of genetics" with his infamous pea plant experiments in the mid-1800s. We might assume he coined the term "gene", but you (and I) would be mistaken.

It was Danish botanist Wilhelm Johannsen in 1909 that became the first person to describe individual units of heredity. He called them "genes". The proposed word traced from the Greek word genos, meaning "birth".

Source

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