

Genetic Ambassadors Call

Kristi Wees, MS Chem

Consumer Engagement Director

Mountain States Regional Genetics Network

May 26, 2020

Hello! I am Kristi





- Social Media Coordinator for MSRGN and MSGRC since 2012
- Consumer Engagement Director for MSRGN in 2018- present
- BS Chemistry Penn State and MS in Chemistry UCLA
- A mom to a child who doctor's suspect had a mitochondrial disease
- My other hat- Patient Advocate for EmpoweredAdvocacy.com



WRAP up- one highlight of being part of MSRGN/GA and one suggestion for improvement



Guest speaker:

Annie Evans

Topic:

Newborn screening

Virtual education

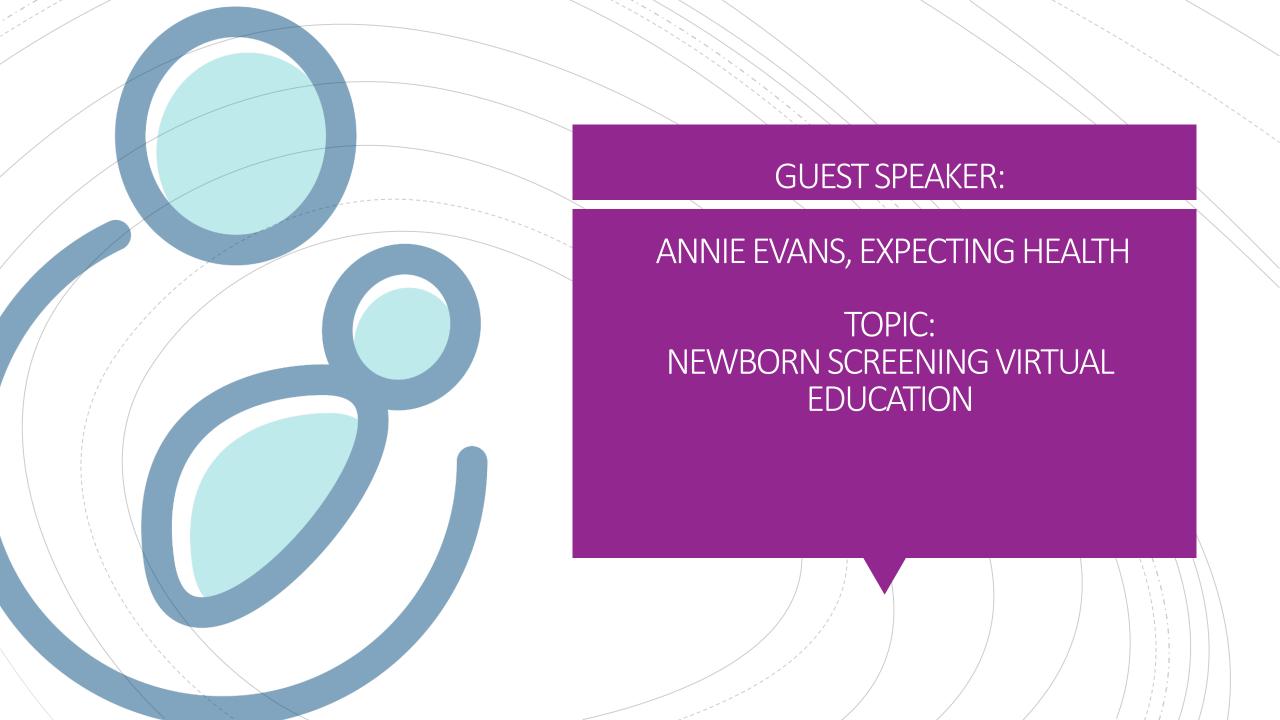


**Public health genetics week

*calendar updates

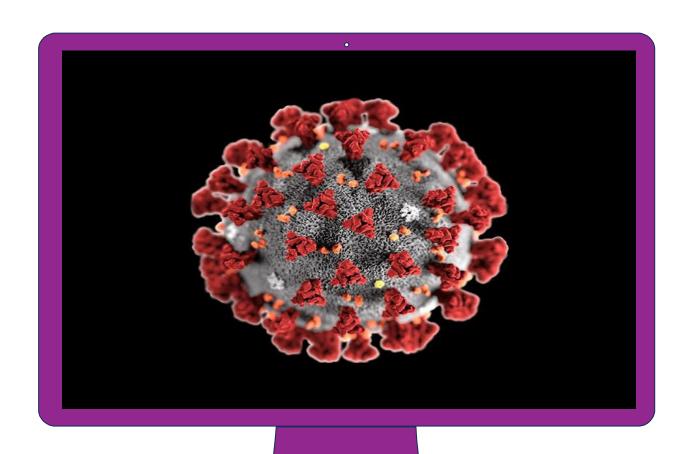
*Big Announcement

Agenda



COVID 19 Resources for Individuals and Families with Genetic Conditions

State specific COVID 19 resource sheets Are Completed!

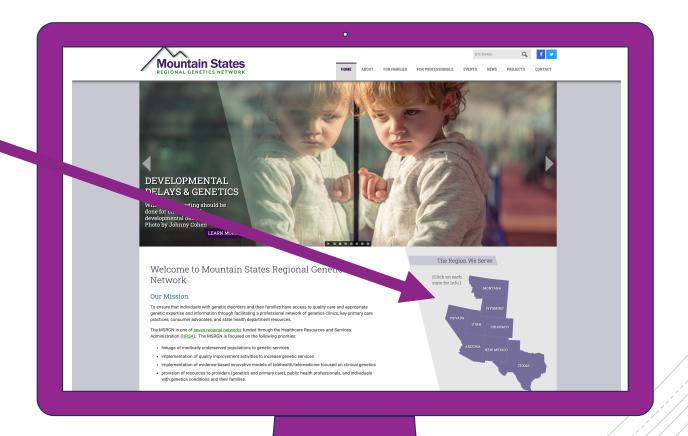


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Click on CLICKABLE MAP

COVID19 Resource at the TOP of each State Team Page



THIS WEEK!!

Public Health Genetics Week

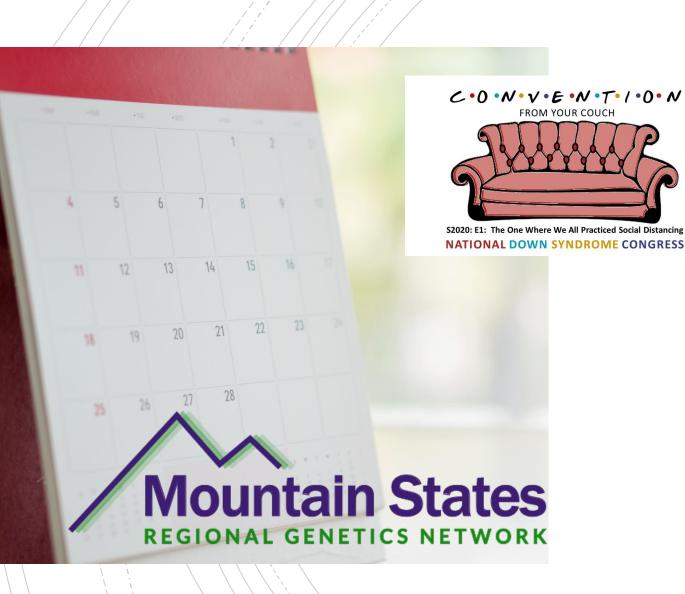
- May 26-29, 2020
- https://phgw.org/
- National Coordinating Center
- Each day of the inaugural Public Health Genetics Week will have a different theme:
- -"What is Public Health Genetics?" May 26
- -"Who is Involved in Public Health Genetics" May 27
- -"Public Health Screening" May 28
- -"Public Health Genetics Resources" May 29





Calendar-Future Months-May 2020

- May 2020
 - TX Virtual Genetics Pop-Up: Alysian ONLINE
 THIS SATURDAY- 5/2/20
 - CO Virtual Genetics Pop-Up: Jamie 5/3/20
 ONLINE THIS SUNDAY- 5/3/20
 - 5/13/20 1pm MT Parent to Parent-Support
 Webinar
 - Living Rare, Living Stronger 2020,
 Cleveland Ohio
 - * May 14-16, 2020 tentatively rescheduled for July 18-20
 - National Down Syndrome Society Adult
 Summit in Phoenix, AZ
 - May 7-9, 2020
 - https://www.ndss.org/engage/ndss-syndromeadult-summit-2020/
 - CANCELLED
 - Last day of MSRGN Current grant cycle: May 31, 2020



Calendar- Future Months June 2020- December 2020

- June 2020
 - June 1- MSRGN New 4-year grant cycle begins
 - National Down Syndrome Congress
 Convention in New Orleans from your couch
 - June 25-28, 2020. May 11-June 27th 1 webinar a week
 - https://www.ndsccenter.org/annual-convention/
- September 2020
 - Global Genes Conference, San Diego, CA
 - Sept 21-23, 2020
- November 2020
 - MT Transition Conference
 - Nov. 16-18, 2020
 - http://montanayouthtransitions.org/attendconference/

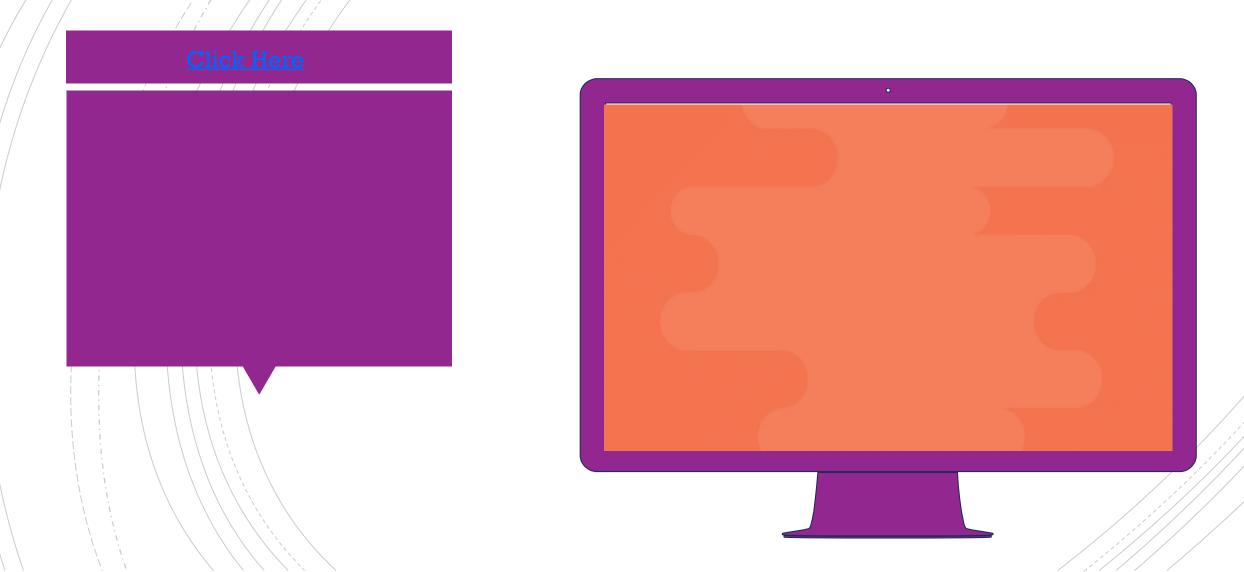
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under FOR FAMILIES TAB:

- "Genetic Ambassador" Drop Down
- "Your Genetics Questions Answered" Drop Down
- "Genetics Pop-Ups"



A Big Announcement!



Genetic Ambassador Facebook Group

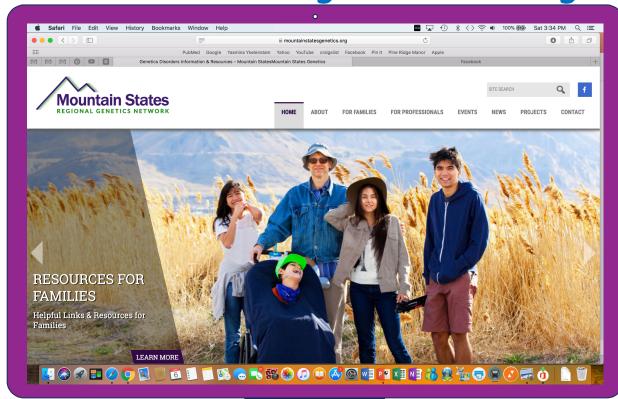
Are you in the group?
If not please send an
Email/text to Kristi and
ask her to add you.



THERE WILL BE NO June 2020 Genetic Ambassador Call- see you in July!

Save the Date

Stay Tuned for July's call date



What days and times work best for the group?



Any questions?

You can find me at

- → kwees@MountainStatesGenetics.org
- → 281-831-3481 (text or call)