



Mountain States

REGIONAL GENETICS NETWORK

Genetic Ambassadors Call

Kristi Wees, MS Chem

Consumer Engagement Director

Mountain States Regional Genetics Network

March 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

Agenda



**INTRODUCTIONS: WHAT WAS YOUR FIRST
EXPERIENCE WITH “FAMILY
ENGAGEMENT”?**



**GUEST SPEAKER:
BETH DWORETZKY, FAMILY VOICES
TOPIC: FAMILY ENGAGEMENT IN
SYSTEMS ASSESSMENT TOOL (FESAT)**



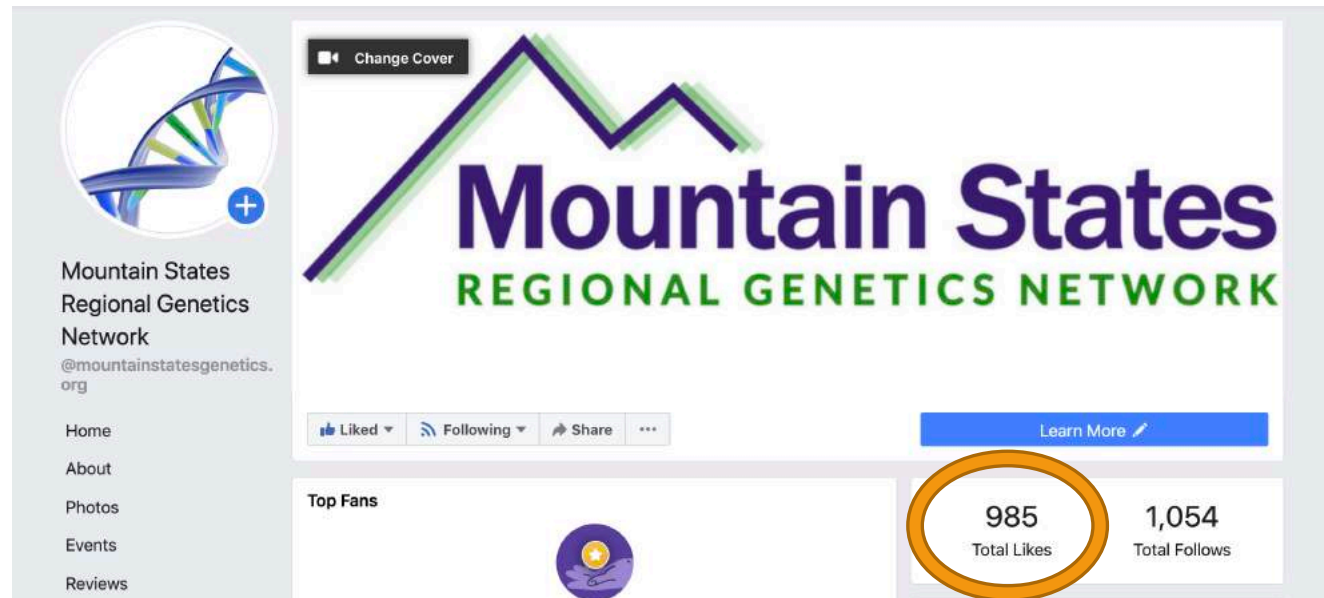
**MSRGN UPDATES
CALENDAR CANCELLATIONS**

Beth Dworetzky

Beth Dworetzky is an Associate Director at Family Voices where her work focuses on family engagement in systems of care. She is the team lead for the Family Voices Family Engagement in Systems Assessment Tool (FESAT) and Family Engagement in Systems (FES) Toolkit. As part of that work, she conducted key informant interviews with family leaders and professional partners and assisted with the qualitative data analysis, which when combined with the findings of a comprehensive literature review, was used to develop the four domains of family engagement and key criteria that informed the development of the FESAT. Beth is also the parent of a young adult with complex health needs.



Facebook Page-
sooo close to
1000
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Mountain States Regional Genetics Network
@mountainstatesgenetics.org

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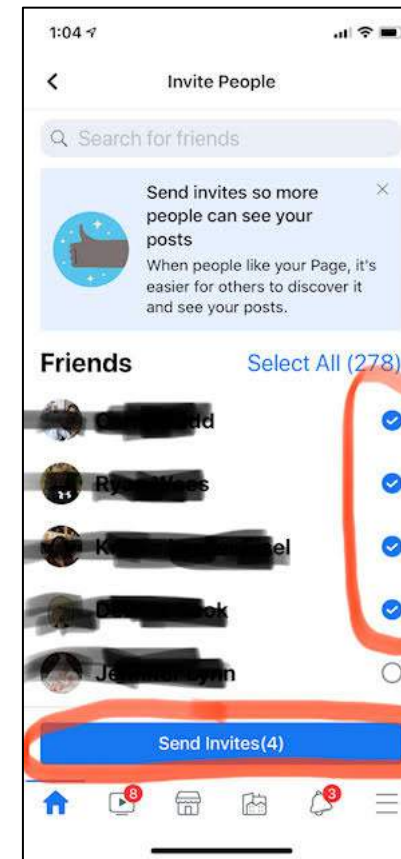
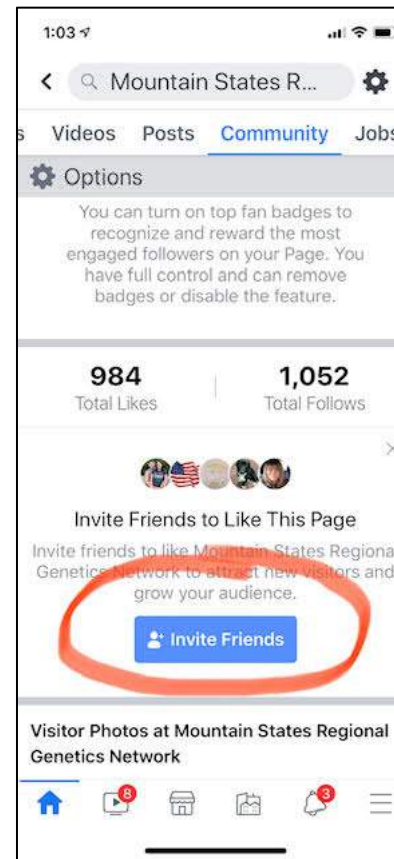
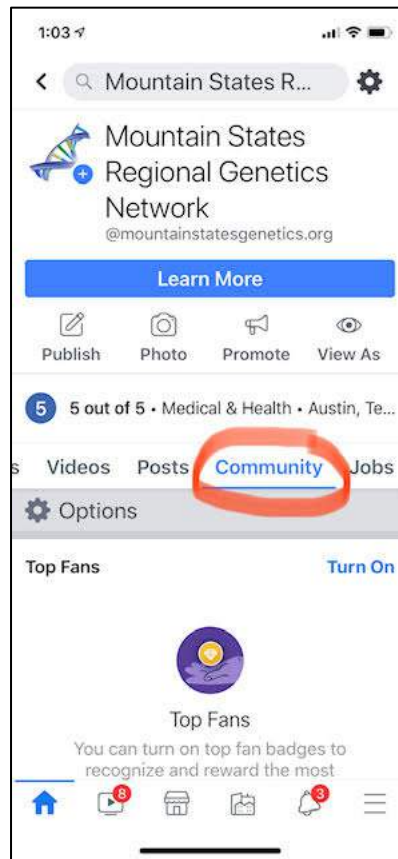
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How to Invite 10 Friends (or 278)!



MSRGN Calendar- March 2020

- **NM Genetics Pop-Up: Elvira & Josey 3/6/20**
- **NV Genetics Pop-Up: Amy & Hannah 3/13/20**



MSRGN Calendar- March 2020



<https://navajofamilies.org/news.html>



MSRGN Calendar- April 2020



- April 2020
 - ~~CO Genetics Pop-Up: Heather~~
~~April 2020 Postponed~~
 - ~~Grand Rounds Miracles for Mito~~
~~CO 4/15/20 Cancelled~~
 - **TX Genetics Pop-Up: Alysian**
4/24/20 or 1st week of May

Calendar- Future Months April 2020- December 2020



- **May 2020**
 - **CO Genetics Pop-Up:** Jamie 5/3/20 **Moving to ONLINE format! Date to be determined.**
 - **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-syndrome-adult-summit-2020/>~~
 - CANCELLED
 - **Last day of MSRGN Current grant cycle:** May 31, 2020
- **June 2020**
 - **National Down Syndrome Congress Conference in New Orleans**
 - June 25-28, 2020
 - <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

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under FOR FAMILIES TAB:

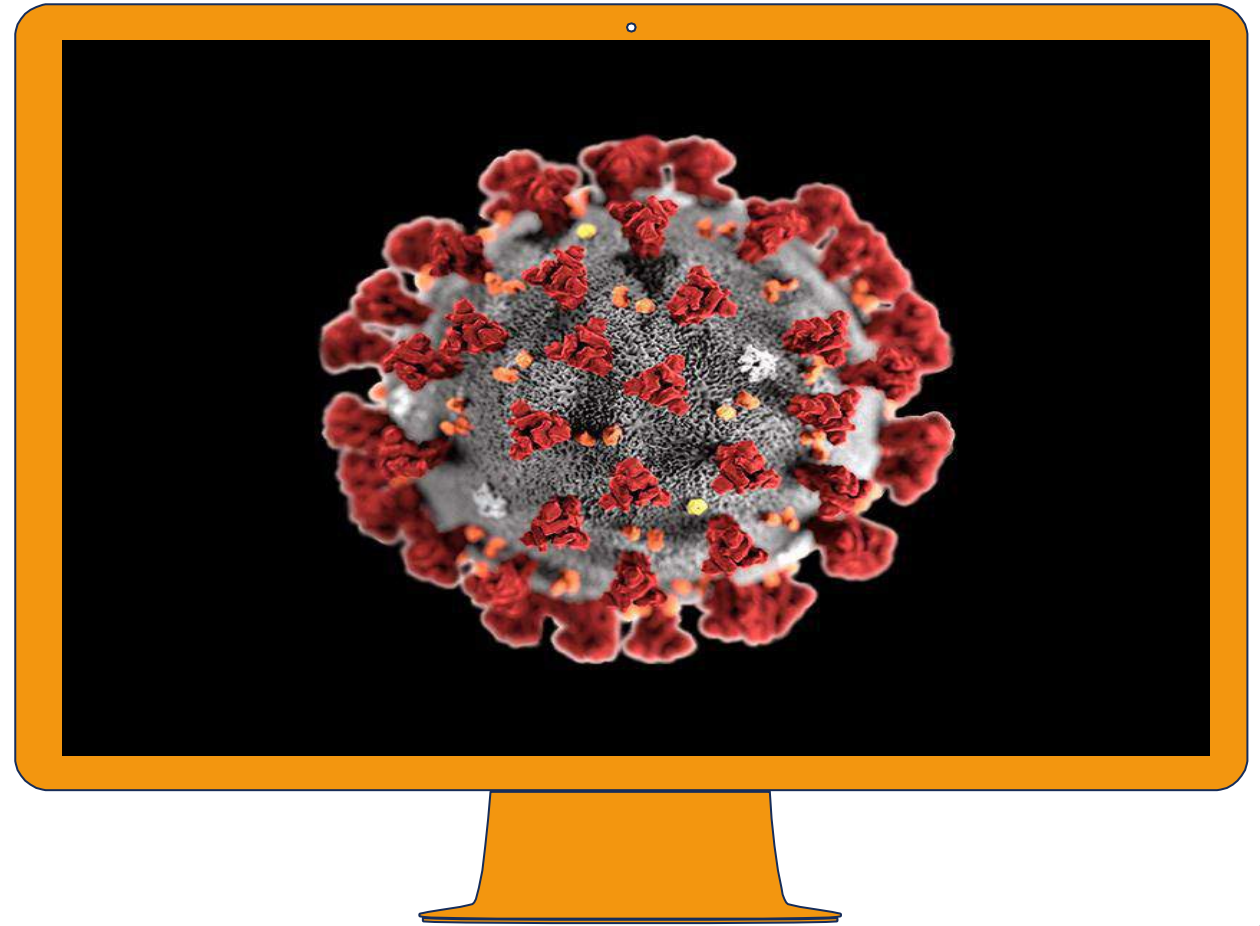
- “Genetic Ambassador” Drop Down
- “Your Genetics Questions Answered” Drop Down
- “Genetics Pop-Ups”



COVID 19 Resources for Individuals and Families with Genetic Conditions

- Working with State Teams to compile a list of Emergency Resources

Would love your input as Genetic Ambassadors! What resources are needed for families of children with Genetic conditions and special needs.



www.MountainStatesGenetics.org

April's 2020 Genetic Ambassador Call

Save the Date

April 29 at 2pm



Genetic Ambassador Facebook Group

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



Thanks!

Any questions?

You can find me at

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