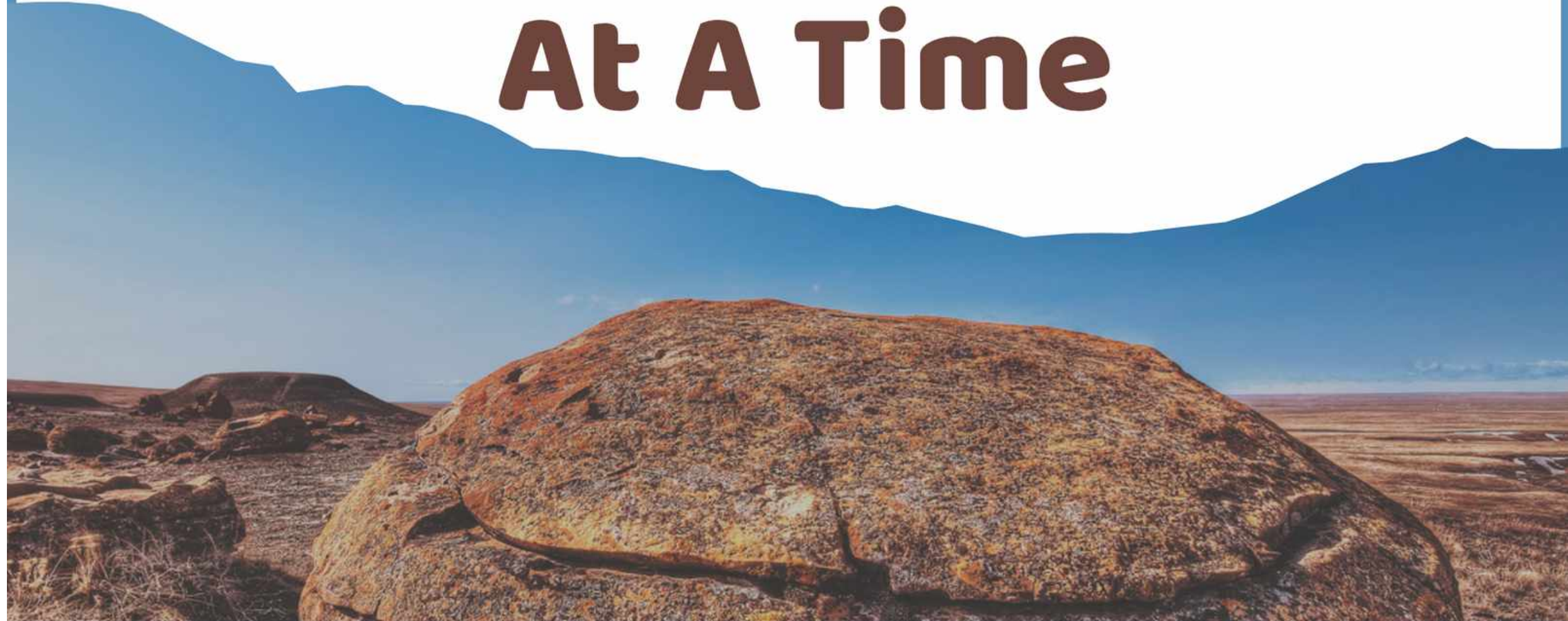




MSRGN Virtual Summer 2022 Meeting

# Moving Mountains: One Boulder At A Time



**June 14, 2022**

9am-1pm PT    11am-3pm CT  
10am-2pm MT    noon-4pm ET

**June 15, 2022**

12:30-3:30 pm PT    2:30-5:30 pm CT  
1:30-4:30 pm MT    3:30-6:30 pm ET

# A statement from our funders

This meeting is supported by the Health Resources and Services Administration (HRSA) of the U.S. Department of Health and Human Services (HHS) as part of an award totaling \$600,000.00 with 0 percent financed with non-governmental sources. The contents are those of the author(s) and do not necessarily represent the official views of, nor an endorsement, by HRSA, HHS, or the U.S. Government. For more information, please visit [HRSA.gov](https://www.hrsa.gov).



**KW**



1

We are asking everyone to stay on MUTE during the presentation portion of the meeting. We will be "Raising Hands" virtually for interactive and discussion portions.

2

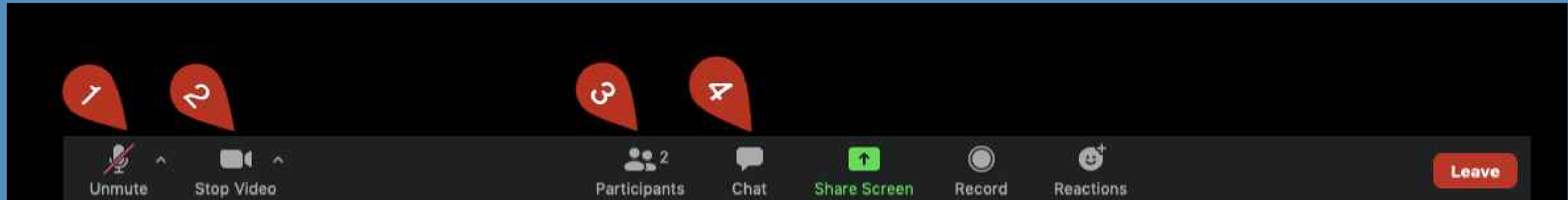
Feel free to turn your camera on if you feel comfortable.

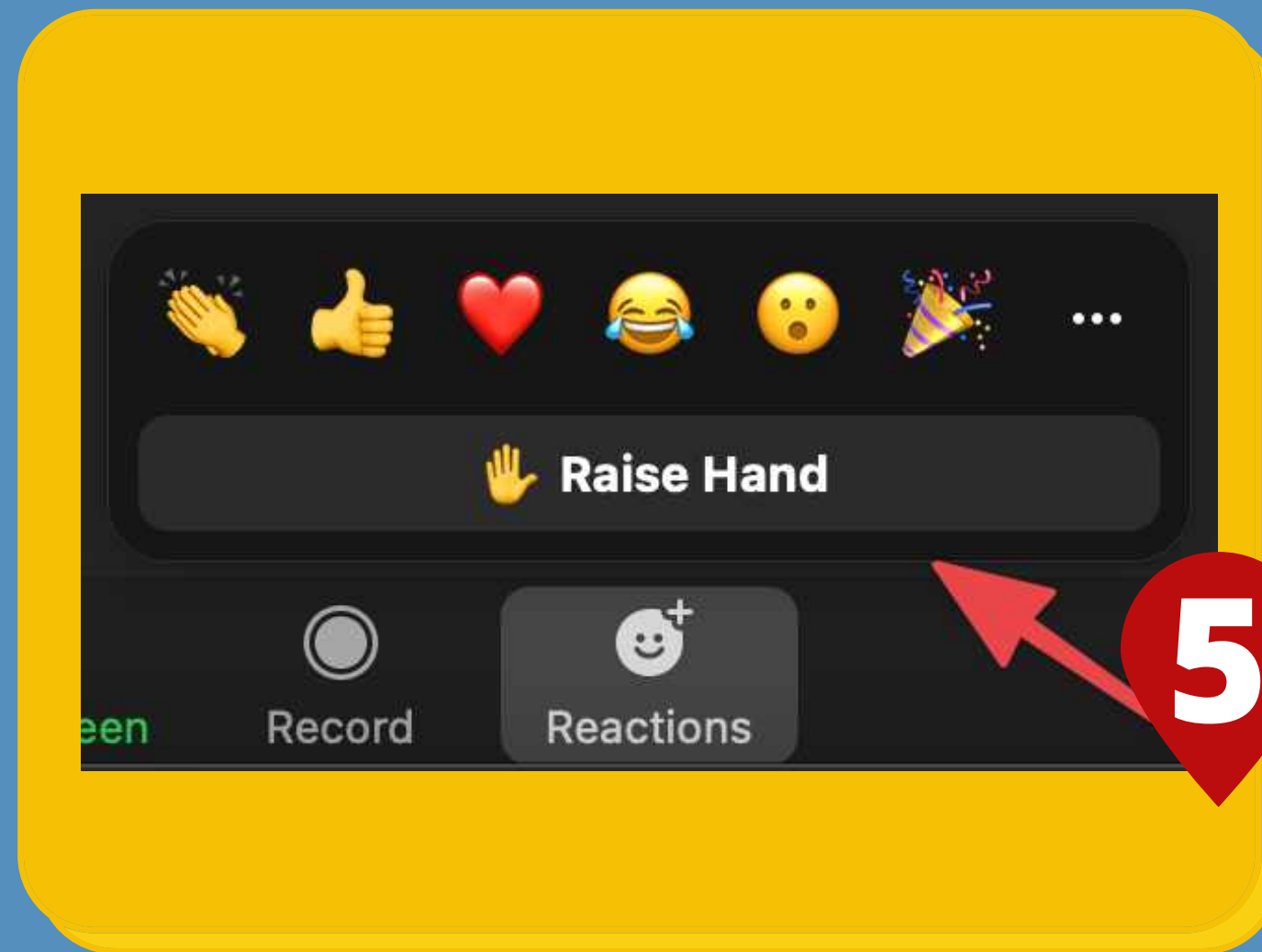
3

This is the active online participants list.

4

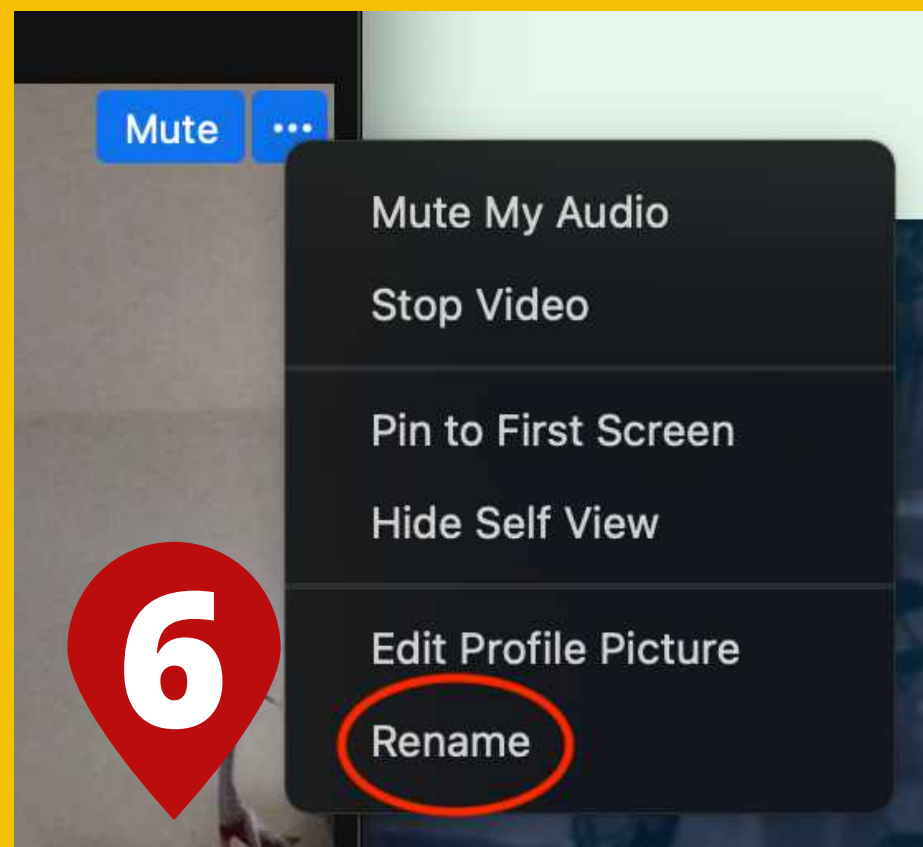
Please use the chat feature for Q&A or tech issues (to: Katie Bradley or Stephanie Ondrias)





5

When asking a question, please raise your hand and wait to be called on, then state your name when you begin to talk



6

Rename

Enter a new screen name:

John Doe (TX)

Your Name Here (2 letter state code)

OK Cancel

6

Look for the 3 dots (...) in the top right corner of your video. Click on that and then click Rename with your First and Last Name and State Code

## How to Rename Yourself and Add Your State



# Day 2 Agenda

Looking Forward: The Next 2 Years

2:30 PM-2:40 PM CT

Time 4 Genetics

2:40 PM-3:00 PM CT

Genetic Navigators: Rock Report Interactive Activity

3:00 PM-3:45 PM CT

Break

3:45 PM-4:00 PM CT

Year 6: State of the Region

4:00 PM-4:30 PM CT

Bridging and Blasting Our Boulders

4:30 PM-5:15 PM CT

Day 2 Wrap-Up

5:15 PM-5:30 PM CT



Day 2: June 15



# Looking Forward: The Next 2 Years

2:30 PM-2:40 PM CT

# Looking Forward: 2022- 2024





Day 2: June 15



# Time 4 Genetics

2:40 PM-3:00 PM CT

Kristi



**1 Topic  
4 Months**

**4 Ways to Learn &  
Take Time 4 Genetics**

**1**

ELECTRONIC  
NEWSLETTER



**2**

WEBINAR



**3**

SNAIL MAIL



**4**

FAMILY CENTERED  
VIEWPOINT





# Time 4 Genetics

## Topic Areas

Cohort #1 Topics  
Completed 4/21- 3/22

Topic #1:  
Red Flags 4 Genetics

Topic #2:  
Developmental Delays

Topic #3:  
Ehlers Danlos Syndrome

Topic #4:  
Genetic Testing

Topic #5:  
Autism

Topic #6:  
TBD

We Are Here!



# Time 4 Genetics

## Cohort #1: 7 Clinics



# Time 4 Genetics

## Cohort #1



North Country HealthCare

Flagstaff, AZ



Pediatric Partners of the Southwest

Durango, CO



Dell Children's Medical Group

Round Rock, TX



Desert Valley Pediatrics

LasVegas, NV



Taos Clinic Children/Youth

Taos, NM



Intermountain West Jordan Clinic

West Jordan, UT



Meadowlark Pediatrics LLC

Laramie, WY

# Time 4 Genetics

## Cohort #2: 11 Clinics






# Time 4 Genetics


## Cohort #2

 Yavapai Pediatrics  
**Prescott Valley, AZ**

 Pence Pediatrics  
**Monte Vista, CO**

 Gabert Medical Clinic  
**Glendive, MT**


 SWMTCHC  
**Butte, MT**

 Providence St. Joseph  
Medical Center  
**Polson, MT**


 Partners in Pediatrics, PC  
**Helena, MT**

 The Healthcare Center  
**Reno, NV**

 Oshiro Pediatrics  
**Las Vegas, NV**

 Sandra L Whisler, MD  
**Albuquerque, NM**

 Paso del Norte Children'  
Development Center  
**El Paso, TX**

 Northeast Wyoming  
Pediatric Associates  
**Sheridan, WY**

# Time 4 Genetics

## Cohort #1 + Cohort #2

### 18 Clinics Combined



# Time 4 Genetics Feedback

“

I am so impressed with the resources  
T4G has for us on their website.

With such rapid growth in genetic discoveries and  
testing, and an increasing need for primary care  
providers to screen, evaluate and provide care for  
children with autism and developmental delays, their  
guidelines are extremely useful to lean on.

Joining in the webinars has increased my knowledge  
and comfort level in ordering some genetic screening  
tests and built my confidence in having these  
conversations with families.

”

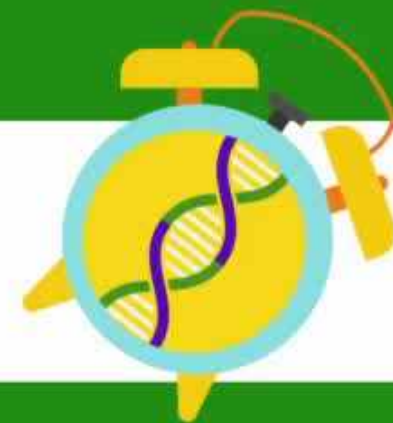
Kelly Miller, MD

Pediatric Partners of the Southwest  
American Academy of Pediatrics -  
Colorado Chapter Board Member





## Time 4 Genetics



# Testimonial

# Time 4 Genetics Feedback

Marta Katalenas MD, FAAP  
Pediatrician  
Dell Children's Medical Group



# Cohort #3 will be our LAST Cohort for the 2020-2024 Grant Cycle

Application opens for Cohort #3: **July 1, 2022**

Application deadline: **January 15, 2023**

GOAL: **5 clinics per state in total**

to reach regional goal of 40 Clinics enrolled in T4G  
by January 15, 2022

Application and video here:

[www.mountainstatesgenetics.org/t4info/](http://www.mountainstatesgenetics.org/t4info/)

**KW**



## Time 4 Genetics Clinic Counts (as of June 2022)

Arizona: 2

Colorado: 2

Montana: 4

Nevada: 3

New Mexico: 2

Texas: 2

Utah: 1

Wyoming: 2

*Goal by January 15, 2023: 5 per state total*



# What topic do you think should be Topic #6 for T4G?

Topic #1:  
Red Flags 4 Genetics

Topic #2:  
Developmental Delays

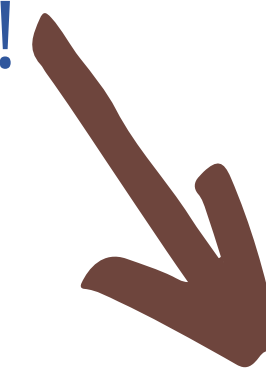
Topic #3:  
Ehlers Danlos Syndrome

Topic #4:  
Genetic Testing

Topic #5:  
Autism

Topic #6:  
TBD– Tell us your suggestions  
in the chat!

Vote in Chat!



Day 2: June 15



# Genetic Navigators: The Rock Report Interactive Activity

3:00 PM-3:45 PM CT

Kristi, Jamie, Jen, Noan

**KW**

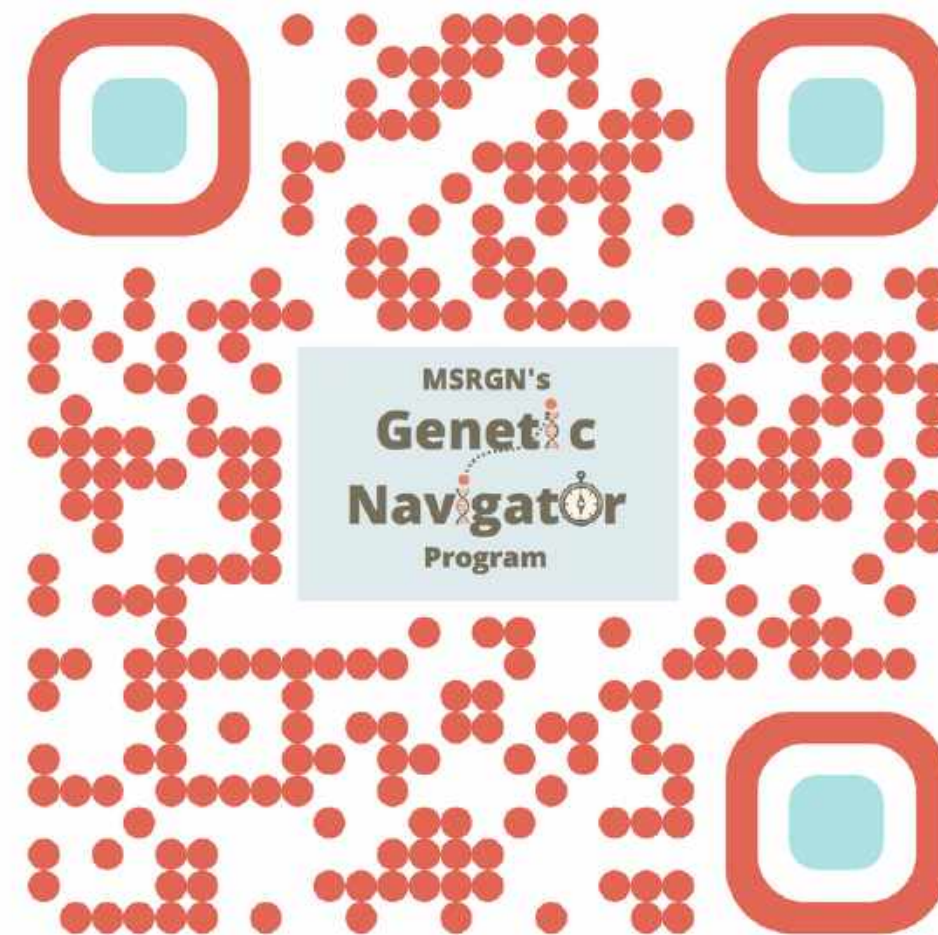


# Year 5 MSRGN Genetic Navigators





# Year 6 Genetic Navigators Application OPEN for New Mexico and Utah

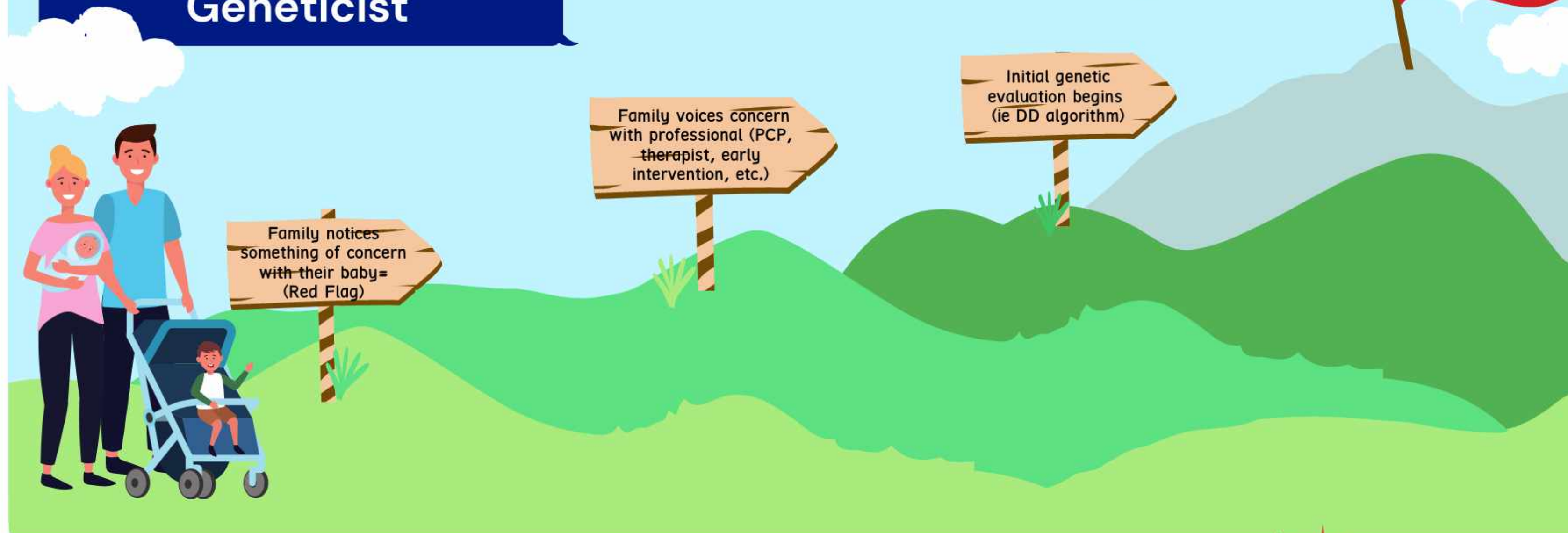


# What is the Rock Report?

Thinking about and visualizing  
barriers families face in accessing  
Genetic Services as **BOULDERS**  
(big rocks/barriers)  
and then thinking about ways we can  
**BLAST** (eliminate) or  
**BRIDGE** (partnerships) those  
boulders so family can move forward  
in their journey.



# Example: A Family's Genetic Journey to a Geneticist



1

Fill in each of the milestones a family might reach on the way to their goal.

Step 1

2

What are the BOULDERS that might stop a family from reaching these milestones?

Genetic Testing is not covered by Insurance

Family does not follow up on concern

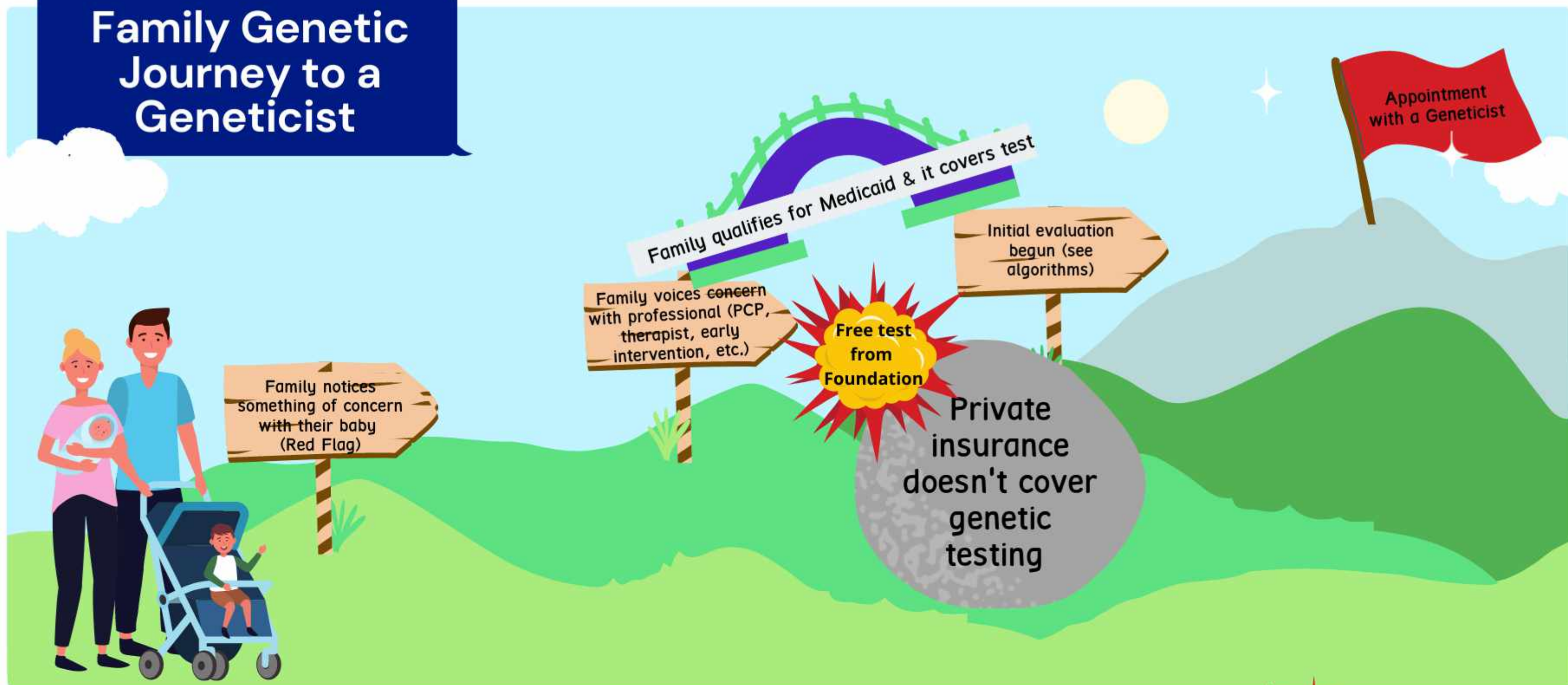
3

How might a family find a way over or through these BOULDERS?  
BLASTS & BRIDGES





# Family Genetic Journey to a Geneticist



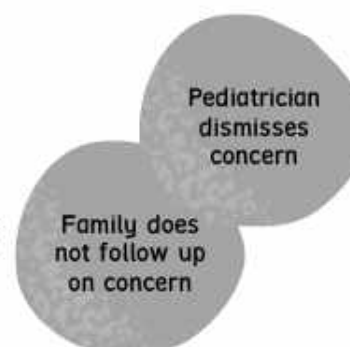
1

Fill in each of the milestones you would like to reach on the way to your goal.



2

What are the blockers that might stop you from reaching these milestones?



3

How might you find a way over or through these blockers?  
BLASTS & BRIDGES





# Break Out Rooms

**Goal of the next 30 minutes:**

To solve all the genetic challenges in the MSRGN region! Just Kidding!

True Goal: To brainstorm about BOULDERS and BLASTS and BRIDGES for your state.

But, our hope is that the conversation does not end here...

we challenge each state to take this conversation to your state team meeting in July (and beyond) and allow these boulders to inspire state team project solutions!

Day 2: June 15

# Breakout Rooms:

Room #1:  
Nevada/Wyoming  
Kristi

Room #2:  
Montana/New Mexico  
Jenn

Room #3:  
Colorado/Texas  
Jamie

Room #4:  
Arizona/Utah  
Noan



Day 2: June 15



# Pull Up Mentimeter Polls

Moderators to pull up polls  
in each  
breakout room

**KW**



Day 2: June 15



**BREAK**

3:45- 4:00 PM CT

Up next:

**Year 6 State of the Region**

**4:00 PM-4:30 PM CT**

Zoom link (same as now- Day 2 Link!)



Day 2: June 15



# Year 6: State of the Region

4:00 PM-4:30 PM CT

Kathy, Janet,  
Kristi, Jamie, Liza



# Year 6: State of the Region

Telegenetics Needs Assessment

Year 6 Deadlines & Cross Pollination

Genetics Explained: Variants of Uncertain Significance



Hold for slides from Liza  
Telegenetics Needs Assessment post COVID  
(10 min)



## Looking ahead:

- State Team Funding Deadlines
- Cross Pollination Funding
- Time 4 Genetics Deadline



## State Team Funding Deadlines for Year 6

- Applications OPEN: July 1st
- Applications CLOSE: September 30th
- Up to \$2000 can be requested per state team.
- If no application is received by September 30th, the state funds will be donated to the cross pollination fund.
- Application link will be shared at July state team meetings and with the co-leads.



## Cross Pollination Funding

- A new funding opportunity for innovative solutions to boulders in our region!
- This funding opportunity is separate from state team funding but state team members can apply.
- Open to anyone in our 8 state region who has a project idea to improve access to genetic services.
- Priority given to projects that cross-pollinate between 2 or more states in our region.



# Cross Pollination Funding Deadlines

Applications OPEN:

**July 1st**

Applications CLOSE:

**September 30th**

Projects completed and data due to MSRGN:

**May 31, 2023**



## Time 4 Genetics Deadlines

- Cohort #3 applications OPEN: **July 1**
- Applications CLOSE: **January 15, 2023**
- MSRGN Goal is 40 total clinics by January 15th.
- Goal for each state team is to have **5 TOTAL** clinics enrolled in the program (Cohort 1,2,3) by January 2023.
- Currently there are 18 total clinics across our 8 state region.



## Time 4 Genetics Clinic Counts (as of June 2022)

Arizona: 2

Colorado: 2

Montana: 4

Nevada: 3

New Mexico: 2

Texas: 2

Utah: 1

Wyoming: 2

*Goal by January 15, 2023: 5 per state total*





**MSRGN Presents:**

# **Genetics Explained**



# **World Wide Video Premiere: Genetics Explained~VUS**

**KW**





Day 2: June 15



# Bridging and Blasting Our Boulders

4:30 PM-5:15 PM CT

Kristi



Day 2: June 15



# Switch to Mentimeter For All Group Feedback

4:30 PM-5:15 PM CT  
Kristi

**KW**



Day 2: June 15



# Day 2 Wrap-Up

5:15 PM-5:30 PM CT

Kathy, Janet



# Day 2 Wrap-Up

## Observation #1 Janet

---

Janet to offer her insights here

## Observation #2 Kathy

---

Kathy to offer her insights here

## Observation #3 Janet & Kathy

---

Both Project Co-Directors to offer their BIG takeaway and guidance for the next 2 years here.

**KH&JT**



# Next Steps

## July State Team Meetings

---

State team meetings will resume in July. Stay tuned for calendar invites!

Please continue your conversations about the boulders in your state and how your team can blast and bridge them with your state team projects and funding.

## Genetics Summit 2022

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Save the date:  
Virtual  
November 9-10  
2022

Theme: Momentum  
in the Mountains

## Enjoy Your Summer!

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We appreciate you all and hope you take some time to unplug and relax with your loved ones this summer!

PLEASE FILL OUT THE EVALUATION FIRST though!

**JT**



# Evaluation

Summer Meeting Evaluation Link

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[https://uoflcik.co1.qualtrics.com/jfe/form/SV\\_0CBXLFqjo2MttT8](https://uoflcik.co1.qualtrics.com/jfe/form/SV_0CBXLFqjo2MttT8)



**SMILE!**  
**Your on**  
**MSRGN CANDID CAMERA!!**  
**Turn Your Camera ON Please!**

**Group Photo!**

