

# Consumer Engagement in a Virtual World



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Consumer Engagement Director and Social Media Coordinator

Mountain States Regional Genetics Network

# Objectives

## Learning Objectives-

After this session attendees will be able to:

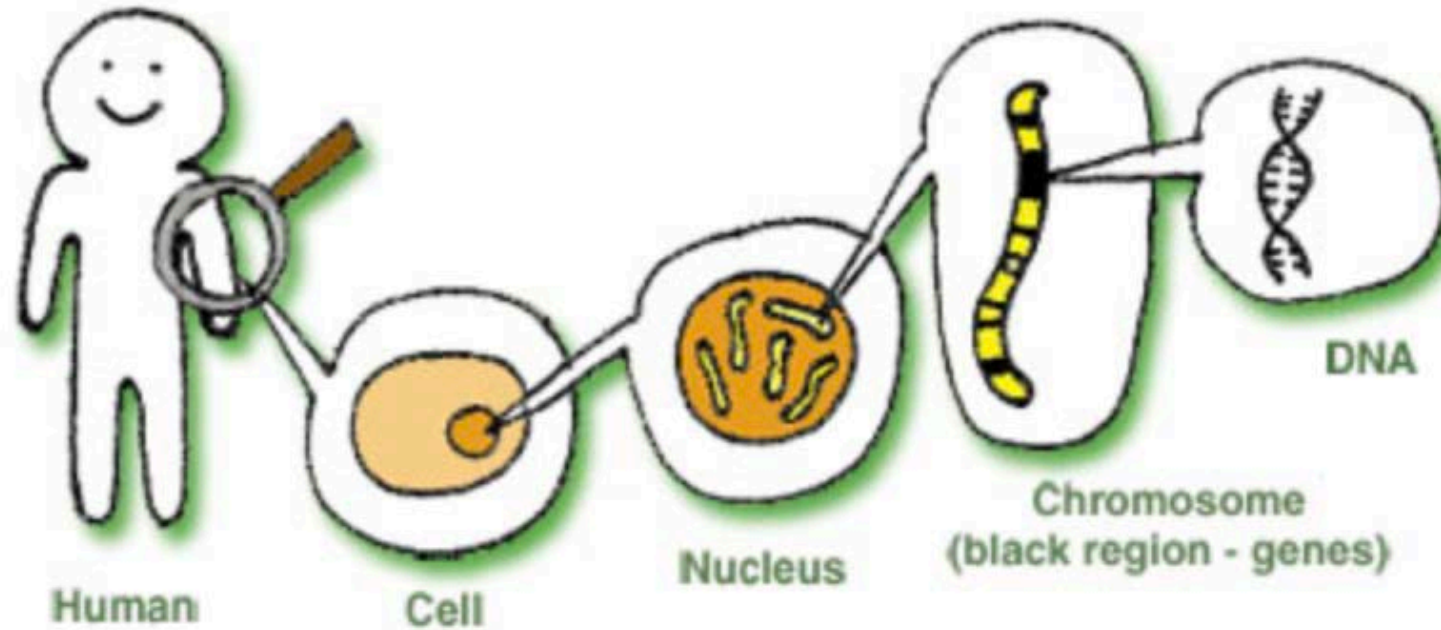
- 1) Identify 3 ways to connect and outreach to underserved populations virtually, using technology.
- 2) Describe how to utilize video platforms (such as Facebook LIVE) to increase consumer engagement.
- 3) Identify 2 examples of ways to engage consumers in-person in creative ways.



# Genetics

What does Genetics Mean?

# Genetics

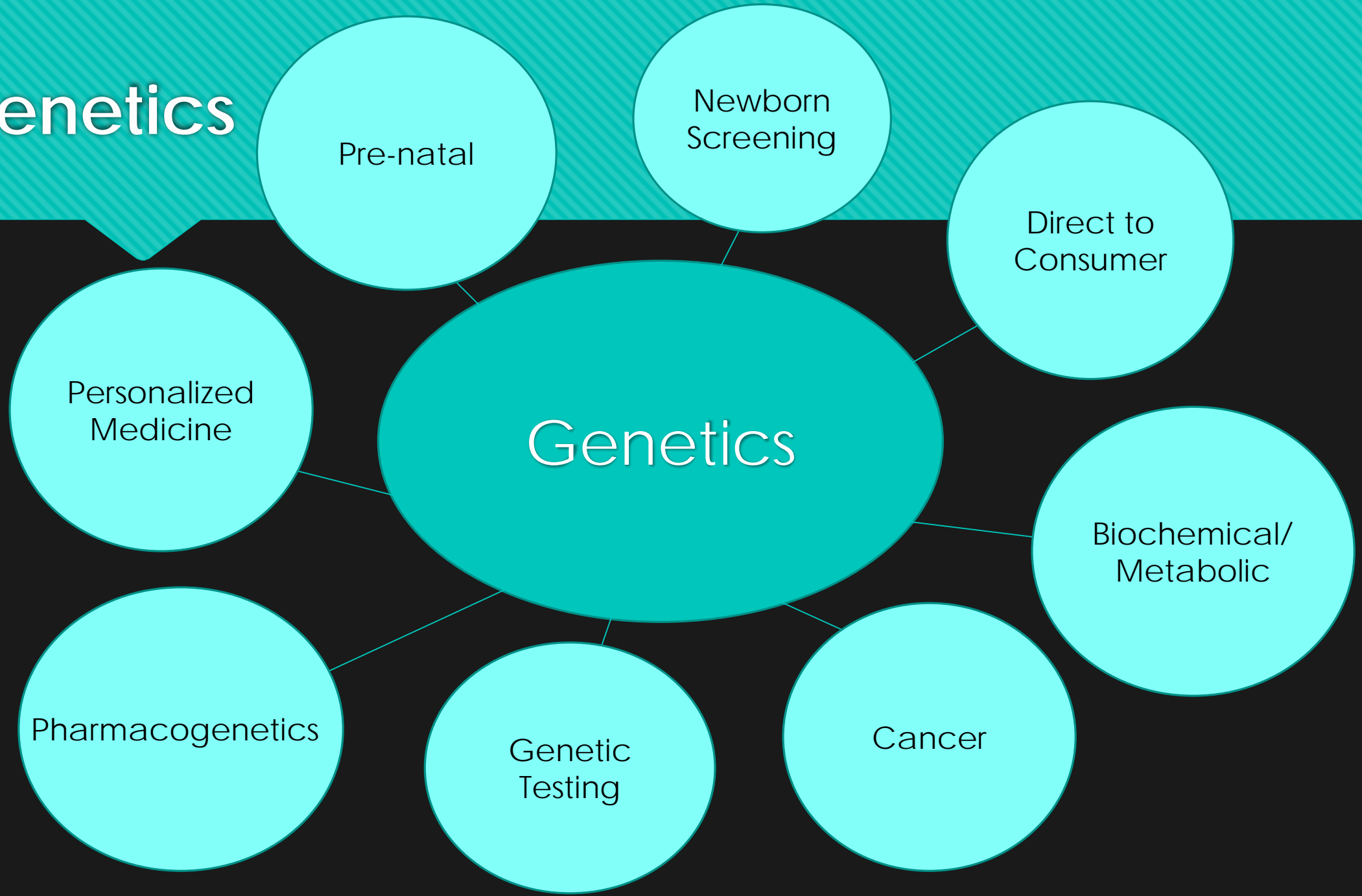


# Genetic Disease

## Inpatient Care in a Children's Hospital

- The Burden of Genetic Disease on Inpatient Care in a Children's Hospital
- Am J Hum Genet. 2004 Jan; 74(1): 121–127.
- An underlying disorder with a significant genetic component was found in 71% of admitted children.
- The vast majority (96%) of underlying chronic disorders in children in this study were either clearly genetic or had a genetic susceptibility.
- Total charges for 1996 were >\$62 million, of which \$50 million (81%) was accounted for by disorders with a genetic determinant.

# Genetics





# Genetics Networks

What are the Regional Genetics Networks?

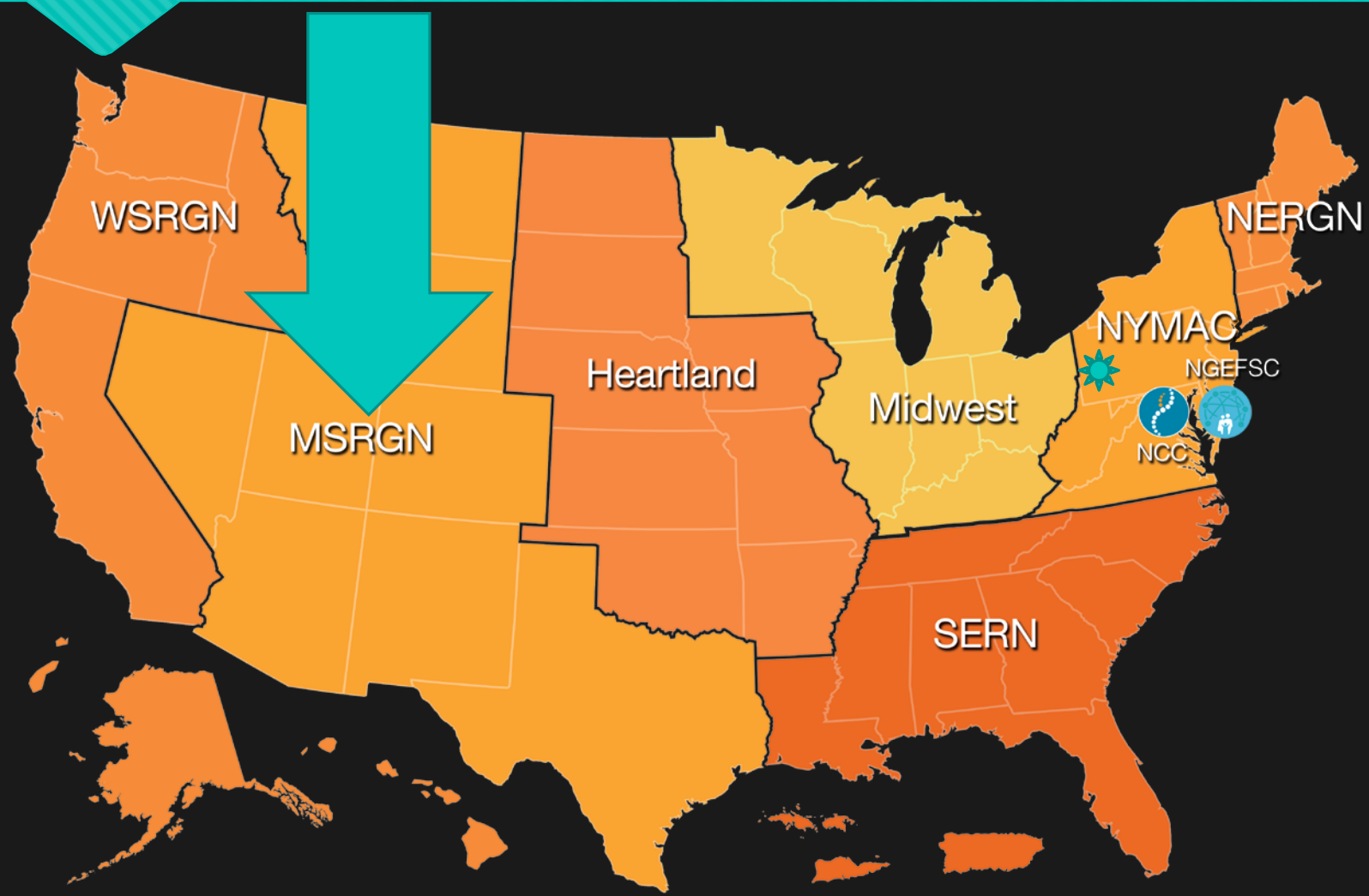


# What are the Regional Genetics Networks?

- Who knows what the RGN's are?
- In 2017, the Maternal and Child Health Bureau of the Health Resources and Services Administration (MCHB/HRSA), Genetic Services Branch (GSB)
- Awarded grants to establish the seven Regional Genetics Networks (RGNs)
- 3 year cycle ends in May 2020
- On-going efforts to improve the health of medically underserved by promoting the translation of genetic medicine into public health and health care services.
- Who has worked with your local RGN?



# 7 Regional Genetics Networks



# National Genetics Education and Family Support Center (Family Center)

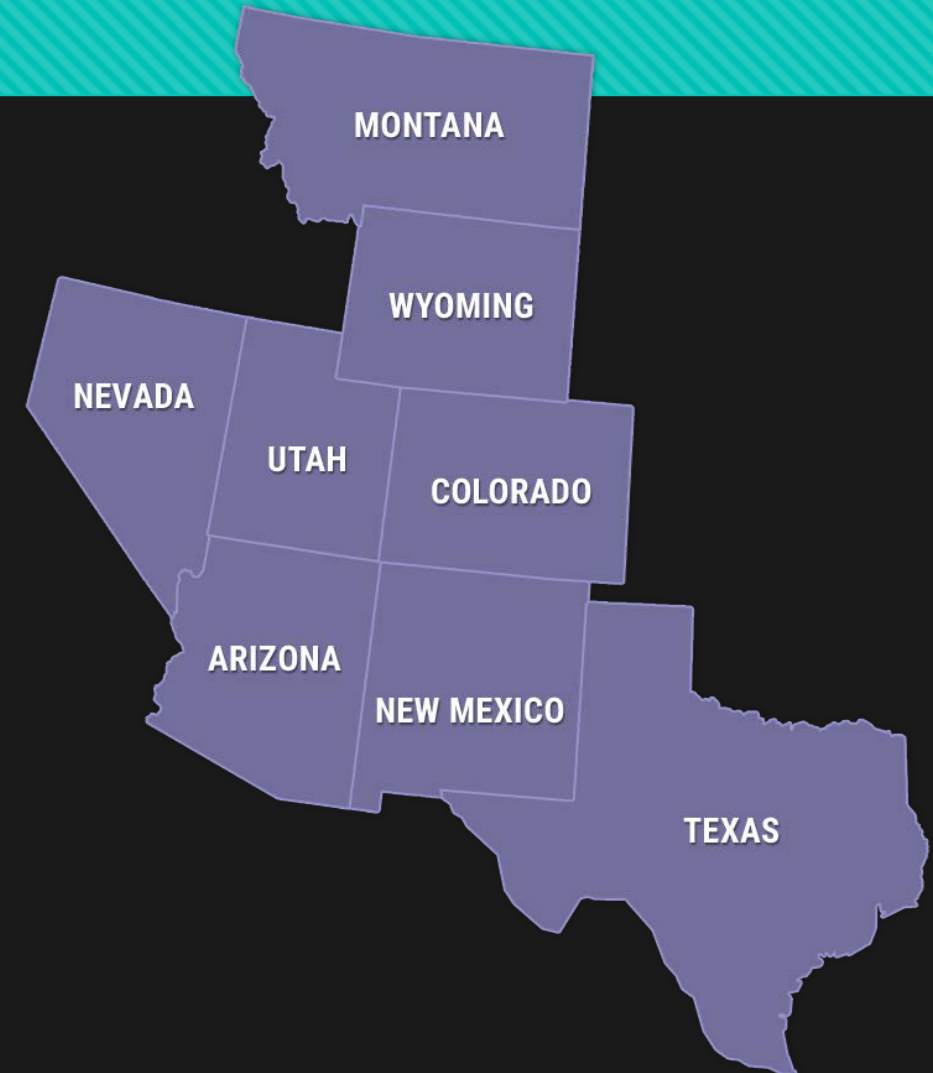
- The National Genetics Education and Family Support Center is a three-year initiative (June 2017- May 2020) led by:
- Genetic Alliance in partnership with the Regional Genetics Networks,
- Family Voices, and
- Parent to Parent USA.
- The focus of Family Center is to build a network of partners and develop accessible tools to improve access to and the quality of genetic services.

# MSRGN- Mountain States Regional Genetics Networks

- 8 State Region

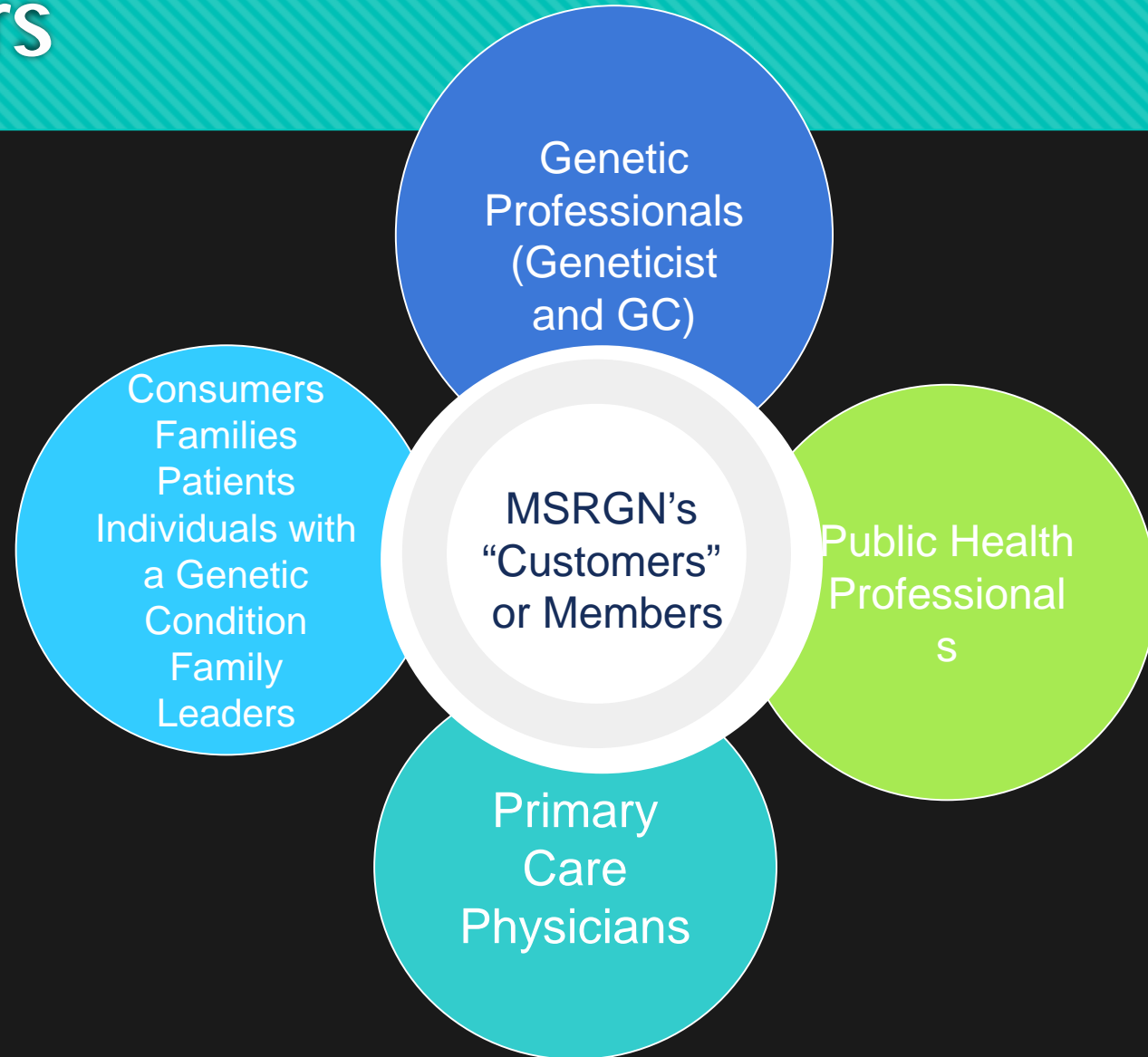
MSRGN's mission is to ensure that individuals with genetic disorders and their families have access to quality care and appropriate genetic expertise and information through facilitating a professional network of :

- genetics clinics,
- key primary care practices,
- consumer advocates,
- and state health department resources.



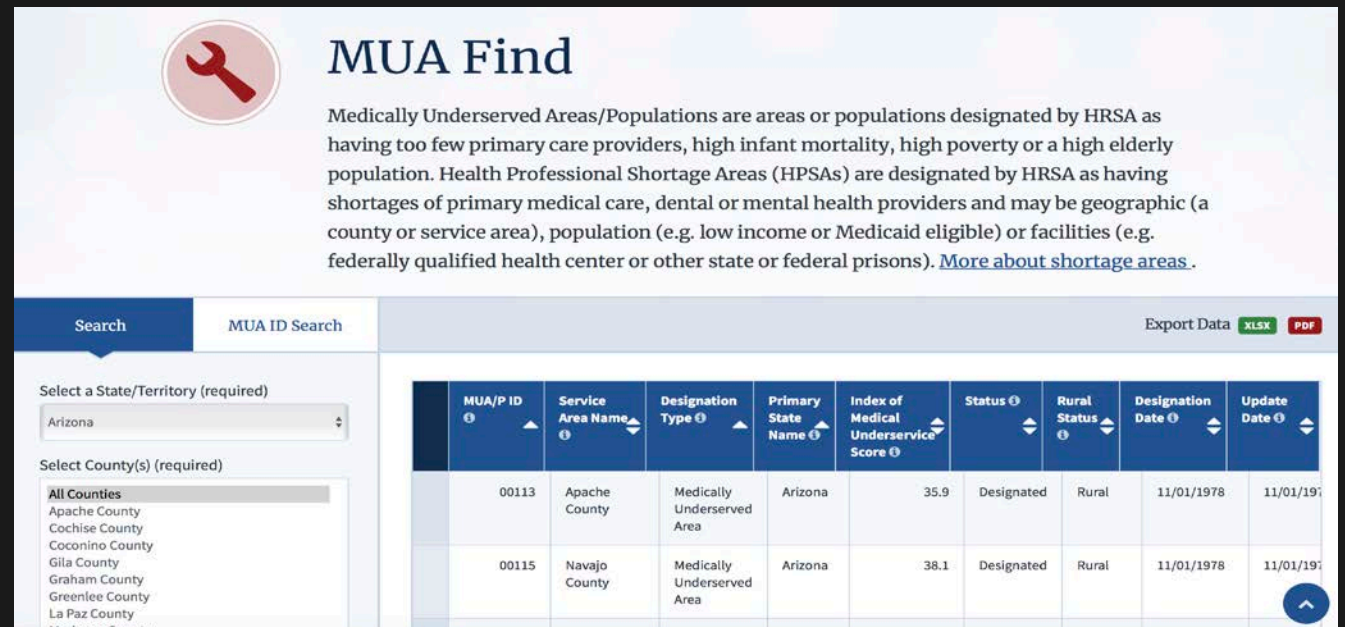
# MSRGN's Infrastructure: UPP, State Teams & Genetic Ambassadors

- State Teams: 5-10 individuals- consumers, genetics professionals, primary care professionals, and public health staff with 2 co-leads.
- Underserved Populations Project- 3 Pilot sites in year #1 of grant with 3 underserved populations (more about this in 2 slides!)
- Genetic Ambassadors- Families, Consumers, and Individuals impacted by and living with genetic conditions



# Who is Underserved?

- Medically Underserved Areas/Populations are areas or populations designated by HRSA as having:
  - too few primary care providers,
  - high infant mortality,
  - high poverty or
  - a high elderly population.



**MUA Find**

Medically Underserved Areas/Populations are areas or populations designated by HRSA as having too few primary care providers, high infant mortality, high poverty or a high elderly population. Health Professional Shortage Areas (HPSAs) are designated by HRSA as having shortages of primary medical care, dental or mental health providers and may be geographic (a county or service area), population (e.g. low income or Medicaid eligible) or facilities (e.g. federally qualified health center or other state or federal prisons). [More about shortage areas.](#)

Search MUA ID Search Export Data [XLSX](#) [PDF](#)

Select a State/Territory (required)  
Arizona

Select County(s) (required)  
All Counties  
Apache County  
Cochise County  
Coconino County  
Gila County  
Graham County  
Greenlee County  
La Paz County  
Maricopa County

MUA/P ID	Service Area Name	Designation Type	Primary State Name	Index of Medical Underservice Score	Status	Rural Status	Designation Date	Update Date
00113	Apache County	Medically Underserved Area	Arizona	35.9	Designated	Rural	11/01/1978	11/01/1978
00115	Navajo County	Medically Underserved Area	Arizona	38.1	Designated	Rural	11/01/1978	11/01/1978

- Search your state: Google: MUA FIND
- <https://data.hrsa.gov/tools/shortage-area/mua-find>



# Medically Underserved in MSRGN

- UPP project
- 3 Pilot sites: 3 Underserved Populations:
  - San Antonio Texas: Hispanic
  - Grand Junction/Durango Colorado: Rural
  - Tuba City Arizona: Native American
- Other Underserved Populations in our region:
  - The Undiagnosed
  - The Developmentally Delayed
  - Geographically isolated- frontier counties
  - Culturally isolated





# Engagement

Live? In Person? Virtual? Remote? which is better?



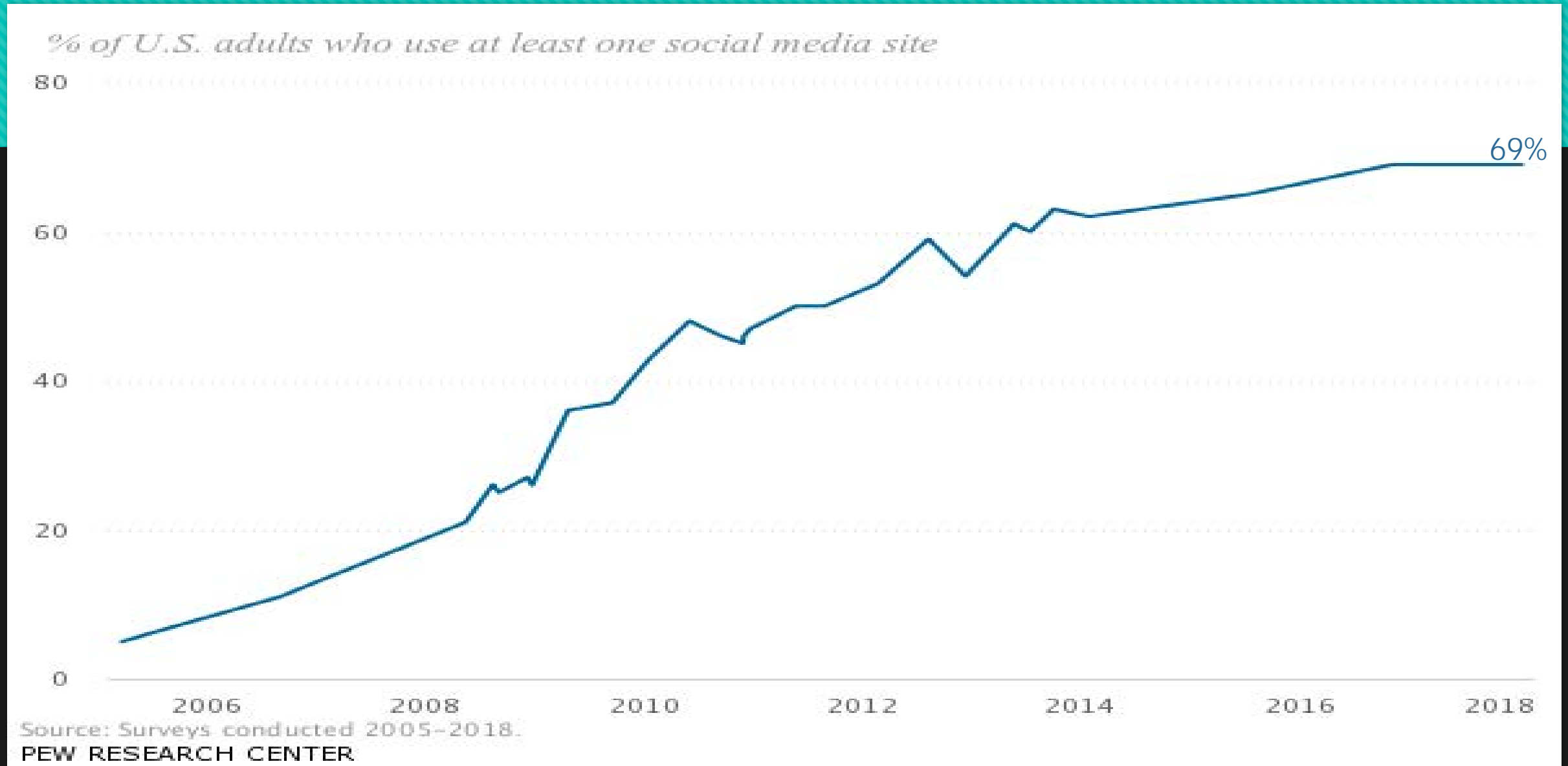
# Technology Usage in Underserved Populations

- A total of 291 individuals participated and were predominantly female (69.0%). Majority reported incomes less than \$30,000 (72.9%) and identified as African American/Black/Caribbean (49.3%) or Mexican/Mexican American (34.3%). Most participants regularly used smartphones (63.2%) and the Internet (75.9%). Respondents frequently used Facebook (84.8%), and less commonly used Instagram (43.6%), and Twitter (20.0%).

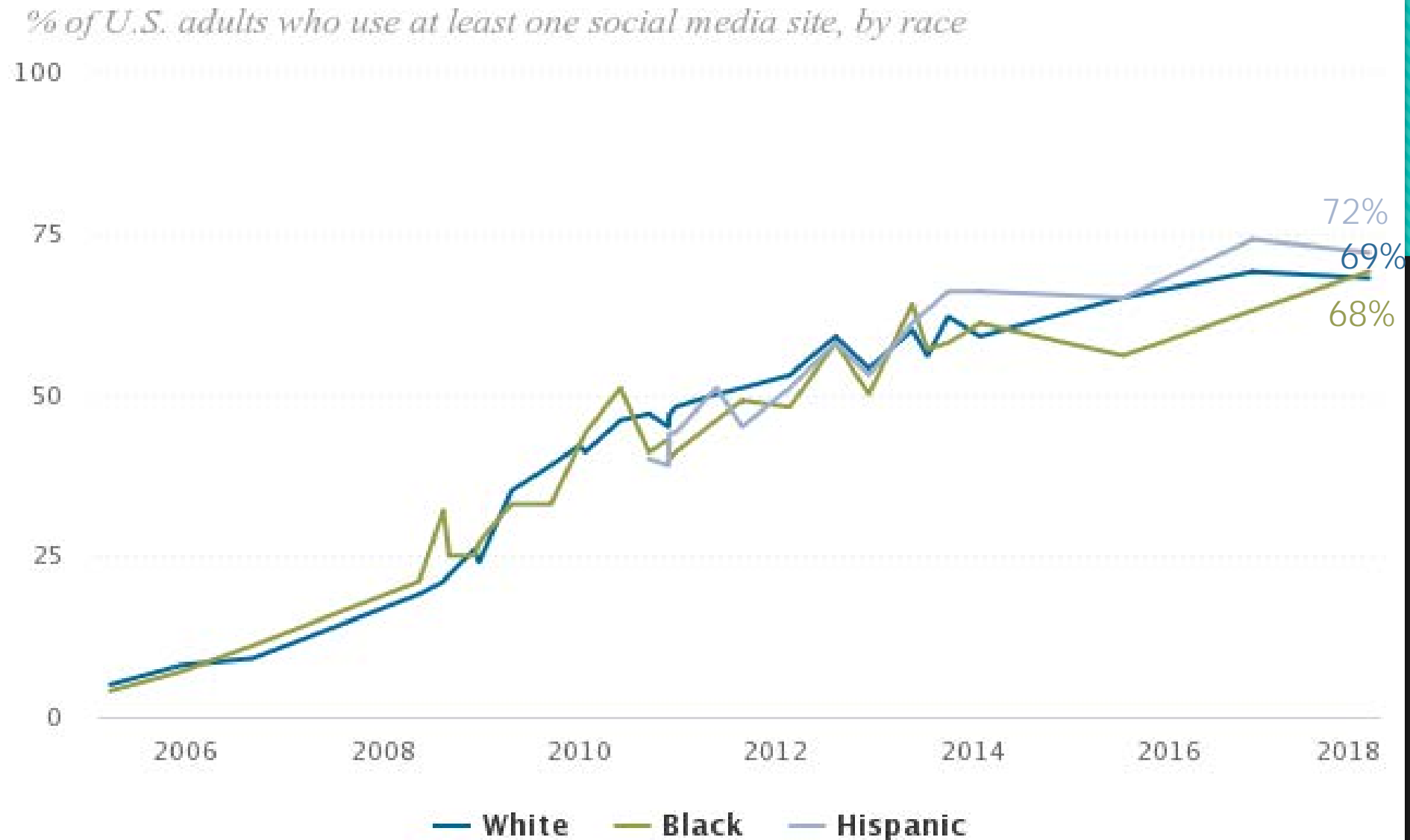
- **Physical Activity in an Underserved Population: Identifying Technology Preferences**

- <https://journals.humankinetics.com/doi/abs/10.1123/jpah.2016-0162>

# US Adults who use at least 1 social media site



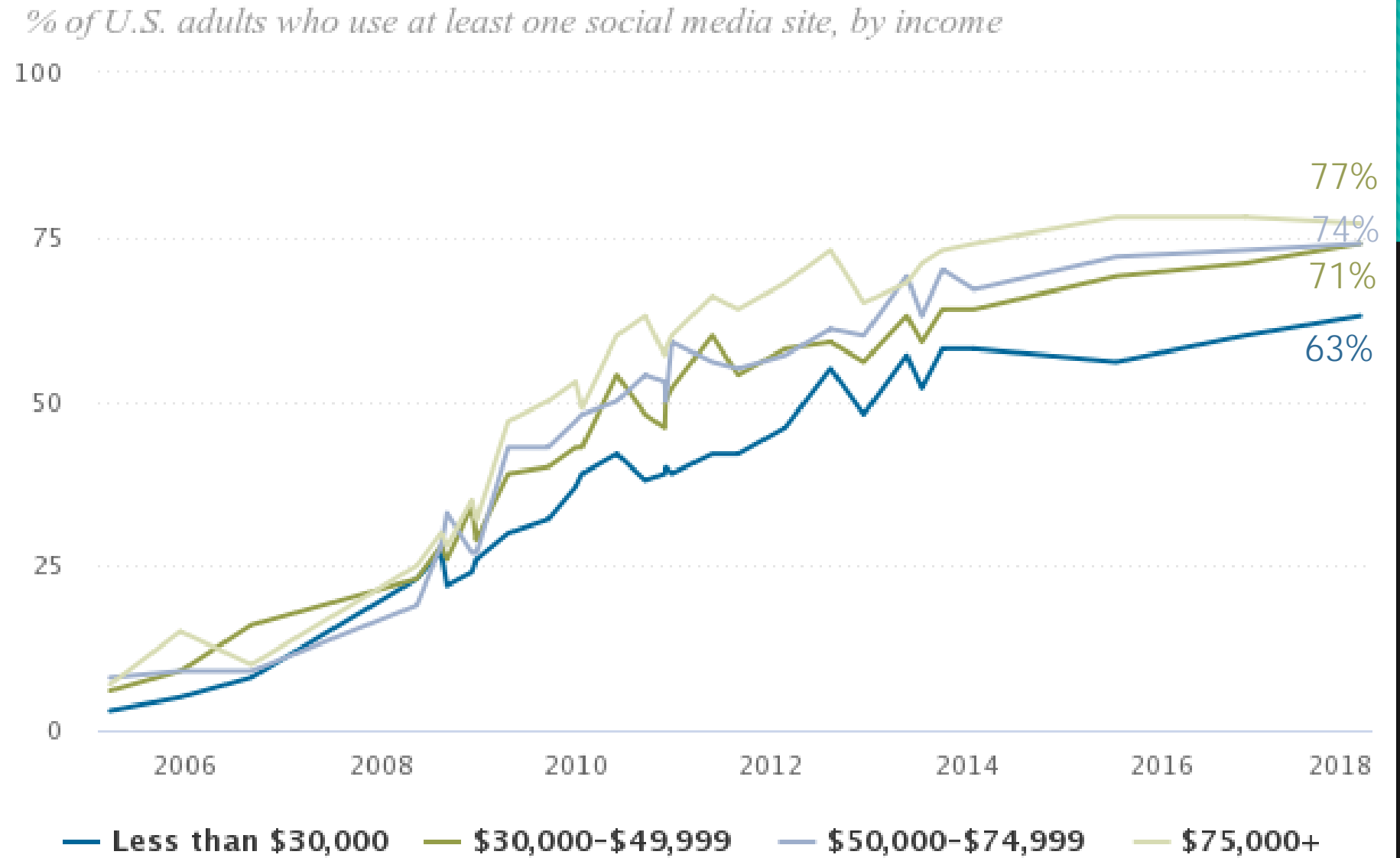
# By Race



Source: Surveys conducted 2005–2018. Data for Hispanics includes only surveys that included Spanish-language interviews.

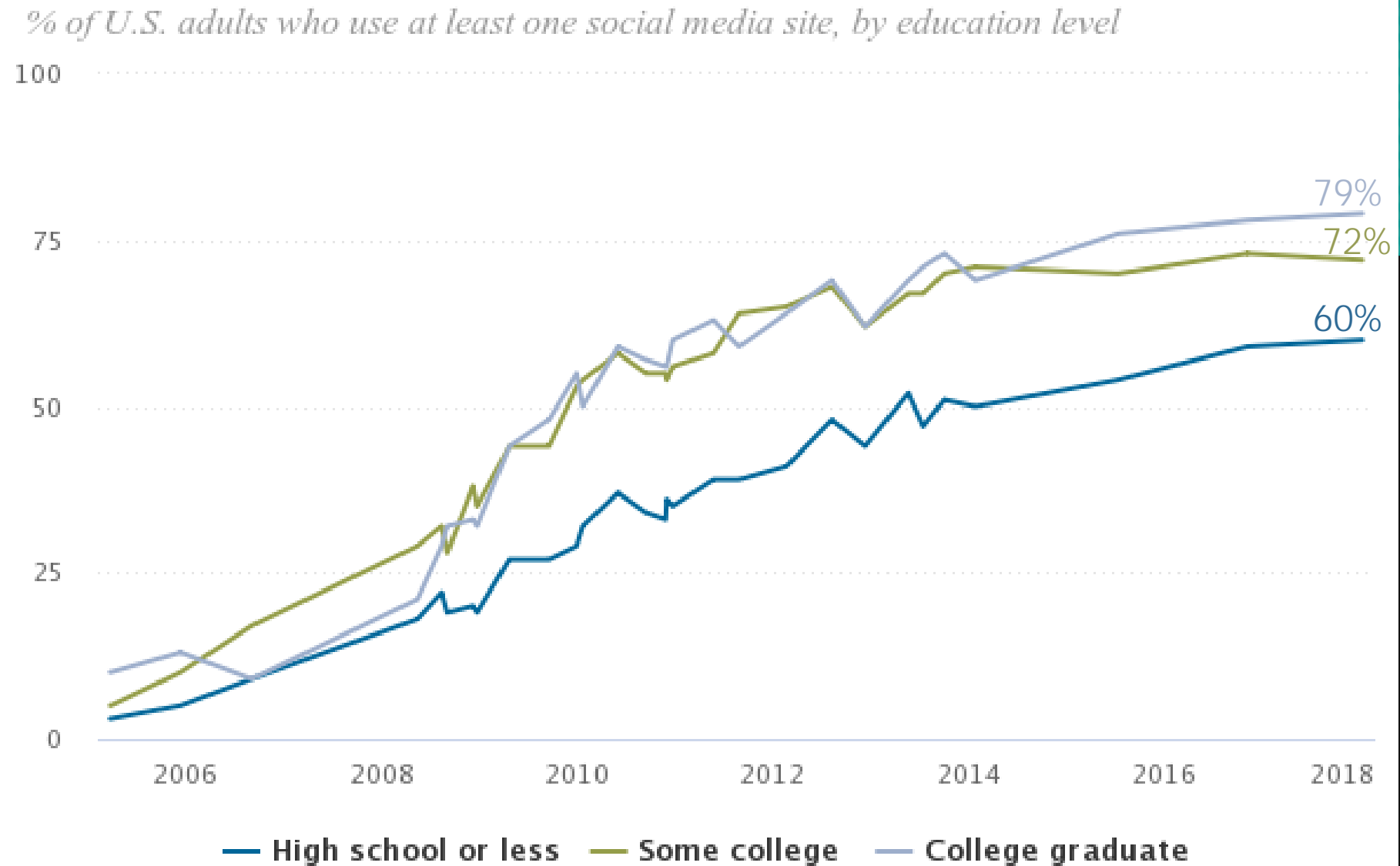
PEW RESEARCH CENTER

# By Income



Source: Surveys conducted 2005-2018.  
PEW RESEARCH CENTER

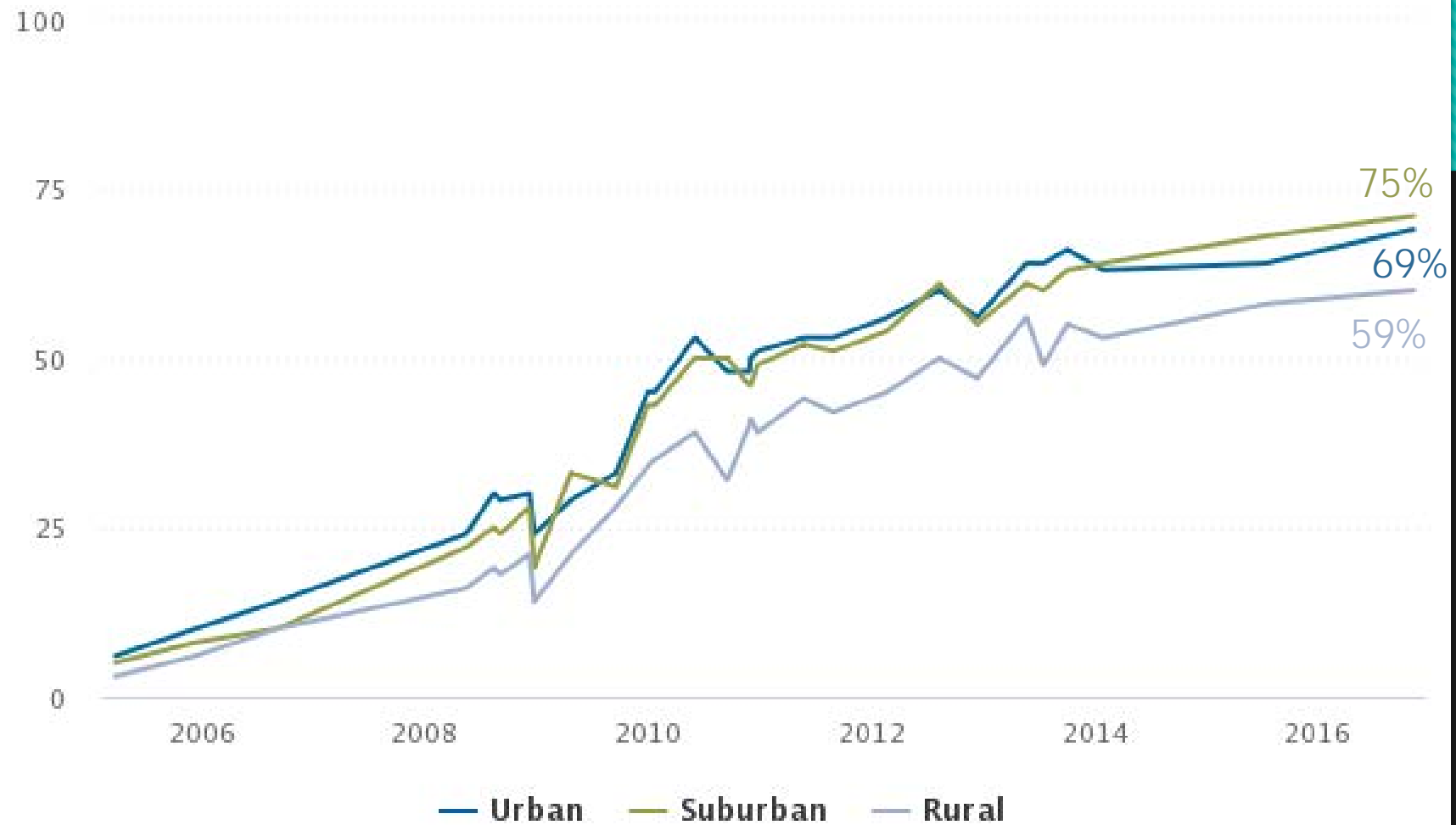
# By Education



Source: Surveys conducted 2005-2018.  
PEW RESEARCH CENTER

# By Community

*% of U.S. adults who use at least one social media site, by community type*

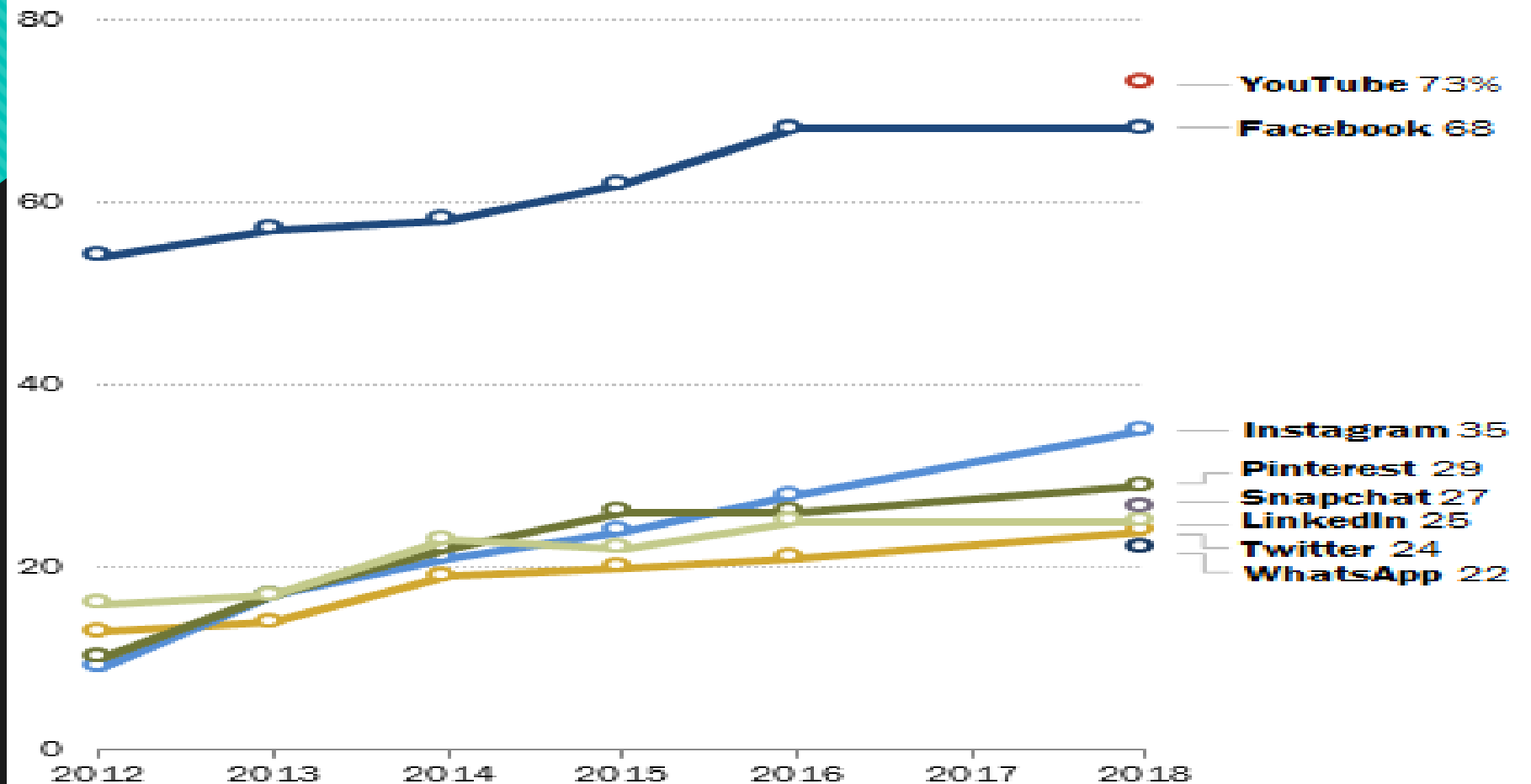


Source: Surveys conducted 2005-2016.  
PEW RESEARCH CENTER

# By Social Media Platform

## Majority of Americans now use Facebook, YouTube

% of U.S. adults who say they use the following social media sites online or on their cellphone



Note: Pre-2018 telephone poll data is not available for YouTube, Snapchat or WhatsApp.  
Source: Survey conducted Jan. 3-10, 2018. Trend data from previous Pew Research Center surveys.

"Social Media Use in 2018"

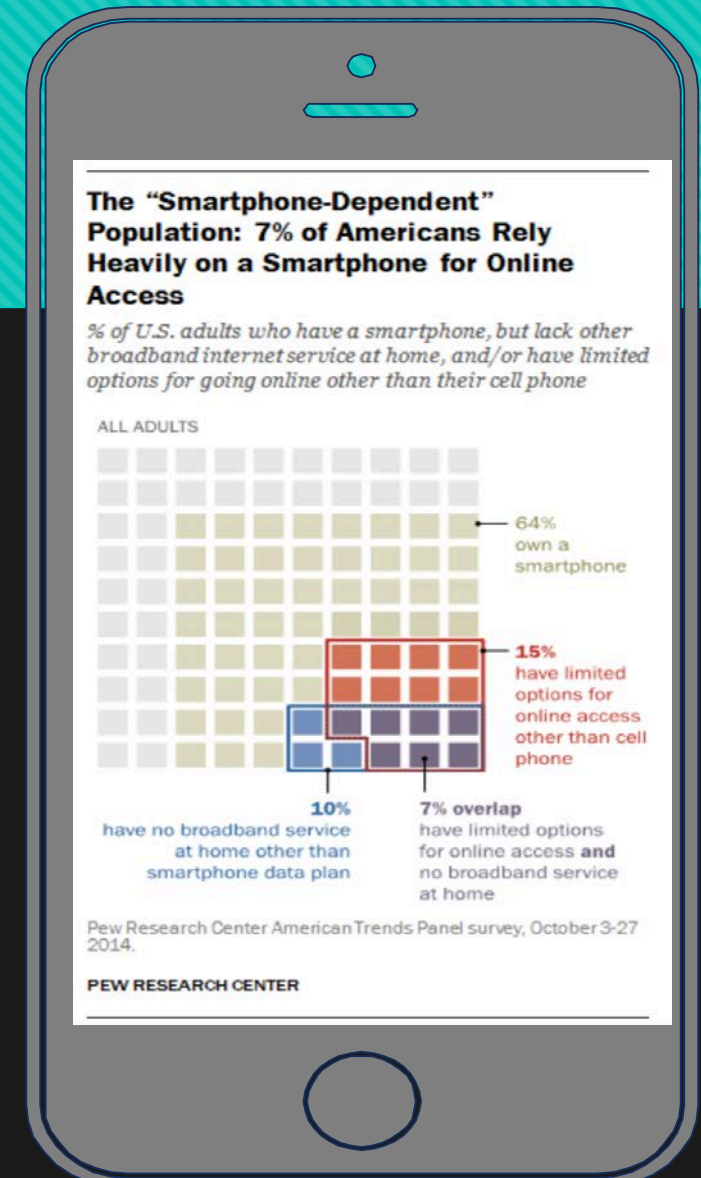
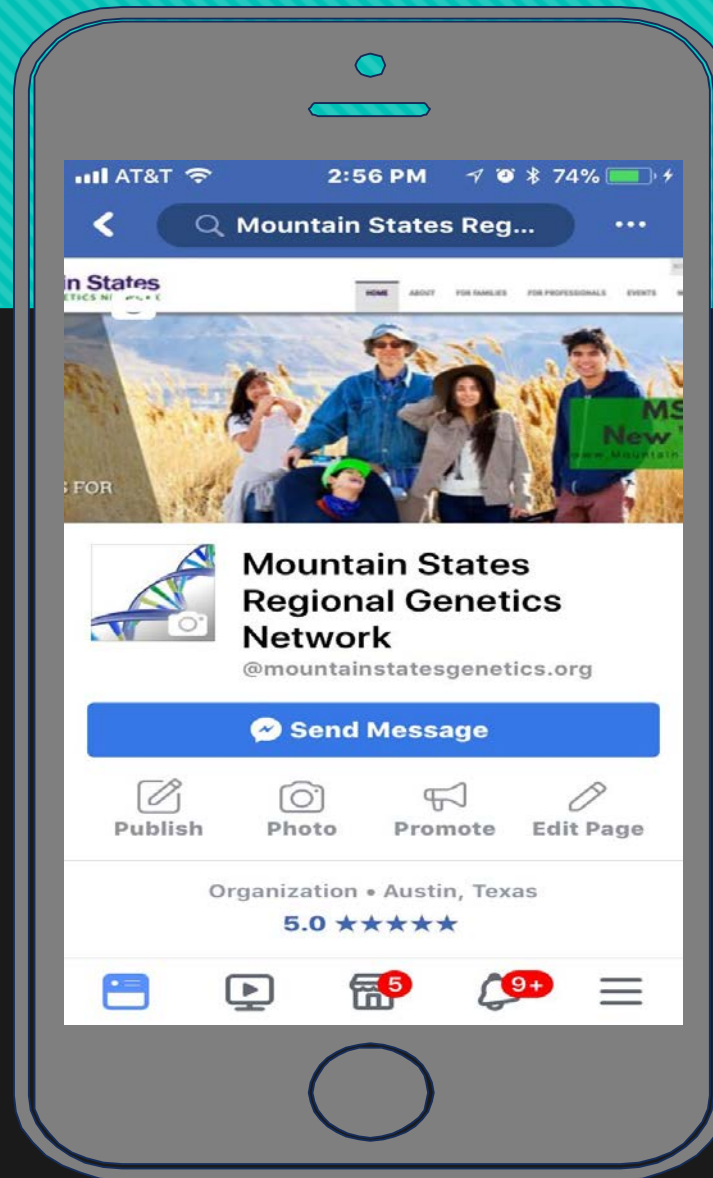
PEW RESEARCH CENTER



# Mobile friendly

UPP project revealed certain underserved populations that have access to social media through smart phones

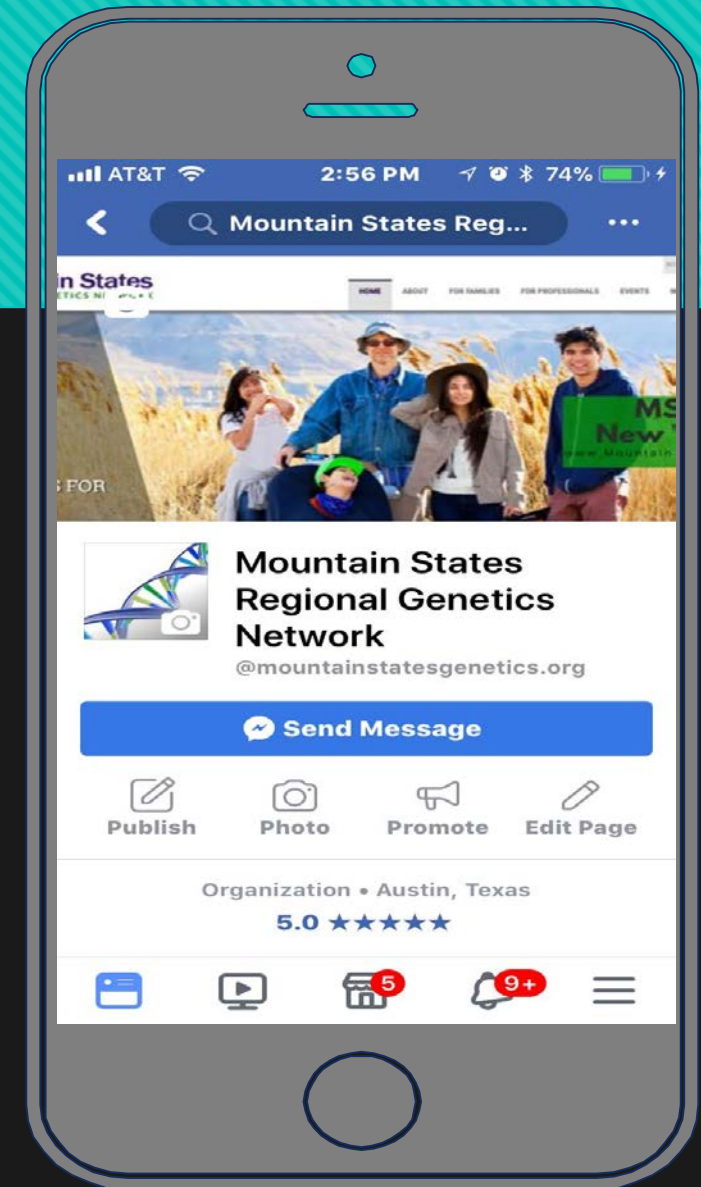
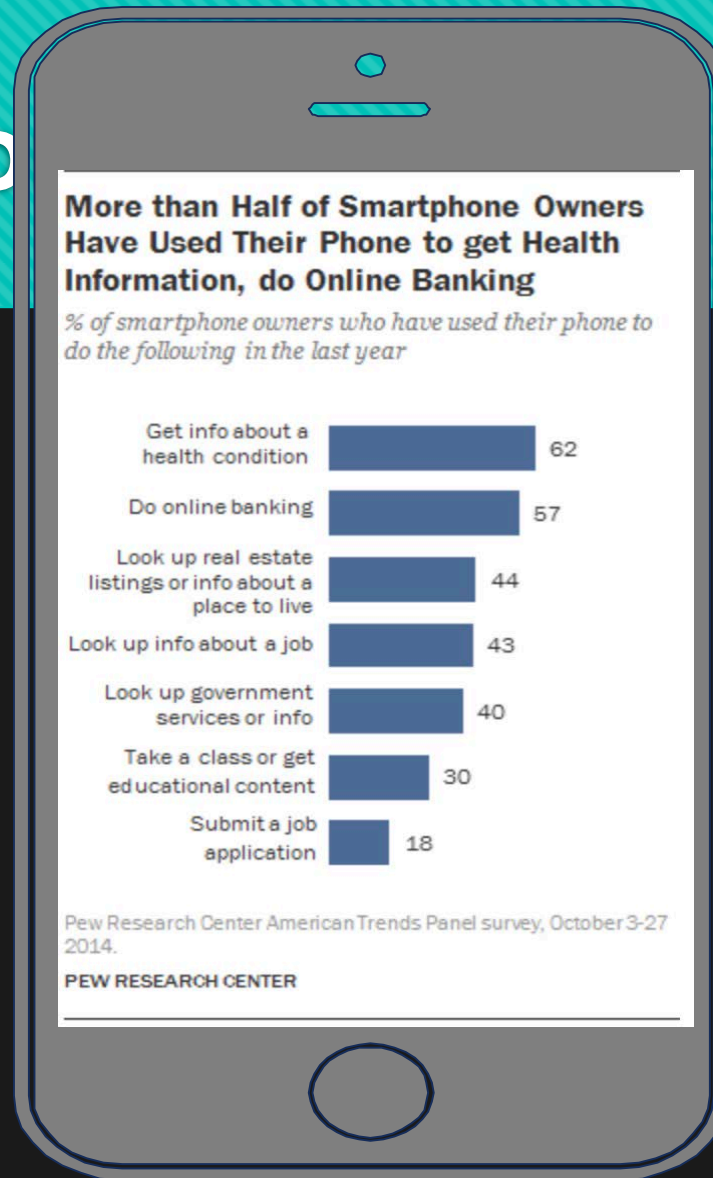
Statistics show a portion of the population rely on smartphones (don't have internet services at home).



<http://www.pewinternet.org/2015/04/01/us-smartphone-use-in-2015/>

# Health Information

- Statistics show 62% of smartphone owners have used their phone to get info about a health condition.
- Question for MSRGN, can we contribute to being a SOURCE of that information for genetics in order to engage



<https://www.pewinternet.org/2015/04/01/us-smartphone-use-in-2015/>

# Engagement- Virtual or In-person?

New Website  
Development

Consumer  
Scholarship  
for Summit

Genetic  
Ambassador  
Program  
Begins  
+SOG training  
+FB Group

Facebook  
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Texas  
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Genetic  
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2017 Family  
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Facebook  
Live- Your  
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Questions  
Answered

Genetic  
Pop-Ups

2017

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2019

2020



# Consumer Scholarships @ Genetics Summit

Giving new members an opportunity to engage with MSRGN at our 2018 Genetics Summit.



# Genetic Ambassadors + Facebook Group

A place for our families and consumers to connect, network, get involved, learn and grow in MSRGN

- Launched in November 2018
- A place for Genetic Ambassadors to connect
- A place to share MSRGN news, scholarships, updates, between calls
- Quick Response: Tagging members
- A subset of active families

# Genetic Ambassadors Facebook Group

The screenshot displays the Facebook interface for the 'Genetic Ambassadors MSRGN' group. On the left, a sidebar lists navigation options: 'Genetic Ambassadors MSRGN' (labeled as a 'Secret group'), 'About', 'Discussion' (highlighted), 'Chats', 'Members', 'Events', 'Photos', and 'Moderate Group'. Below these is a search bar and a 'Shortcuts' section with links to 'Pittsburgh 4 Choice', 'Documenting Hope', 'SUPER moms', and 'Empowered Medical ...'. The main content area features a blue header with the text 'Mountain States Regional Genetics Network'. Below this is a large banner for the 'Genetic Ambassador Program' with the website 'www.MountainStatesGenetics.org' and two green DNA double helix graphics. Under the banner are buttons for 'Joined', 'Notifications', and 'More'. The post creation area includes 'Write Post', 'Add Photo/Video', 'Live Video', and 'More' options, followed by a text input field 'Write something...'. At the bottom of the post area are buttons for 'Photo/Video', 'Watch Party', 'Tag Friends', and a menu icon. On the right side, there is an 'INVITE MEMBERS' section with a search bar, a 'MEMBERS' section showing '20 Members' with profile pictures, and a 'SUGGESTED MEMBERS' section with a 'Hide' button.

Genetic Ambassadors MSRGN  
Secret group

About  
Discussion  
Chats  
Members  
Events  
Photos  
Moderate Group

Search this group

Shortcuts

- Pittsburgh 4 Choice
- Documenting Hope
- SUPER moms
- Empowered Medical ...

Mountain States Regional Genetics Network

Genetic Ambassador Program  
www.MountainStatesGenetics.org

Joined Notifications More

Write Post Add Photo/Video Live Video More

Write something...

Photo/Video Watch Party Tag Friends

INVITE MEMBERS  
+ Enter name or email address...

MEMBERS  
20 Members

SUGGESTED MEMBERS  
Hide

# Engagement- Virtual or In-person?

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# Facebook Live: Your Genetic Questions Answered

A way to increase consumer engagement through genetics education to families and answer some of their top questions

- Launched in January 2019
- Once a month on the Mountain States Regional Genetics Network Facebook Page
- Based on a consumer FB survey done in the fall of 2018
- Answers recorded using zoom with subject matter experts and then played through FB live.
- Think about what education you can deliver through FB LIVE

# Facebook LIVE

## Example:

### Autism & Genetics



**Join Us... April 24th**  
*Autism Awareness Month*  
April 24th : 3 Questions and 3 Facebook Lives:  
7/8/9pm ET, 6/7/8pm CT, 5/6/7pm MT, 4/5/6pm PT  
on the Mountain States Genetics Facebook Page

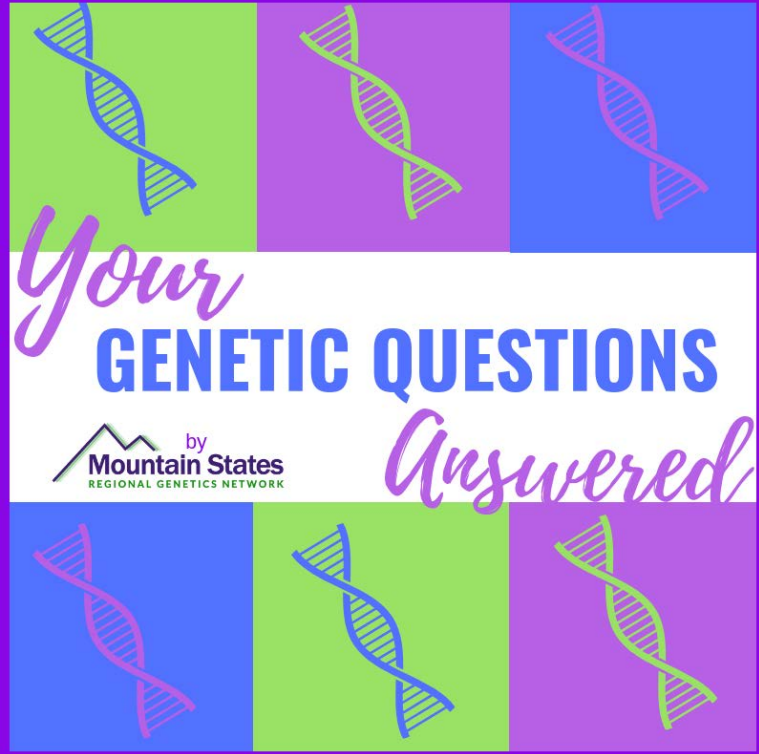
Dr. Scott  
Answers  
3 Common  
Questions  
about  
#Genetics  
and #Autism  
on Facebook Live



*Your Questions Answered about...*  
**GENETICS AND AUTISM**  
by Mountain States  
REGIONAL GENETICS NETWORK



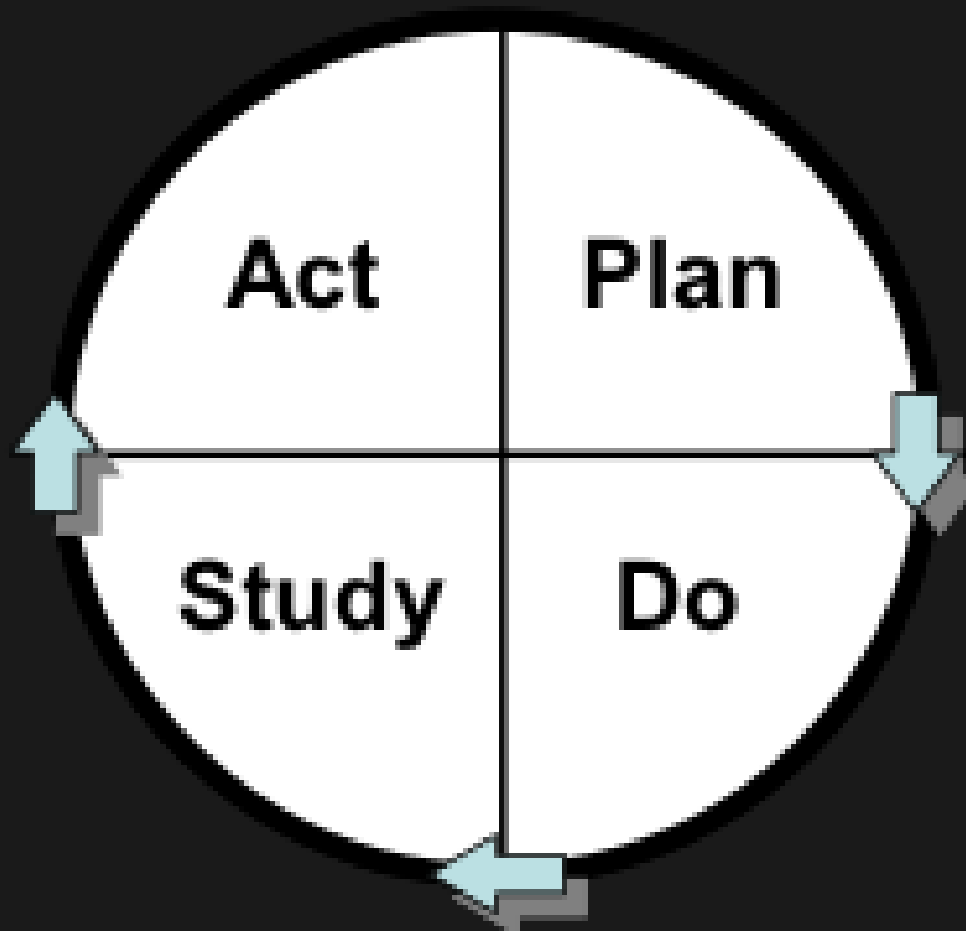
*Dr. Daryl Scott*  
Associate Professor  
Molecular and Human Genetics  
Baylor College of Medicine



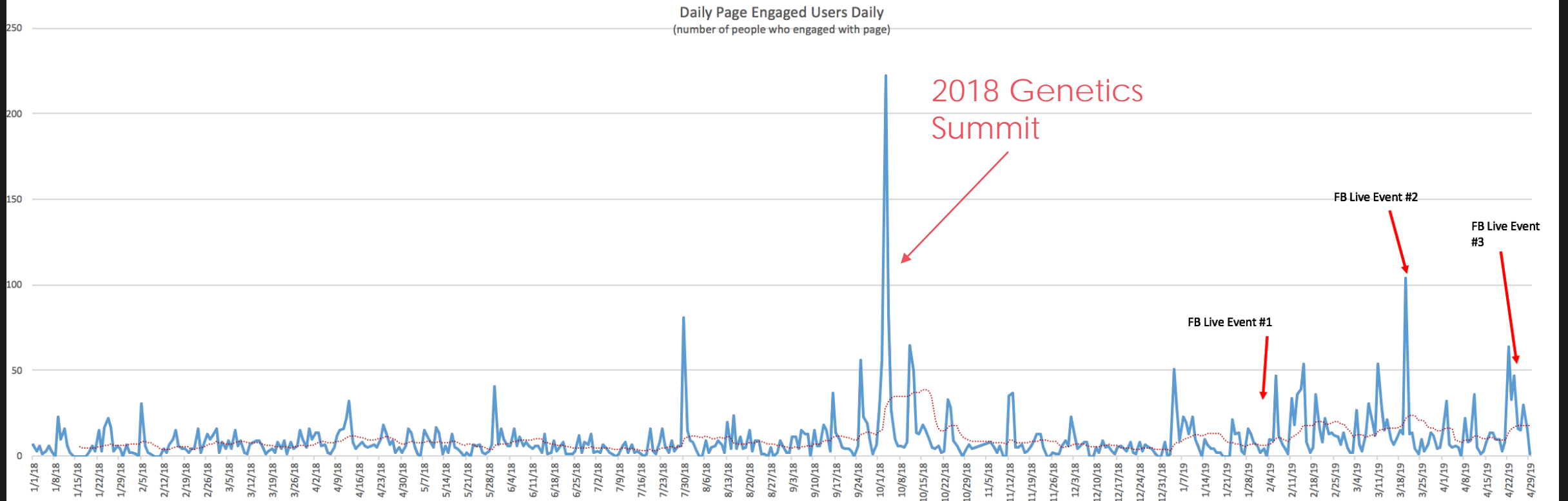
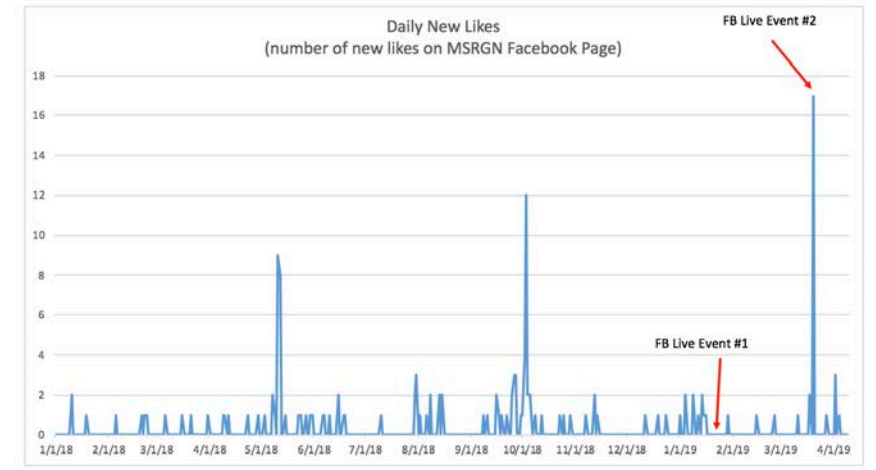
*Your*  
**GENETIC QUESTIONS**  
*Answered*  
by Mountain States  
REGIONAL GENETICS NETWORK

<https://www.youtube.com/watch?v=sgFNCGFts-o>

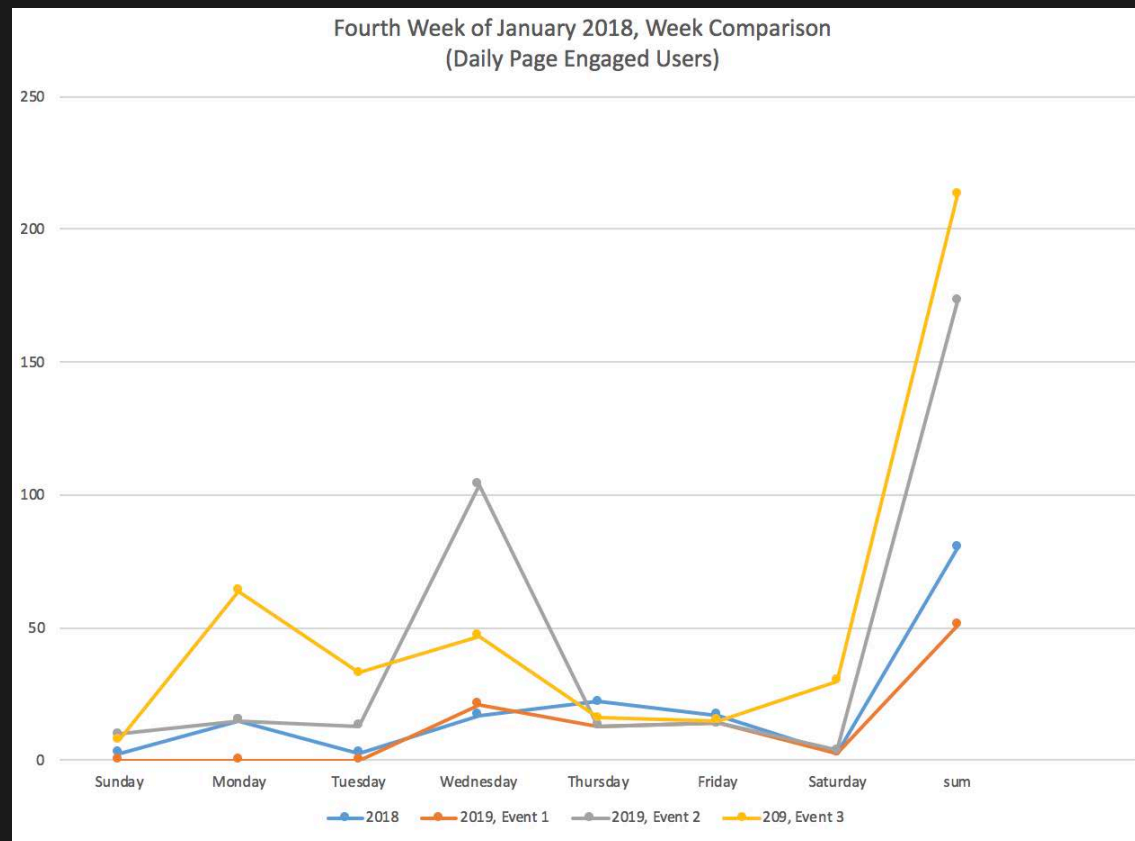
# Facebook LIVE- A QI Project



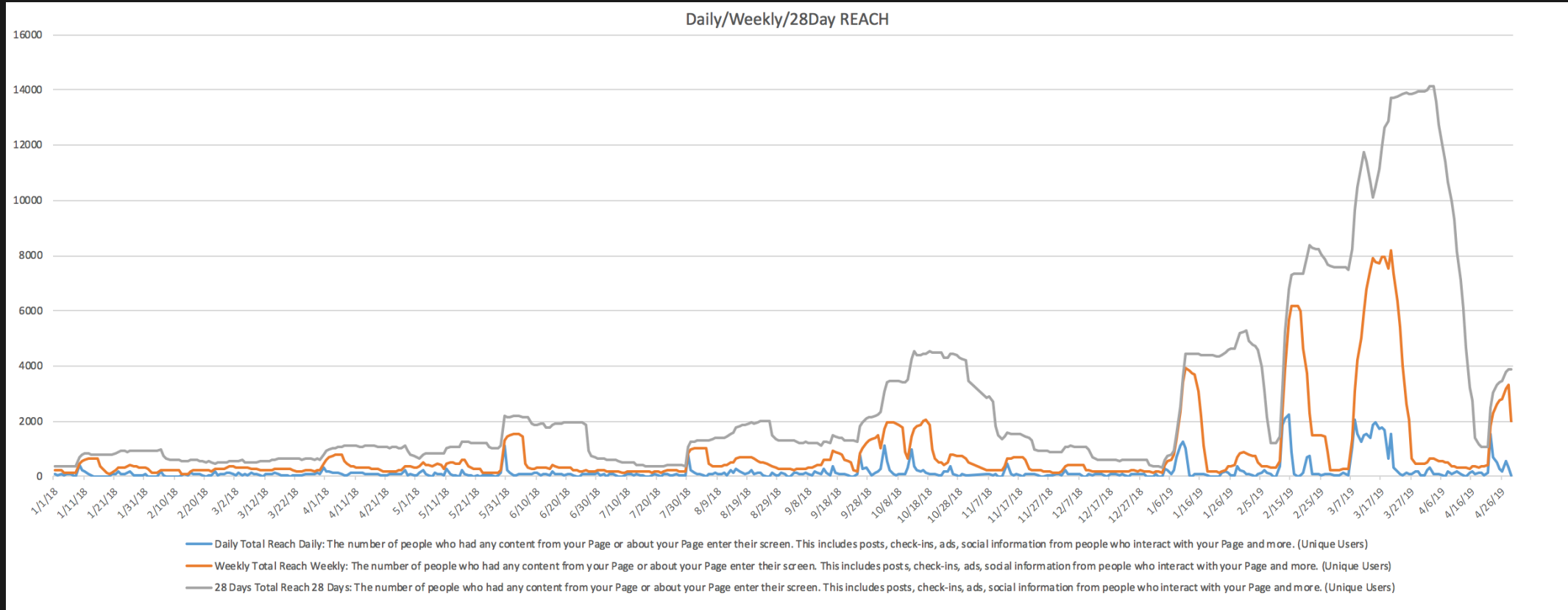
# Facebook LIVE- DATA



# Facebook LIVE- DATA



# Facebook LIVE- DATA



# Engagement- Virtual or In-person?

New Website  
Development

Consumer  
Scholarship  
for Summit

Genetic  
Ambassador  
Program  
Begins  
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# Facebook Advertising in order to reach a specific audience


An Example from our Texas Team, who wanted to reach parents in Texas with Genetic resources

- Led by our Texas team to outreach to parents in their state with resources
- \$5/day
- \$200 budget
- 3 ads
- Reach= 18,000
- Impressions= almost 40,000
- Link Clicks= approx. 200
- \$1/link click

# Facebook Advertising



**Mountain States Regional Genetics Network**  
Sponsored · 

Raising a child with a genetic condition can be an amazing yet, sometimes challenging experience. To find genetic resources in [#Texas](#) to help make your journey a bit easier, click below.




[WWW.MOUNTAINSTATESGENETICS.COM](http://WWW.MOUNTAINSTATESGENETICS.COM)  
**Genetics Resources in Texas**

[LEARN MORE](#)

**Mountain States Regional Genetics Network**  
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[MOUNTAINSTATESGENETICS.COM](http://MOUNTAINSTATESGENETICS.COM)  
**Genetic Resources in Texas**  
Resources for Families in Texas

[LEARN MORE](#)



# In-Person Engagement: Genetics Pop-Up

The “old fashion” way or the wave of the future?

# Engagement- Virtual or In-person?

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# Genetics Pop-Ups

A way to engage families at a community level

*Are you curious about #Genetics?  
Come and Learn about  
Genetics Resources for families in Colorado!*

Join Us for ...

*A Genetics Pop-Up*

  
MOUNTAIN STATES REGIONAL GENETICS NETWORK

*Free Event!  
Snacks and Drinks!*

May 5, 2019 from 1pm- 4pm  
7400 Quincy Ave.  
Littleton, CO 80123

*For more info:  
jnstefanski@gmail.com*



# *What is a Genetic Pop-Up?*

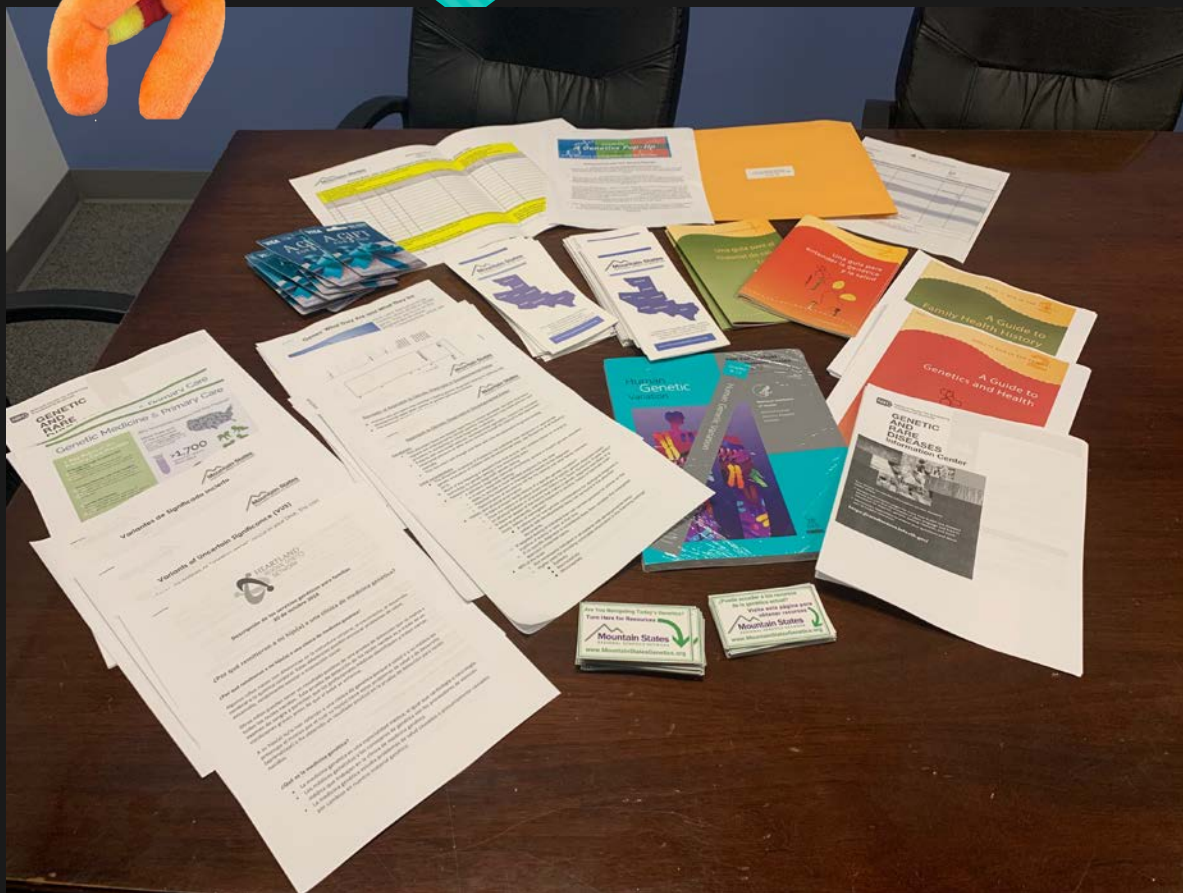


MOUNTAIN STATES REGIONAL GENETICS NETWORK

- ❖ **A Genetics Pop-up** is a small (5-8 person) gathering, held in the local community, spearheaded by a genetic ambassador, to share genetic resources with families and those who work with families impacted by genetics.
- ❖ MSRGN sends a Gene-in-a-Box resource kit
- ❖ MSRGN provides a \$300 budget to cover a \$20 stipend/gift card per attendee, and the remainder of the budget may be used for food/drink (no alcohol!) at the pop-up!



# Gene-in-a-Box

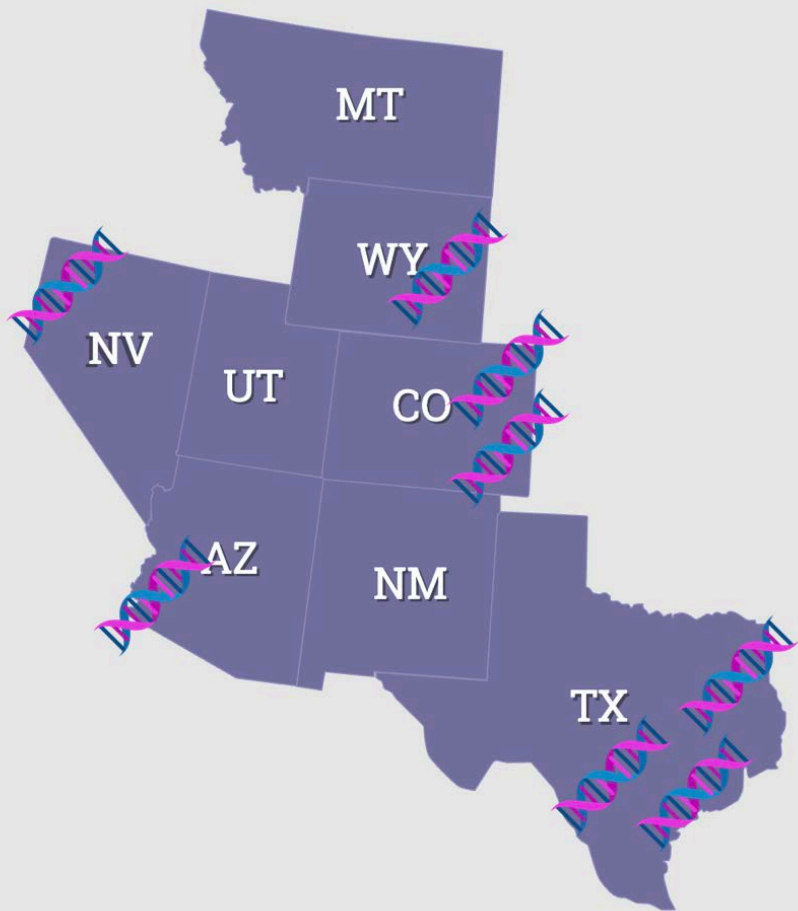




# Our First Genetics Pop-Up: Texas Sickle Cell



# Do you want to get involved: Genetics POP-UP?



- Houston, TX  
(date of popup 4/27/19)
- Edgewater, CO  
(date of popup: 5/4/19)
- Littleton, CO  
(date of popup 5/5/19)
- Yuma, AZ  
(date of popup:  
week of May 13)
- Dallas Area, TX  
(week of 5/20)
- Reno, NV  
(date of popup:  
5/23/19)
- Austin, TX  
(date not set yet)
- Sheridan, WY  
(date not set yet)

# Wrapping Up

- Consumer engagement cannot be ONE SIZE FITS ALL... a HYBRID approach has worked for our organization
- Virtual and In-person engagement COMPLEMENT one another and can be used to ENHANCE one another
- Using different modes of engagement- videos, pop-ups, scholarships, facebook lives, online groups, and even advertising can help you reach your audience.

# Questions and a Challenges

- Questions?
- Challenge: Connect with your Regional Genetics Network
- Challenge: Try a Facebook Live for your organization
- Challenge: Are you near a genetic pop-up site?



Questions?

My Contact Info

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- [www.MountainStatesGenetics.org](http://www.MountainStatesGenetics.org)
- 281-831-3481