



Improving Access to Quality Medical Care Webinar Series

Presented by

The UArizona Health Sciences Genetic
Counseling Graduate Program, the
Southwest Telehealth Resource Center, &
Arizona Telemedicine Program

Welcome

- SWTRC region - AZ, UT, CO, NM & NV
- Fellow HRSA Grantees
- All other participants from the US & abroad



The University of Arizona Health Sciences Genetic Counseling Graduate Program, the Arizona Telemedicine Program, and Southwest Telehealth Resource Center welcome you to this free webinar series!

The series will discuss the the use of telegenetics to improve access to genetics services for patients & providers.

Telemedicine can help you achieve these goals!

Webinar Tips & Notes

- When you joined the webinar your phone &/or computer microphone was muted
- Time is reserved at the end for Q&A
- Please use the **Chat function** to ask questions
- Please complete the post-webinar survey
- Webinar is being recorded
- Recordings will be posted on the ATP website
 - <http://telemedicine.arizona.edu/webinars/previous>





Applications of Telegenetic Counseling in Research and the Clinic

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Applications of Telegenetic Counseling in Research and the Clinic

Valerie Schaibley, PhD

Arizona Telemedicine Program Webinar Series on Telegenetics

January 9, 2020

Conflict of Interest

- None to disclose.

Learning Objectives

1. Define how a telegenetics program can be incorporated into clinical practice.
2. Discuss the use of telegenetics to return research results.
3. Describe the integration of education into a telegenetics program.

Webinar Outline

- Access to genetic services – where are we now?
- Using telegenetics to expand clinical service
- Using telegenetics to return research results
- Using telegenetics to support educational programs



What is clinical genetics?

- Medical specialty that provides diagnostic and counseling for individuals or families with or at risk of conditions with a genetic basis
- Examples of genetic conditions:
 - Chromosomal abnormalities (i.e. Down syndrome)
 - Single gene disorders (i.e. cystic fibrosis)
 - Inherited cancer syndromes (i.e. breast cancer associated with BRCA1/2 variants)
 - Inherited cardiovascular conditions (i.e. familial hypercholesterolemia)

Barriers to Accessing Clinical Genetics

- Lack of healthcare providers in genetics
- Distance to care
- Lack of recognition among primary care providers about the need for referral to genetics clinics
- Poor insurance coverage
- Misconceptions about genetics services

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Genetics Health Care Providers

- Clinical geneticists
- Genetic counselors
- Genetics nurses
 - “A genetics nurse is a licensed professional nurse with special education and training in genetics.” *International Society of Nurses in Genetics*
- Other healthcare providers
 - Nutritionists
 - Physician assistants

Who are clinical geneticists?

“Clinical geneticists are **physicians** who care for patients in **clinical settings** and often carry out clinical or translational research related to patient care. They hold **American Board of Medical Genetics and Genomics (ABMGG) certification** in the specialty of **clinical genetics and genomics** and have **broad training** in the evaluation, diagnosis, management and treatment of **inherited conditions in patients across all ages** from birth to adulthood.”

American College of Medical Genetics



Lack of Clinical Geneticists

- In the US, there are about **1,600 medical geneticists** (ABMGG Statistics)
- Nationwide, there are only about **0.2 practicing clinical geneticists per 100,000** people (Maiese et al., 2015)
- A 2015 study found over **100 open positions** for clinical geneticists (Maiese et al., 2015)

Lack of Clinical Geneticists

State	Population (US Census Bureau, 2018)	Clinical Geneticists (ABMGG, 2018)*	Clinical Geneticists per 100,000
Arizona	7,171,646	13	0.18
Minnesota	5,611,179	30	0.53
Washington	7,535,591	46	0.61
Virginia	8,517,685	26	0.31
North Carolina	10,383,620	36	0.35

*Likely overestimates of the number of *practicing* clinical geneticists.

Lack of Provider Stream in Clinical Genetics

NRMP Match Rates for Pediatrics-Medical Genetics

Year	Positions Offered	Positions Filled	%
2019	21	16	76%
2018	20	18	90%
2017	15	13	87%
2016	14	14	100%
2015	15	15	100%

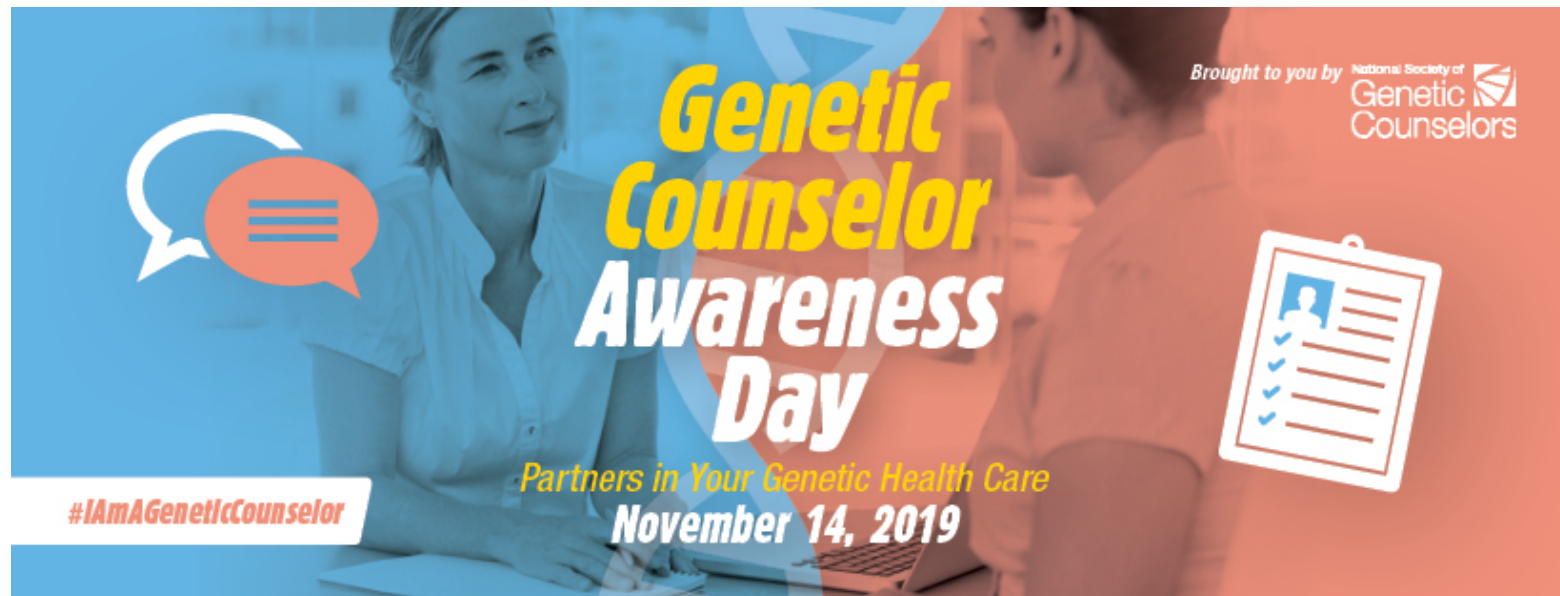
NRMP Match Rates for Medicine-Medical Genetics

Year	Positions Offered	Positions Filled	%
2019	3	1	33%
2018	1	1	100%
2017	2	1	50%
2016	1	0	0%
2015	4	4	100%

Who are genetic counselors?

“Genetic counselors are professionals who have **specialized education in genetics and counseling** to provide **personalized help** patients may need as they **make decisions about their genetic health.**”

National Society of Genetic Counselors



Who are genetic counselors?

- Board certification by the American Board of Genetic Counseling (ABGC)
- Trained medical professionals
- Deliver pre and post test counseling
- Work with the healthcare team to identify appropriate testing
- Work in a variety of specialized areas of medicine (prenatal, pediatrics, adult, cancer, etc)



Increasing Numbers of Genetic Counselors

- Currently over 5,000 certified genetic counselors
- Increase of 68% over the number of certified genetic counselors in 2009
- Over 570 positions posted on the NSGC job board
- Job growth expected to grow 27% from 2018 – 2028 (Bureau of Labor Statistics)



Barriers to Accessing Clinical Genetics

- Lack of healthcare providers in genetics
- **Distance to care**
- Lack of recognition among primary care providers about the need for referral to genetics clinics
- Poor insurance coverage
- Misconceptions about genetics services

Travel Time is a Barrier to Genetics Services

- Many patients with positive genetic tests need to travel significant distances to meet with a genetic counselor.
- This situation is even worse in more specialized areas of genetic counseling, such as cardiovascular genetics.

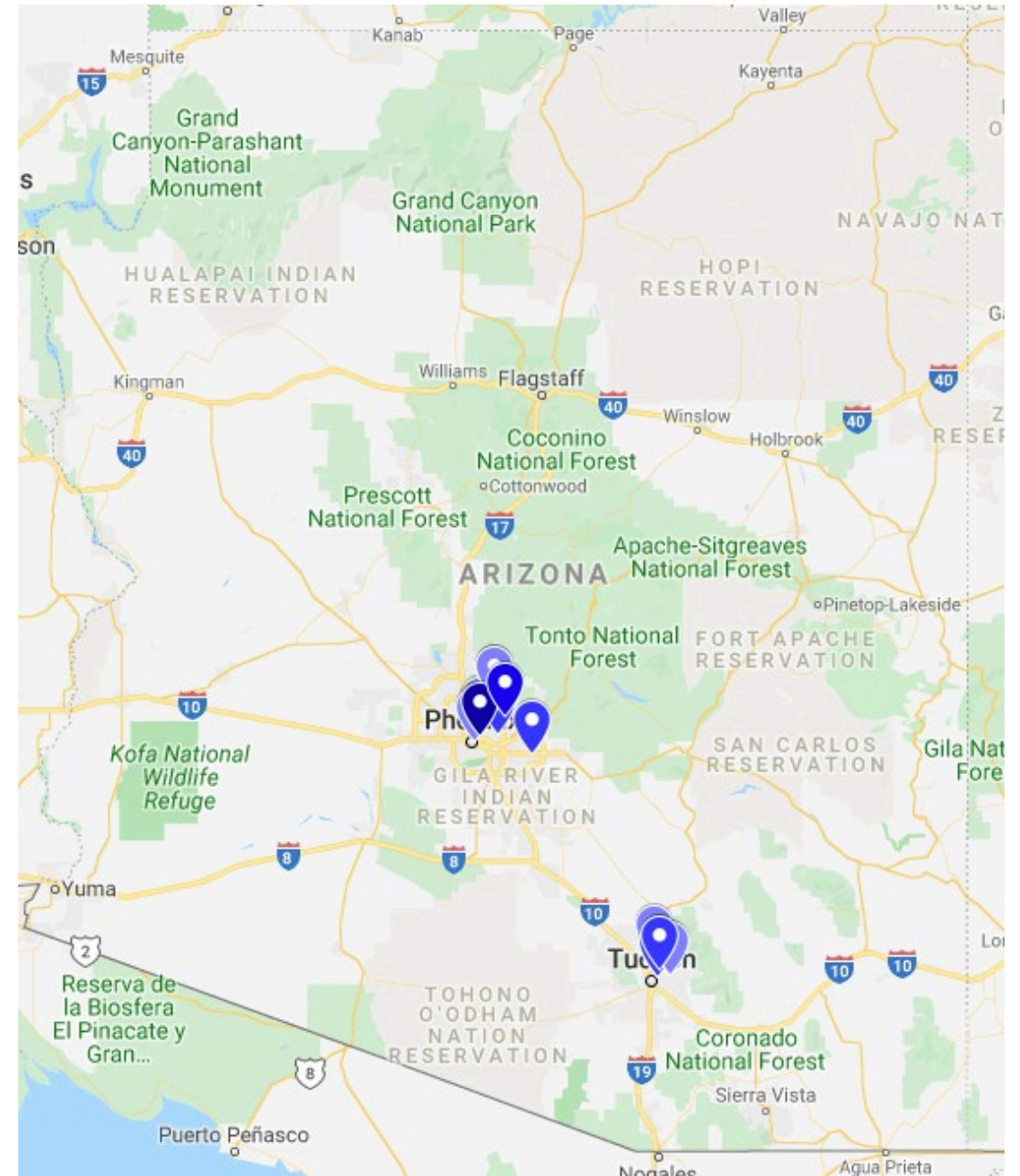


Travel Time is a Barrier to Genetics Services

- Study performed by Color Genetics, a genetic counseling company offering telegenetic counseling:
 - Analyzed distance from a genetic counselor for >4,000 individuals with a positive cancer or cardiovascular genetic test
 - Customers with a positive genetic test for cancer predisposition
 - N=3,987, 50 states
 - Average distance from a cancer genetic counselor: 28.3 miles
 - Customers with a positive genetic test for a cardiovascular condition
 - N=194, 35 states
 - Average distance from a cardiovascular genetic counselor: 49.7 miles

Location of Clinical Geneticists and Genetic Counselors in Arizona

- All clinical genetic counselors, medical geneticists and genetics nurses are in Tucson or Phoenix
- Nogales – 66 miles
- Sierra Vista – 76 miles
- Flagstaff – 145 miles
- Yuma – 185 miles
- Page – 273 miles



How can telegenetics help?

- Decrease travel time for patients and providers
- Increase access to services, especially those in rural and traditionally underserved areas



"You can't list your iPhone as your primary-care physician."

<https://www.newyorker.com/cartoon/a19128>

What is telemedicine?

“Telemedicine is the use of telecommunications technology to provide health care services to patients who are geographically separated from a physician or other health care providers.”

Arizona Telemedicine Program



What is telegenetics?

“Telegenetics allows comprehensive genetics services to reach children and families when **travel, distance, and shortage of genetics professionals interfere with access**. By utilizing interactive video and a secure high-speed connection, genetic counselors can “virtually meet” with a patient at a regional clinic or hospital in real time.”

National Society of Genetic Counselors

TELEGENETICS

THE USE OF TELEMEDICINE/TELEHEALTH
MODALITIES TO PROVIDE GENETIC SERVICES

15.8%*

OF GENETICISTS
REPORTED USE OF
TELEGENETICS

Barriers to Accessing Clinical Genetics

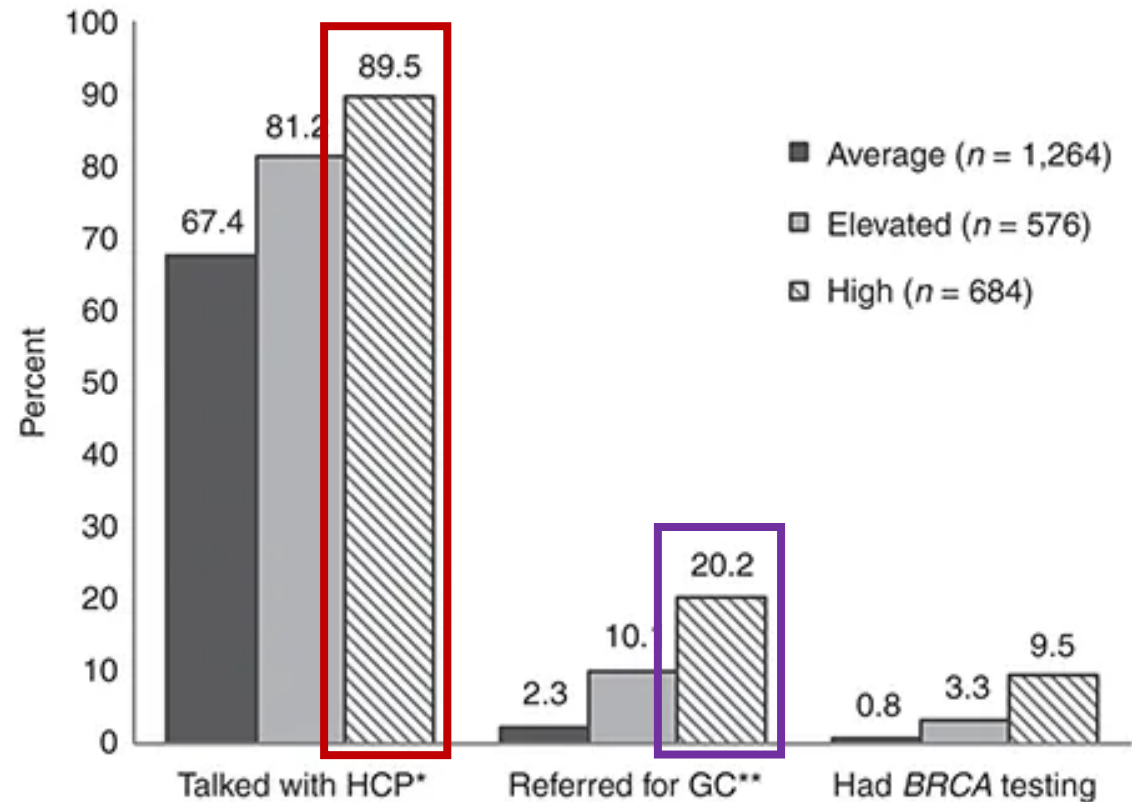
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Referrals to Genetic Counselors

Referring Physician Specialty	Number of Genetic Counselors with Referrals from Specialty Physician	% of Respondents
Ob/Gyn	961	68.4%
Patient (self-referral)	925	65.8%
Primary Care	865	61.6%
Medical Genetics/Other GC	674	48.0%
Oncology	588	41.9%

Underutilization of Genetic Counseling

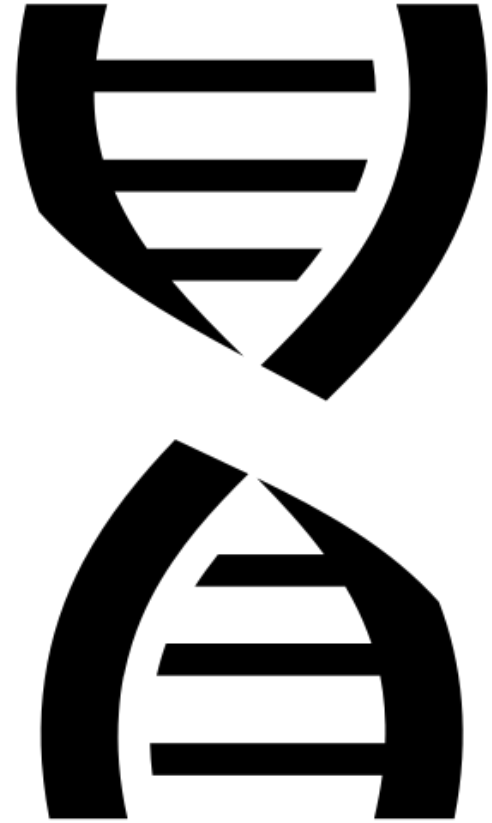
- Study interviewed 2,524 women, stratifying their risk of ovarian cancer based on family history
- **89.5%** of women with high risk for ovarian cancer talked to their healthcare provider about their family history
- Only about **20%** of women with high risk of ovarian cancer reported being referred to genetic counseling



Telegentics Can Expand Genetics Care to Additional Settings

“The use of technology in a healthcare setting *can allow a patient, without local access to geneticist, to receive a genetics assessment* and it can allow a primary care provider to contact a genetics provider to become better equipped to provide care to an individual with a complex genetic disorder.”

<https://nccrcg.org/focus-areas/telegenetics/>



Room to Grow Clinical Telegenetics, Especially in Arizona

- Less than 17% of genetics healthcare reported using telemedicine in clinic (Maiese et al., 2015)
- Several companies operate clinical genetic counseling services nationwide, including Arizona
- Few *health systems* offering clinical genetic counseling services via telemedicine in Arizona

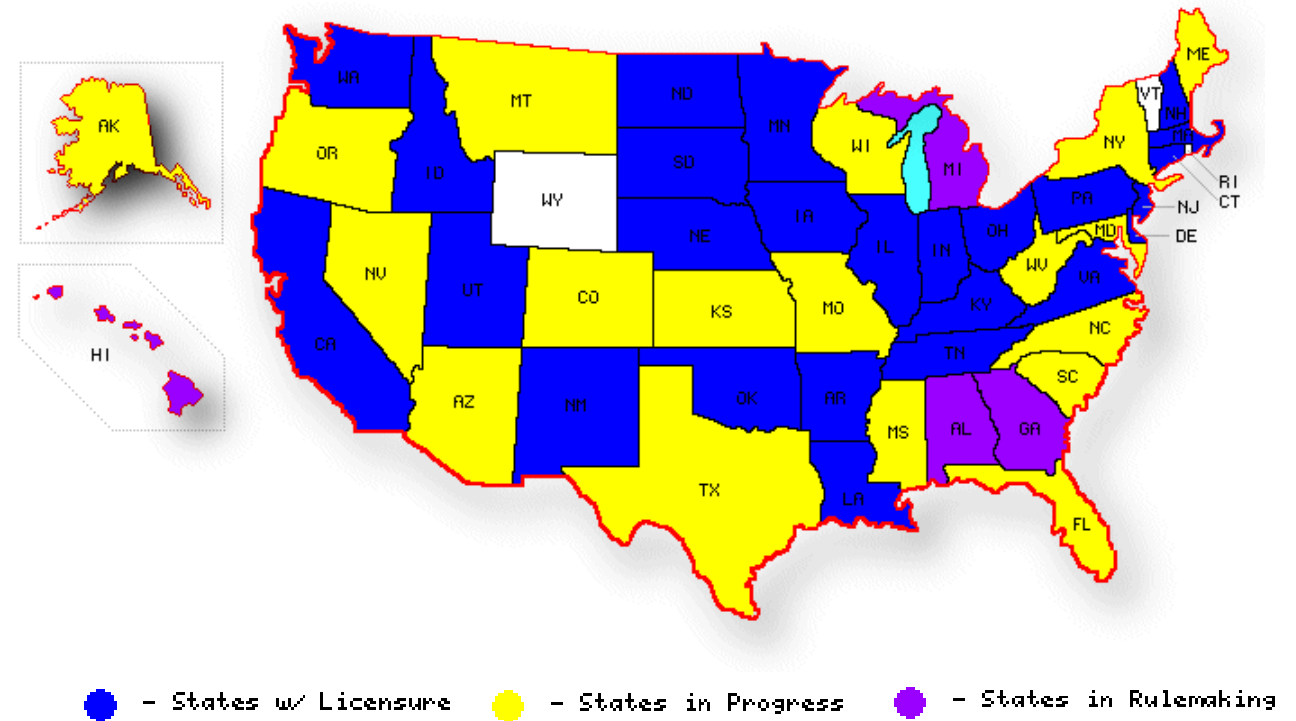
Benefits to Starting with Telegenetic Counseling

- Setting up telegenetic counseling services can be a good way to start a telegenetics service
 - No physical exam necessary
 - No need for advanced telemedicine equipment beyond computer, webcam, phone system, good internet connection
 - Many genetic counseling sessions can take place with the patient in their home, further expanding access to services
- One study showed >80% of genetic counselors have used telemedicine in some capacity (Zierhut et al., 2018)
- Once established, programs can expand to include physician and other healthcare provider appointments

Challenges to Starting with Telegenetic Counseling

- Billing for genetic counseling services is complex and inconsistent
- Genetic counselors are not currently recognized as healthcare providers under Medicare/Medicaid
- Incomplete licensure across states further complicates reimbursement
- Need for multiple licenses depending on patient location

States Issuing Licenses for Genetic Counselors



Billing for Genetic Counseling Services

- Overall, 57% of genetic counselors providing direct patient care bill for services
- Typically, in-person genetic counselors bill under:
 - Incident to physician/in supervising MD name only
 - Facility fees
 - Their own name
- Telephone and web-based/video genetic counseling sessions are less likely to be billed than in-person genetic counseling



Billing for Telegenetics

- Fee for Service Model
 - Most common method for billing
 - Bill insurance companies for clinical geneticist or genetic counseling visit
- Contracted Service Model
 - Negotiate a contract to provide Telegenetics services to either a hospital or physician group
 - Payment received either per patient encounter, per clinic session, etc
- Direct-to-consumer Model
 - Patients billed directly for services



Webinar Outline

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- Incorporating Telegenetics into clinical practice
- Using telegenetics to return research results
- Using telegenetics to support educational programs



Population Health Research Studies with a Genetics Twist

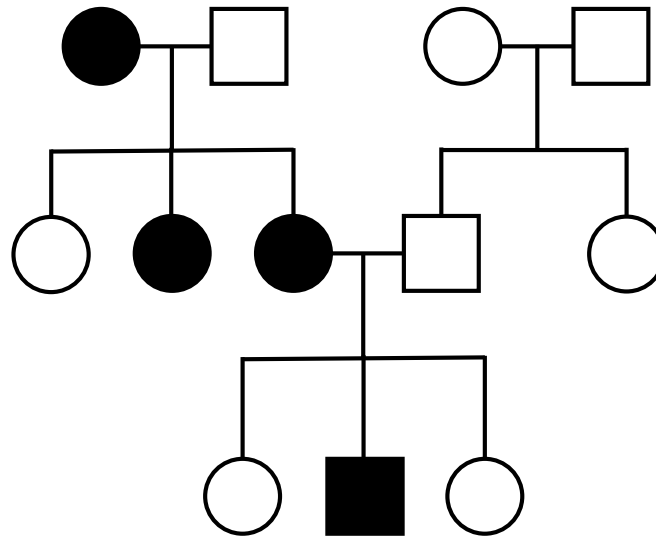


Large-Scale Studies are Returning Genetic Information

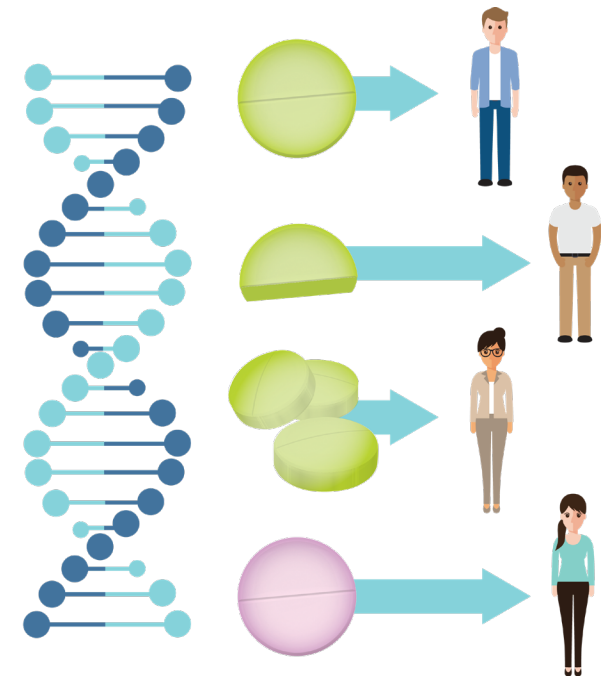
Genetic Ancestry and Traits



Medically Actionable Conditions

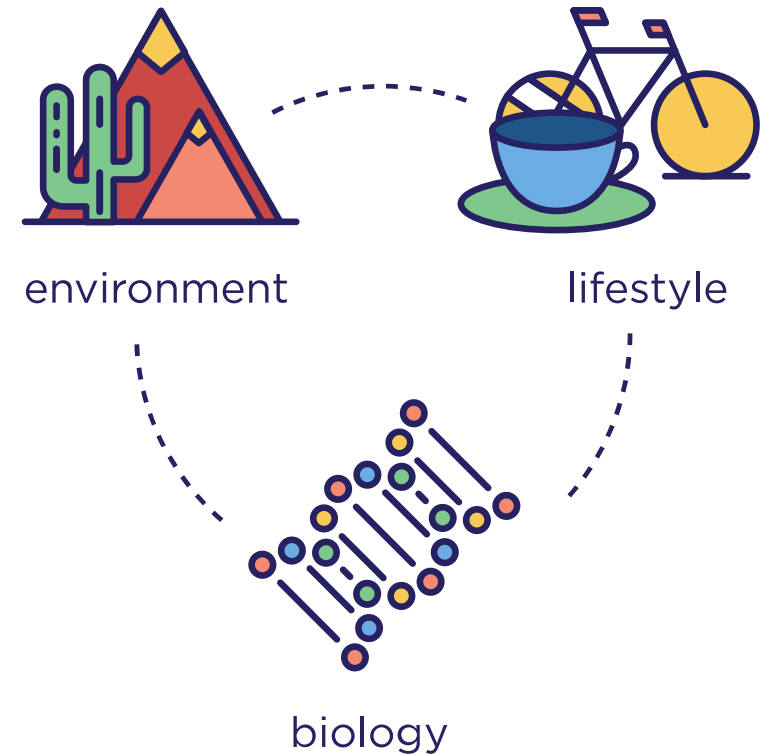


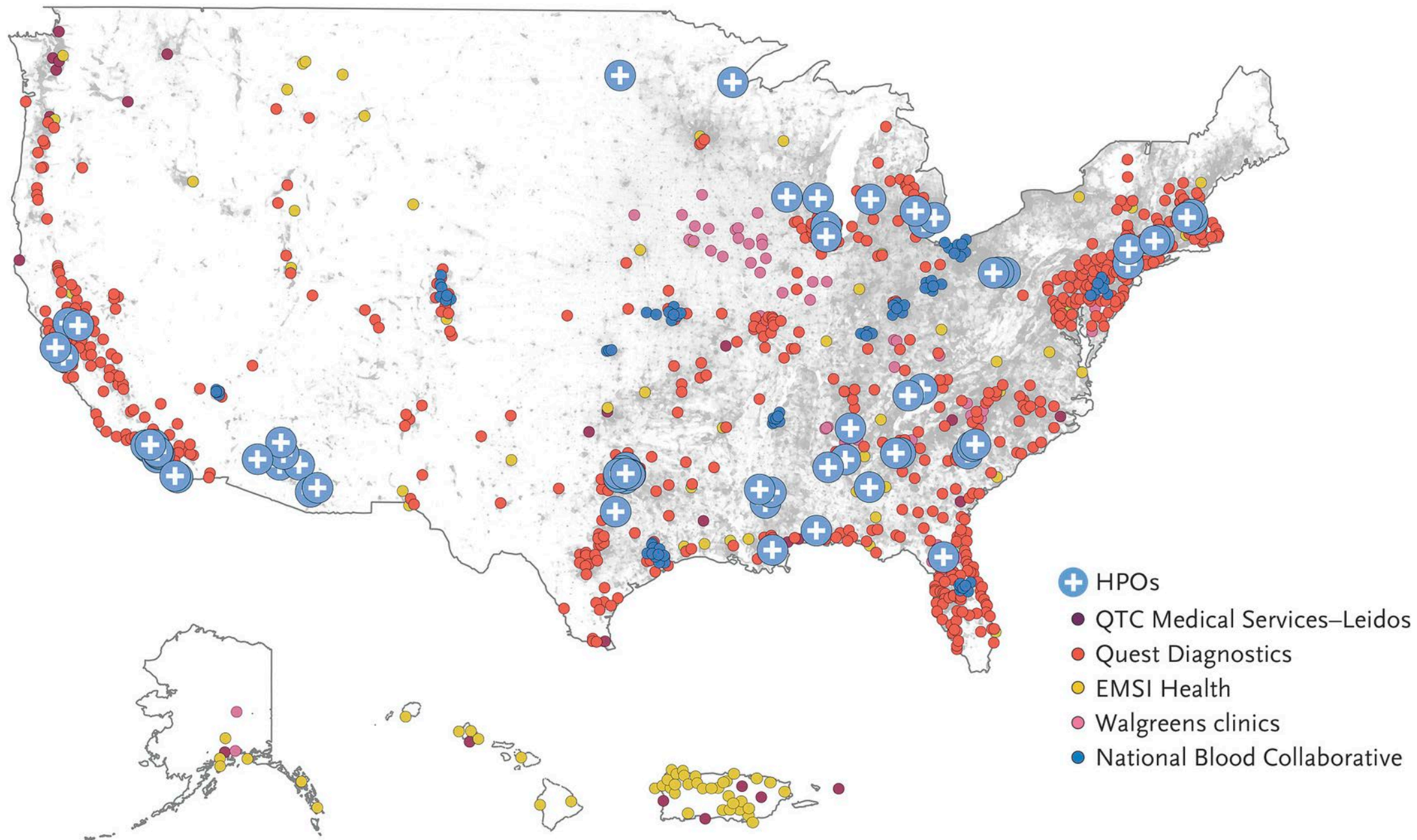
Pharmacogenomics



All of Us Research Program

- Large-scale biobank project led by the NIH
- Goal is to understand the contribution of environment, lifestyle and biology on disease
- Enrolling over 1 million research participants, focused on participants from traditionally underrepresented populations in biomedical research
- Working with participants to collect:
 - Electronic Health Record data
 - Basic physical measurements: BMI, height, BP, etc.
 - Survey information: basic information, family history, mental health, environmental information, etc.
 - Biospecimens: blood and urine
- Participants as Partners





Returning Genomic Information in *All of Us*

- Participants who consent to participate in genomics research will have their DNA sample genotyped
- Participants who consent to receiving their genomic Information will likely get the following information:
 - Genetic trait and ancestry information
 - Genetic variants from 59 genes associated with increased risk of cancer, cardiovascular disease
 - Established guidelines for treatment or prevention of these conditions
 - Pharmacogenomic information

Returning Genomic Information in *All of Us*

- Free telegenetic counseling support to discuss
 - Risks for the individual and family members
 - Guidelines for management
 - Support resources
 - Next steps
- Education materials for participants and providers to learn more about genetics and genomic medicine
- Connect participants to relevant health care providers

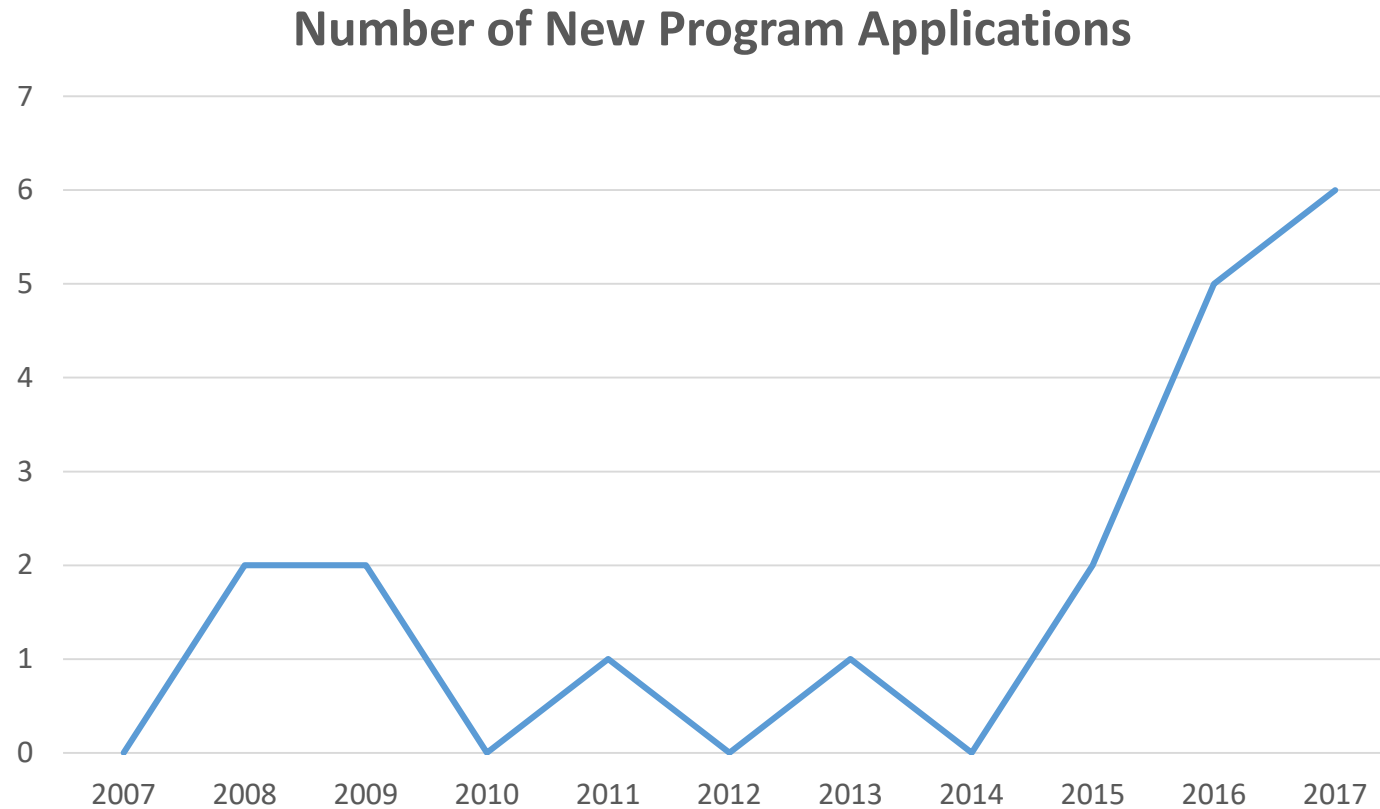


Webinar Outline

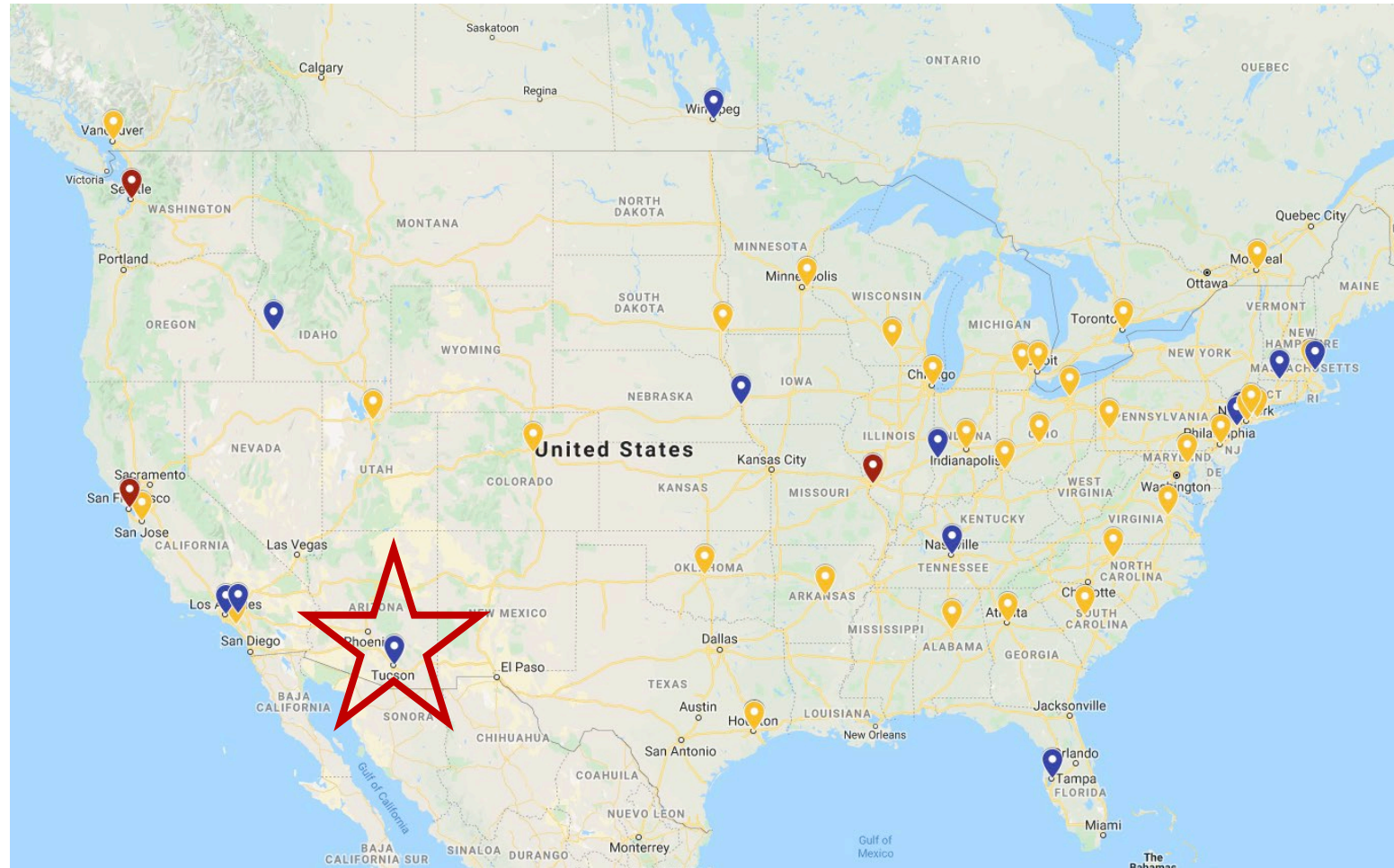
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Expanding Genetic Counseling Graduate Programs



Expanding Genetic Counseling Graduate Programs



- Accredited (35)
- Accredited, New Program (16)
- Candidate (3)

High Demand for Genetic Counseling Programs

NMS Match Rates for Genetic Counseling Graduate Programs

Year	N Programs	N Positions Offered	% Programs Filled
2019	48	468	95.80%
2018	43	404	97.70%

University of Arizona Health Sciences Genetic Counseling Graduate Program

- New genetic counseling graduate program at the University of Arizona Health Sciences
- First class started in Fall 2020
- Combination of coursework and clinical fieldwork training
- Accepting 5 students per year
- Applications for Fall 2020: 112
- <https://gcbp.uahs.arizona.edu/>

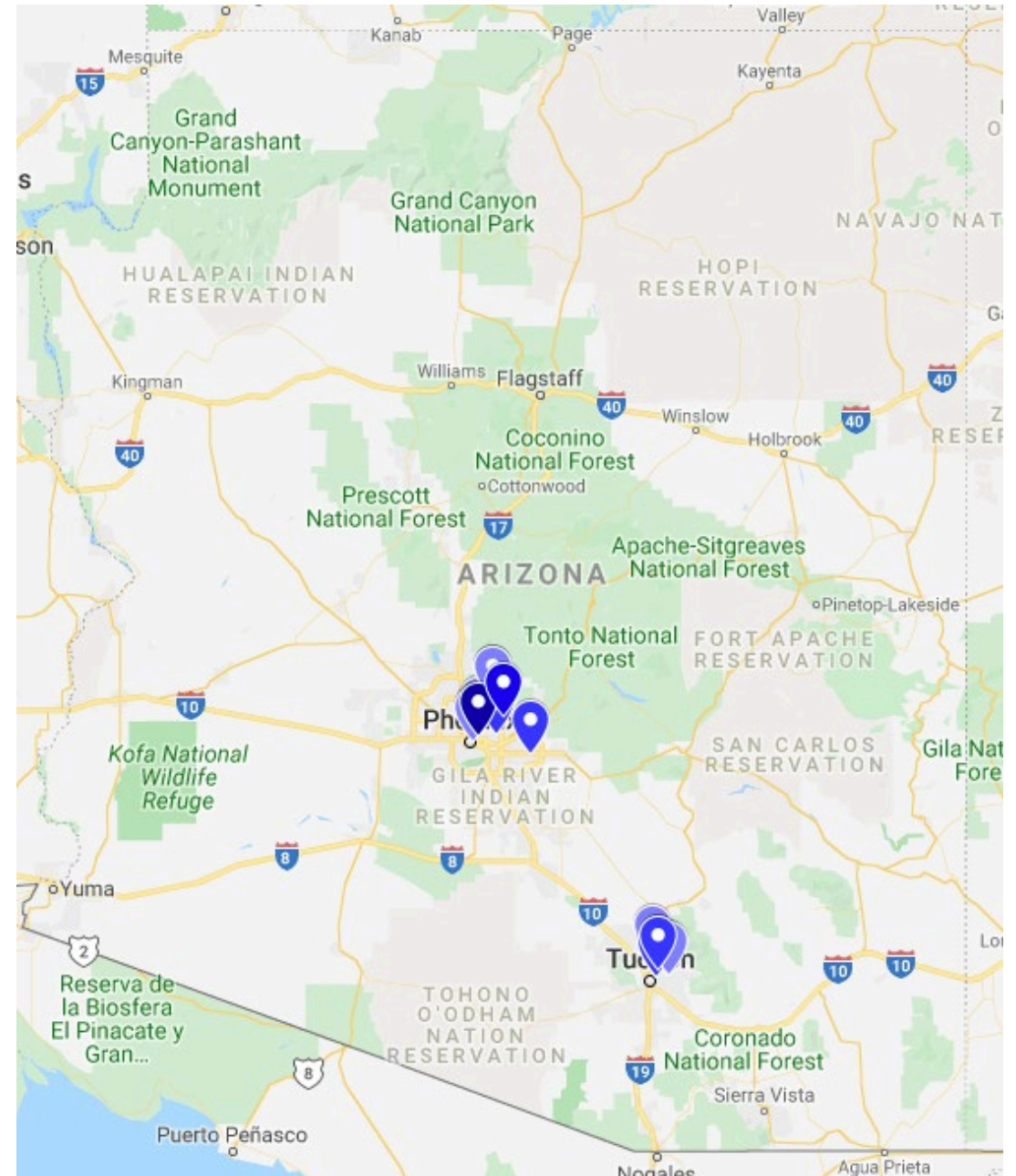


THE UNIVERSITY OF ARIZONA
COLLEGE OF MEDICINE TUCSON

**Genetic Counseling
Graduate Program**

Expanding Rotation Opportunities with Telegenetics

- Currently, there are 17 board-certified *clinical* genetic counselors in Arizona
- Located in Tucson and Phoenix
- Limiting factor to growing educational programs in genetic counseling in Arizona
- Expanding service by offering telegenetic counseling could help grow educational programs



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Thank you!

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Improving Access to Quality Medical Care Webinar Series

February 13, 2020: Incorporating Genetics in the Clinic

Valerie Schaibley, PhD

March 12, 2020: Diagnostic Genetic Testing: The Who, What, When and How

Shannon Kieran, MS, LCGC

April 9, 2020: Direct to Consumer Genetic Testing

Shannon Kieran, MS, LCGC

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<http://www.telemedicine.arizona>



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<https://www.surveymonkey.com/r/SWTRCWebinar>

This webinar series is made possible through funding provided by Health Resources and Services Administration, Office for the Advancement of Telehealth.