

G3C Case Study: Providing Healthcare for Indigenous Patients with Inherited Cardiomyopathy

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Indigenous Populations

- 574 federally-recognized tribal nations in the U.S.
 - ▶ Across 35 states
 - ▶ 229 villages in Alaska
- Sovereign nations that have a direct relationship with the state and US governments
- Unique culture, language, traditions, government, social norms, and research priorities



Why is this project important?

- Underrepresented in genomics research
 - Participation of Native participants in GWAS studies did not change 2009 to 2016.
 - Arizona State University vs. Havasupai case
 - Nuu-Chah-Nulth study
 - Moratorium on genetic research studies on Navajo Nation
- Personal story
- Resource for educators/healthcare providers
- Gives a voice for Indigenous patients

Patient Case for G3C

(Global Genetics and Genomics Community)

The screenshot shows the G3C website interface. At the top left is the G3C logo and the text 'Global Genetics and Genomics Community'. To the right are navigation links: 'Home', 'Resources', 'About', and 'Login / Register'. The main content area features a large banner with a silhouette of a person's head containing the text 'YOU ASK THE QUESTIONS' and a red question mark. To the left of the silhouette is a red-bordered box with the text 'GENOMIC HEALTH CARE SIMULATIONS'. Below this box is a bulleted list of features. At the bottom of the page is a 'HOW IT WORKS' section with three numbered steps on yellow sticky notes.

Global Genetics and Genomics Community

Home Resources About Login / Register

GENOMIC HEALTH CARE SIMULATIONS

- Interview "patients" at your own pace
- Complete supplemental educational activities
- Assess your genomic competency
- Consider commentary about specific cases from genomic experts
- Earn CNE or CME credit for each case

YOU ASK THE QUESTIONS

HOW IT WORKS

- 1 Login or Register**
Join the G3C Learning Portal for free and expand your genetic/genomic knowledge.
- 2 Choose from 17 Cases**
Narrow your search based on topic and level of difficulty.
Before logging in, view a summary of our cases.
- 3 Start Seeing Patients**
Apply what you learn today.
Lead your "patients" to quality healthcare outcomes.

Online interactive education simulation of patient cases

NAME

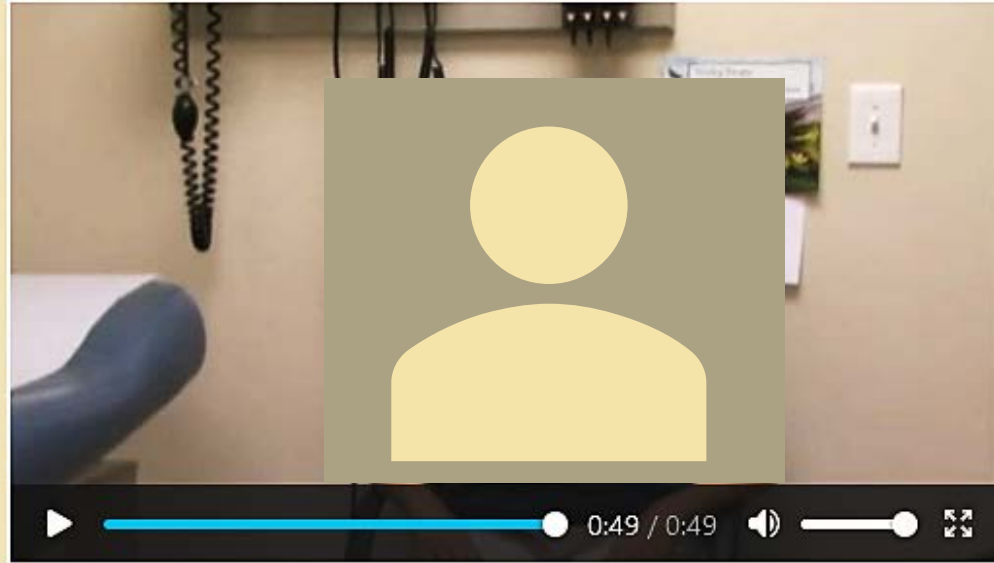
View Patient Info

Learner Activity

Explore genetic testing sites to pull together information about sample utilization. Create an answer for Lena of what happens with blood samples after genetic testing is completed.

Resources:

- Genetic Alliance: Newborn Screening Quarterly Newsletter
- Genetic Alliance: Baby's First Test
- OBRR: The Ethical Use of Pediatric Biospecimens in



CC SHOW CLOSED CAPTION

Question A

Do you want to have genetic testing?

Question B

What prompted your sister to create such a detailed family tree?

Question C

What kind of genetic testing did your sister have?

CLICK HERE TO CHOOSE ANOTHER QUESTION

Efforts so far

Primary
team

Weekly
meetings

Literature
review

G3C case
template

Consultation
with experts

G3C Case Study Components

- ❑ Case Objectives
- ❑ Story
- ❑ Case background
- ❑ Questions for user, Patient responses
- ❑ Resources
- ❑ Education content
- ❑ Learner activities
- ❑ Faculty guide
- ❑ Filming

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- Questions for user, Patient responses
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- Education content
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- Faculty guide
- Filming: Telemedicine, Native male actor & family member, Zoom

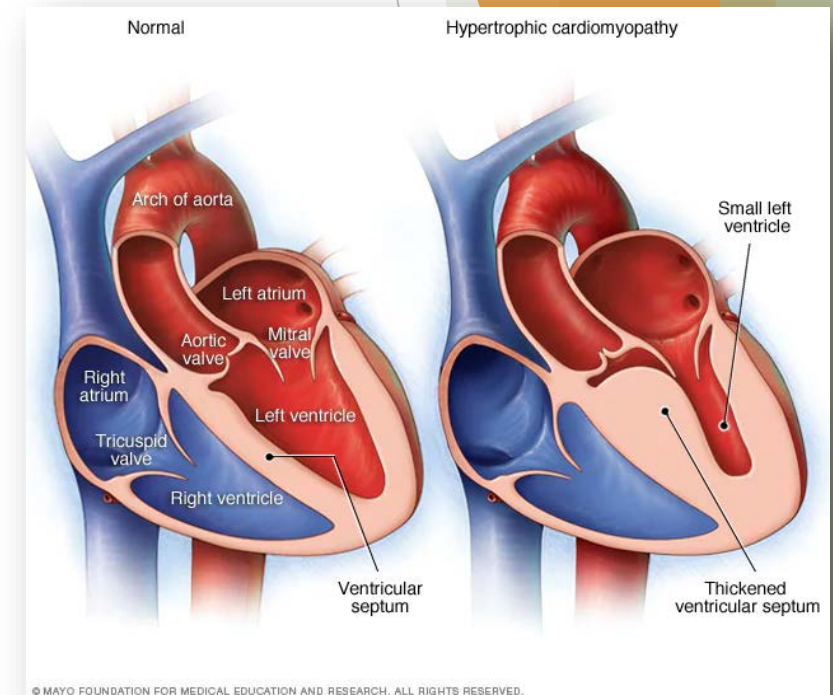
Case Study: Patient with Indigenous identity (American Indian/Alaska Native) has a cardiac genetic condition

- Indigenous male, 38 years old, faints while playing basketball.
- Seen at the ED. He is released and told to visit his primary care physician. He decides to go to the Indian Health Service to visit his primary care doctor.
 - Doctor recommends cardiac testing and is referred to a cardiologist at an urban non-tribal clinic in the city
- Diagnosed with Hypertrophic Cardiomyopathy



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1. Cultural awareness and humility
2. HCM education & resources

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Feedback/Comments Become a Reviewer? Or Both?

https://docs.google.com/forms/d/e/1FAIpQLSdpiZchqgYWqLq4ILMh5_9Mbp4iS2kMXX4PwyLRc4dlqF9vJQ/viewform?usp=pp_url

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Axhe'hee (Thank you)

NHGRI
ISCC-PEG

Mentors: Yi Liu, Christina Daulton and Carla Easter