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**INSTITUTE FOR  
HEALTH & EQUITY**

# GENETIC RISK AND FAMILY HISTORY: HOW SHARING STORIES CAN SAVE LIVES

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# AGENDA

1

**Risk  
Assessment**

2

**Risk Reduction  
& Management**

3

**Overcoming  
Barriers**

4

**Discussion**

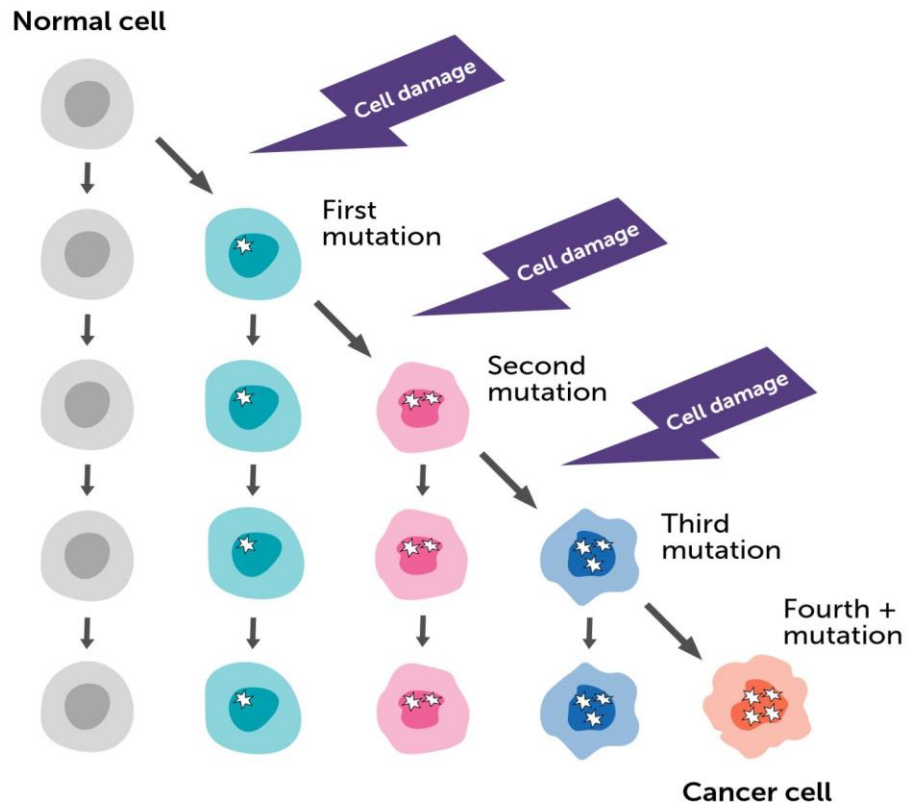


AM I AT  
HIGHER RISK?



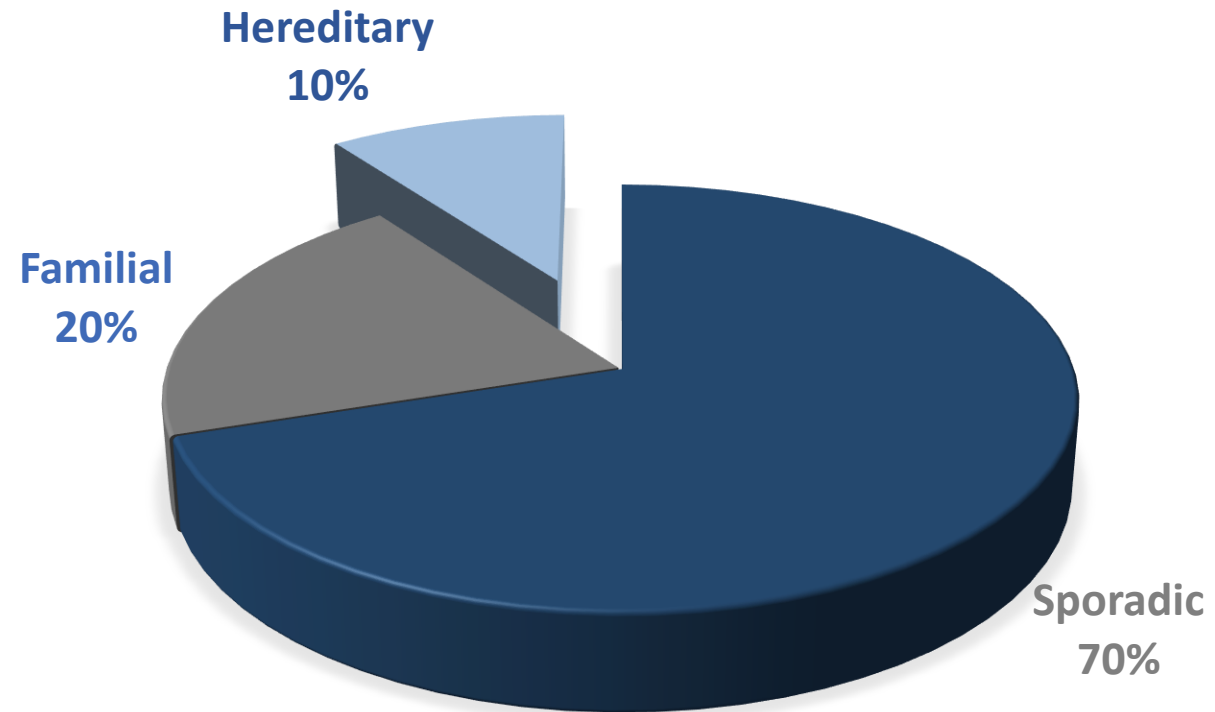
# RISK ASSESSMENT

With sporadic cancers, many mutations build up in cells over time, eventually leading to cancer.



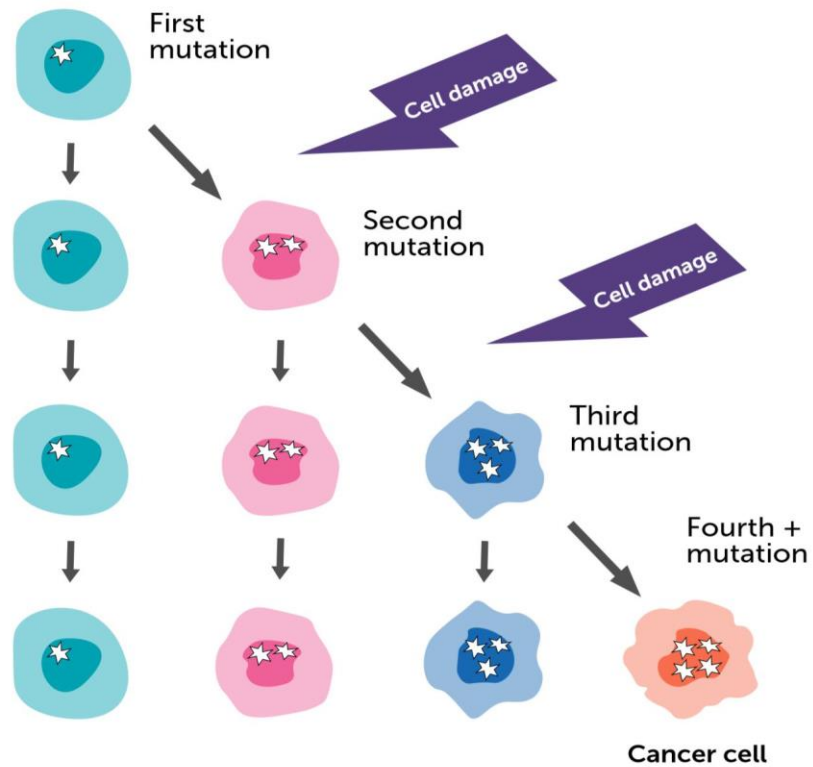
Adapted from "Understanding Gene Testing" - NIH 1995

# CANCER IS A GENETIC PROCESS



**WHAT CAUSES CANCER?**

With hereditary cancers, the first mutation is inherited and already present at birth. Additional mutations build up over time, leading to cancer.



Adapted from "Understanding Gene Testing" - NIH 1995

# HEREDITARY CANCER RISK

# RED FLAGS FOR HEREDITARY RISK



- **E**arlier than expected age at diagnosis
  - breast cancer < 50yo
- **M**ultiple primary cancers diagnosed in the same patient or multiple family members affected by same type of related type of cancer
  - breast, ovarian, prostate & pancreas
  - colon & endometrial
- **U**ncommon cancer
  - male breast cancer
  - metastatic prostate cancer
  - ovarian cancer
  - pancreatic cancer
- Known cancer gene mutation in family

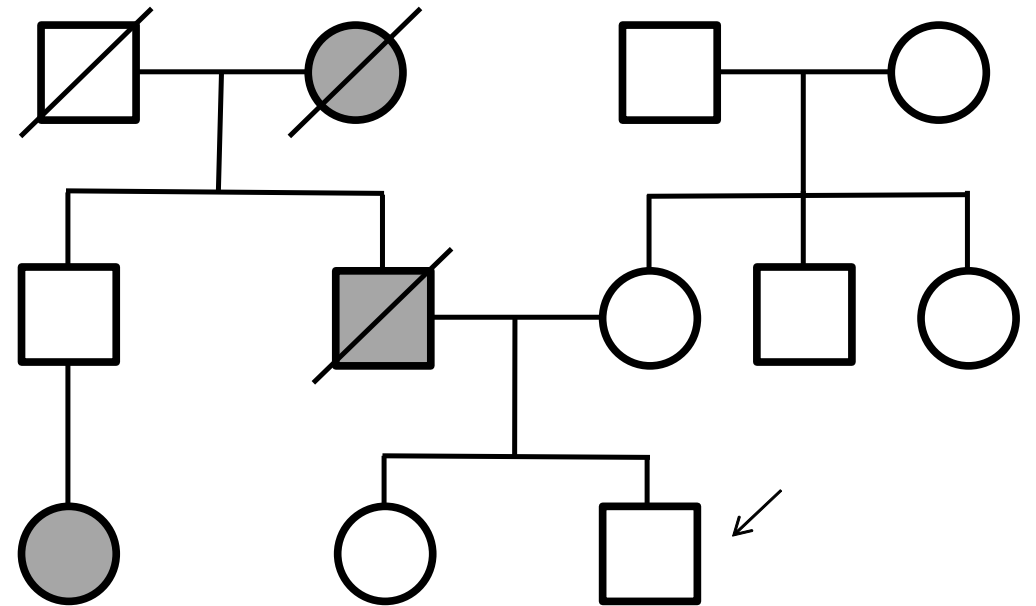
# EVALUATION TOOLS

## Family History

- 3 generation pedigree
- Cancer pathology
- Age of onset

## Genetic Testing

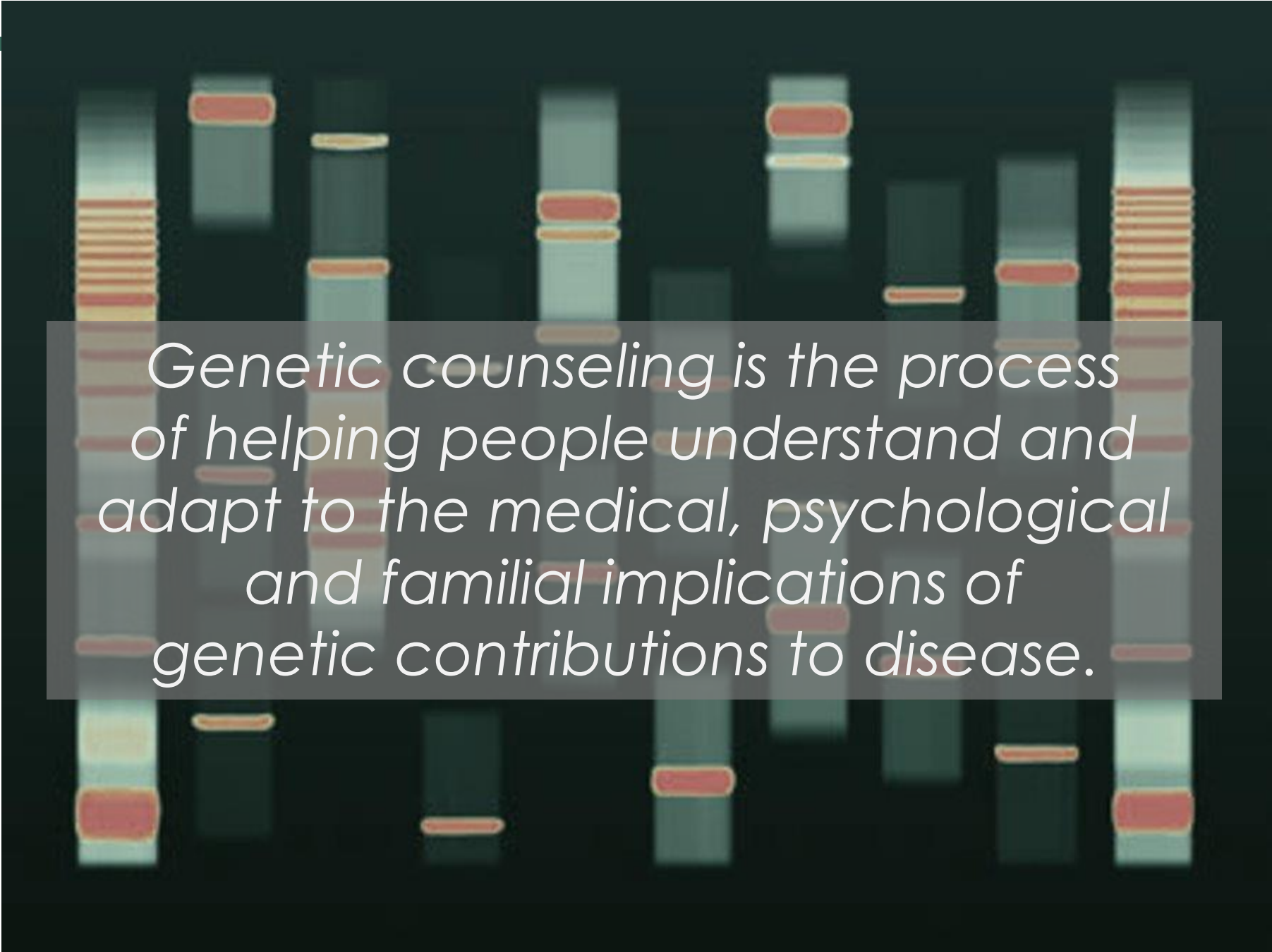
- Testing Strategy
- Gene Panels
- DNA banking







# GENETIC COUNSELORS



*Genetic counseling is the process of helping people understand and adapt to the medical, psychological and familial implications of genetic contributions to disease.*

# GENETIC COUNSELING APPOINTMENT

- Establish mutual goals, address patient's expectations
- Review medical history
- Family history
- Risk assessment: Analyze medical and family history, assess inheritance patterns
- Discuss genetic testing options & informed consent
  - Risks, benefits and limitations
  - *Address insurance concerns*, review genetic discrimination laws (GINA)
  - Possible results (positive, negative, inconclusive), turnaround time
- Psychological impact of test for patient and other family members

## REASONS TO NOT PURSUE TESTING

- Ineffective detection/prevention options for at risk individuals
- 'I don't want to know' (knowledge=burden)
- Not a good time/Unprepared to Learn Result
- Personality Type/Emotional Well-being





## REASONS TO PURSUE TESTING

- Proactive Health: Effective early detection and risk reduction options
- 'I want to know' (knowledge=power)
- This can impact my immediate cancer treatment
- Children are approaching 'that age'
- Good time/Readiness to Learn Result
- Personality Type/Emotional Well-being



WHAT CAN I  
DO ABOUT IT?



# RISK REDUCTION & MANAGEMENT

# APPROACHES

- Screening for early detection
- Medications to lower risk
- Risk-reducing surgery before cancer develops
- Precision medicine treatment





WHAT IS BEING  
DONE?



# OVERCOMING BARRIERS



# AWARENESS

Evans et al. *Breast Cancer Research* 2014, **16**:442  
<http://breast-cancer-research.com/content/16/5/442>

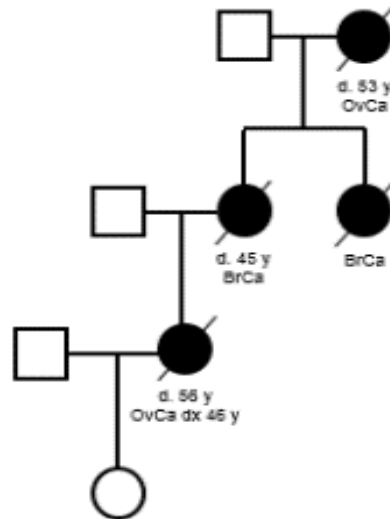


## RESEARCH ARTICLE

## Open Access

### The Angelina Jolie effect: how high celebrity profile can have a major impact on provision of cancer related services

D Gareth R Evans<sup>1,2,14\*</sup>, Julian Barwell<sup>3†</sup>, Diana M Eccles<sup>4</sup>, Amanda Collins<sup>4</sup>, Louise Izatt<sup>5</sup>, Chris Jacobs<sup>5</sup>, Alan Donaldson<sup>6</sup>, Angela F Brady<sup>7</sup>, Andrew Cuthbert<sup>8</sup>, Rachel Harrison<sup>9</sup>, Sue Thomas<sup>10</sup>, Anthony Howell<sup>1</sup>, The FH02 Study Group, RGC teams, Zosia Miedzybrodzka<sup>11,12</sup> and Alex Murray<sup>13</sup>

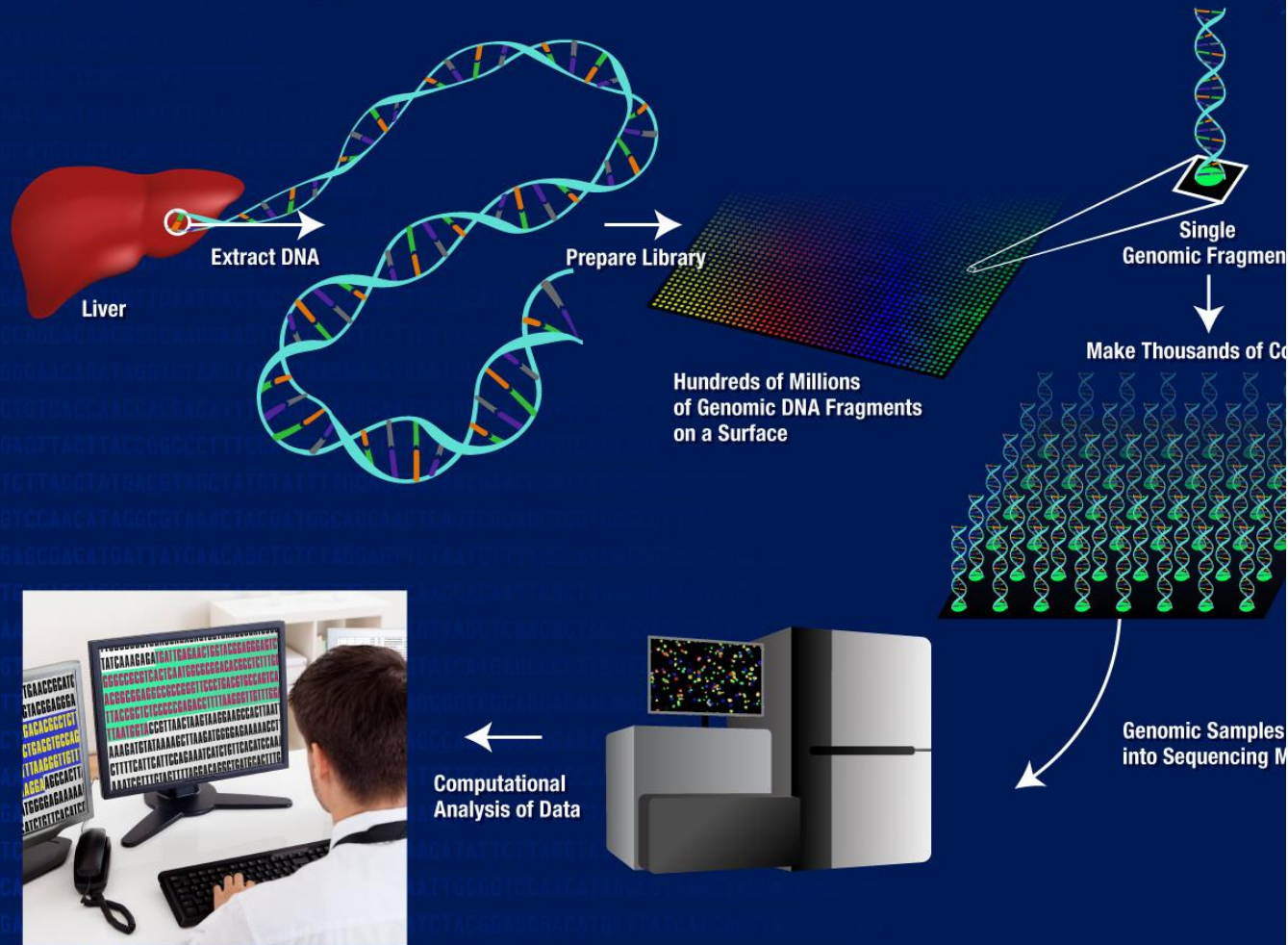


Your Genes Have Been Freed.



POLICY

# Dna Sequencing



TECHNOLOGY





SO WHAT ARE  
THE BARRIERS?

> [Cancer](#). 2017 Jul 1;123(13):2497-2505. doi: 10.1002/cncr.30621. Epub 2017 Feb 9.

## Racial disparities in BRCA testing and cancer risk

manag  
young

> [J Gen Intern Med](#). 2021 Jan;36(1):35-42. doi: 10.1007/s11606-020-06064-x. Epub 2020 Jul 27.

## Racial and Ethnic Disparities in Genetic Testing at a

**Hereditary** > [Ethn Health](#). 2021 Aug;26(6):787-810. doi: 10.1080/13557858.2018.1562053. Epub 2018 Dec 27.

Eloise Chapman-Da  
Katherine J Sapra <sup>2</sup>

## Layers of info breast cancer i American won

**Review** > [JCO Precis Oncol](#). 2021 Nov 3;5:PO.21.00233. doi: 10.1200/PO.21.00233.  
eCollection 2021.

Tasleem J Padamsee <sup>1</sup>, Rac

## Systemic Barriers to Risk-Reducing Interventions for Hereditary Cancer Syndromes: Implications for Health Care Inequities

Kathleen F Mittendorf <sup>1</sup>, Sarah Knerr <sup>2</sup>, Tia L Kauffman <sup>1</sup>, Nangel M Lindberg <sup>1</sup>,

Katherine

Galen Jos

Benjamin

**Review** > [Oncologist](#). 2022 Apr 5;27(4):285-291. doi: 10.1093/oncolo/oyab082.

## Genetic Evaluation for Hereditary Cancer Syndromes Among African Americans: A Critical Review

Ambreen Khan <sup>1</sup>, Charles R Rogers <sup>2</sup>, Carson D Kennedy <sup>2</sup>, AnaMaria Lopez <sup>3</sup>, Joanne Jeter <sup>1</sup>

Deborah Cra  
Susan T Vada



## DISPARITIES IN HEREDITARY RISK

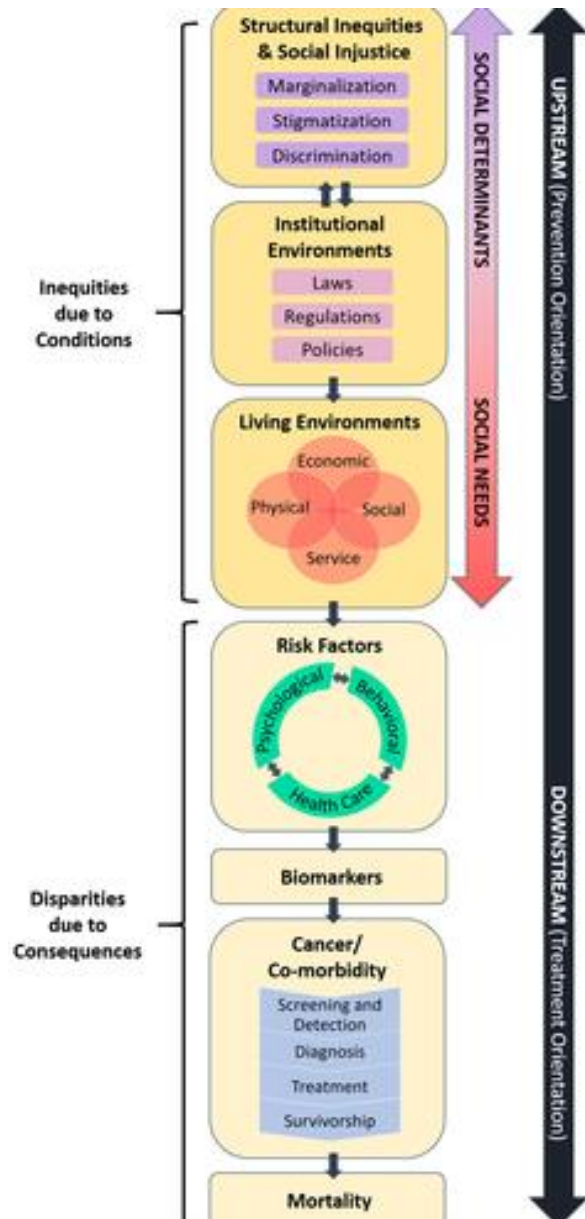
- Equal mutation rates
- Information from provider
- Referrals to genetics
- Preventative care
- Advanced stage cancer
- Missed opportunity for mutation detection and cancer prevention!



# LISTENING

- Genetic Risk and Family History: How Sharing Stories Can Save Lives





# WHAT CAN BE DONE?

## Clinician education

- Lack of awareness
- Incorrect information

## Care coordination

- Management
- Prevention
- Early detection

## Communication

- Framing: Risk Reduction

## Access Barriers

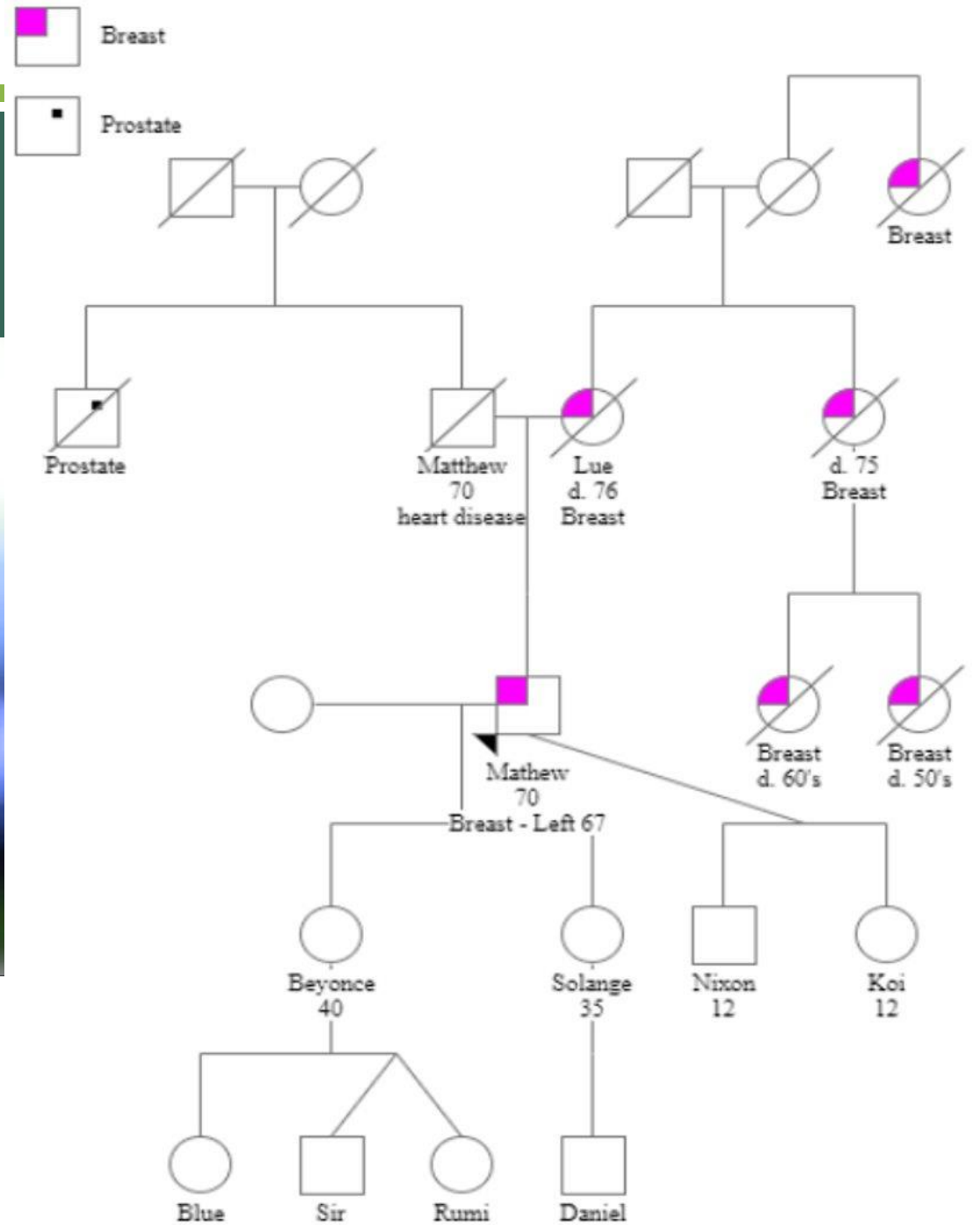
- Financial
- Geographical

## Medical system mistrust

- Uncertain results
- Lack of representation
- Medical abuses/poor treatment



# AWARENESS





**There's a gap in  
medical research  
that only you can fill.**



# TECHNOLOGY

<https://allofus.mcw.edu/>



# POLICY

- TESTING CRITERIA
- ACCESS



National Society of  
**Genetic  
Counselors**



**#AccesstoGCs**

# Support

**Access to Genetic  
Counselor Services Act**



# REPRESENTATION



Our mission is to cultivate  
**exceptional genetic counseling leaders**  
who reflect the  
**VISIBLE**  
and  
**INVISIBLE**  
*diversity*  
of the communities we serve.



Master of Science in  
Genetic Counseling  
Program



# SUMMARY: HOW SHARING STORIES CAN SAVE LIVES

- ~10% of cancers are inherited
  - Family history
  - Genetic testing
- Knowing risk may improve health
  - Risk reduction
  - Early detection
  - Precision cancer treatments
- There are barriers to overcome
  - Historically marginalized groups have not fully benefited from genetic advances
  - Clinicians, researchers, hospital administrators, public health officials and policy makers have a moral and ethical obligation to do better
- Action is needed
  - Listen & learn
  - Awareness
  - Technology
  - Policy
  - Representation

THANK YOU!

## Let's Connect!



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Instagram: @mcwmsgc

Email:

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Q&A  
DISCUSSION

