March 23, 2019

Detecting Unaffected Individuals with Lynch Syndrome (DUAL)

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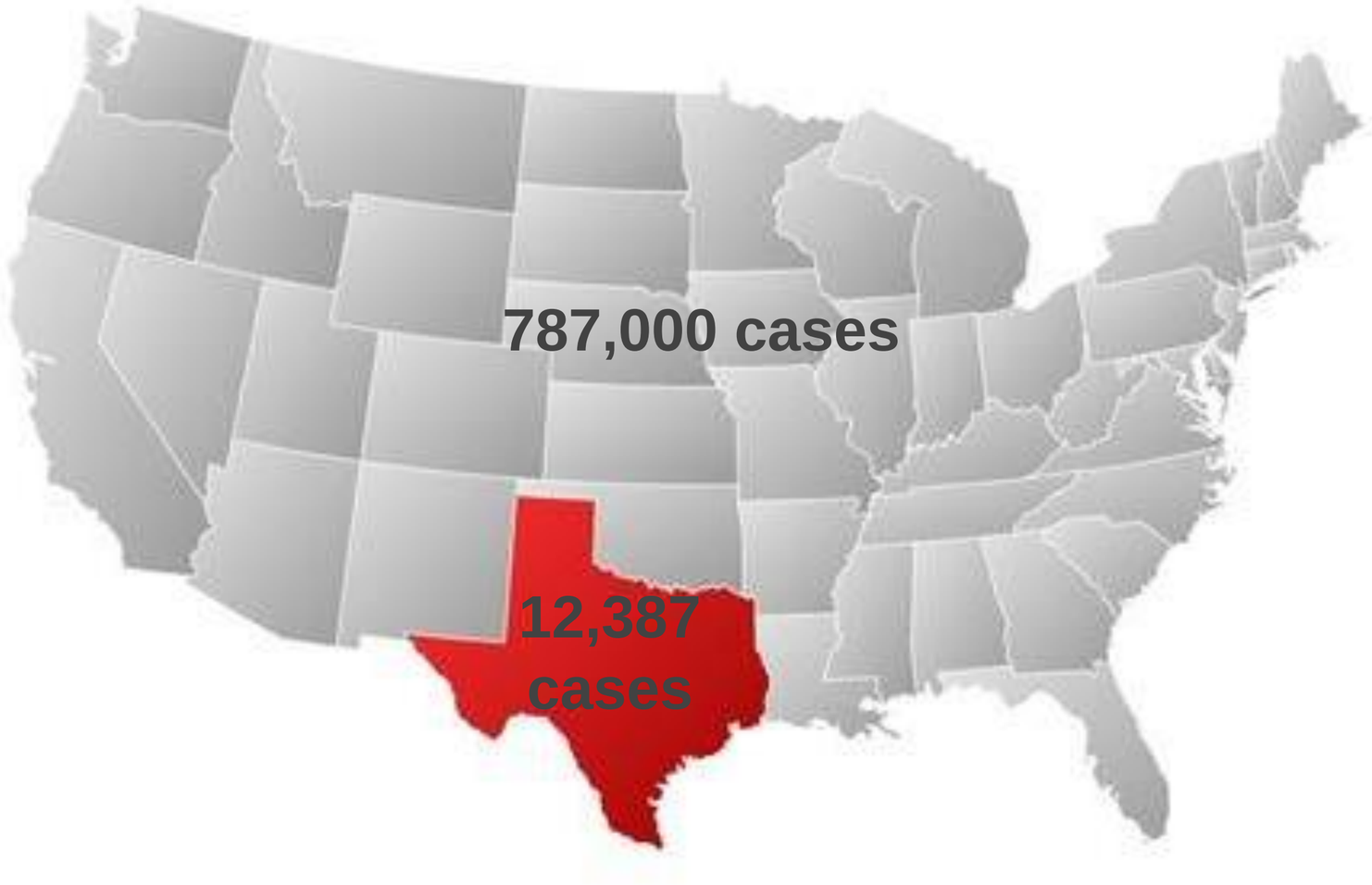
DISCLOSURES

Full-time employee at UT Southwestern Medical Center

No financial conflicts of interest

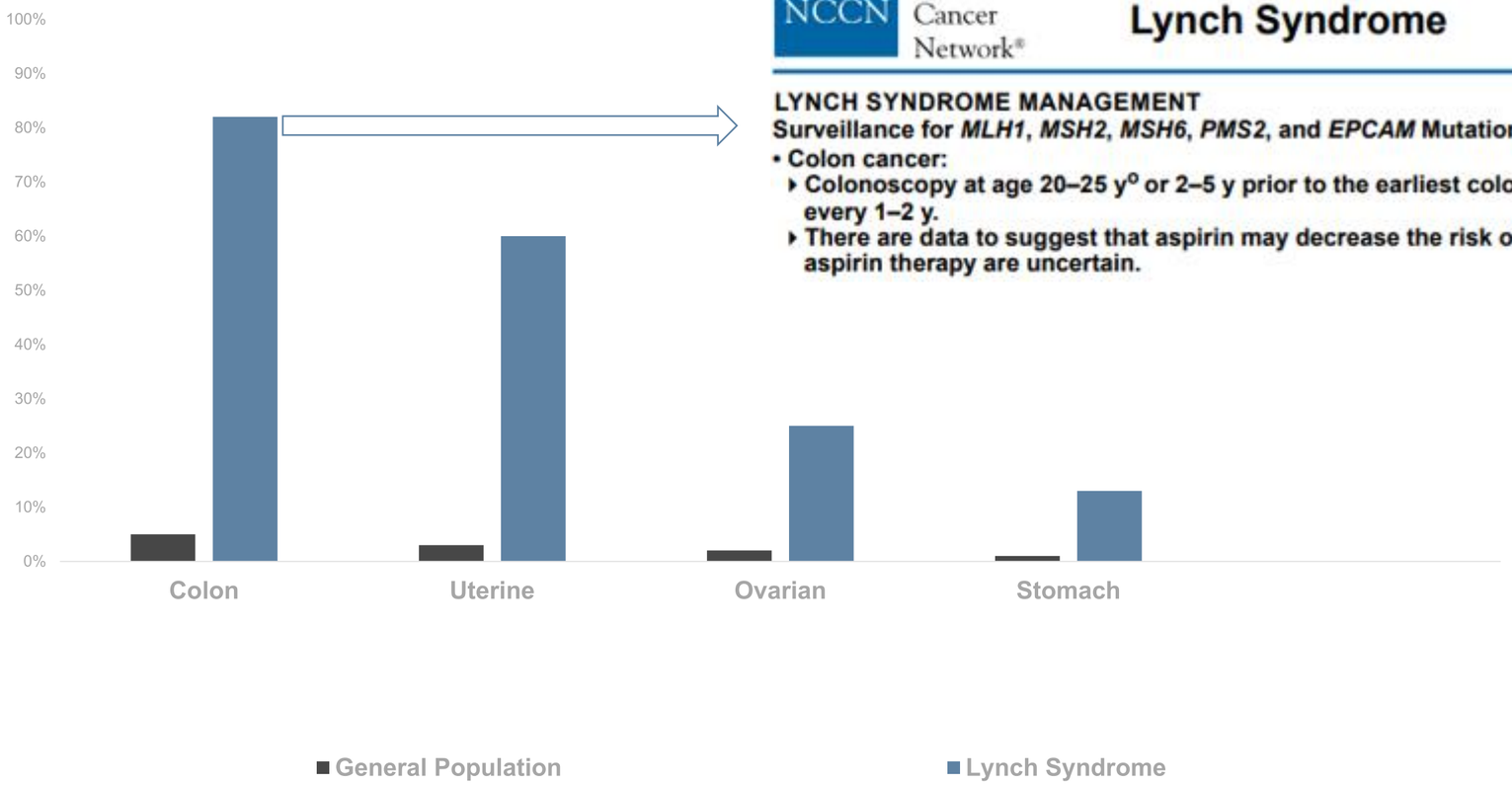
Scope of the Problem

- Annual Colon Cancer Treatment Costs:
  - $14 billion nationally
  - $3.7 billion in Texas
- Lynch syndrome:
  - Prevalence: 1 in 300
  - ~5% of colorectal cancers
  - Only ~3% identified



Risser DR et al. Tex Med 2010
Http://www.healthypeople.gov/2020/default.aspx.
National Cancer Institute https://doi.org/10.1093/jnci/djt021

Lynch Syndrome (LS) Cancer Risks



National Comprehensive Cancer Network®

NCCN Guidelines Version 1.2018
Lynch Syndrome

LYNCH SYNDROME MANAGEMENT
Surveillance for *MLH1*, *MSH2*, *MSH6*, *PMS2*, and *EPCAM* Mutation Carriers[l,m,n]

- **Colon cancer:**
  - **Colonoscopy at age 20–25 y[o] or 2–5 y prior to the earliest colon cancer if it is diagnosed before age 25 y and repeat every 1–2 y.**
  - **There are data to suggest that aspirin may decrease the risk of colon cancer in LS, but optimal dose and duration of aspirin therapy are uncertain.**

60%

>20 years

*Other Lynch syndrome cancers: urinary tract, bile duct, small bowel, brain, pancreas, sebaceous neoplasms

**Breast and prostate cancers

Win AK, et al. Breast Cancer Res 2013
Ryan S, et al. Cancer Epidemiol Biomarkers Prev 2014
Stupart DA, et al. Colorectal Dis 2009

Barriers to Identifying LS

- Strict testing criteria (Amsterdam & Bethesda)
- Testing focused on affected individuals
- LS is often unrecognized by physicians
- Inaccurate reporting of family history by the patient

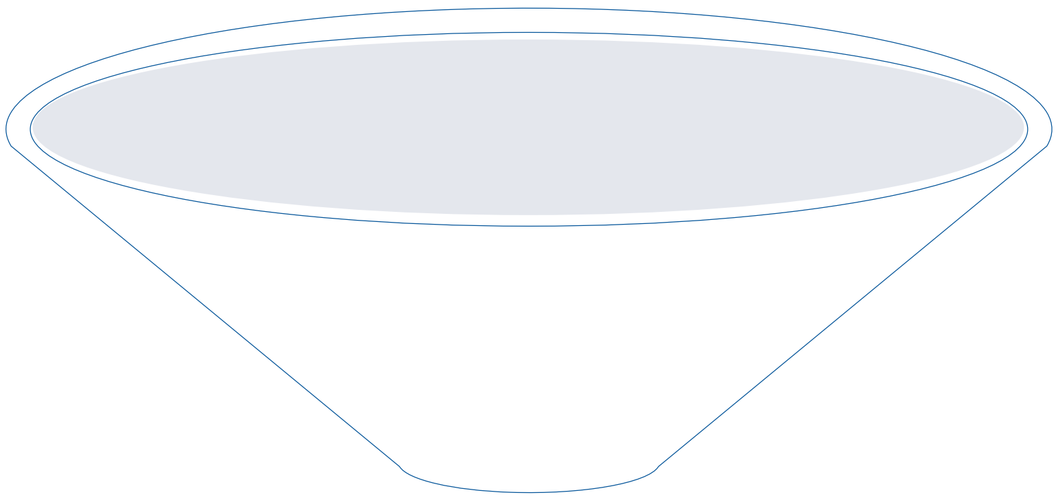
Disparities in Access to Genetic Health Services

Minority and geographically isolated groups experience significant disparities in access to cancer genetics services

RURAL GEOGRAPHIC ISOLATION

EDUCATION SOCIOECONOMIC STATUS

CULTURAL INSURANCE ACCESS



Medical care

Financial burden on family

Poor outcomes

- Later stage of dx
- Higher mortality

Call to Action

There are currently no large-scale programs in the US that screen for LS in unaffected individuals

CDC and WHO criteria for population screening for genetic predisposition include:

- Disease is an important public health burden 1:300 individuals have LS
- Risk for disease is known: >80% CRC risk; Risk known for other cancers
- Effective interventions: CRC screening; prophylactic surgery; cascade testing

DUAL: **D**etecting **U**n**A**ffected Individuals with **L**ynch syndrome

Cancer
Prevention
Research
Institute
Texas

Identification
- General population screening
- Awareness campaigns
- Community outreach
- Cascade testing

Genetic Services
- Navigation of high-risk patients to genetic counseling
- Genetic counseling: telemedicine/in-person
- Genetic testing via at-home saliva kits

Follow Up
- Patient/provider education: management recommendations
- Genetic Patient Navigator: coordinate care + cascade testing
- Assess compliance

CANCER PREVENTION

Multiple Approaches

Identification

General Population

- UTSW Mammo/GI
- PHHS Mammo/GI
- CSPAN coalition
- Self referrals
- Physician referrals

Awareness Campaigns

- Family history cards
- DUAL website
- 24 Hour Fitness Campaign

Community Outreach

- Lynch Leadership
- Presentations/ publications

Cascade testing

- Family letters
- Improved access via phone counseling
- Testing cost covered

Navigating Barriers to Genetics Services

RURAL GEOGRAPHIC ISOLATION

Partnership with CSPAN: 23 counties

Provider education/outreach

INSURANCE SOCIOECONOMIC STATUS

Safety-net hospitals

Grant funding for uninsured/underinsured

ACCESS

Navigation

Tele counseling

Saliva kits

EDUCATION

Awareness campaigns

Educational handouts

Community outreach

Genetic Testing

- Panel testing covered by DUAL grant

  Common Hereditary Cancer Panel

APC	ATM	AXIN2	BARD1	BMPR1A	BRCA1	BRCA2
BRIP1	CDH1	CDKN2A	CHEK2	CTNNA1	DICER1	EPCAM
GREM1	HOXB13	KIT	MEN1	MLH1	MSH2	MSH3
MSH6	MUTYH	NBN	NF1	NTHL1	PALB2	PDGFRA
PMS2	POLD1	POLE	PTEN	RAD50	RAD51C	RAD51D
SDHA	SDHB	SDHC	SDHD	SMAD4	SMARCA4	STK11
TP53	TSC1	TSC2	VHL			

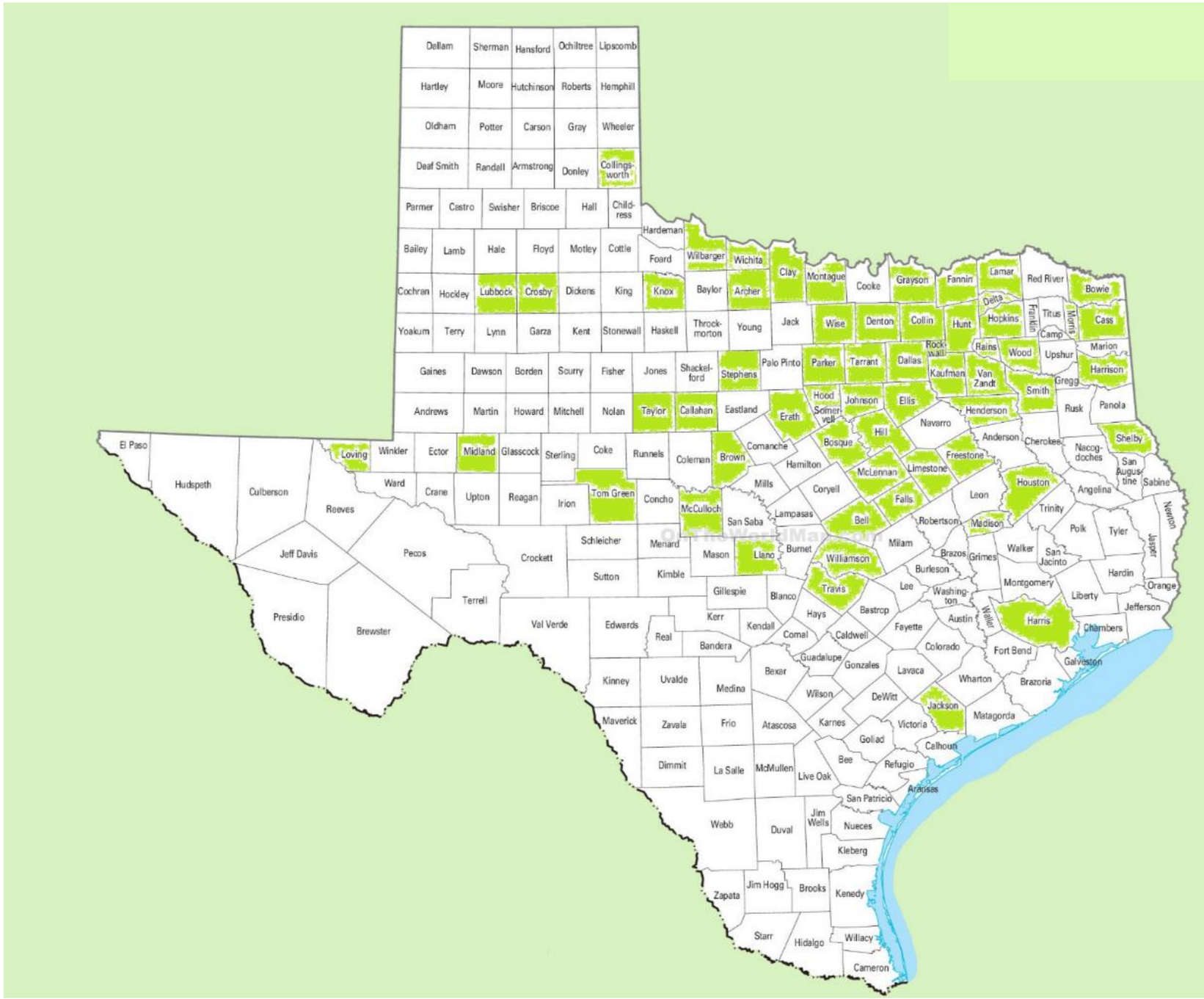
- Saliva samples for at-home testing

Reach within Texas

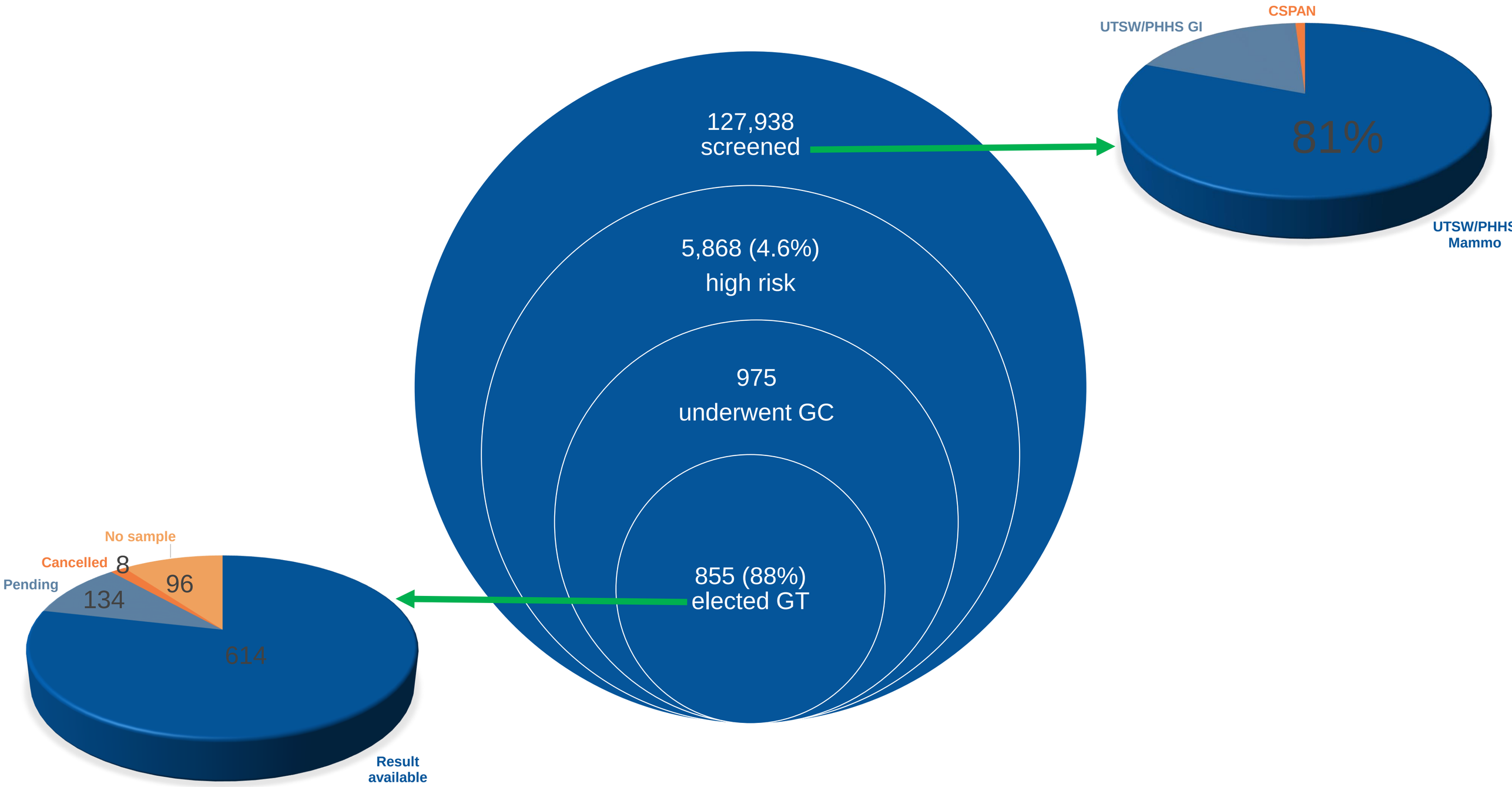
- 59 counties touched
- 12.6 million impressions via digital signage
    - 24 Hour Fitness digital signage

- 283,269 people reached
- 911 people directly educated
- 1,594 providers reached
- 1,358 providers directly educated

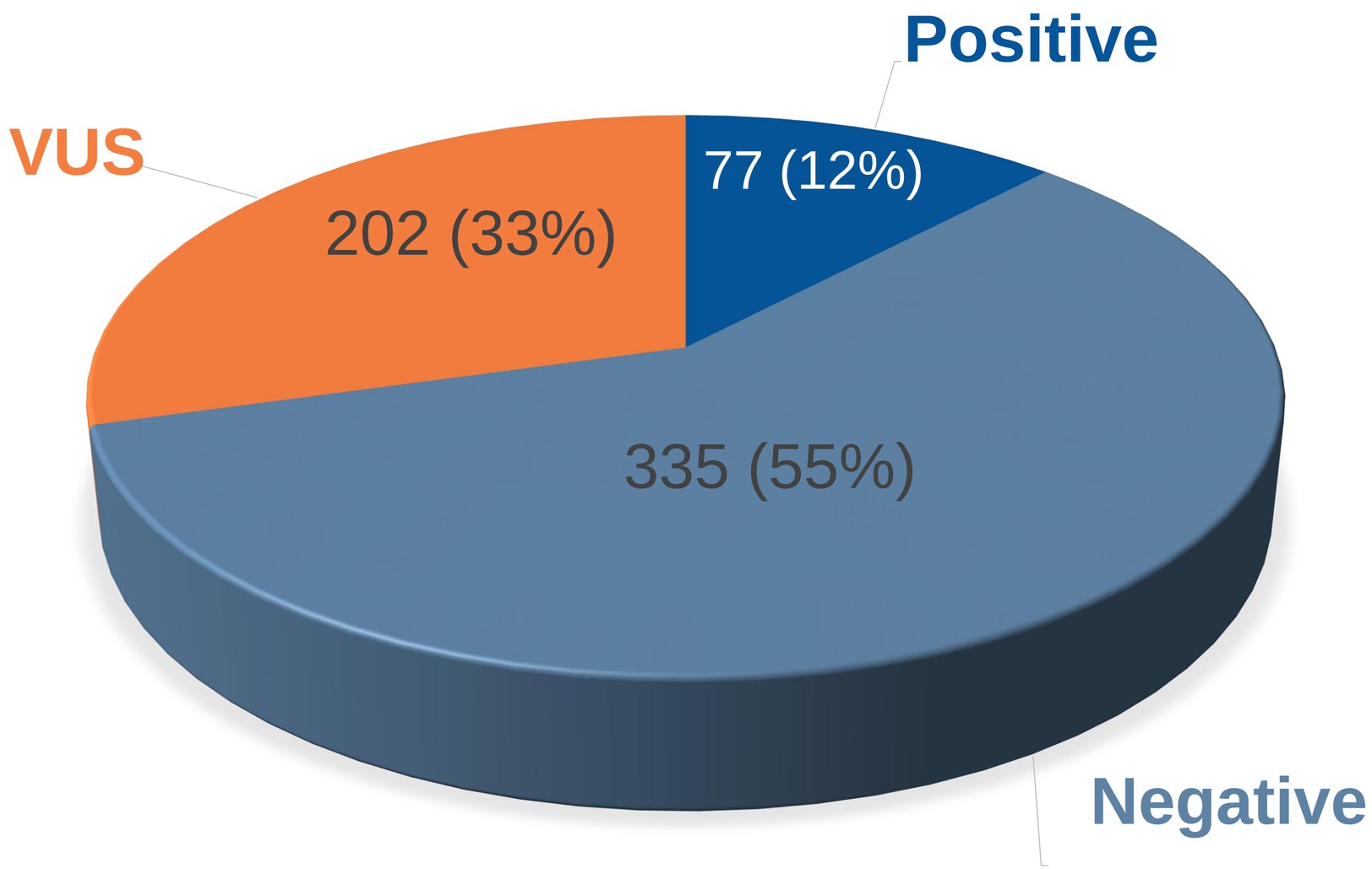
- ~60% of our patients are underserved



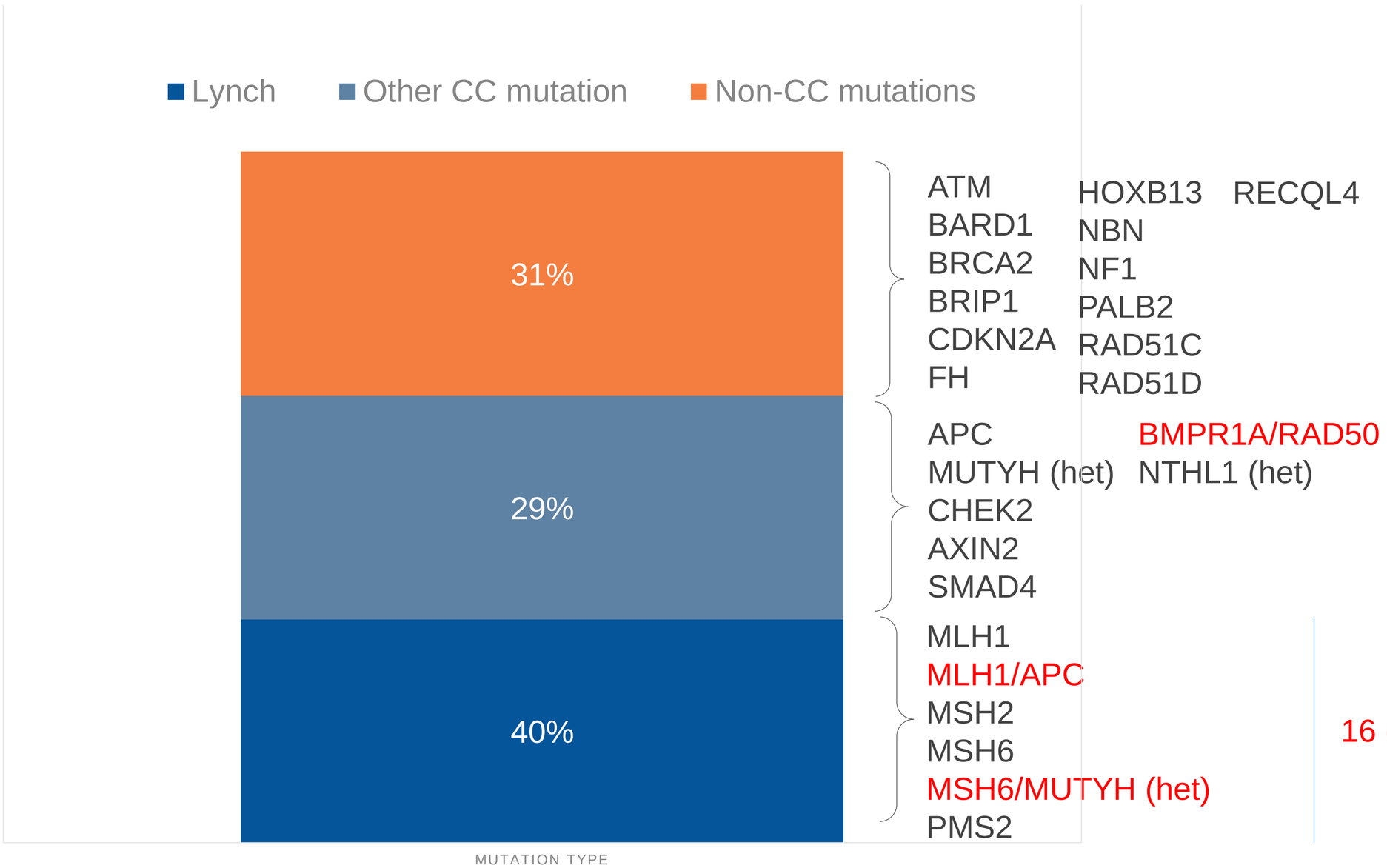
Results– 30 months



Results Breakdown



Mutation Spectrum



Challenges

- “No show” rate: 32%
- Tests not completed: 11%
- Cascade Testing: <1:1 (Goal = 1:2)

Next Steps

- Automation of EMR family history screening
- Automated messaging for colonoscopies
- Improve uptake of phone counseling, test completion, cascade testing

Acknowledgements

Theodora Ross, M.D., Ph.D-Medical Director
Sara Pirzadeh-Miller, M.S., C.G.C- Assistant Director

Genetic Counselors
Amber Gemmell, M.S., C.G.C
Annelise Pace, M.S., C.G.C
Brian Reys, M.S., C.G.C
Caitlin Mauer, M.S., C.G.C
Elise Watson, M.S., C.G.C
Jacqueline Mersch, M.S., C.G.C
John Zimmerman, M.S., C.G.C
Jordan Berg, M.S., C.G.C
Kelsey Moriarty, M.S., C.G.C
Maggie Clifford, M.S., C.G.C
Parker Read, M.S., C.G.C
Remington Fenter, M.S., C.G.C

Navigators
Angie Flores
Kathy Pratt, BSN, RN, OCN, CBCN
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Alexa Badalamenti
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