The hereditary cancer community shoulders a disproportionate cancer burden. It is crucial that our community has a voice in policies which impact us, our families, and our access to care.
Challenges

Over 2 million Americans are at increased risk of HBOC due to a hereditary predisposition. We face:

- Significantly elevated lifetime risk of cancer
- Diagnoses at younger ages
- More aggressive disease
- Increased risk of 2nd and 3rd diagnoses
- Multiple family members affected
- Lack of understanding, clear guidelines or policies on management of high risk patients, leading to health insurance coverage/reimbursement challenges

Challenges

- Higher out-of-pocket health care costs due to:
  - Earlier, more intensive cancer screening
  - Surgery and/or treatment
  - Associated loss of income, childcare costs, etc. due to earlier start of screening and preventive services and younger ages at diagnosis

Challenges

- Long-term quality of life issues due to young-onset cancer diagnosis, treatment, and/or early menopause, including:
  - Infertility
  - Osteoporosis
  - Cardiac disease
  - Quality of life issues
  - Concerns about genetic privacy and discrimination
  - Psycho-social distress due to the familial and health implications
Patient Protection and Affordable Care Act (ACA)

- Access to health insurance for all Americans
- Elimination of pre-existing conditions as barrier to coverage
- Coverage for screening and preventative services without copay or deductible
- Coverage of young adults up to the age of 26 on parent’s plan
- Abolishment of annual and lifetime caps
- Capping out-of-pocket healthcare expenditures
- Coverage for those enrolled in clinical trials

ACA, USPSTF & Prevention for High-Risk Women

Reliance on USPSTF to guide insurance coverage of preventive services has pros and cons

Example

- USPSTF failed to assign letter grades to most of the expert-recommended interventions for high-risk women
  - Mammograms (before age 40)
  - Breast screening MRI
  - Prophylactic salpingo-oophorectomy
  - Risk-reducing mastectomy
Current Gaps in Coverage

**USPSTF Guidelines Do Not Address**

- Increased screening and preventive options for high-risk women (other than chemoprevention for certain women)
- Cancer survivors in treatment
- Genetic counseling and testing for Lynch and other hereditary cancer syndromes - single gene or multigene panel
- Second genetic test for women who previously tested negative
- Genetic testing for men

*Some health plans use lack of USPSTF letter grade A/B as justification to exclude or deny ANY coverage for these services*

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Consequences of these Gaps

**Some people at high-risk of inherited cancer are...**

- Deprived of the opportunity to receive genetic counseling with a certified genetic counselor
- Unable to access genetic testing and important risk information
- Denied coverage of evidence-based preventive services, i.e. screening mammograms, breast MRIs, chemoprevention, and surgery
- Faced with substantial out-of-pockets expenses year after year

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Consequences of these Gaps

**This puts them at risk for...**

- Financial toxicity
- Foregoing standard-of-care prevention and detection due to financial constraints
- Need for more treatment due to more advanced cancer at diagnosis
- Impact on relatives who may also be at similar risk
Hereditary Cancer Landscape

Annual Screening Mammograms

- USPSTF Breast Cancer Screening Guidelines
- Stop the Guidelines Campaign
- PALS Act
- Women ages 40-49 continue to have access to annual mammogram screenings with no cost-sharing
- Waiting until age 50 to start screening mammograms could lead to more aggressive cancers being missed, more treatment, and premature death

Hereditary Cancer Landscape

Breast Density

- 50% of women have increased density
- Notification laws
  - Inform women who have undergone mammography about the risks posed by breast density
  - Only 4 states have laws requiring insurance coverage for additional imaging for women with dense breasts

Hereditary Cancer Landscape

3D Mammograms (Tomosynthesis)

- Expands legal definition of breast cancer screening mammogram to include tomosynthesis
- Guarantees health insurance coverage
Hereditary Cancer Landscape

Medicare covers
- BRCA testing for people who have had breast or ovarian cancer
- BRCA testing for people who have pancreatic cancer (some regions)
- BRCA testing for men with breast cancer (some regions)
- Multigene panel testing (some regions)

Medicare Expansion
- Medicare recipients in 19 States have expanded access to genetic testing
- Expanded coverage of BRCA testing to include those affected by prostate and pancreatic cancer
- Coverage of multigene test panel if indicated
- Clarification of BRCA testing policy for use of Lynparza (Olaparib)

Hereditary Cancer Landscape

Medicare doesn’t cover
- BRCA counseling and testing for people who haven’t had cancer (unaffected carriers)
- Prophylactic surgery for unaffected carriers (however some have been able to get coverage)
- Genetic counseling with a certified genetic counselor
Hereditary Cancer Landscape

Medicaid
- Coverage of BRCA genetic counseling, testing, screening and risk management services varies by state
  - Current information indicates about 75% of states cover BRCA counseling and testing
  - Data on coverage of related services such as breast MRI or preventive surgeries is difficult to find

Oral Chemotherapy Parity
- Working to ensure that patients have equality of access (and equality of insurance coverage) to all approved anticancer regimens

Hereditary Cancer Landscape

Oral Chemotherapy Parity
- Working to ensure that patients have equality of access (and equality of insurance coverage) to all approved anticancer regimens

“A patient’s out of pocket costs related to coverage for orally administered chemotherapy shall be on a basis no less favorable than current coverage provided for intravenously administered or injected chemotherapy under the policy.”

PSA Testing
- USPSTF guidelines give a grade “C” to the use of prostate-specific antigen (PSA) testing to screen for prostate cancer
- High-risk men benefited when the USPSTF modified its recommendation to clarify that BRCA+ Men should not be precluded from PSA testing

“This recommendation also does not include ... SA-based testing in men with known BRCA gene mutations who may be at increased risk for prostate cancer.”
Recent Accomplishments

- Successfully advocated for a 2-year extension of the medical expense deduction at 7.5% of one's adjusted gross income (2017 and 2018 tax years)
- Worked to preserve mammograms with no out-of-pocket costs for women ages 40-49 for another year—until January 1, 2020
- Supported passage of oral parity laws in 43 states

Recent Accomplishments

- Collaborated in successful challenge of EEOC regulations allowing employers to impose penalties on employees who do not participate in wellness programs
- Facilitated health insurance appeals and coverage of screening and preventive services for numerous members of the high-risk community
- Increased or sustained medical research funding (NIH and DoD CDMRP)
- Expanded of genetic testing in 4 Medicare regions, covering 19 states

Public Policy Efforts... looking ahead

- Supporting legislation to continue mammograms with no out-of-pocket costs for women ages 40-49 indefinitely
- Working to make 7.5% medical expense deduction threshold permanent
- Engaging in efforts to pass state and federal legislation ensuring equal access to anticancer treatments, regardless of how they are administered
Public Policy Efforts... looking ahead

- Spearheading legislation to facilitate Medicare coverage of screening and preventive services for previvors
- Driving establishment of fertility preservation assistance fund for previvors
- Collaborating in efforts to require insurance coverage of fertility treatments for previvors and survivors

Fertility Preservation & Treatments

Coverage Varies by State

- 16 states have infertility insurance coverage laws
- 4 states have laws for medically-induced infertility

Exemptions may include:

- Religious employers
- Employers with fewer than 50 employees
- Employers who self-insure
- Storage of sperm or oocytes
- Experimental infertility procedures
- Surrogacy

Public Policy Efforts... looking ahead

- National guidelines around cancer screening (PSA testing, genetic testing, mammograms, etc.)
- Medicare & Medicaid coverage of broader cancer genetic services for high-risk individuals
- Coverage of screening and preventive interventions for those with private/group health insurance
- Equity in insurance coverage of cancer treatments (IV vs. oral, injections, etc.)
- Preservation of pre-existing condition protections
Public Policy Efforts... looking ahead

- Maintenance of key ACA components
- Federal regulation of genetic and genomic testing
- Direct-to-Consumer genetic testing
- Breast density notifications laws
- 3D mammography/tomosynthesis coverage
- Essential health benefits and pre-existing conditions
- International data sharing initiatives
- Genetic protections and privacy

Patient Advocate Leaders (PALs)

- San Francisco, CA - Previvor
- Phoenix, AZ - Colon & Kidney Cancer
- Boulder, CO - Ovarian Cancer
- Houston, TX - Previvor
- Minneapolis, MN - Breast Cancer
- Chicago, IL - Previvor
- Pittsburgh, PA - Previvor
- NJ (central) - Previvor
- DC area - Previvor
- DC area - Previvor
- DC area - Previvor
- Tampa, FL - Previvor
- Orlando, FL - Breast & Ovarian Cancer

Patient Advocate Leaders

- Grow and expand our advocacy efforts
- Harness the power of patient advocates
- Mobilize members of the hereditary cancer community
  - Stronger, more strategic role in driving state and national policies
  - Represent the distinct needs of those affected by hereditary cancer—women, men, survivors, previvors, young and old
- More comprehensive program & capacity