Current issues in advocacy and public policy
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Legislative and oversight challenges to the hereditary breast and ovarian cancer community

Challenges facing members of the hereditary breast, ovarian and related cancer community are many. This community faces significantly elevated lifetime cancer risks, diagnoses at younger ages and treatment-related long-term quality of life issues (early menopause, infertility, osteoporosis and cardiac disease), more aggressive disease, increased risk of multiple diagnoses, having multiple family members affected, and a lack of understanding of guidelines or policies on management. This high-risk population also tends to have higher out-of-pocket health care costs from earlier, more intensive cancer screening and preventive services, and risk-reducing surgeries and/or treatment. High-risk individuals often suffer associated loss of income, extensive childcare costs, and other expenses related to hereditary cancer or its prevention/treatment.

The Affordable Care Act and the United States Preventive Services Task Force

The Affordable Care Act (ACA) established some patient protections and required access to health insurance for all Americans. This legislation eliminated pre-existing conditions as a barrier to coverage. It abolished annual and lifetime caps on what insurance companies pay out. It also capped out-of-pocket healthcare expenditures for the individual. It provides coverage for screening and preventative services without copay or deductible; however, it specifically identifies which preventative services it does and does not cover. It covers young adults on their parents’ plan up to the age of 26. The ACA required insurance coverage for any complications experienced while an individual is enrolled in a clinical trial.

The United States Preventive Services Task Force (USPSTF) determines preventative guidelines for individuals of average risk. However, the task force did recommend some guidelines on risk assessment, genetic counseling, and genetic testing for BRCA-related cancer in women. It identified specific criteria that must be met, and if met, requires insurance coverage of BRCA genetic testing at no out-of-pocket cost.

However, the USPSTF for does not address the following:

- Screening and prevention options other than chemoprevention for certain high-risk women.
- Cancer survivors in treatment.
- Genetic counseling and testing for Lynch and other hereditary cancer syndromes through either single gene or multi-gene panels.
- Secondary genetic testing for women who previously tested negative.
- Genetic testing for men.

Because the task force does not address or assign a letter grade to these guidelines, some health plans use that as justification to exclude or deny coverage for these services. (FORCE can help with appeals for denial of coverage.) Denials that are upheld can result in high-risk individuals being deprived of the opportunity to receive genetic counseling with a certified genetic counselor and being unable to access genetic testing and important risk information. This puts them at risk for financial toxicity (financial problems an individual has as a result of their cancer treatment), foregoing of standard care prevention and detection due to financial constraints, need for more treatment due to more advanced cancer at diagnosis, and an impact on relatives who may also be at risk.

Regarding hereditary cancer, the USPSTF recommended that mammograms not begin until age 50. However, waiting that long could lead to more aggressive cancers being missed, more treatment, and deaths that are more premature. Through FORCE’s advocacy efforts, the Protecting Access to Lifesaving Screenings (PALS) Act was passed in 2015, establishing a moratorium on the USPSTF recommendation and keeping the previous guideline of beginning mammograms at age 40 to help both the high-risk and average-risk communities. As a result, women ages 40-49 continue to have access to annual mammogram screenings. However, the moratorium expires on January 1, 2020.

**Breast density**

Notification laws in parts of the U.S. require women who have undergone mammography to be informed about the risk posed by breast density. Only 4 states have laws requiring insurance coverage for the additional imaging that is recommended for women with dense breasts. However, other states are working to pass laws that will ensure health insurance coverage for the additional imaging.

**3D mammograms**

Recent laws expand the legal definition of breast cancer screening to guarantee health insurance coverage for 3D mammograms. Medicare covers 3D mammograms, and FORCE is working to ensure that Medicaid also provides coverage.

**Oral chemotherapy**

Currently, most states have laws in place to ensure coverage of anti-cancer regimens, regardless of how they are administered. Legislative efforts are ongoing to ensure that patients have equal access and insurance coverage to all approved anti-cancer regimens.
PSA testing for prostate cancer

USPSTF guidelines gave a “C” grade to the use of prostate specific antigen (PSA) testing, which means that health insurance companies are not required to cover it. However, the task force modified its recommendation to clarify that BRCA-positive men should not be precluded from PSA testing.

Medicare and Medicaid coverage

Medicare does not guarantee coverage for preventive medicine; however, it currently covers BRCA genetic testing for men with breast cancer and women with breast or ovarian cancer. These are the only two nationwide Medicare policies in place, because the program is operated by 10 different contractors who oversee specific regions. These contractors can create their own region-specific coverage policies, as long they do not conflict with Medicare’s national policies. As a result, BRCA testing for people who have pancreatic cancer and multigene panel testing are only covered in some regions. Medicare does not cover genetic counseling with a certified genetic counselor, counseling and testing for people who have had cancer, or prophylactic surgery for unaffected carriers (although some individuals have been able to get coverage).

Each state determines its own policies and coverage for low-income Medicaid services, including coverage of BRCA genetic testing, counseling, screening, and risk management services. FORCE is working to determine the policy and coverage of each state. Current information indicates about 75% of states cover the cost of BRCA genetic testing and counseling, but whether the costs of risk management and risk-reducing strategies are covered is unclear.

Future legislative goals for the high-risk community

In the future, continued legislative support will ensure that mammograms for women ages 40-49 can occur with no out-of-pocket cost, and continued support will make the 7.5% medical expense deduction permanent. FORCE wants to engage in efforts to pass state and federal legislation that ensure equal access to anti-cancer treatments, regardless of how they are administered. Efforts will be made to pass legislation that facilitates Medicare coverage of screening and preventive services for previvors. Collaborative efforts will also require insurance coverage of fertility treatments for previvors and survivors.