

The Role of State Public Policy Efforts in Breaking Down Barriers to Care

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BACKGROUND

Genetic testing helps assess cancer risk. The Affordable Care Act requires coverage of specific preventive health services without patient cost-sharing, based on U.S. Preventive Services Task Force (USPSTF) recommendations. Designed for primary care professionals, these guidelines focus on the needs of the general population.

Individuals at high risk of cancer due to an inherited genetic mutation need more intensive and frequent screenings at younger ages than the general population. The USPSTF does not address these needs. National Comprehensive Cancer Network (NCCN) guidelines recommend annual breast screening MRIs starting at age 25 for BRCA mutation carriers. However, the cost of these screenings—sometimes \$3000 or more—is often applied to the individual’s deductible. This causes many patients to forgo the guideline-recommended care.

INTERVENTION

State laws requiring coverage for supplemental cancer screenings help reduce financial barriers for high-risk patients, offering a practical route for expanding access when federal change is difficult.

FORCE established the Patient Advocate Leaders (PALs) program to engage its community in educating lawmakers about the needs of individuals at increased risk of cancer. With 130 trained volunteers in 2025 (Table 1), these advocates are instrumental in helping drive policy change in their respective states. Partnering with other patient advocacy and healthcare professional organizations, to date this year, FORCE has collaborated in passing 15 new state laws facilitating coverage of crucial services such as genetic counseling and testing, supplemental cancer screenings, and diagnostic imaging, without patient cost-sharing (See Figure 1).

In addition, FORCE established the Hereditary Cancer Advocacy Coalition, bringing together over 50 patient advocacy and healthcare groups to improve policy and practices for people with or at risk of hereditary cancer, and empowering smaller organizations to participate in advocacy. The group collaborates on numerous advocacy efforts (See Figures 2 and 3, and associated QR codes). Organizations interested in the coalition should contact Lisa Schlager at LisaS@facingourrisk.org for information.

RESULTS

State Policy Program Progress					
Measurable	2022	2023	2024	2025 to date ^c	% Increase ^c
# of PALs	18	33	97	130	622%
# of States Represented	13	33	35	36	177%
# of State Bills & Issues Addressed	a	19	39	66	247%
# of State Laws Passed	a	6	19	15	150%
# of Engagment Opportunities	b	b	138	333	141%

Table 1
^aTracking/numbers for this time period are not available.
^bMeasurement criteria differ from those used in 2024 and 2025, so these numbers have been omitted.
^cNumbers may change between now and year-end.

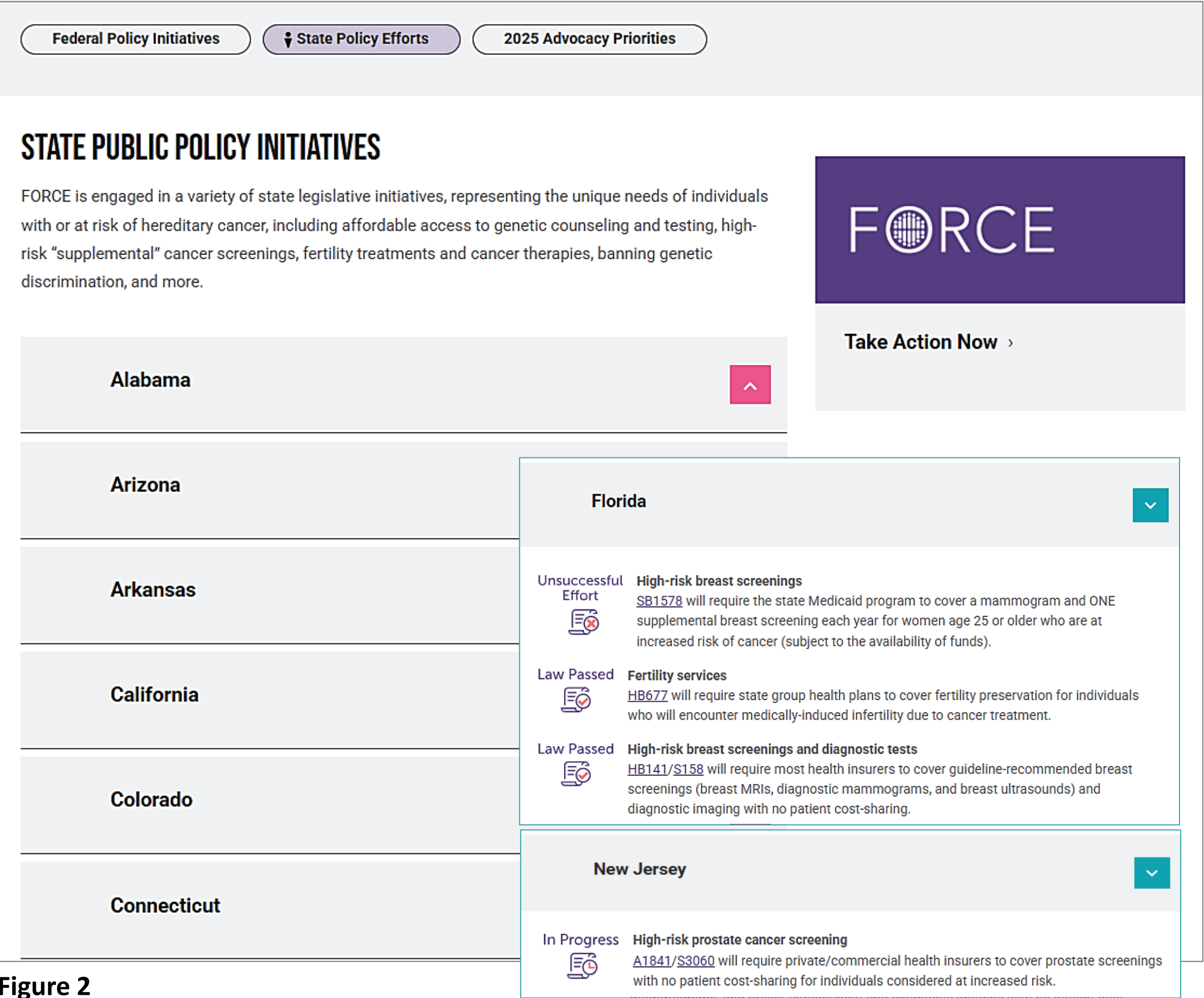


Figure 2

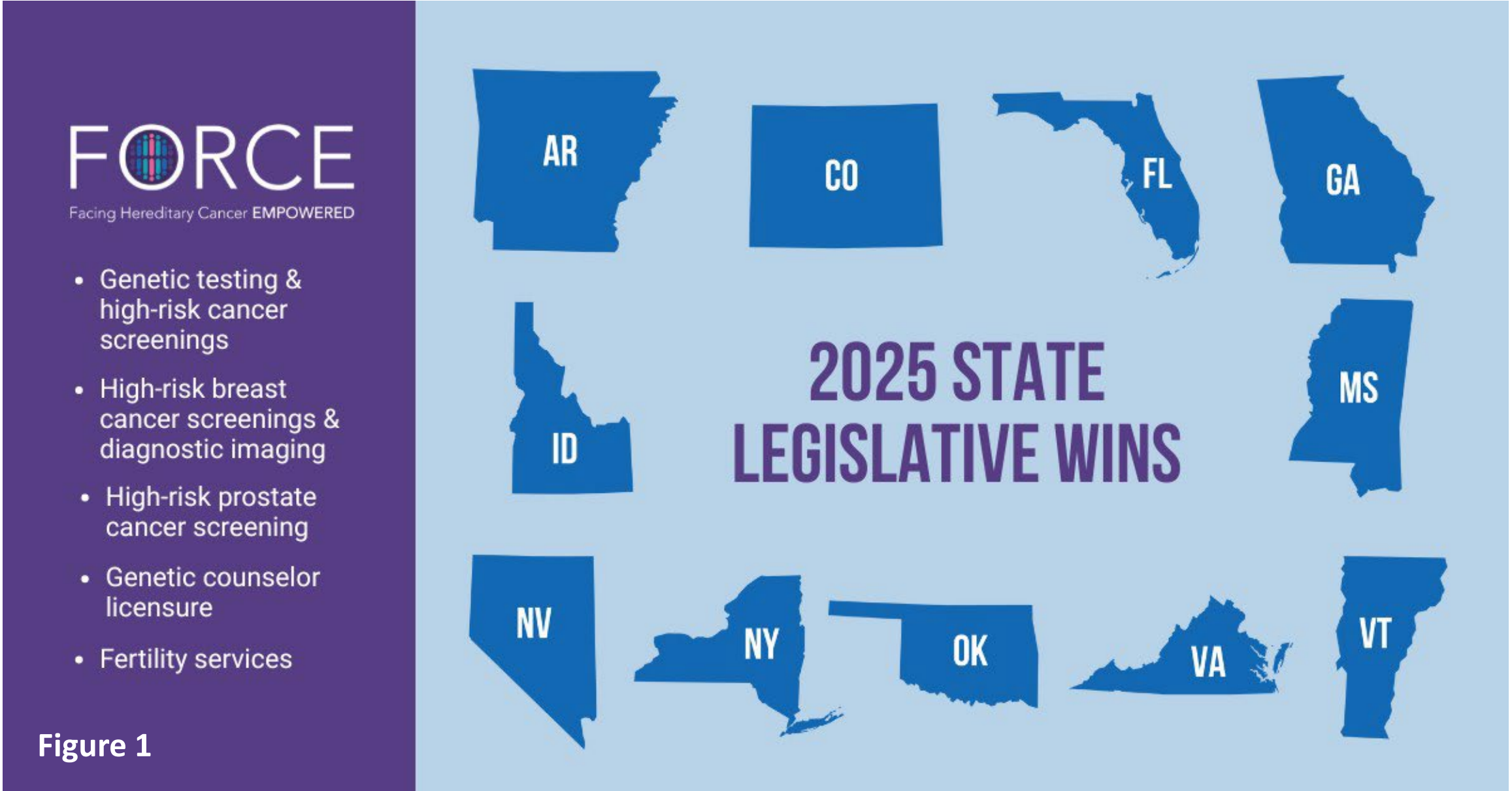


Figure 1

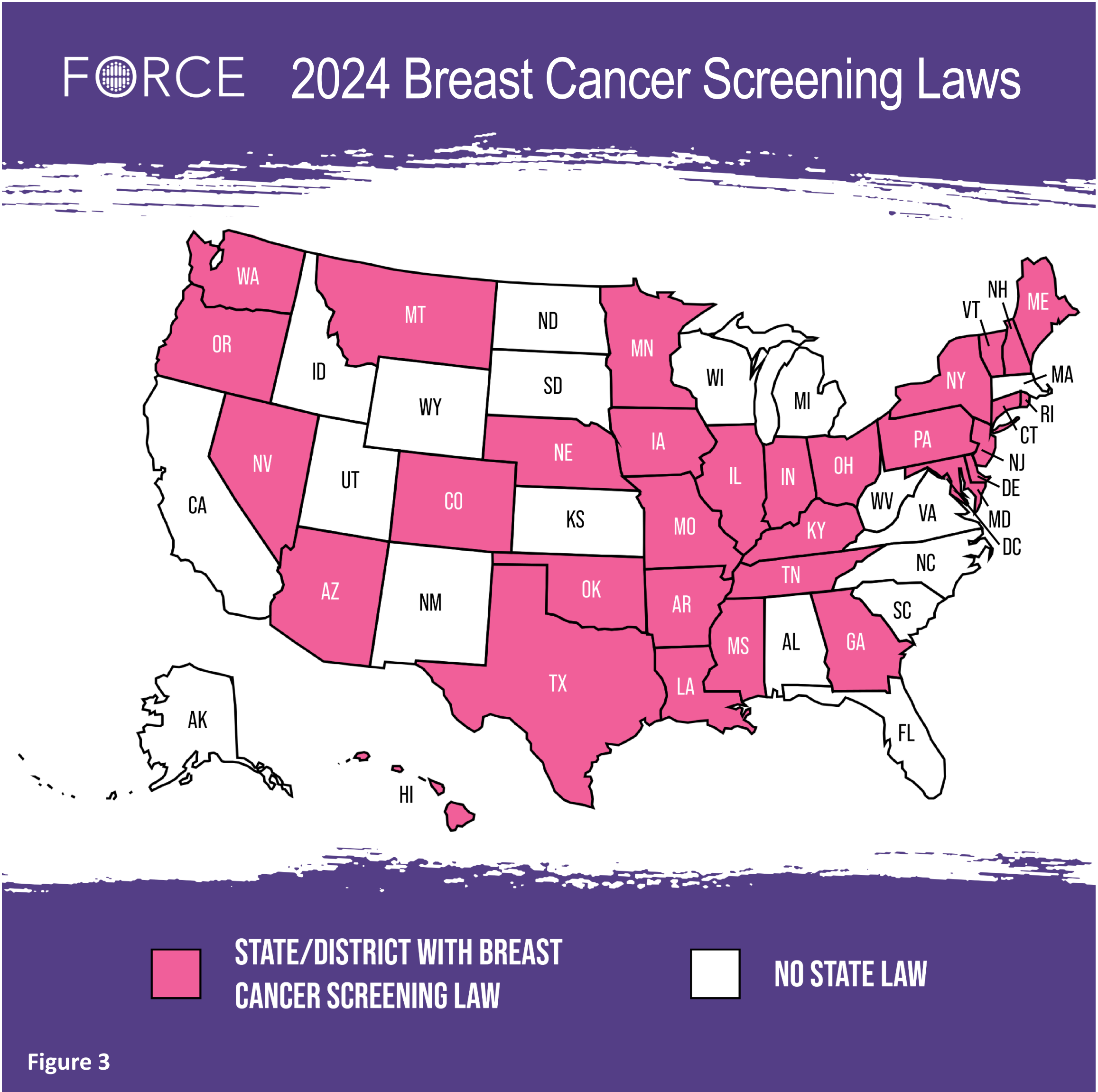


Figure 3

FINDINGS

Out-of-pocket costs deter people from getting recommended cancer screenings and, if indicated, follow-up diagnostic tests. Coverage of screening and diagnostic health services with no patient cost-sharing increases access and uptake by removing cost as a barrier.

The U.S. healthcare system is complex, with varying types of insurance, often bound by different rules and regulations. This results in inconsistent coverage of care, even for insured individuals in the same state. Still, state laws can play an important role in expanding access to screening and preventive services.

DISCUSSION

There is tremendous opportunity for stakeholders in the hereditary cancer community to make an impact at the state level. Genetic testing can identify individuals at increased cancer risk, but this knowledge is beneficial only if mutation carriers can engage in the guideline-recommended screening and preventive care. Supplemental cancer screenings, such as breast MRIs or more frequent colonoscopies, are costly. Ensuring that high-risk individuals can access appropriate care without cost barriers increases uptake and leads to earlier detection of cancer, when it is easier and less expensive to treat. This has the potential to save lives and lower healthcare costs.

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State Breast Screening Laws



State Public Policy Efforts