

# HOW DO YOU **MEASURE UP?**

A Progress Report on State Legislative Activity to Reduce Cancer Incidence and Mortality  
*2016 • 14th Edition*



# MISSION STATEMENT

## American Cancer Society Cancer Action Network (ACS CAN)

ACS CAN, the nonprofit, nonpartisan advocacy affiliate of the American Cancer Society, supports evidence-based policy and legislative solutions designed to eliminate cancer as a major health problem. ACS CAN works to encourage elected officials and candidates to make cancer a top national priority. ACS CAN gives people extraordinary power to fight cancer with the training and tools they need to make their voices heard. For more information, visit [acscan.org](http://acscan.org).



## Our 14th Edition

The 14th edition of *How Do You Measure Up?* illustrates where states stand on issues that play a critical role in reducing cancer incidence and death. The goal of every state should be to achieve “green” in each policy area delineated in the report. By implementing the solutions set forth in this report, state legislators have a unique opportunity to take a stand and fight back against cancer. In many cases, it costs the state little or nothing to do the right thing. In most cases, these solutions will

save the state millions and perhaps billions of dollars through health care cost reductions and increased worker productivity. To learn more about ACS CAN’s programs and/or inquire about a topic not covered in this report, please contact the ACS CAN State and Local Campaigns Team at (202) 661-5700 or call our toll-free number, 1-888-NOW-I-CAN, 24 hours a day, seven days a week. We want to put you in contact with ACS CAN staff in your state. You can also visit us online at [acscan.org](http://acscan.org).



# TABLE OF CONTENTS

14th Edition

1

## How Do You Measure Up?

<b>Tackling Tobacco Use</b> .....	<b>4</b>
<b>Tobacco Excise Taxes</b> .....	<b>6</b>
<b>Smoke-Free Laws</b> .....	<b>10</b>
<b>Tobacco Cessation Services</b> .....	<b>13</b>
<b>Tobacco Control Program Funding</b> .....	<b>16</b>
<b>Healthy Eating and Active Living</b> .....	<b>20</b>
<b>Indoor Tanning</b> .....	<b>24</b>
<b>Access to Care</b> .....	<b>28</b>
<b>Prescription Drug Transparency and Cost-Sharing</b> .....	<b>28</b>
<b>Network Adequacy</b> .....	<b>30</b>
<b>Oral Chemotherapy Fairness</b> .....	<b>32</b>
<b>Increase Access to Health Coverage Through Medicaid</b> .....	<b>34</b>
<b>Cancer Pain Control: Advancing Balanced State Policy</b> .....	<b>39</b>
<b>Access to Colorectal Cancer Screening</b> .....	<b>42</b>
<b>Funding for Breast and Cervical Cancer Screening</b> .....	<b>44</b>
<b>Palliative Care</b> .....	<b>48</b>
<b>State Appropriations for Cancer Researching Funding</b> .....	<b>52</b>
<b>References</b> .....	<b>54</b>



## More CAN, Less Cancer

On September 1, 2012, American Cancer Society divisions across the country integrated their advocacy programs with ACS CAN. By aligning all federal, state and local advocacy efforts within a single, integrated nationwide structure, our advocacy work has become more efficient and effective, and we will sooner achieve our shared mission to save lives from cancer. Like the Society, ACS CAN continues to follow the science and supports evidence-based policy and legislative solutions designed to eliminate cancer as a major health problem. ACS CAN also remains strictly nonpartisan. The only side ACS CAN is on is the side of cancer patients.

# HOW DO YOU MEASURE UP?

2



We're closer than ever to a day when a cancer diagnosis is no longer life threatening. We have a better understanding of the causes of many cancers and what we need to do to prevent the disease. Thanks to investments in cancer research that have led to an astounding number of scientific breakthroughs, we can better treat the disease by more accurately targeting cancer cells and have improved screenings that help detect cancer earlier. Today, we also know that by living an active lifestyle, eating a healthful diet, not using tobacco products and getting recommended screenings, we can prevent nearly half of all cancer deaths.

This knowledge is powerful and has led to nearly 500 more lives being saved from this disease each day than just over a decade ago.<sup>1</sup>

But we need to do more to reduce suffering and death from cancer. This year alone, it is estimated that nearly 1.7 million people nationwide will hear the words, "you have cancer," and nearly 600,000 will die from it.<sup>2</sup> Knowing how to prevent and treat cancer won't be enough if people still don't have access to new screenings and more effective treatments or tobacco cessation services, healthy foods and safe places to exercise.

That's why it's critical to pass proven public health policies at the federal, state and local levels to prevent tobacco use and help those already addicted to quit, to protect youths from skin cancer, increase access to affordable health coverage and promote patient access to palliative care that improves quality of life during and after treatment. If we do these things, we will save lives and reduce health care costs.

## We've Made Great Progress

With limited state budgets, lawmakers are seeing the value in investing in public health. Not only does it save countless lives, but it also saves money. Cancer costs the nation's economy an estimated \$216 billion each year and research shows for every dollar spent to increase physical activity, improve nutrition, and prevent smoking and other tobacco use, the return on investment is almost \$5.60.<sup>3,4</sup>

In the last few years, legislation to increase access to palliative care and improve the quality of life of cancer patients and others dealing with chronic diseases has been implemented throughout the country. Palliative care is specialized medical care that works to treat the whole person, not just their disease, by giving patients more control and helping to take away some of the pain, fear and anxiety that many patients feel after diagnosis, during treatment and into survivorship. Just four years ago, no states had legislation to increase access to and awareness of palliative care services for patients and their families. As of July 1, 2016, 13 states have passed the American Cancer Society Cancer Action Network's (ACS CAN) model legislation with consistent, bipartisan support. That's a big win for cancer patients, their families and health care providers. Not only can this type of care preserve a patient's quality of life, but it also has been shown to save medical facilities money.

Additionally, 42 states and the District of Columbia have enacted legislation to ensure patients whose doctors recommend oral chemotherapy as the most effective treatment for them have the same access to the drug as those who use intravenous chemotherapy by requiring insurance companies to cover it in the same way with no additional cost burden. This has already improved treatment options for countless cancer patients.

Many states have also been taking action to help prevent cancer. Local city and council members have been making progress in protecting their constituents from the cancer-causing toxins found in secondhand smoke. This year, New Orleans celebrated its one-year anniversary of their city going smoke-free, and many other cities and counties have passed comprehensive smoke-free ordinances for the first time, including Farmington, Missouri; South Bend, Indiana; and Waco, Texas. California voted to strengthen its smoke-free law to cover all workplaces, and to include electronic cigarettes, because no one should have to choose between their job and their health. Today, nearly 60 percent of the United States population is protected from secondhand smoke while at work.

Finally, in just the last three years, seven states and the District of Columbia have passed legislation to protect young people from the increased cancer risk associated with indoor tanning devices – which the World Health Organization has recently categorized as “carcinogenic to humans.” Young people are especially susceptible to the harmful effects of UV radiation, so it’s critical lawmakers take action to protect them.

## There’s More Work to Do

Despite this progress, we have a long way to go in passing proven policies to reduce suffering and death from cancer and save health care dollars. Tobacco still claims the lives of 480,000 people in the United States each year, and in 2016, an estimated 178,000 cancer deaths will be caused by tobacco use.<sup>5</sup> Yet, progress in passing strong, statewide tobacco control policies has slowed recently. Pennsylvania is the only state to significantly increase its cigarette tax by one dollar or more to save lives. Since 2012, only one state has implemented a comprehensive statewide smoke-free law covering all workplaces, including bars and restaurants, and states are currently spending less than 2 percent of their revenue from tobacco taxes and Master Settlement Agreement payments on proven programs to reduce tobacco use. As a result, tobacco continues to cost the nation approximately \$170 billion in health care expenditures and more than \$150 billion in lost productivity each year.<sup>6</sup>

For the majority of Americans who do not use tobacco, weight control, healthy dietary choices and physical activity are the best

ways to prevent cancer. State lawmakers have the opportunity to make the healthy choice an easier choice while helping young people form lifelong, healthy habits by strengthening physical education requirements in schools and implementing critical nutrition standards for school meals. Encouraging healthy lifestyles from a young age will help reduce cancer diagnoses and deaths in the future.

While policies to prevent cancer are critical, it’s also important lawmakers are working to ensure those diagnosed with cancer have affordable access to the treatment they need. Access to health care is one of the most significant factors that determine the chances of surviving cancer.<sup>7</sup> It’s important lawmakers increase access to care for vulnerable populations, protect funding for programs that help uninsured individuals access cancer screenings and treatment and ensure that available health plans not only cover the drugs cancer patients need but also make it easy for consumers to understand what their coverage provides.

In 2016, ACS CAN staff and volunteers held events at nearly 50 state capitols and the District of Columbia supporting policies that help save lives from cancer. Across the country, we are working closely with lawmakers to pass comprehensive smoke-free laws, significantly increase tobacco taxes, improve the quality of life for cancer patients, prohibit the use of tanning devices for minors and guarantee access to health care and lifesaving cancer screenings. ACS CAN is encouraged by the many investments lawmakers are making in public health and we will continue to work with local, state and federal decision makers to pass and implement effective policies to prevent, detect and treat cancer.

Now in its 14th year, *How Do You Measure Up?* offers a blueprint for state and elected government officials to reduce the burden of cancer by tackling the problem at city, county and state levels, and gives a snapshot of how states are progressing on critical public health measures. We know these policies can save millions of lives, and that they’ll also significantly reduce the financial strain cancer puts on states and the nation as a whole. ACS CAN calls on lawmakers at every level of government to help us reduce death and suffering from this disease.

## How does your state measure up?

# TACKLING TOBACCO USE

## 4

The burden of tobacco use is staggering. According to the Surgeon General, more than 20 million premature deaths over the past half century can be attributed to cigarette use.<sup>1</sup> Tobacco use costs our nation \$289 billion in health care and productivity losses each year.<sup>2</sup>

We have made progress in the last few decades. Currently, 9.3 percent of youths<sup>3</sup> and 16.8 percent of adults<sup>4</sup> smoke cigarettes – lower rates than ever before. The low cigarette smoking rate among youths is proof that implementing a comprehensive tobacco control strategy works. Additionally, increased access to cessation coverage in Medicaid and private insurance plans, as well as hard-hitting media campaigns like the Centers for Disease Control and Prevention’s national Tips from Former Smokers Campaign, have supported adults in quitting permanently.<sup>5,6</sup>

However, the decline in cigarette smoking rates is only half of the story. Some young people and price-sensitive adults are turning to other tobacco products that:

1. Are less expensive because the product is not taxed at the same rate as cigarettes;
2. Are allowed to be used in places that are otherwise smoke-free; or
3. Are developed, packaged, or marketed in ways that may appeal to youths.

Currently one in four (25.3 percent) high school students and seven in every 100 middle school students (7.4 percent) use some form of tobacco product. Hookah use among youths almost doubled between 2011 and 2015, and the use of e-cigarettes among middle and high school-aged students is now more common than cigarette use.<sup>7</sup>

The American Cancer Society Cancer Action Network is pleased that the Food and Drug Administration has finalized its long overdue proposal to regulate all other tobacco products – including e-cigarettes earlier this year – and continues to urge federal and state lawmakers to combat the industry’s tactics by subjecting these products to tobacco control policies that increase the price, limit the use and help people quit.

In order to achieve a tobacco-free generation, lawmakers must continue to utilize the evidence-based solutions they have at their fingertips to reduce use of all tobacco products by young people. Research has proven what works to prevent young people from using tobacco, help more adults quit and reduce exposure to secondhand smoke. ACS CAN supports a comprehensive approach to tackling tobacco use through policies that:

1. Increase the price of all tobacco products through regular and significant tobacco tax increases;
2. Implement comprehensive smoke- and tobacco-free policies that apply to all tobacco products; and
3. Fully fund and sustain evidence-based, statewide tobacco prevention and cessation programs and increase comprehensive insurance coverage for cessation.

Like a three-legged stool, each component works in conjunction with the others, and all three are necessary to overcome this country’s tobacco epidemic. ACS CAN works in partnership with state and local policymakers across the country to ensure tobacco use is addressed comprehensively in each community. In addition to these three-legged stool tobacco policy interventions, ACS CAN pursues other policies that will prevent tobacco use. Some of these additional policies are raising the age of sale for tobacco products, restricting the sale of flavored tobacco products, and limiting the quantity and location of tobacco retailers.

## Did You Know?



According to a 2012 Surgeon General’s report, each day in the United States, more than 3,200 kids 18 years old or younger smoke their first cigarette and an additional 2,100 youths and young adults become daily cigarette smokers.<sup>8</sup>

The 2015 National Youth Tobacco Survey shows that a record-high of 3 million middle and high school students were current users (past 30-day) of e-cigarettes in 2015, while 1.4 million youths used cigars and 1.2 million used hookahs.<sup>9</sup>



## Volunteer Story



*For the past 25 years, acclaimed percussionist Tris Imboden has been the lead drummer for the band Chicago, after previously touring with Kenny Loggins, Al Jarreau, Firefall, Crosby, Stills & Nash and Neil Diamond, during a career that began in high school as a founding member of the 1970s band Honk.*

I have been a professional drummer nearly my entire life, and now I'm proud to be an ACS CAN volunteer ambassador drumming up support to increase the tobacco tax in California.

Like many musicians, my early rock-n-roll lifestyle included smoking and sundry other debaucheries. Cigarettes were far harder to give up than anything else. I believe doctors when they say it is worse than heroin to kick.

Ultimately, I paid the price. In 2008, a decade after quitting, I was diagnosed with Stage IIIA lung cancer. I endured grueling treatment including radiation, chemotherapy and surgery to remove two lobes of my right lung.

I vowed that if I beat cancer, I'd join efforts to fight the devastating disease. And what more powerful way to help out than by meeting with lawmakers and the media to promote tobacco reforms in my home state of California.

I want to keep kids from a lifetime of addiction to nicotine and raising the tobacco tax will help do that. So on the mornings of concerts, when Chicago is performing in California, you'll find me inviting local reporters backstage to talk about the \$2 per pack tobacco tax.

I'm one of the lucky ones. I still surf off the coast of Malibu. I still entertain Chicago fans. But my mother lost her battle with tobacco and many of the cancer patients I grew close to during my treatment didn't survive. I've been given a mission and will add my voice to the ACS CAN volunteers I now call my friends as we work to make a difference.

*Rock-n-Roller Tris Imboden, Malibu, California  
Emboldened by His New Role as ACS CAN Ambassador*

**Hookah**, which uses an indirect heat source (such as lit charcoal) to slowly burn tobacco leaves, has gained popularity among youths and young adults in the U.S. in recent years. Despite common misconceptions, hookah is not a safe alternative to cigarettes and other combustible tobacco products.<sup>10</sup>

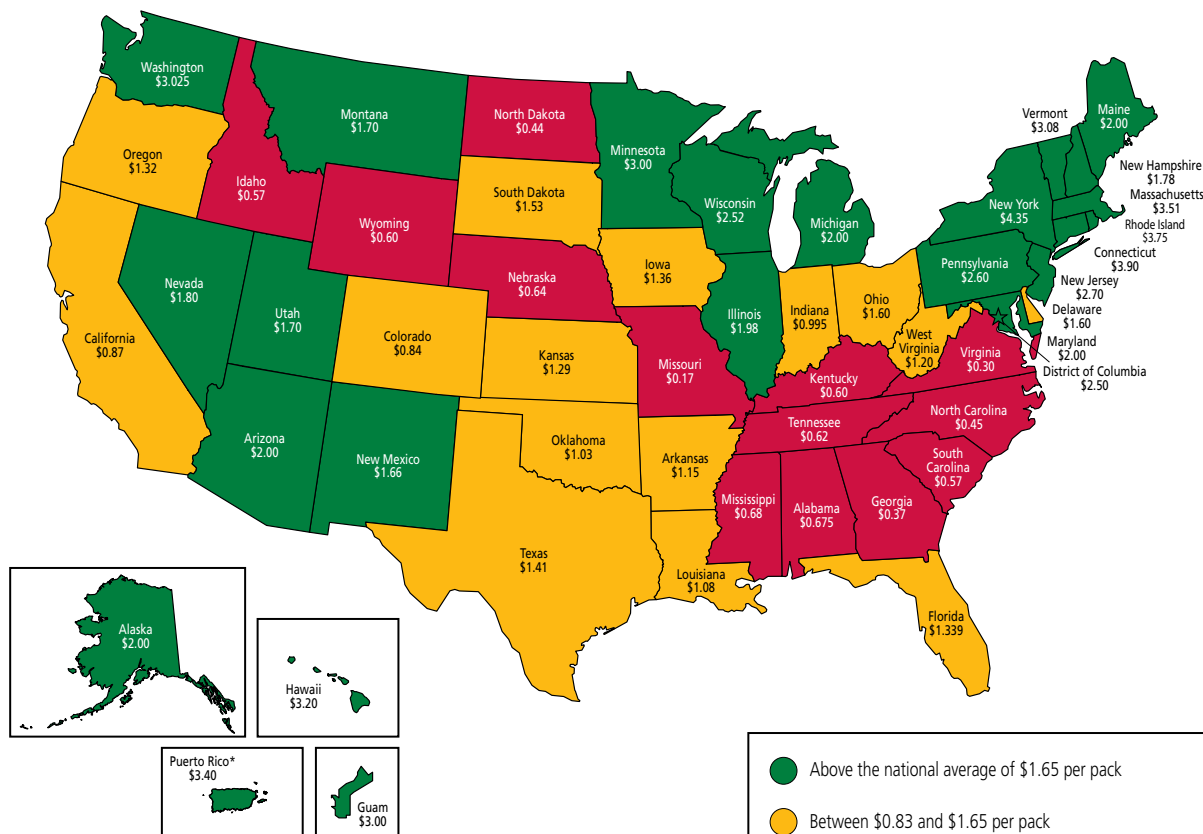
From 2011-2015, hookah use significantly increased among high school students (4.1% to 7.2%) and middle school students (1.0% to 2.0%).<sup>11</sup>

**ACS CAN supports the regulation of all tobacco products and the passage of strong smoke-free laws to protect people from the harms of secondhand smoke from all tobacco products.** Hookah bars should not be exempt from smoke-free laws that prohibit smoking in public places, including workplaces, restaurants and bars.

# TOBACCO EXCISE TAXES

6

## State Cigarette Excise Tax Rates



## How Do You Measure Up?

Only taxes in the 50 states and DC in effect as of 7/15/16 are included in the national average.  
 \*2015, Lexis Juris.  
 As of 8/1/16

## The Challenge

By increasing taxes on cigarettes, regular cigars, little cigars, smokeless tobacco and all other tobacco products (OTP), states can save lives, reduce health care costs and generate much needed revenue. Evidence clearly shows that raising tobacco prices through regular and significant excise tax increases encourages tobacco users to quit or cut back and helps prevent young people from ever starting to use tobacco.

The American Cancer Society Cancer Action Network advocates for regular, significant increases in excise taxes on cigarettes and OTP, and urges legislators to reject any proposals to roll back tobacco taxes. As of August 1, 2016, the average state cigarette excise tax is \$1.65 per pack, but state cigarette excise tax rates vary widely, from a high of \$4.35 per pack in New York to a low of 17 cents per pack in Missouri. Since 2000, all but



three states – California, Missouri and North Dakota – have raised their cigarette taxes in at least 130 separate instances.<sup>1</sup> However, progress in increasing cigarette and OTP tax rates has stalled in recent years.

## The Solution

Many state lawmakers have recognized the public health and economic benefits of tobacco tax increases, as evidenced by the fact that 35 states plus the District of Columbia, Guam and Puerto Rico, have raised their cigarette tax rates in the last decade, and 15 states, the District of Columbia, Puerto Rico and Guam have cigarette taxes of \$2 or more per pack. ACS CAN challenges states to raise cigarette and OTP taxes regularly and significantly, as research shows this is the best way to curb tobacco use. ACS CAN recommends increasing cigarette taxes by a minimum of \$1 per pack to have a meaningful public health impact. States should also tax OTP at a rate equivalent to the state's tax on cigarettes. Additionally, dedicating tobacco tax revenues to tobacco prevention and cessation programs, along with other programs that help prevent cancer and benefit cancer patients, can help to amplify the benefits of a tax increase and further reduce suffering and death from tobacco-related diseases.

## Measuring the Public Health and Economic Benefits of State Tax Increases

ACS CAN, in partnership with the Campaign for Tobacco-Free Kids, has developed a model to estimate the public health and economic benefits of meaningful increases in state cigarette excise taxes. The model can predict the amount of new annual revenue from increases in the state's cigarette tax, as well as the following public health and economic benefits:

- Reduction in adult smokers;
- Reduction in future smokers;
- Adult smoker and future smoker premature deaths prevented;
- Smoking-affected births prevented;
- Lung cancer health care cost savings;
- Heart attack and stroke health care cost savings;
- Smoking-affected pregnancy and birth-related health care cost savings;
- Medicaid program savings for the state; and
- Long-term health care cost savings.

State-specific projections are available upon request.

## A Win-Win-Win for States

Regular increases of \$1 or more in the price of cigarettes – and parallel increases in the price of other tobacco products – are a win-win-win for states.

**Saves Lives** - Regular and significant tobacco tax increases are one of the most effective ways to reduce tobacco use and, therefore, suffering and death from tobacco-related diseases like cancer.

**Saves Money** - Significant increases to cigarette and tobacco taxes result in substantial revenue increases for states.

**Voters Approve** - National and state polls consistently have found overwhelming public support for tobacco tax increases. In fact, many polls have shown voters are more likely to support a candidate that supports increasing the price of tobacco.

## Missed Opportunity

Raising the tobacco tax on all tobacco products is one of the best strategies for preventing kids from using tobacco products and getting adults to quit. Tobacco tax revenue can fund important state and local tobacco prevention and control programs, as well as other health programs, and can fill state budget gaps. The tobacco industry and its allies know that a tobacco tax, especially when coupled with comprehensive smoke-free laws and a well-funded state tobacco control program, will reduce the number of current and future tobacco users, striking a blow to the industry's financial bottom line. Despite our efforts to increase state cigarette taxes by at least \$1 per pack, legislatures in Louisiana and West Virginia caved to industry pressure and adopted much lower increases. Alaska and Indiana have yet to take action on increasing their tobacco taxes and ACS CAN volunteers and staff, along with coalition partners, are educating lawmakers in these states about the importance of raising the tax on cigarettes and other tobacco products by at least \$1 or more. We emphasized that income from higher tobacco taxes not only could help fund vital health programs but also provides a very predictable revenue stream for states. ACS CAN plans to double-down on our efforts to urge lawmakers across the nation to pass laws supporting this important policy during the next legislative session.

## The Importance of Tax Parity for All Tobacco Products

**As states increase taxes on cigarettes and smoking rates decline, increasing taxes on all other tobacco products to achieve tax parity takes on greater importance.**

### Flavored Cigars

In 2014, among middle and high school students who used cigars in the past 30 days, 63.5% reported using a flavored cigar during that time.\*



### Smokeless Tobacco

Smokeless tobacco, consumed orally or nasally, increases the risk of cancer and leads to nicotine addiction.



### Electronic Cigarettes

Electronic cigarettes, or e-cigarettes, allow users to inhale an aerosol filled with nicotine, flavors and other chemicals.



### Cigarettes

Cigarettes are often taxed at a much higher rate than other tobacco products (OTP). ACS CAN urges states to raise taxes on all tobacco products regularly and significantly, as research shows this is the best way to curb tobacco use.

All OTP should be taxed at the same rate as cigarettes to encourage smokers to quit rather than switching to lower-priced alternatives.



### Little Cigars

Lower tax rates make little cigars appealing to young smokers.



### Large Cigars

Manufacturers can manipulate weight to evade higher taxes.



### Hookah

Secondhand hookah smoke poses equal or greater danger than secondhand cigarette smoke.\*\*



**Recent research shows cigarette taxes must increase by a minimum of \$1.00 per pack to have a meaningful public health impact.**

**By increasing taxes on all tobacco products, states can save lives, reduce health care costs and generate much needed revenue.**

\* Corey CG, Ambrose BK, Apelberg BJ, and King BA. Flavored Tobacco Product Use Among Middle and High School Students — United States, 2014. *MMWR* 2015;64:1066-1070.  
\*\*Barnett TE, Curbow BA, Soule EK, et al. "Carbon Monoxide Levels Among Patrons of Hookah Cafes". *American Journal of Preventive Medicine* 2011; 40(3): 324-328.

## Achieving Tax Parity

As states increase taxes on cigarettes and smoking rates decline, increasing the tax on all OTP to achieve tax parity becomes particularly important. In many states, cigarettes are taxed at a much higher rate than OTP, making the lower-priced tobacco alternatives – such as cigars, snus and newer

products such as dissolvable orbs – more appealing to youths.

Young people are particularly price sensitive, and are most likely to be impacted by price differential.

### *ACS CAN Position on Raising the Minimum Age of Sale*

The American Cancer Society Cancer Action Network (ACS CAN) supports raising the minimum age of sale of all tobacco products to age 21 with strong retailer compliance and active enforcement as part of its comprehensive strategy to reduce youth initiation. It is important to evaluate each proposal as the tobacco industry has specifically used minimum age of sale laws to weaken restrictions on sales to youths, penalize youths, create carve outs for certain products, and to interfere with other effective tobacco control policies. As such, ACS CAN supports legislation that will best protect youths, and not benefit the tobacco industry, when raising the minimum age of sale to the age of 21.

For any legislation raising the minimum age of sale to 21, ACS CAN recommends including the following provisions that:

- Cover all tobacco products, including electronic cigarettes;
- Provide public education and training and technical assistance to retailers;
- Implement measures for active enforcement, such as retailer licensing and penalties, including license suspension and revocation;
- Do not create categories of products, which could exempt them from other tobacco control laws;
- Do not penalize youths; and
- Do not preempt other jurisdictions from passing strong tobacco control laws.

Most importantly, raising the minimum age of sale to 21 for all tobacco products must be a part of a strong, comprehensive tobacco control strategy to adopt evidence-based programs and policies.

### *Impact of Raising the Minimum Age of Sale*

Tobacco initiation and use by youths and young adults can be substantially reduced by the most effective tobacco control strategies, including increasing the price of tobacco products through regular and significant cigarette and other tobacco product taxes, implementing comprehensive smoke-free and tobacco-free laws and policies for all public places, and fully funding evidence-based tobacco prevention and cessation programs. Restricting youths and young adult access to tobacco products can be a critical component to a comprehensive strategy to reduce initiation and lifelong addiction. Laws intended to restrict the commercial access of youths to tobacco products are only effective when combined with interventions to educate retailers, mobilize the community, and actively enforce the laws. Raising the minimum age of sale to 21, coupled with these additional interventions, has the potential to reduce the initiation of youths and young adults to tobacco products.

# SMOKE-FREE LAWS

10

## The Challenge

According to the U.S. Surgeon General,<sup>1,2</sup> there is no safe level of exposure to secondhand smoke. Secondhand smoke contains approximately 70 known or probable carcinogens<sup>3</sup> and more than 7,000 substances, including formaldehyde, arsenic, cyanide and carbon monoxide.<sup>4</sup> Each year in the United States, secondhand smoke causes 42,000 deaths among nonsmokers, including 7,300 lung cancer deaths.<sup>5,6</sup> It can also cause or exacerbate a wide range of other adverse health issues, including cardiovascular disease, stroke, respiratory infections and asthma.

As of July 1, 2016, 25 states, Puerto Rico, the U.S. Virgin Islands, the District of Columbia and 822 municipalities across the country have laws in effect that require 100 percent smoke-free workplaces, including restaurants and bars.<sup>7</sup> Sixteen of these states, plus Puerto Rico and the U.S. Virgin Islands, also include gaming facilities in their comprehensive smoke-free laws. Combined, these laws protect nearly 60 percent of the U.S. population.<sup>8</sup>

Unfortunately, progress in passing comprehensive statewide smoke-free laws has slowed in recent years. Only one state,

## Success Story

In April 2016, the California Legislature passed the most significant tobacco control legislation in the state in nearly two decades which was signed into law in May by Governor Jerry Brown. The legislature and Governor Brown's leadership puts California at the forefront of the modern tobacco control movement once again, and elevates the critically important issue of preventing the next generation from becoming addicted to the latest tobacco products marketed to youths.

Overall, enormous progress was marked by these new laws to curb youth tobacco consumption and prevent future addiction, regulate e-cigarettes and fund efforts to enforce youth tobacco access policies.

ACS CAN recognizes Governor Brown and the California Legislature for taking historic steps to address the public health scourge of our time and rein in the tobacco industry that will result in lives and taxpayer money saved. This success in California also has a nationwide impact. Closing the exemptions alone in the state's smoke-free workplace law and the continued passage of laws at the local municipal level means that nearly 60 percent of the U.S. population is now covered by smoke-free laws in all workplaces including restaurants and bars. This is up from 49.8 percent of the population covered in 2015.

ACS CAN staff and volunteers worked with coalition partners to build support for the following bills that were signed into law and went into effect on June 9, 2016.

**SB 5 X2** by Senator Mark Leno classifies e-cigarettes as tobacco products. This will make them subject to state smoke-free laws, age restrictions and other rules governing tobacco products.

**SB 7 X2** by Senator Ed Hernandez raises the minimum age of sale for tobacco products from 18 to 21.

**AB 7 X2** by Assemblymember Mark Stone closes loopholes in the state's smoke-free workplace law.

**AB 9 X2** by Assemblymembers Tony Thurmond and Adrin Nazarian requires all schools to be tobacco-free.

**AB 11 X2** by Assemblymember Nazarian increases tobacco retail licensing fees and protects funding for the state's tobacco control program.

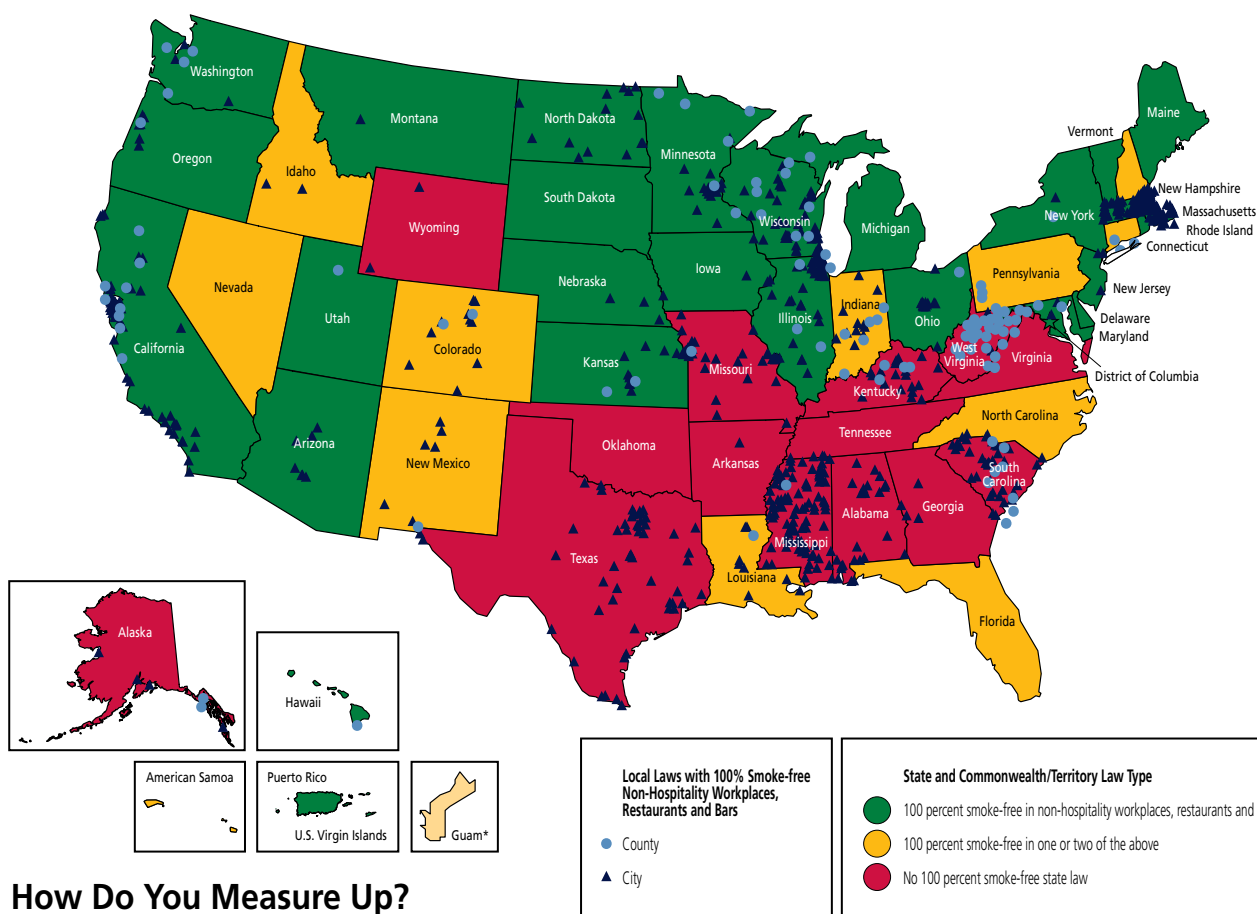


California (see success story), has implemented a comprehensive statewide smoke-free law protecting all workers' rights to breathe smoke-free air at work. As a result, certain segments of the population, such as hospitality and gaming facility workers in states or communities without comprehensive laws, continue to be denied their right to breathe smoke-free air. The American Cancer Society Cancer Action Network (ACS CAN) believes everyone has the right to breathe smoke-free air and no one should have to choose between their health and a paycheck.

## The Solution

The best way to reduce exposure to secondhand smoke is to make all public places, including workplaces, restaurants, bars and casinos, 100 percent smoke-free. Smoke-free laws reduce exposure to secondhand smoke, encourage and increase quitting among current smokers and reduce health care, cleaning and lost productivity costs.<sup>9, 10, 11</sup> Smoke-free laws also reduce the incidence of cancer, heart disease and other conditions caused by smoking and exposure to tobacco smoke.<sup>12</sup>

### Smoke-Free Legislation at the State, County and City Level



Note: American Indian and Alaska Native sovereign tribal laws are not reflected on this map.

\*Legislation goes into effect in 2017.

Source: American Nonsmokers' Rights Foundation U.S. Tobacco Control Laws Database(c)  
In effect as of July 1, 2016

ACS CAN urges state and local officials to pass or maintain comprehensive smoke-free laws in all workplaces, including restaurants, bars and gaming facilities, in order to protect the health of all employees and patrons. However, despite the evidence of the positive impact of the laws on people's health, legislators in several states are considering repealing or weakening existing smoke-free laws by adding exemptions for places such as cigar bars, hookah bars and gaming facilities. Policymakers are encouraged to reject legislation that weakens smoke-free laws or restricts a lower level of government from enacting stronger smoke-free laws than exist at a higher level of government. Preemption laws slow and prevent future progress to protect all workers from the cancer-causing toxins in secondhand smoke.

ACS CAN also recommends including electronic cigarettes, or e-cigarettes, in smoke-free laws. E-cigarettes are battery-operated devices that allow users to inhale an aerosol produced from cartridges filled with nicotine, flavors and other chemicals.

E-cigarettes often resemble traditional cigarettes, making it difficult for business owners to distinguish between the two and making enforcement of smoke-free laws difficult. As a result, ACS CAN advocates that states should prohibit the use of e-cigarettes in all venues where smoking is prohibited – including workplaces, restaurants, bars and gaming facilities.

## Did You Know?



- Tobacco smoke contains more than 7,000 chemicals, including hundreds that are toxic and about 70 that can cause cancer.<sup>3</sup>
- As of 2012, 58 million non-smoking Americans were exposed to secondhand smoke.<sup>13</sup>
- Lost productivity from exposure to secondhand smoke is estimated at \$5.6 billion per year.

## Volunteer Story



I am a musician, ambassador for the preservation of Zydeco music, advocate for a smoke-free Acadiana, and a cancer survivor. I was diagnosed with cancer at age 32 after years of playing in venues filled with secondhand smoke. My diagnosis made it clear to me that efforts to create a healthy performance environment and community can't be ignored and I'm grateful to the many other musicians who have been active and vocal supporters of smoke-free ordinances across Louisiana. It's for my own right and the right of all my musician colleagues to breathe smoke-free air while we work that I took a stand during smoke-free New Orleans, Lafayette and a number of other statewide Louisiana tobacco campaigns, encouraging all Louisiana businesses, events and facilities to go smoke-free. My band, *Same Ol 2 Step*, and I were the first to request and receive a smoke-free venue at Whiskey River, a well-known smoke-filled Louisiana dancehall for Zydeco music, and we have been advocating for smoke-free environments for musicians for a number of years.

I am passionate about Zydeco music and proudly play the music my grandfather played and listened to. This music is part of my heritage and I want my children to know and enjoy Zydeco music and culture for many years to come. My hope is by lending my voice to smoke-free campaigns and tirelessly advocating for 100 percent smoke-free air policies, many other artists, musicians and Louisianans, as well as myself, can reduce exposure to toxic secondhand smoke and keep Zydeco culture alive and rocking for many generations to come.

*Wayne Singleton, New Orleans, Louisiana*

All tobacco users need access to a range of treatments to find the most effective cessation tools for them. States with comprehensive tobacco prevention and cessation programs that include a wide scope of their population experience faster declines in cigarette sales, smoking prevalence, and lung cancer incidence and mortality rates than states that do not invest in these programs. Research shows that the most effective tobacco cessation treatments

combine cessation counseling and medications approved for that purpose by the Food and Drug Administration (FDA).

The Affordable Care Act (ACA) requires Medicaid expansion plans, marketplace plans on state or federal health insurance exchanges and most private plans, including employer offered plans, to cover without any cost sharing tobacco screening and cessation services. “Grandfathered plans” are exempted because the plans were created before the ACA was signed into law.

Plans must cover at least four sessions of telephone, individual and group counseling, and at least a 90-day supply of all FDA-approved medications per quit attempt. These services must be covered without cost sharing and for at least two quit attempts per year.<sup>2</sup>

As of March 2015, West Virginia was the only state that had all FDA-approved cessation medications on the formularies for all of its marketplace plans.<sup>3</sup>

While more updated state- and plan-specific summary data are not available, the American Lung Association found that, as of August 2015, coverage for cessation medications in marketplace plans had increased and information on coverage had been made more available.<sup>4</sup> With respect to state employee plans, as of April 2016, only five states – Illinois, Minnesota, Missouri, North Dakota and Rhode Island – provided comprehensive coverage including individual, group and phone counseling and all seven FDA-approved medications.<sup>5</sup>

While progress has been made, significant barriers to accessing cessation services still exist in both marketplace and state employee plans.

Additionally, ensuring individuals on Medicaid have access to tobacco cessation services is critical. Medicaid beneficiaries have a smoking rate that is more than 50 percent higher than that of the general population – 32 percent of adult Medicaid beneficiaries ages 18-64 smoke, compared with 17 percent of adults nationwide.<sup>6</sup> Despite this high smoking rate, in 2013, only 23 percent of smokers enrolled in Medicaid nationwide received cessation medications.

Utilization of cessation services varies significantly from state to state.<sup>7</sup> When tobacco users have access to more cessation medication and counseling options and fewer barriers to accessing them, they are more likely to be able to take advantage of proven cessation services. States that accept federal funds to broaden access to health care coverage for individuals earning up to 138 percent of the federal poverty level are required to provide recommended tobacco cessation services without cost sharing to the newly eligible adults. In traditional Medicaid, cessation services must only be offered to all pregnant women at no cost.

Under the ACA, states have an incentive to improve access in their Medicaid program to preventive services with an “A” or “B” rating by the U.S. Preventive Services Task Force (USPSTF), including tobacco cessation support, in the form of a 1 percent increase in

**A TIP FROM A FORMER SMOKER**


**I quit so I'd be more than a memory to my daughter.**

Rico, age 48, California  
Gabby, daughter, age 20

After surviving cancer, Rico quit smoking. Quitting not only increased his chances of survival, it was the start of a new and happier life for him and his family. In 2013, he witnessed his daughter graduate high school and go off to college.

You can quit smoking.

For free help, call  
**1-800-QUIT-NOW.**

 U.S. Department of Health and Human Services  
Centers for Disease Control and Prevention  
[CDC.gov/tips](http://CDC.gov/tips)

#CDCTips

Rico and Gabby, 1999



## Recommendations

USPSTF's recommendations for tobacco cessation in adults, include:

- Asking all adults about their tobacco use status;
- Advising all adults to quit tobacco;
- Providing counseling for adults who use tobacco; and
- Offering FDA-approved tobacco cessation medications to adults other than pregnant women. FDA-approved cessation medications include nicotine replacement therapy, sustained-release bupropion and varenicline.<sup>8</sup>

the amount of funds the federal government provides to support the program. However, only five states – Connecticut, Indiana, Maine, Massachusetts and Missouri – provide comprehensive tobacco cessation coverage in traditional Medicaid that includes individual, group and telephone counseling and all seven FDA-approved tobacco cessation medications.

While Medicaid programs in all 50 states and the District of Columbia provide access to some tobacco cessation coverage, many gaps in coverage and barriers to accessing covered services exist. Common barriers in place as of March 2016 include limits on how long you can use certain cessation services, (38 states and the District of Columbia) annual limits to the number of times an individual can try to quit (35 states), prior authorization requirements (38 states and the District of Columbia), step therapy, which requires patients to try certain services before others, despite what's recommended by their doctor (21 states), copayments that may make cessation services unaffordable (28 states), and counseling requirements for use of medications (22 states).<sup>9</sup> Only one state – Minnesota – has no barriers to accessing cessation services.<sup>10</sup> Research has shown that these barriers reduce utilization of evidence-based cessation support, which, in turn, makes it less likely that tobacco users will successfully quit.<sup>11, 12</sup>

## The Solution

Requiring all non-grandfathered health insurance plans, employee plans and Medicaid programs to cover a comprehensive cessation benefit that includes all evidence-based treatment options will curb tobacco-related death and disease in states, and ultimately save money.

Covering tobacco cessation services for all population groups through health coverage is critical to reducing tobacco use and saving lives, especially for low-income populations that need it most.

The American Cancer Society Cancer Action Network continues to work to ensure that the full range of cessation services is covered at all levels of benefits and in all plans. In addition, state and local governments can use tobacco tax revenue to increase access to and promote cessation services.

# TOBACCO CONTROL PROGRAM FUNDING

16

## The Challenge

One of the most effective ways to reduce tobacco use long-term is to prevent it altogether. While smoking rates have declined some in recent years, nine out of 10 current tobacco users started before the age of 18, and 99 percent of adults who use tobacco started before age 26. Furthermore, as some young people are turning away from traditional cigarettes, they're shifting their use to other tobacco products. For example, while cigarette use has declined to a record low 9.3 percent of high school students, 16.0 percent now use e-cigarettes.<sup>1</sup> With this in mind, it's imperative that steps are taken to ensure programs are in place to protect the next generation from a lifetime of addiction.

The 2014 U.S. Surgeon General's report on tobacco concluded that comprehensive statewide and community tobacco control programs prevent and reduce tobacco use by keeping young people from becoming addicted and helping individuals who use tobacco to quit.<sup>2</sup> With this in mind, the report called for states to fully fund these programs at levels recommended by the Centers for Disease Control and Prevention (CDC) as part of a comprehensive strategy to accelerate progress in eliminating death and disease caused by tobacco use.

These CDC recommendations are based on the knowledge that the level of funding for and the emphasis states place on proven tobacco prevention and cessation programs over time directly influence the health and economic gains the programs are able to make. Comprehensive, adequately funded tobacco control programs reduce tobacco use, and therefore tobacco-related health care costs and death, at a higher rate than woefully underfunded or under prioritized programs.

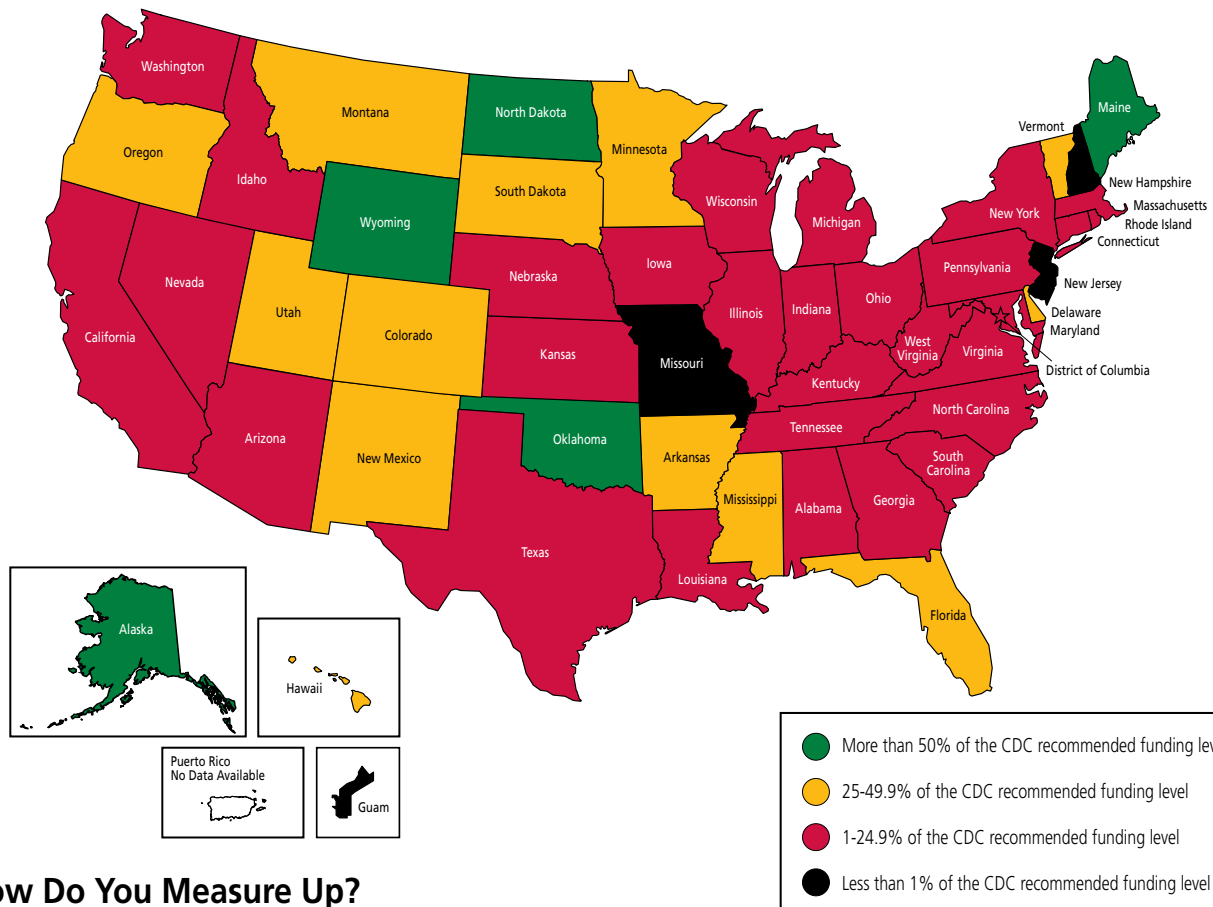
Despite this well-established link between comprehensive tobacco control programs and reductions in tobacco use, the majority of states are falling behind when it comes to adequately funding these programs. Although states are estimated to collect \$25.8 billion this year in tobacco taxes and Master Settlement Agreement (MSA) payments (billions of dollars in yearly installments the tobacco companies agreed to pay states and territories as compensation for costs associated with tobacco-related diseases), they are slated to spend less than 2 percent of those revenues on tobacco control programs.

In fiscal year 2016, states budgeted a total of \$468 million for tobacco prevention and cessation programs, more than 30 percent less than the \$717.2 million<sup>3, 4</sup> dedicated to tobacco



\*Broken Promises to Our Children, A State-by-State Look at the 1998 State Tobacco Settlement 17 Years Later, December 8, 2015, <http://truthinitiative.org/sites/default/files/Broken%20Promises%20to%20Our%20Children%202012.7.15.pdf>

## Fiscal Year 2016 State Funding for Tobacco Control



## How Do You Measure Up?

Sources: Robert Wood Johnson Foundation, Campaign for Tobacco-Free Kids, American Cancer Society Cancer Action Network, American Heart Association, American Lung Association, and Americans for Nonsmokers' Rights. *Broken Promises to Our Children: A State-by-State Look at the 1998 State Tobacco Settlement 17 Years Later*. December 2015. Available at <http://www.tobaccofreekids.org/microsites/statereport2016/>. Centers for Disease Control and Prevention (CDC). *Best Practices for Comprehensive Tobacco Control Programs — 2014*. Atlanta: U.S. Department of Health and Human Services, CDC, National Center for Chronic Disease Prevention and Health Promotion, Office on Smoking and Health. 2014. Current annual funding includes state funds for FY2014 and does not include federal funds directed to states.

control funding eight years ago.<sup>5</sup> At the same time states are reducing funding for programs to combat tobacco use, the tobacco industry is ramping up its manipulative marketing tricks to addict young people and create a new generation of lifetime customers. This year alone, the tobacco industry will spend \$9.6 billion marketing their deadly products nationwide.

Furthermore, the \$468 million in state-budgeted funds represents only about 14 percent of the CDC-recommended

level of funding for statewide tobacco control programs. Only one state – North Dakota – currently funds its program at the CDC-recommended level. Only four additional states – Alaska, Maine, Oklahoma and Wyoming – fund their programs at even half the CDC-recommended level. It would take no more than 13 percent of annual state tobacco tax and settlement revenue to fund all states' programs at CDC-recommended levels.<sup>6</sup>



The current low funding levels threaten the viability of state tobacco control programs that promote the health of residents, reduce tobacco use and provide services to help people quit.

## The Solution

Comprehensive, adequately-funded tobacco control programs reduce tobacco use and tobacco-related disease, resulting in reduced tobacco-related health care costs. To help states implement effective tobacco control programs, the CDC lays out its evidence-based recommendations for state investment in tobacco control in the recently-updated edition of *Best Practices for Comprehensive Tobacco Control Programs*.<sup>7</sup> The CDC recommends that comprehensive tobacco control programs consist of the following five components:

1. State and community interventions, which include supporting and implementing programs and policies to influence societal organizations, systems and networks that encourage and support individuals to make behavior choices consistent with tobacco-free norms.
2. State health communication interventions, which deliver strategic, culturally-appropriate and high-impact messages about the health impact of tobacco use.
3. Cessation interventions, which ensure that all patients are screened for tobacco use, receive brief interventions to help them quit and, if needed, more intensive counseling services and FDA-approved cessation medications, as well as telephone-based cessation quit-line counseling for all tobacco users who wish to access the service.
4. Surveillance and evaluation to monitor the achievement of overall tobacco prevention and cessation program goals and to assess the implementation and outcomes of the program and demonstrate accountability.
5. Implementation of effective tobacco prevention and control programs requires substantial funding. An adequate number of skilled staff enable programs to plan their strategic efforts, provide strong leadership and foster collaboration between the state and local tobacco control communities.



Funding statewide tobacco control programs as outlined in the CDC's best practices guide and at CDC-recommended levels will result in many fewer tobacco users and increase lives saved from premature tobacco-related deaths. California, the state with the nation's longest-running tobacco control program, has reduced lung and bronchus cancer rates four times faster than the rest of the United States.<sup>8</sup> In Washington State, an estimated 13,000 premature deaths have been prevented by reducing tobacco use through the state's tobacco control program.<sup>9</sup> In Florida, the high school smoking rate fell to just 6.9 percent in 2015, far below the national rate.<sup>10</sup> All of these states have made significant, long-term investments in tobacco control.

The American Cancer Society Cancer Action Network (ACS CAN) challenges states to combat tobacco-related illness and death by sufficiently funding comprehensive tobacco control programs at CDC-recommended levels or higher; implementing strategies to continue that funding over time; and applying the specific components delineated in the CDC's best practices guide. When considering tax increases on cigarettes and other tobacco products, states should always dedicate a portion of the funds to state tobacco control programs. The cost to fully fund state tobacco control programs is tiny compared to the cost of tobacco-caused diseases and the potential tobacco-caused health care cost savings states stand to gain in the long-term.

## Did You Know?



- States with sustained, well-funded prevention programs have cut youth smoking rates in half or even more, saving lives and reducing state health care costs.
- Major cigarette and smokeless tobacco companies spend more than a million dollars an hour on marketing in the United States.<sup>11, 12</sup>

## State Tobacco Control Funding - FY 2016

State	State Tobacco Prevention Funding Allocations (FY16)*	CDC Recommended Spending	Tobacco Prevention Spending % of CDC Recommended
North Dakota	\$10.0 million	\$9.8 million	102.0%
Alaska	\$8.8 million	\$10.2 million	86.4%
Oklahoma	\$25.0 million	\$42.3 million	59.1%
Wyoming	\$4.6 million	\$8.5 million	54.1%
Maine	\$8.1 million	\$15.9 million	50.6%
Hawaii	\$6.8 million	\$13.7 million	49.3%
Delaware	\$6.4 million	\$13.0 million	49.2%
Arkansas	\$17.4 million	\$36.7 million	47.4%
Montana	\$6.4 million	\$14.6 million	44.1%
Vermont	\$3.7 million	\$8.4 million	44.0%
Colorado	\$21.8 million	\$52.9 million	41.3%
Minnesota	\$21.5 million	\$52.9 million	40.6%
South Dakota	\$4.5 million	\$11.7 million	38.5%
Utah	\$7.1 million	\$19.3 million	36.8%
Florida	\$67.7 million	\$194.2 million	34.9%
Mississippi	\$10.9 million	\$36.5 million	29.9%
New Mexico	\$5.9 million	\$22.8 million	26.0%
Oregon	\$9.8 million	\$39.3 million	25.0%
Arizona	\$15.5 million	\$64.4 million	24.0%
New York	\$39.3 million	\$203.0 million	19.4%
California	\$65.5 million	\$347.9 million	18.8%
Idaho	\$2.9 million	\$15.6 million	18.4%
Maryland	\$8.7 million	\$48.0 million	18.2%
West Virginia	\$4.9 million	\$27.4 million	17.8%
Iowa	\$5.2 million	\$30.1 million	17.4%
District of Columbia	\$1.4 million	\$10.7 million	12.7%
Nebraska	\$2.6 million	\$20.8 million	12.4%
Louisiana	\$7.0 million	\$59.6 million	11.7%
Pennsylvania	\$13.7 million	\$140.0 million	9.8%
South Carolina	\$5.0 million	\$51.0 million	9.8%
Wisconsin	\$5.3 million	\$57.5 million	9.2%
Ohio	\$12.1 million	\$132.0 million	9.2%
Virginia	\$8.3 million	\$91.6 million	9.1%
Indiana	\$5.9 million	\$73.5 million	8.0%
Tennessee	\$5.0 million	\$75.6 million	6.6%
Massachusetts	\$3.9 million	\$66.9 million	5.8%
Kentucky	\$2.5 million	\$56.4 million	4.4%
Texas	\$10.2 million	\$264.1 million	3.9%
Connecticut	\$1.2 million	\$32.0 million	3.7%
Kansas	\$946,671	\$27.9 million	3.4%
Nevada	\$1.0 million	\$30.0 million	3.3%
Rhode Island	\$397,908	\$12.8 million	3.1%
Alabama	\$1.5 million	\$55.9 million	2.7%
Illinois**	\$3.1 million	\$136.7 million	2.3%
Georgia	\$1.8 million	\$106.0 million	1.7%
Michigan	\$1.6 million	\$110.6 million	1.5%
North Carolina	\$1.2 million	\$99.3 million	1.2%
Washington	\$640,500	\$63.6 million	1.0%
New Hampshire	\$125,000	\$16.5 million	0.8%
Missouri	\$107,380	\$72.9 million	0.1%
New Jersey	\$0.0	\$103.3 million	0.0%
Guam***	\$0.0	N/A	N/A

Source for Tobacco Prevention Funding, unless otherwise noted: Robert Wood Johnson Foundation, Campaign for Tobacco-Free Kids, American Cancer Society Cancer Action Network, American Heart Association, American Lung Association, and Americans for Nonsmokers' Rights. *Broken Promises to Our Children: A State-by-State Look at the 1998 State Tobacco Settlement 17 Years Later*. December 2015. Available at <http://www.tobaccofreekids.org/microsites/statereport2016/>.

Source for Funding Recommendations: Centers for Disease Control and Prevention (CDC). *Best Practices for Comprehensive Tobacco Control Programs - 2014*. Atlanta, GA: U.S. Department of Health and Human Services, CDC, National Center for Chronic Disease Prevention and Health Promotion, Office on Smoking and Health, 2014.

\*Only state government allocations are included in this chart.

\*\*Source for IL funding: IL Public Act 099-0491. Available at <http://www.ilga.gov/legislation/publicacts/99/PDF/099-0491.pdf>.

\*\*\*Data for Guam provided by local ACS CAN staff.

# HEALTHY EATING AND ACTIVE LIVING

20



Science shows that achieving and maintaining a healthy weight, eating a healthy diet and being physically active reduces the long-term risk of cancer, cardiovascular disease, diabetes and a host of other chronic diseases. That is why the American Cancer Society Cancer Action Network (ACS CAN) is focused on changing policies and environments to make it easier for people to consume a healthy diet and lead a more physically active lifestyle.

## The Challenge

For the majority of Americans who do not use tobacco, the greatest behavioral risk factors for cancer are weight, diet and physical activity levels. In fact, 20 percent of all cancers are tied to poor nutrition, physical inactivity and excess weight.<sup>1</sup> Excess weight increases a person's risk for many cancers, including colon, endometrium, esophagus, gall bladder, kidney, pancreas, rectum and possibly postmenopausal breast cancer.<sup>2</sup> There is also highly suggestive evidence of a link between excess weight and cancers of the cervix, liver and ovary, for multiple myeloma, Hodgkin disease and aggressive prostate cancer.<sup>3</sup>

In addition to increasing the risk for cancer and other chronic diseases, overweight and obesity place a huge financial burden on the health care system in the United States. Obesity alone costs the nation \$147 billion in direct medical costs each year, approximately half of which is paid for by federal and state

governments through Medicaid and Medicare and half by individuals and private payers.<sup>4</sup> While rates of overweight and obesity have begun to level off over the past decade, currently 70.7 percent of adults<sup>5</sup> and 31.8 percent of young people ages 2 through 19<sup>6</sup> are overweight or obese. These high rates of childhood overweight and obesity are particularly troubling because children who are overweight and obese are much more likely to remain so as adults. Increasing opportunities for physical activity and healthy eating and promoting smart choices are critical for cancer prevention.

## The Solution

The American Cancer Society's Guidelines on Nutrition and Physical Activity for Cancer Prevention recommend that individuals achieve and maintain a healthy weight; adopt a physically active lifestyle; consume a healthy diet with an emphasis on plant-based foods, like whole grains, legumes, fruits and vegetables; and limit consumption of alcoholic beverages.<sup>7</sup> The guidelines also recommend that public, private and community organizations work collaboratively at all levels of government to implement policy and environmental changes that increase access to affordable, healthy foods in communities, schools and at work; decrease access to and the marketing of foods with low nutritional value, particularly to youths; and provide safe, enjoyable and accessible places for physical activity at school, work and in local communities.<sup>8</sup>

Overall, these recommendations focus on making healthy choices easier – meaning healthy foods should be more convenient and affordable and physical activity should be more easily incorporated into a person’s daily routine.

Multi-faceted policy approaches across a population can significantly enhance nutrition and physical activity and reduce obesity rates by removing barriers, changing social norms and increasing awareness. ACS CAN stands ready to work with state and local policymakers to plan, implement and evaluate these strategies and move the nation toward a healthier future – one with less cancer.

## Setting Priorities

ACS CAN’s healthy eating and active living policy priorities include:

- Establishing science-based nutrition standards for all foods and beverages sold or served in schools
- Increasing the quality and quantity of physical education in K-12 schools, supplemented by additional school-based physical activity

- Increasing funding for research and interventions focused on improving nutrition, increasing physical activity and reducing obesity
- Reducing the marketing of unhealthy foods and beverages, particularly to youths,

ACS CAN recommends that legislators focus their efforts on changing policies in these key areas, which research shows could have a significant impact on making healthy choices easier, particularly for youths.

## Physical Education

State legislators can help to increase physical activity by setting strong requirements for physical education and physical activity in schools. The *Physical Activity Guidelines for Americans*<sup>9</sup>, the Institute of Medicine,<sup>10, 11</sup> and the American Cancer Society<sup>12</sup> recommend that children and adolescents engage in at least one hour of physical activity each day.

Quality physical education is the best way for kids to get a significant portion of their recommended physical activity,

## Volunteer Story



On March 7, 2014, I was diagnosed with Stage 3 Colon Cancer at the age of 44 and my life changed instantaneously. Within two weeks of my diagnosis, I had surgery and underwent 12 sessions of chemotherapy for eight months. The importance of a healthy diet was conveyed and reinforced to me upon diagnosis, during treatment and post chemotherapy. As I looked to change my and my family’s eating habits, I became quickly discouraged. Even as a middle class family, our new diet was difficult to afford and therefore hard to maintain. Not only did I find healthier food to be too expensive for our budget, but these foods weren’t even available in my neighborhood. I faced a number of barriers to establishing a healthy diet for my family and while I found a way to make it work, I often think of families less fortunate or more isolated and can’t imagine how difficult, and in some cases unattainable, eating healthy is for them.

As a cancer survivor, I believe that if we are going to make an effort to decrease and prevent cancer, we must do something immediately to focus on the affordability and accessibility of healthy foods in all neighborhoods. I am committed to improving access to healthy foods, not just for my family but for everyone in New York. I am an active participant in ACS CAN’s New York State advocacy efforts, and am grateful that lawmakers in New York took steps in the state’s budget to make it easier for kids and families to eat healthy. I believe that policy makers have the power to help in the effort to make healthy, available and affordable foods a societal norm. I sincerely hope that New York state continues to make healthy eating a priority in the future and that other states follow suit.

Diane Nathaniel, Brooklyn, NY

## *Why healthy eating and active living?*

ACS CAN primarily focuses on reducing overweight and obesity by improving healthy eating and active living. Changing policies and environments to make it easier for people to consume a healthy diet and lead a more physically active lifestyle are what science shows will ultimately support Americans in achieving and maintaining a healthy weight and reducing their long-term risk of cancer, cardiovascular disease, diabetes and a host of other chronic diseases.

improve their physical fitness and obtain the knowledge and skills they need to be physically active throughout their lifetimes. In addition to setting themselves up for lifelong health, children who are more active also demonstrate higher scholastic achievement, better classroom behavior, greater ability to focus and less absenteeism than their peers.<sup>13, 14, 15, 16, 17</sup> Physical education should be part of a comprehensive physical activity program, which also provides other opportunities and encourages students to be active before, during and after school. These other opportunities should supplement – rather than supplant – physical education.

School districts should be held accountable for fully implementing quality physical education and physical activity programs and policies. They should assess the quality of the program using existing tools and assess student fitness and cognitive achievement, with aggregate results being reported to parents, the community and relevant state agencies.

## **Active Transportation and Recreation**

In addition to school-based physical activity, it is important for both children and adults to have opportunities to be physically active in their communities. ACS CAN supports policies that promote safe and accessible opportunities for active transportation and recreation. Active transportation, or active travel, involves non-motorized transportation from one point to another, including walking and bicycling. Active recreation involves unstructured and structured physical activity, like hiking or playing on a playground, and other leisure physical activities

that can occur either indoors or outdoors. People who live in walkable neighborhoods or near parks or recreational facilities are more physically active than people who do not.<sup>18, 19, 20, 21</sup> ACS CAN supports state and local policies that:

- Allocate adequate long-term funding for community-based infrastructure, safety improvements and programs to improve and promote neighborhood and community walkability and bikeability, and create and improve parks and other recreational facilities;
- Provide for the design and adoption of Complete Streets policies at the state, regional and local levels as part of any transportation and community design planning policy; and
- Encourage shared use of school and community facilities and reduce or eliminate liability issues associated with these agreements.

## **Did You Know?**



- Twenty percent of all cancer cases are due to poor diet, physical inactivity, overweight and obesity.
- Children and teens who are overweight and obese are likely to remain so as adults, increasing their lifelong risk for harmful and costly diseases, including many forms of cancer.



## ***Approaches in Legislation for Improving Student Physical Fitness in Schools through Physical Education and Physical Activity***

### **Quality Physical Education**

- Using a planned, sequential K-12 physical education curriculum that adheres to national and state standards to implement physical education
- Adequate equipment, facilities, student-teacher ratios
- No waivers, substitutions, exemptions
- Taught by licensed, certified physical education teachers
- Annual professional development for physical education teachers that is specific to their field and integrates the public health model
- Include modifications or adaptations that allow physical education courses to meet the needs of disabled students rather than providing them with waivers
- Require 150 minutes of physical education per week in elementary school and 225 minutes per week of physical education in middle school and high school



### **School-based Physical Activity Should Include:**

- Daily use of classroom physical activity breaks
- An implemented school wellness policy that establishes requirements for physical activity and physical education
- An active transportation policy to and from school
- Daily elementary school recess for at least 20 minutes
- A shared use policy that makes physical activity facilities available to the community during out-of-school time
- Intramural/club/sports activities provided by the school/district



### **Assessment/Accountability**

- Fitness and cognitive assessment in physical education that is reported to parents for individual student progress and to the community and relevant state agencies in an aggregate manner
- School-based comprehensive self-assessment of physical education programs and physical activity offerings using existing tools such as the Physical Education Curriculum Analysis Tool; the results of the assessment should be integrated into the school district or school's long-term strategic planning and/or school improvement plan, and school wellness policy



## ***The Problem with Preemption***

While some states and localities have advanced policies aimed at promoting healthier foods and beverages, other states have passed laws that would prevent localities within their state from doing so. For example, a law in Kansas would prohibit localities from taking action on any policy relating to providing nutrition information such as menu labeling, preventing giveaways in restaurants, zoning to reduce food-related health disparities, and limiting the sale, distribution, serving, growing or raising of any specific foods. It is important for localities across the country to have the opportunity to put their own innovative initiatives in place that have the potential to improve nutrition, increase physical activity and decrease obesity in order to promote the health of residents. Just as is the case with tobacco control, local control to pass laws stronger than state and federal laws is essential for good public health.

## 24

Skin cancer is the most commonly diagnosed cancer in the United States, with rates continuing to rise over the past 30 years.<sup>1</sup> In 2016, an estimated 83,510 cases of skin cancer (the majority of those being melanoma) will be newly diagnosed. Millions more cases of basal and squamous cell skin cancers will also be diagnosed. In total, more than 13,650 men and women are expected to die of skin cancer this year in the United States, and 10,130 of those deaths will be from melanoma.<sup>2</sup>

Exposure to ultraviolet (UV) radiation, through sunlight and indoor tanning devices, is one of the most avoidable risk factors for skin cancer. In fact, the effects of UV radiation are so harmful that they have drawn local, state, national and international attention resulting in additional restrictions being placed on the use of tanning devices, especially among youths under age 18. The World Health Organization's International Agency for Research on Cancer (IARC) categorizes tanning devices into its highest cancer risk category – “carcinogenic to humans.”<sup>3</sup> In 2014, the FDA reclassified tanning devices to a higher risk category as a class II device.

## How Do You Measure Up?

Sources: Health Policy Tracking Service & Individual state bill tracking

† There is no medical indication for the use of a tanning device in the diagnosis or treatment of a disease.



### **Volunteer Story**

"I became involved in the Tan-Free Teens initiative in South Dakota because of my own experience; I used tanning devices as a teenager. I never imagined it would lead to a cancer diagnosis at age 26. I know the incredible peer pressure to fit in can cause teenagers to make poor choices, and I work every day to educate children about the risks of indoor tanning devices as a dermatologist. I joined the effort to prohibit indoor tanning for children in South Dakota because I don't want my children to go through what I did. No peer pressure, no exceptions, no tanning devices - period. That's our goal, and we will get there."

*Jocelyn Frohm, MD is a Sioux Falls, SD dermatologist*

resulting in improved safety measures and regulatory requirements for manufacturers, like placing warning labels on every device.

Despite the dangers, misconceptions about the risks and benefits of indoor tanning exist, due, in part, to misleading advertising and health claims put forth by the tanning industry.<sup>4, 5</sup> Youths are especially susceptible to the tanning industry's manipulative marketing tactics, as the industry frequently targets them in their marketing promotions (i.e. back-to-school, prom and homecoming specials).<sup>6</sup> This is a serious cause for concern as teens are tanning at increasingly higher rates.

The most recent data indicates that nearly one in nine high school girls used a tanning device, with numbers increasing to one in six high school girls by their senior year.<sup>7</sup> These statistics are worrisome, as studies show using an indoor tanning device before the age of 35 increases the risk of melanoma by 59 percent, squamous cell carcinoma by 67 percent and basal cell carcinoma

by 29 percent.<sup>8, 9</sup> Among teens who tanned, 58 percent also reported getting a burn from a tanning device within the past year, further increasing their risk of developing skin cancer.<sup>10</sup>

### **The Solution**

Age restriction laws that prohibit the use of indoor tanning devices for individuals under the age of 18 are effective in deterring minors from using tanning devices and help to reduce skin cancer incidence and mortality rates across the country.<sup>11</sup> Conversely, research has found that parental consent laws are not sufficient in effectively deterring minors from using tanning devices.<sup>12, 13, 14</sup> To protect youths from the harmful effects of UV radiation, laws to restrict access of tanning devices to individuals under 18 is essential, without exceptions, in every state. In addition, states need to ensure enforcement measures and oversight mechanisms are in place to guarantee youths are not gaining access to these harmful devices.

### **Missed Opportunity**

Kentucky lawmakers missed an opportunity to pass legislation protecting minors from the dangers of indoor tanning devices. In March, Senate Bill 108 passed out of the Senate Health and Welfare committee 7-2. However, in the final weeks of session, the lawmakers refused to hear the bill, citing parental consent concerns. We are proud of the work our staff, volunteers and skin cancer prevention coalition partners did to educate lawmakers on why parental consent is insufficient to protecting minors from the increased risk of skin cancer incurred by UV radiation. We hope Kentucky lawmakers will use the 2017 legislative session to put in place a law prohibiting minors from using indoor tanning devices, without exemptions. Other states that missed opportunities to protect minors this legislative session include: Arizona, Iowa, Mississippi, Oklahoma and South Dakota.

In December 2015, the Food and Drug Administration (FDA) issued two proposed rules on indoor tanning devices to protect public health through preventing the use of tanning devices by minors, raising awareness of the health risks of these devices for adults and requiring sunlamp manufacturers and tanning facilities to take additional safety measures for these devices. Some of the key changes would include:

- Restricting use of tanning devices to individuals 18 years and older;
- Requiring tanning device users to sign a risk acknowledgment certification that informs them of the health risks of using tanning devices;
- Requiring tanning facility operators to provide a copy of the user manual upon request of the user or prospective user; and
- Modifying the warning statement required to appear on the label of all tanning device products to be more prominent and easier to read.

## Why States Need to Continue to Push Age Restriction Laws for Tanning Devices

A proposed rule is not final and enforceable by law; therefore, there is no federal law currently in place to restrict minors' access to tanning devices. The FDA's proposed regulations are a great first step in acknowledging tanning devices can be harmful and can cause cancer. But it's important for state lawmakers to take action passing strong legislation to protect young people in their state from the risks associated with tanning devices now. Waiting until the FDA has finalized their rule puts lives at stake. Therefore, the American Cancer Society Cancer Action Network (ACS CAN) will continue to advocate for state age restriction laws on tanning devices.

## Success Story

During the 2016 legislative session, Kansas passed legislation protecting minors from the increased risk of developing skin cancer including melanoma. Kansas became the twelfth state along with the District of Columbia that prohibits minors (under 18 years of age) from using indoor tanning devices in commercial salons.

Thanks to the efforts of a broad coalition of medical providers, advocates and volunteers as well as legislative leadership from Representative Dan Hawkins, the measure passed both the Kansas House and Senate with strong bipartisan support. Personal stories and advocacy from skin cancer survivors and family members of Kansans who died from skin cancer were key in swaying lawmakers. After being moved by personal cancer stories, Representative Hawkins tirelessly championed the measure and prevented the addition of harmful amendments.

ACS CAN supported similar laws this year in Massachusetts and Montgomery County, MD. ACS CAN and other advocates nationwide are calling on elected officials in other states and local governments to pass legislation that will protect other minors from the dangers of tanning devices. ACS CAN thanks Governors Brownback (KS) and Baker (MA) and County Executive Ike Leggett (Montgomery County) for signing into law these life-saving legislative policies.



## Did you know?



- Each year more than 3,200 indoor tanning-related injuries (i.e. skin burns, eye injuries, lacerations, etc.) are treated in U.S. hospital emergency departments, with more than 400 of those injuries affecting individuals under the age of 18.<sup>15</sup>
- A 2014 study estimated that more than 400,000 cases of skin cancer may be attributable to indoor tanning in the United States.<sup>16</sup> Of the 400,000, approximately 6,200 cases of melanoma – the deadliest form of skin cancer – have been attributed to indoor tanning.<sup>17</sup>

### Indoor Tanning: Myth vs. Fact



#### Myth:

UV rays are essential for producing Vitamin D, an essential nutrient for good health.

#### Facts:

- Vitamin D is an essential vitamin needed for bone health.
- While the amount of UV light needed to produce enough vitamin D is minimal, it still puts a person at risk for skin cancer.
- Supplements and food are the preferable sources for vitamin D over UVR.\*

#### Facts:

- Many tanning salon employees and operators are teenagers.
- Though taught to use and operate tanning devices, they do not have sufficient information to educate users about the long- and short-term effects of using an indoor tanning device.
- A Federal Trade Commission investigation and multiple studies show tanning salon operators often make false claims to the public regarding the “benefits” of tanning.\*\*. \*\*\*

#### Myth:

Tanning device operators go through training and can properly educate users about the potential risks of tanning.



\* American Cancer Society. “Cancer Prevention and Early Detection Facts and Figures 2015”. Atlanta: American Cancer Society; 2015.

\*\* United States of America Federal Trade Commission. “In the Matter of Indoor Tanning Association, a corporation - Docket Number C-4290 Decision and Order.” May 13, 2010. Available at <http://ftc.gov/os/caselist/0823159/100519tanningdo.pdf>

\*\*\* U.S. House of Representatives Committee on Energy and Commerce Minority Staff. “False and Misleading Information Provided to Teens by the Indoor Tanning Industry – Investigative Report” February 2012.

# ACCESS TO CARE: PRESCRIPTION DRUG TRANSPARENCY AND COST-SHARING

28

## ACCESS TO CARE

Access to health care is a significant determinant of whether or not an individual diagnosed with cancer will survive. Individuals without health insurance are more likely to be diagnosed with cancer at a late stage, when the disease is harder to treat and more difficult to survive.<sup>1</sup> The American Cancer Society Cancer Action Network (ACS CAN) believes all Americans should have access to affordable, quality health insurance. In 2016, ACS CAN is focused on improving access to care through health plan transparency for consumers; prescription drug transparency and affordability; oral chemo fairness; provider network adequacy; increasing access to Medicaid; and the preservation of the Medicaid breast and cervical cancer treatment programs.

## ACCESS TO CARE: PRESCRIPTION DRUG TRANSPARENCY AND COST-SHARING

### The Challenge

In 2013, the most recent data available, costs related to cancer patient care in the United States were \$74.8 billion.<sup>2</sup> While private or public insurance provides coverage for many cancer patients, these patients often face high out-of-pocket costs due to their plans' cost-sharing requirements or coverage limitations. Unfortunately, due to a lack of transparent drug coverage information, patients often buy plans without knowing whether their drug is covered or affordable.

### Volunteer Story



In 2001, at the age of 30, I was diagnosed with ovarian cancer. To make it worse, I was uninsured at the time. As anyone can imagine, I was scared and confused, unsure of where to turn. I was facing having to undergo surgery and chemotherapy without any coverage.

But with the help of social services, I was able to receive indigent care through the Nueces County Hospital District. However, by the time I was able to start chemotherapy treatment, one month after my surgery, the cancer had already spread to my liver and the lining of my stomach. My battle continued and in 2008 I received another blow when I was diagnosed with thyroid cancer.

After my second cancer diagnosis I was at a loss for how to afford my monthly prescriptions that I needed to fight this disease. Eventually, I was able to enroll in a health plan that included prescription drug coverage and allowed me to see the actual dollar amount I would have to pay for the prescriptions I needed to treat the multiple side effects I now have as a direct result from my two cancers. Recently, the state of Texas approved a policy change that requires health plans to disclose the prescription drug coverage that is offered through their plans, including the cost that patients will have to pay for their drugs. Because of this policy change, other Texans facing cancer or other chronic conditions, will be able to evaluate their plan choices based on prescription drug coverage and cost, before they sign up. They will be able to make an informed choice about the right health plan for them, allowing them to focus on healing and surviving instead of coverage and the cost of prescriptions.

*Rebecca Esparza, Corpus Christi, Texas*

In November of 2015, ACS CAN conducted a study of cancer drug coverage in the new health insurance marketplaces and found gaps and inconsistencies in prescription drug formulary information available from health insurance companies.<sup>3</sup> The study also found that patients undergoing chemotherapy administered by a physician would find it challenging to determine if their drug is covered by the available health plans. This study included 2015 data from marketplaces in California, Florida, Illinois, North Carolina, Texas and Washington. Findings showed that coverage transparency has improved somewhat since a previous study conducted in 2014, but significant barriers remain for cancer patients.<sup>4</sup>

In addition to drug coverage transparency, ACS CAN's analysis also examined trends in patient costs for cancer drugs covered

under a health plan. ACS CAN found a continued trend of cancer drugs being placed on the highest, most expensive tier of plan formularies. The research also showed an even greater use of coinsurance assigned to cancer drugs placed on the highest formulary tier, which is often more expensive to the patient than a copayment or flat dollar amount.<sup>5</sup>

For all individuals, but particularly for cancer patients who have already been diagnosed and know which medications they need, it is critically important to have access to clear, complete and comparable information on prescription drug coverage and cost-sharing when choosing a health plan. Of equal importance is ensuring that when someone receives a cancer diagnosis, they have coverage for the drugs they need at a cost they can afford.

## Copay vs Coinsurance and Impact on Consumer Costs

**Copayment:** Flat fee a consumer pays for treatment or when prescription is filled.

**Copay Plan**



Drug A = **\$50**  
Copay  
Drug B = **\$100**  
Copay  
Drug C = **\$500**  
Copay  
**Total Cost = \$650 Per Month**

Copays allow patients to know with certainty their medical expenses.

**Coinsurance:** Percentage a consumer pays of a drug price or treatment.

**Coinsurance Plan**



Drug A **10% of ??**  
Coinsurance = drug price  
Drug B **15% of ??**  
Coinsurance = drug price  
Drug C **10% of ??**  
Coinsurance = drug price  
**Total Cost = ?? Per Month**

Coinsurance leaves consumers without the information needed to manage medical costs.

It's often difficult to determine the price of a drug or treatment that establishes the actual amount of the patient's coinsurance.

# ACCESS TO CARE: NETWORK ADEQUACY

30

## *Success Story*

In 2014, the Texas legislature passed HB 1624 which included strong formulary transparency provisions related to drug coverage and dollar cost / dollar range. The law also gave the Texas Department of Insurance the authority to pass additional regulations for the law's implementation. In early 2016, the Texas Department of Insurance proposed a strong regulation that more specifically defines the way in which health insurers must disclose full coverage and dollar cost / dollar range information for potential enrollees shopping for a health plan. ACS CAN submitted comments in support of the proposed strong regulations. Of importance for cancer patients, the law and the proposed rule require that insurers disclose coverage and dollar cost / dollar range information for drugs administered in a provider's office. Additionally, insurers must include, for each covered drug in a plan, the dollar cost / dollar range the patient will pay. This information must be displayed either on a plan's online formulary document or the insurer's web-based drug coverage search tool. This law and the proposed rule, if it is not weakened in the final rule, will greatly improve a cancer patients' ability to find a plan that covers the lifesaving treatment they need at a cost they can anticipate and afford.

## **The Solution**

ACS CAN recommends that the U.S. Department of Health and Human Services (HHS), state legislatures and departments of insurance adopt the following recommendations to improve prescription drug formulary transparency and reduce patient cost-sharing:

### **Drug Formulary Transparency Legislation/Regulations**

- Require health plans to post standardized and complete prescription drug formularies on their websites, including a list of in-office physician-administered drugs provided under the medical benefit, to make it easier for consumers to know which drugs are covered;
- Require health plans to disclose the actual dollar amount a patient would have to pay for drugs subject to coinsurance (rather than listing a percentage of the cost of the drug);
- Prohibit plans from increasing patient cost-sharing for prescription drugs during the plan year; and
- Provide robust oversight of prescription drug benefits to ensure health plan formularies are not discriminatory in how they provide coverage and cost sharing for drugs that treat serious and chronic conditions like cancer.

### **Cancer Drug Affordability Legislation/Regulations**

- Require patient costs for oral chemotherapy medications to be fair and equitable relative to the cost of intravenous chemotherapy medications covered under the plan;
- Cap patient copayments or coinsurance for specialty-tier medications;
- Define the exceptions process a patient can use to gain coverage for medically necessary drugs not covered under the plan at the same cost as a drug that is covered; and
- Allow patient cost-sharing for drugs provided under an exceptions process to count toward the patient's annual out-of-pocket maximum.

## **ACCESS TO CARE: NETWORK ADEQUACY**

## **The Challenge**

Under the Affordable Care Act (ACA), insurance companies can no longer deny coverage or charge more to patients with pre-existing conditions, and all insurance offered to individuals must cover a broad set of essential health benefits. In order to keep premiums lower, some insurance companies offer products that

limit the range of doctors and specialists available—a practice that results in what are known as “narrow networks.”<sup>6</sup>

Cancer patients often require highly specialized care to treat their specific form of cancer. When patients visit a specialist who is not included in their plan’s coverage network, their insurance company may pay for little or none of the cost of that care. In addition, patient costs for out-of-network providers do not count toward the patient’s annual out-of-pocket maximum. ACS CAN is concerned cancer patients enrolled in plans with narrow networks may face significant financial barriers to receiving appropriate care. In addition, ACS CAN is concerned that cancer patients in active treatment who are shopping for insurance coverage may not be able to accurately identify plans that cover their preferred providers and facilities at in-network rates.

Research by ACS CAN found that it would be very difficult for cancer patients in active treatment to accurately identify marketplace plans that cover their oncologist with the information provided by health plans and the marketplaces.<sup>7</sup> In addition, among the plans reviewed, 43 percent offered no out-of-network coverage.

In November 2015, the National Association of Insurance Commissioners (NAIC) updated its Network Adequacy Model Act, which when implemented by states, will provide important minimum standards for practitioners and services provided in plan networks operating in the state, including but not limited to disclosure of more accurate provider directories and protection from surprise medical bills in emergency situations. Several states, including California, Connecticut, Hawaii, Washington and the District of Columbia, have passed laws and regulations to define provider network standards for plans sold in the marketplaces, and at least 28 states and the District of Columbia have enacted laws or regulations to set provider network standards that impact a broader range of plans sold in that state.<sup>8</sup> Beginning this year, the U.S. Department of Health & Human Services (HHS) now requires plans sold in the federal marketplace to submit detailed provider network information. Despite federal and state actions that have already taken place to ensure adequate access to health care providers, many challenges still remain for patients.

## The Solution

The ACA and its implementing regulations require qualified health plans sold in federal or state marketplaces to make a provider directory available to enrollees and prospective enrollees, including information on whether in-network physicians are accepting new patients. However, many of these directories are difficult to navigate, are out of date or do not include all of the required information. In addition, these regulations often do not apply to plans sold outside of the marketplace. ACS CAN therefore urge states and HHS to:

- Apply the same network adequacy standards to all plans in the individual and small group markets, regardless of marketplace participation;
- Require standardized provider directories with requirements to update directories as soon as a provider is no longer in-network or no longer accepting new patients; and
- Require provider information be made available to consumers before they purchase a plan so shoppers can compare provider networks and choose the plan that best suits their health care needs.

Considering the risks that narrow networks pose to cancer patients, it is important that states and HHS closely monitor the impact these plans are having on individuals diagnosed with serious diseases by:

- Collecting data on out-of-network requests and payments, patient complaints and coverage denials;
- Requiring an exceptions process to allow enrollees to access out-of-network services at in-network cost-sharing rates if no in-network providers are available within a reasonable distance or time frame; and
- Requiring that insurers count all patient costs for out-of-network providers toward the patient’s annual out-of-pocket maximum, if approval of coverage is granted by the plan.



# ACCESS TO CARE:

## ORAL CHEMOTHERAPY FAIRNESS

32

### ACCESS TO CARE: ORAL CHEMOTHERAPY FAIRNESS

#### The Challenge

Scientific advancements have increased the availability and effectiveness of oral medications for cancer treatment.

Approximately one-quarter of all oncology drugs in the development pipeline are oral medications,<sup>9</sup> and many oral chemotherapy drugs have already been approved by the U.S. Food and Drug Administration (FDA). However, health plans often require higher cost-sharing for oral chemotherapy drugs than for drugs administered intravenously (IV) by a physician. This disparity can affect patient and physician decision-

#### Volunteer Story



Like many cancer survivors, I faced a daunting, terrifying cancer diagnosis that threatened to take me from my family, my friends, my hopes and dreams, and take my very life.

I was 59 years old when I was diagnosed with stage-four metastatic stomach cancer in 2010. The prognosis was poor. I was given less than a year to live, and the reality of that sank in quickly.

At the beginning, I considered not even trying chemotherapy. "What was the point?" I thought. When I was given such a small chance at surviving this diagnosis, I wanted to spend as much time as I could with my family, feeling well and able to do the things I wanted to do. I didn't think that was possible with chemotherapy, which would leave me sick, tired and in pain, and would likely not even work.

But I soon learned about a new development in cancer treatment: Herceptin. It was originally a treatment for breast cancer; but just weeks before I was diagnosed, it had just been approved for my specific type of stomach cancer – a cancer that I wasn't expected to survive.

In addition to Herceptin, I was prescribed a couple other oral chemotherapy drugs, rather than the IV infusion that has historically been used for similar diagnoses to mine. This allowed me to save myself from multiple trips to the hospital by taking pills, three times a day.

Many people don't always understand the hurdles that come with different types of cancer treatment, until they experience it for themselves. Because I was taking oral medication, I was able to be at home and to do the things I love while being treated. While there were still side effects, I wasn't as wiped out or sore or nauseous as many are with IV chemo. I could continue going to work, traveling with my family and enjoying the lifestyle I'd always lived.

It's been disheartening for me to hear from many stomach cancer patients who can't access the oral chemo medications that gave me back some control over my life. High pharmacy co-pays have led many cancer patients to avoid choosing oral chemo altogether, forcing them to make medical decisions based on cost and not on what their doctor has recommended.

The truth is, I don't think I would have fared as well through metastatic stomach cancer if it weren't for oral chemotherapy. It gave me the strength, the confidence and the willpower I needed to push through a cancer diagnosis. It's something I wish for every person who has to hear the words, "You have cancer."

*Dr. Randy Hilliard, East Lansing, Michigan*

making about treatment options and may lead patients to forgo the best treatment for their situation. In addition, research suggests high cost-sharing for oral chemotherapy medications may lead patients to abandon treatment.<sup>10</sup>

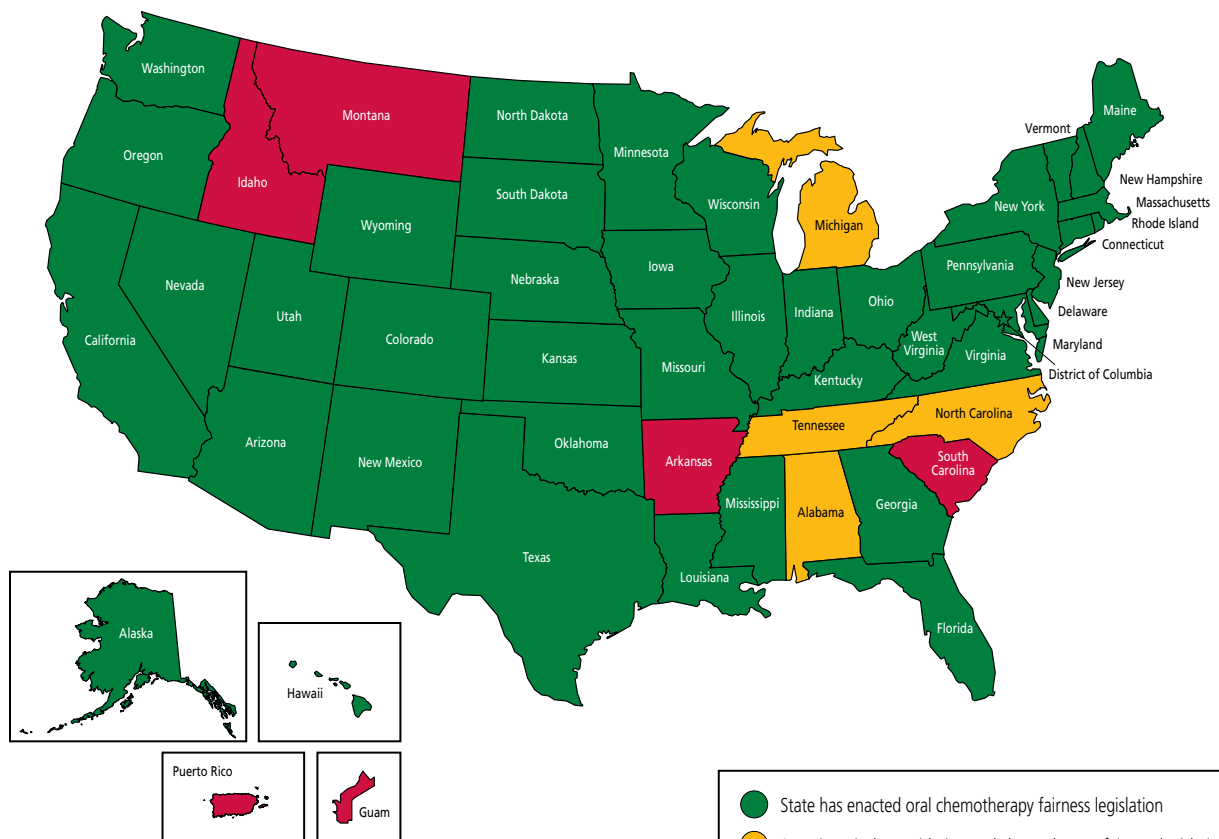
Oral chemotherapy can offer advantages to patients and caregivers, such as:

- Fewer visits to a doctor's office or cancer treatment center
- Less need to schedule long appointments for infusions

- Less worry about finding transportation to and from appointments

This flexibility is particularly important for people living in rural areas who would have to travel long distances to the nearest treatment facility, as well as for employed patients and family members who are trying to limit time away from work during treatment. Patients need affordable and accessible access to all forms of chemotherapy so their doctors can use the treatments best suited for their condition and circumstances.

## Enactment of State Oral Chemotherapy Fairness Legislation



## How Do You Measure Up?

As of May 31, 2016

# ACCESS TO CARE: INCREASE ACCESS TO HEALTH COVERAGE THROUGH MEDICAID

34

## The Solution

To date, 42 states and the District of Columbia have passed oral chemotherapy fairness legislation to help equalize patient out-of-pocket costs for oral chemotherapies and IV chemotherapies. These laws generally require state-regulated health insurance companies and group health plans to apply cost-sharing to orally administered anticancer drugs “on a basis no less favorable than” IV-administered drugs. Over time, states have added additional protections for cancer patients, such as prohibiting insurance companies from increasing IV chemotherapy cost-sharing to comply with the law.

Cancer patients’ access to anticancer oral drugs has improved as a result of these states’ legislative efforts and successes. ACS CAN applauds these state efforts and encourages all states to pursue similar legislation.

## ACCESS TO CARE: INCREASE ACCESS TO HEALTH COVERAGE THROUGH MEDICAID

### The Challenge

Medicaid is a health coverage option for lower-income Americans. It is jointly financed and administered by the federal government and the states. States have a great deal of flexibility in how they design and administer their Medicaid programs, which leads to significant variation in eligibility, benefits and coverage from one state to the next.

Historically, health care coverage through Medicaid was only available to certain eligible populations, such as pregnant women, children, some parents, the elderly, and people with disabilities. In January 2014, states were given the option of increasing Medicaid to all non-elderly adults who earn up to

### Success Story



In 2016, New Hampshire’s legislature supported bipartisan legislation that reauthorized the New Hampshire Health Protection Program (NHHPP) through 2018. The self-styled NHHPP provides 50,000 low-income, hardworking Granite Staters access to health care coverage through premium assistance, allowing individuals to enroll in health insurance plans available on the New Hampshire Marketplace Exchange. ACS CAN fought to ensure that NHHPP enrollees did not have to pay monthly premiums as a condition of enrollment and successfully advocated for reduced cost-sharing/copayments for individuals over 100 percent of the federal poverty level.

For more than a year and a half, ACS CAN staff, volunteers and coalition partners engaged members of the House, educating them about the importance of reauthorization. Survivors, caregivers, and providers offered stories, wrote and submitted letters to the editor and opinion editorials to their local papers, made calls to lawmakers and held two in-district forums, ultimately winning the support of the Speaker, Shawn Jasper. When the bill was being considered in the House, the vote was tied and Speaker Jasper cast the deciding vote. Senate leadership quickly passed the bill and ACS CAN volunteers stood proudly behind Governor Hassan as she signed the reauthorization into law.

### ***1115 Waivers: States Pursuing Medicaid Program Flexibility***

Over the past three years, a number of states have filed 1115 Research and Demonstration Project waivers requesting permission from the Centers for Medicare and Medicaid Services (CMS) to allow them to take an alternative approach to covering individuals in the newly eligible Medicaid population. ACS CAN has been actively involved in state efforts to take alternative approaches to increasing access to coverage through Medicaid by filing public comments at both the state and federal levels regarding the 1115 Medicaid expansion waivers.

ACS CAN's comments have emphasized the unique health care needs of people with cancer, including the newly diagnosed, those in active treatment and survivors. ACS CAN's primary focus has been on ensuring that these alternative approaches provide adequate access and coverage to low-income residents and do not have the effect of creating barriers to care for low-income cancer patients. ACS CAN continues to closely monitor all proposals that seek to take an alternative approach to providing coverage for the newly eligible population, and strongly advocates for policies that adequately provide coverage for individuals who will receive a cancer diagnosis, are currently undergoing treatment or are cancer survivors.

To date, the following states have received approval for 1115 Medicaid expansion waivers:

- Arkansas (approved September 2013)
- Iowa (approved December 2013)
- Michigan (approved December 2013)
- Indiana (approved January 2015)
- New Hampshire (March 2015)
- Montana (November 2015)

ACS CAN opposes the following 1115 waiver provisions:

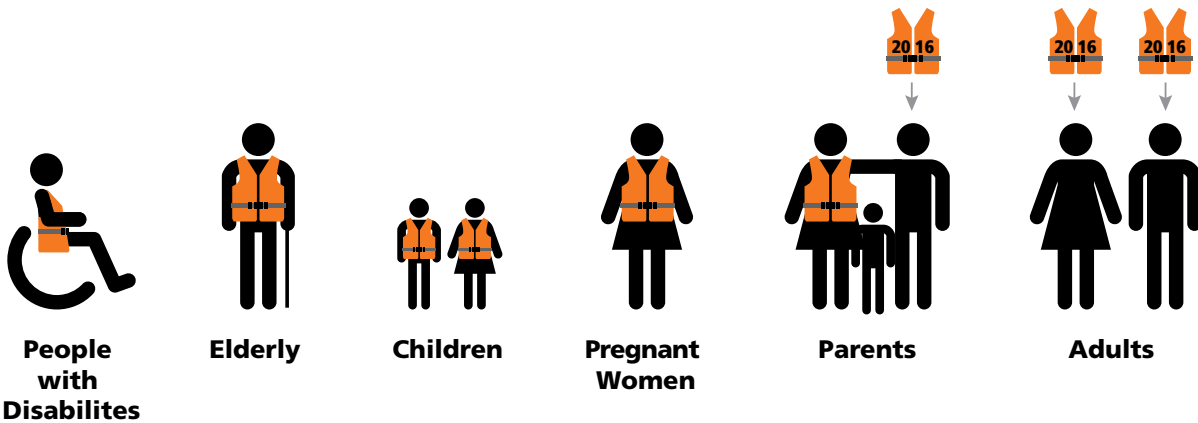
- Proposals that seek to impose various types of cost-sharing for enrollees, including premiums, copayments and the use of health savings accounts (HSAs). These approaches could render these plans unaffordable and cause cancer patients and those in active treatment to reach their plan's annual out-of-pocket limit faster than they otherwise would.
- Waivers from providing non-emergency medical transportation to newly eligible populations.
- Proposals that would result in a "lock-out" period. During "lock-out" periods, cancer patients are denied access to health insurance, making it difficult or impossible to continue cancer treatment.



## Improved Access to Health Care Coverage Through Medicaid

Historically, Medicaid has covered people with disabilities, children, the elderly, pregnant women and some parents/adults.

*As a result of the federal health care law, states have the option to broaden access to health care coverage to Americans who earn up to 138% of the federal poverty level (FPL)\**



\*For 2016, 138% of the FPL is equal to \$16,394 for an individual and \$27,821 for a family of three.

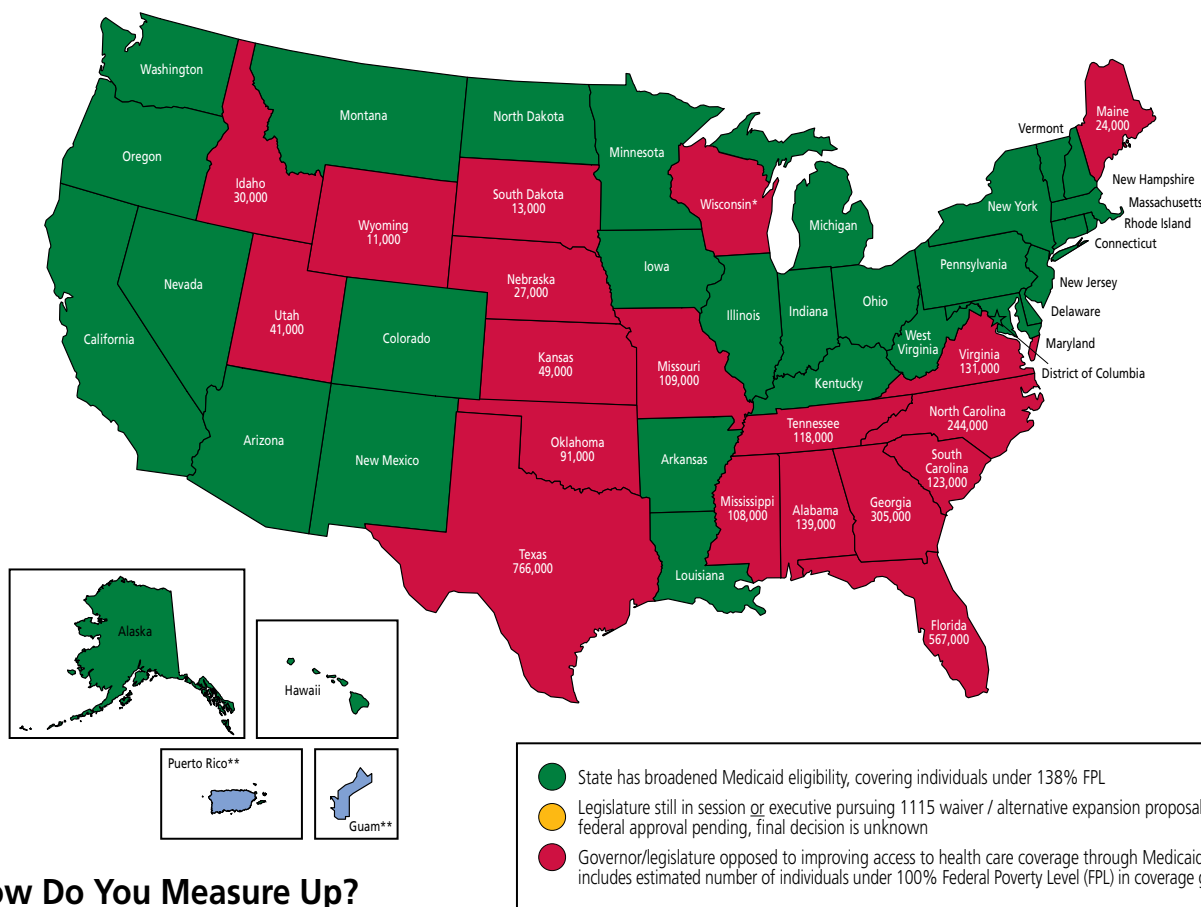
Sources: <https://aspe.hhs.gov/poverty-guidelines> and GAO -12-821 MEDICAID EXPANSION: States' Implementation of the Patient Protection and Affordable Care Act

138 percent of the federal poverty level (FPL) (or \$16,394 for a single adult in 2016).<sup>11</sup> The federal government will pay 100 percent of the states' costs to cover the newly eligible population through the end of 2016, and will pay no less than 90 percent of the cost after that. President Obama's 2017 budget proposes offering states 100 percent financing for the first three years that Medicaid access is broadened, regardless of when the state chooses to expand eligibility.<sup>12</sup>

As of January 2016, 31 states and the District of Columbia have chosen to accept federal funds to cover more uninsured people through Medicaid, resulting in more than nine million individuals gaining access to health care coverage.<sup>13</sup> However, 5.2 million low-income adults and families below the FPL will continue to lack access to affordable health care coverage solely because their states have not increased access to Medicaid.<sup>14</sup> Nearly three million of these individuals fall into the "coverage gap" – they do not qualify

for Medicaid, they earn too little to receive federal tax credits for private insurance and they cannot afford health coverage in the private market.<sup>15</sup> By refusing to increase access to their Medicaid programs, governors and lawmakers in these states are denying affordable health care coverage to state residents and are asking hospitals and providers to continue providing billions of dollars in uncompensated care.<sup>16</sup> These states are walking away from millions of dollars already set aside by the federal government to help cover these individuals – turning down an opportunity to return millions of their own federal taxpayer dollars to their state. Safety net programs and charity care for individuals and families in the coverage gap are woefully underfunded or nonexistent in many states and are seldom able to provide appropriate primary and preventive care, including cancer screening services. In addition, safety net and charity programs are rarely able to provide affordable or adequate care to treat a complex and often expensive diseases, such as cancer.

## State Decisions on Increasing Access to Health Care Through Medicaid Up to 138% FPL



Source: ACS CAN and Kaiser Family Foundation: New Estimates of Eligibility for ACA Coverage among the Uninsured

\*State provides low income residents access to health care coverage, not consistent with the provisions of the federal health care law / ACA

\*\*U.S. Territories received additional ACA funding for their Medicaid programs, however expansion of eligibility was not a requirement to receive funds.  
Updated June 2016

## The Solution

Providing low-income adults and families access to affordable, comprehensive health care coverage is critical in the fight against cancer. Governors and lawmakers have the opportunity to provide millions of Americans access to health care coverage to help detect cancers early, when treatment is more effective and less costly, and to save lives by preventing some cancers from occurring in the first place. ACS CAN encourages states

to protect and improve access to health care coverage through Medicaid by:

- Increasing eligibility to cover all individuals up to 138 percent of the FPL;

# ACCESS TO CARE: MEDICAID BREAST AND CERVICAL CANCER TREATMENT PROGRAMS

38

- Imposing reasonable cost-sharing, consistent with that allowed under the Affordable Care Act, and limiting barriers to care through high out-of-pocket cost-sharing, wellness programs that create unintended barriers, employment referral programs and lock-out provisions that deny enrollees access to care for extended periods of time;
- Adequately covering benefits and services critical to cancer patients, such as non-emergency transportation, as low-income cancer patients often do not have a car or other means of transportation to treatment and failure to provide this benefit could lead patients to skip treatment, increasing their risk of dying from cancer; and
- Providing patients managing complex, chronic conditions, such as cancer, the option to enroll in coverage designed for the medically frail, while providing greater flexibility in benefits, delivery system, care management and cost-sharing.

ACS CAN believes increasing access to health coverage through Medicaid to all low-income adults will ensure that they have access to routine cancer prevention, early detection screenings and treatment services, which may allow them to live longer, healthier lives.

Women who may still rely on the NBCCEDP include those who:<sup>18</sup>

- Reside in a state that did not increase access to coverage through Medicaid
- Have language or literacy challenges
- Qualify for an exemption from the individual mandate
- Experience coverage disruptions
- Lack knowledge or understanding of ACA coverage options

## ACCESS TO CARE: MEDICAID BREAST AND CERVICAL CANCER TREATMENT PROGRAMS

### The Challenge

On October 24, 2000, the federal Breast and Cervical Cancer Prevention and Treatment Act was signed into law, giving states the option to provide Medicaid coverage to eligible women who are diagnosed with breast or cervical cancer through the National Breast and Cervical Cancer Early Detection Program (NBCCEDP). (See page 44 for more information on the companion screening program.) Every year, through their state Medicaid program, the NBCCEDP provides tens of thousands of women access to lifesaving health care coverage through the end of their treatment.

All 50 states and the District of Columbia, five U.S. territories, and 11 American Indian/Alaska Native organizations provide cancer control and screening services through the NBCCEDP. Unfortunately, several states have considered proposals that would eliminate the treatment program. States considering the elimination of the treatment program are basing this policy change on the incorrect assumption that all women will have access to health care coverage due to the passage of the ACA, especially in states that have chosen to increase Medicaid coverage to everyone up to 138 percent of the FPL, including childless adults. However, even in the 31 states and the District of Columbia, that have increased access to Medicaid coverage, millions of women remain uninsured and are eligible for the program in 2016.

### The Solution

It's imperative that state lawmakers protect eligibility and maintain funding for lifesaving breast and cervical cancer treatment programs. Any attempts to eliminate these programs in Medicaid are premature and ACS CAN strongly opposes them. ACS CAN encourages states to monitor and evaluate the demand and continued need for their treatment programs prior to considering any proposals to eliminate eligibility for state breast and cervical cancer treatment programs.

# CANCER PAIN CONTROL:

## ADVANCING BALANCED STATE POLICY

14th Edition

39

### The Challenge

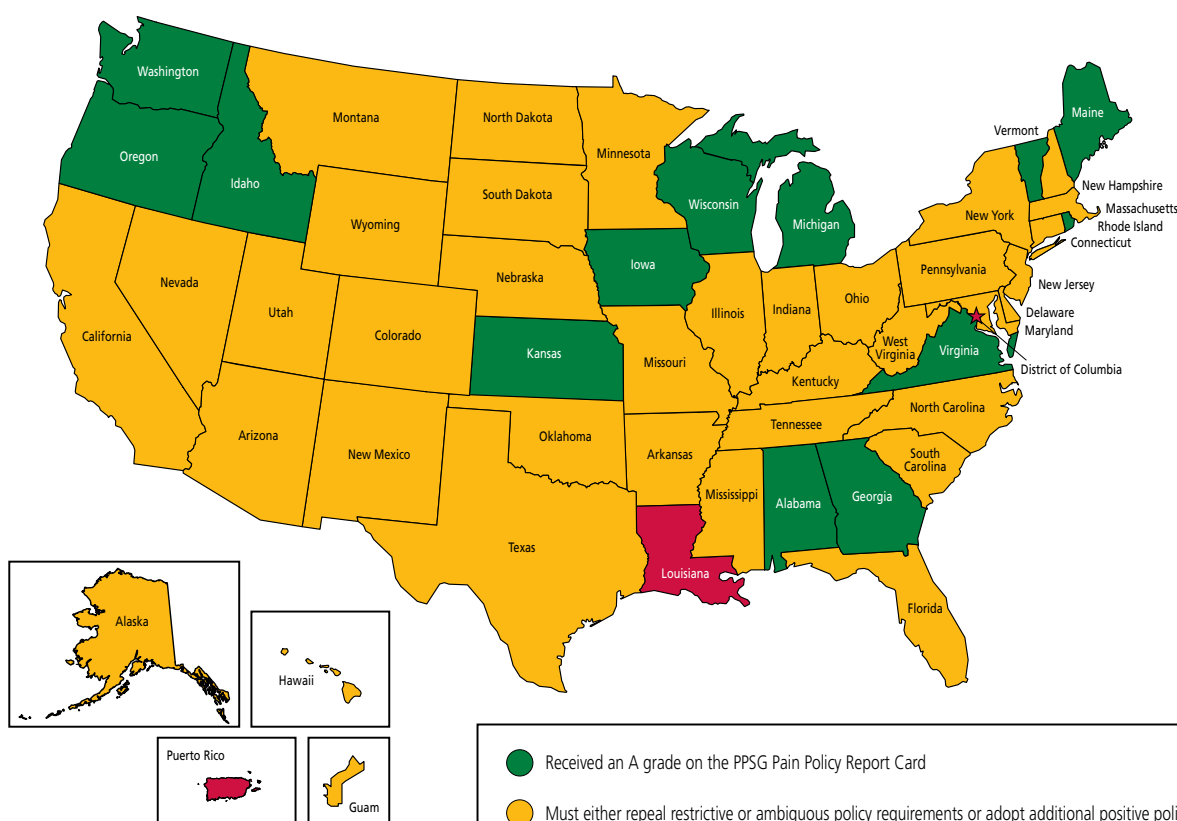
Pain remains one of the most feared and burdensome symptoms for cancer patients and survivors. Cancer-related pain can interfere with the ability of patients to adhere to recommended treatments and can devastate quality of life – affecting work, appetite, sleep and time with family and friends. But the good news is that nearly all cancer pain can be relieved.

The prevalence of pain and its inadequate treatment has remained consistently high despite the recognition that pain

relief is an integral part of comprehensive palliative care for patients. Research shows pain is still a problem for nearly 60 percent of patients with advanced disease or those undergoing active treatment, along with 30 percent of patients who have completed treatment.<sup>1</sup> Still more troubling, significant pain treatment and access disparities in medically underserved and socioeconomically disadvantaged populations continue to be documented.

Integrative pain care that includes non-drug therapies along with medications is encouraged to keep patient pain under control.

### 2015 Pain Policy in the States



### How Do You Measure Up?

Source: Pain Policy Studies Group (PPSG) at the University of Wisconsin. For more information on this report card, please visit: [www.acscan.org/painreportcard](http://www.acscan.org/painreportcard)  
As of December 31, 2015



## Success Story

In 2016, as part of a declared commitment to taking action to address the growing heroin and opioid addiction problem, Maine's Governor Paul LePage introduced legislation to place restrictions on the prescribing of opioids. The original proposal would have made it much more difficult for cancer patients to get pain medication, as the legislation included prescribing limits on both strength of dosage prescribed and prescription duration. ACS CAN quickly went to work educating legislators about the importance of taking a balanced approach that promotes safe prescribing and dispensing of pain management medication that does not interfere with access to these medicines for the patients who need them. Working with partners like the Maine Medical Association, leveraging existing relationships with trusted lawmakers, and persistent lobbying to share the impact of this proposal on cancer patients resulted in the successful passage of a balanced approach, which exempted pain associated with a cancer diagnosis, end-of-life care, and palliative care from the opioid prescribing limits.

Jeff Bennett from Portland, Maine, is a survivor of an aggressive male breast cancer – as part of his treatment, which included both surgery and chemotherapy, Jeff suffered severe and acute post-operative pain. "In the days and weeks immediately after my surgery, it would have been nearly impossible for me to go to the pharmacy every three days to refill the pain medication that was necessary to live my daily life," said Bennett, "I can't imagine how many cancer patients would be able to deal with their diagnosis and treatment if they were unable to obtain appropriate pain management, including opioids," said Bennett. "That's why ACS CAN's efforts to ensure this legislation included a balanced approach to pain management was such a lifesaver for many living with acute and chronic cancer related pain here in Maine."

While not the only tool, opioid medications are recognized as a mainstay of treatment for moderate to severe cancer pain and can be a beneficial treatment for managing serious, persistent pain in carefully selected patients. These medications provide much needed pain relief to patients, but their properties also make them subject to misuse and abuse. Deaths from overdoses of opioids has become a major public health issue.

Pressure has mounted for policymakers at both the federal and state levels to address opioid misuse and curtail the use of these medications. While inappropriate and illegal use of opioids must be reduced, it is important to simultaneously keep sight of the needs of patients who are suffering from pain. Unfortunately, policies that are targeted at reducing opioid use are sometimes developed and applied without distinguishing between legitimate and illegitimate uses, making it difficult for cancer patients and survivors to access needed pain medications, or subjecting them to stigmatization. In March of 2016, federal officials released a final opioid prescribing guideline that unfortunately was based on weak evidence and failed to balance efforts to reduce inappropriate use with the needs of patients in pain. While well-intended, this guideline will likely impede access to pain relief for cancer survivors struggling with

pain that limits their quality of life. In the current environment, it is more important than ever to create and promote balanced public policies that will make medications available to patients who need them, while also keeping those medications away from those who are likely to misuse them.

## The Solution

State policies play a significant role in whether or not balance is achieved in ensuring patient access to pain relief while controlling misuse and adverse events associated with pain medication. States should put measures in place that include the use of state prescription drug monitoring programs and examine whether pain management is encouraged or discouraged. States also should not interfere with normal medical practice by adding special requirements on prescriptions of opioid pain medicines, such as relegating them to treatment of last resort and limiting doses or duration. Many recently enacted state policies have focused solely on preventing illicit drug abuse and have therefore shifted the policy balance such that legitimate patient access to pain relief is jeopardized.

In order to ensure ongoing balance in pain policies the American Cancer Society Cancer Action Network (ACS CAN) recommends the following:

- **Develop pain policies**
  - Based on scientific evidence
  - That recognize the need to preserve access to treatment for patients in pain
- **Evaluate pain policies**
  - Using evaluation mechanisms that might take the form of task forces, commissions, advisory councils or summit meetings
  - Including pain patients and pain specialists as members of any review body
  - Appropriately balancing between providing patients access to pain medications and efforts to reduce abuse
- **Implement pain policies**
  - Educating practitioners and the public about the policies that govern pain management
  - Avoiding stigmatization of pain

While good policies are necessary, written policies by themselves can be ineffective when practitioners are unaware of them or are confused by conflicting messages.

ACS CAN continues to work with federal, state and local lawmakers to ensure pain policies strike a balanced that reduce inappropriate use of pain medications without impeding access to necessary relief for individuals fighting pain from cancer and other causes.



**The prevalence of pain and its inadequate treatment has remained consistently high despite the recognition that pain relief is an integral part of comprehensive palliative care for patients.**

# ACCESS TO COLORECTAL CANCER SCREENING

42

## The Challenge

Colorectal cancer is the second leading cause of cancer death among men and women combined in the United States. Despite the fact that colorectal cancer is one of the most preventable cancers, nearly 50,000 deaths from the disease are expected to occur in 2016.<sup>1</sup> Screening helps to detect the disease early when treatment is most likely to be successful and when, in some cases, the disease can be prevented by removal of precancerous polyps. Only approximately half of Americans between the ages of 50 and 75 are up-to-date with U.S. Preventive Services Task Force (USPSTF) colorectal cancer screening recommendations,<sup>2</sup> and it is estimated that nearly 135,000 people in this country will be diagnosed with colorectal cancer this year.<sup>3</sup> Individuals less likely to get screened are those who are younger than 65, are racial/ethnic minorities, do not receive physician recommendations for screening and face other barriers such as lower education levels, lack health insurance and are recent immigrants.

## The Solution

### 80% by 2018: A National Effort to Increase Colorectal Cancer Screening

The National Colorectal Cancer Roundtable (NCCRT), the American Cancer Society and the American Cancer Society Cancer Action Network (ACS CAN) are spearheading an initiative

to substantially reduce colorectal cancer as a major health problem by working toward the shared goal of 80 percent of adults aged 50 and older being regularly screened for colorectal cancer by 2018. More than 200,000 lives could be saved if we achieve the 80 percent goal.<sup>4</sup> To date, nearly 1,000 state, local and national organizations have joined the effort. While many states are above the national average, with Massachusetts and New Hampshire leading the way, not one has reached an 80 percent screening rate. On the other hand, some states, specifically Alaska, Montana and Wyoming, have screening rates well below the national average and have a long way to go to reach 80 percent.<sup>5</sup>



More than 24 million adults need to be regularly screened to reach the goal of 80 percent.<sup>6</sup> ACS CAN is working with state policymakers to help make colorectal cancer screening a priority by working across all sectors to increase screening rates in their states. Specifically, state policymakers can:

- Broaden access to health care coverage and health insurance programs, such as Medicaid.

## Success Story

In 2015, Governor Earl Ray Tomblin of West Virginia committed to using his position and office to raise awareness about colorectal cancer and to help in the effort to reach the goal of 80 percent screening rate by 2018. Governor Tomblin was the first governor in the nation to sign the 80% by 2018 pledge and he took advantage of his role as host of the National Governors Association (NGA) Summer Meeting, to speak about colorectal cancer, the 80% by 2018 movement and encouraged other governors to get involved. Through collaborative efforts between ACS CAN, the Society and other partners in cancer control and prevention, West Virginia hosted a state colorectal cancer summit and has had more than 60 partners sign the 80% by 2018 pledge. Because of his commitment, Governor Tomblin was recognized by the National Colorectal Cancer Roundtable (NCCRT), receiving the 2015 Distinguished State Leadership Award, which was accepted by his Director of Communications, Christopher Stadelman, a colorectal cancer survivor. Governor Tomblin remains committed to 80% by 2018 and continues to support policies to improve access to health care, while reducing barriers to colorectal cancer screening and treatment services.

## Despite the fact that colorectal cancer is one of the most preventable cancers, nearly 50,000 deaths from the disease are expected to occur in 2016.

- Invest in their state's Centers for Disease Control and Prevention-funded Colorectal Cancer Control Program (CRCCP) or support the appropriation of funds to create a state colorectal cancer screening and control program. Programs should raise public awareness about colorectal cancer screening and improve access to screening, including patient navigation and treatment services, as well as should use evidence-based patient and provider interventions to promote screening and reduce barriers to eligible adults.
- Introduce and/or support legislation that will identify and eliminate cost and access barriers to colorectal cancer screening in their state to make screening more accessible.
- Support legislative and regulatory policies that require insurers to cover follow-up colonoscopies after a positive stool test and guarantee that patients do not face cost-sharing for polyp removal, anesthesia, pre-screening consultations or laboratory services related to the screening colonoscopy.
- Make sure that they are up-to-date with their own colorectal cancer screening and challenge fellow lawmakers to get screened and learn more about the 80 percent by 2018 movement.
- Utilize their public platform to raise public awareness about colorectal cancer screening on social media or in their constituent newsletter.
- Learn more about the 80 percent by 2018 movement and pledge their commitment to the effort. Learn more at: <http://nc crt.org/about/80-percent-by-2018/>.



Through collaborative efforts with state policymakers; health care providers and systems; and community and business leaders, we can reach this challenging yet achievable goal.

### Did you know?

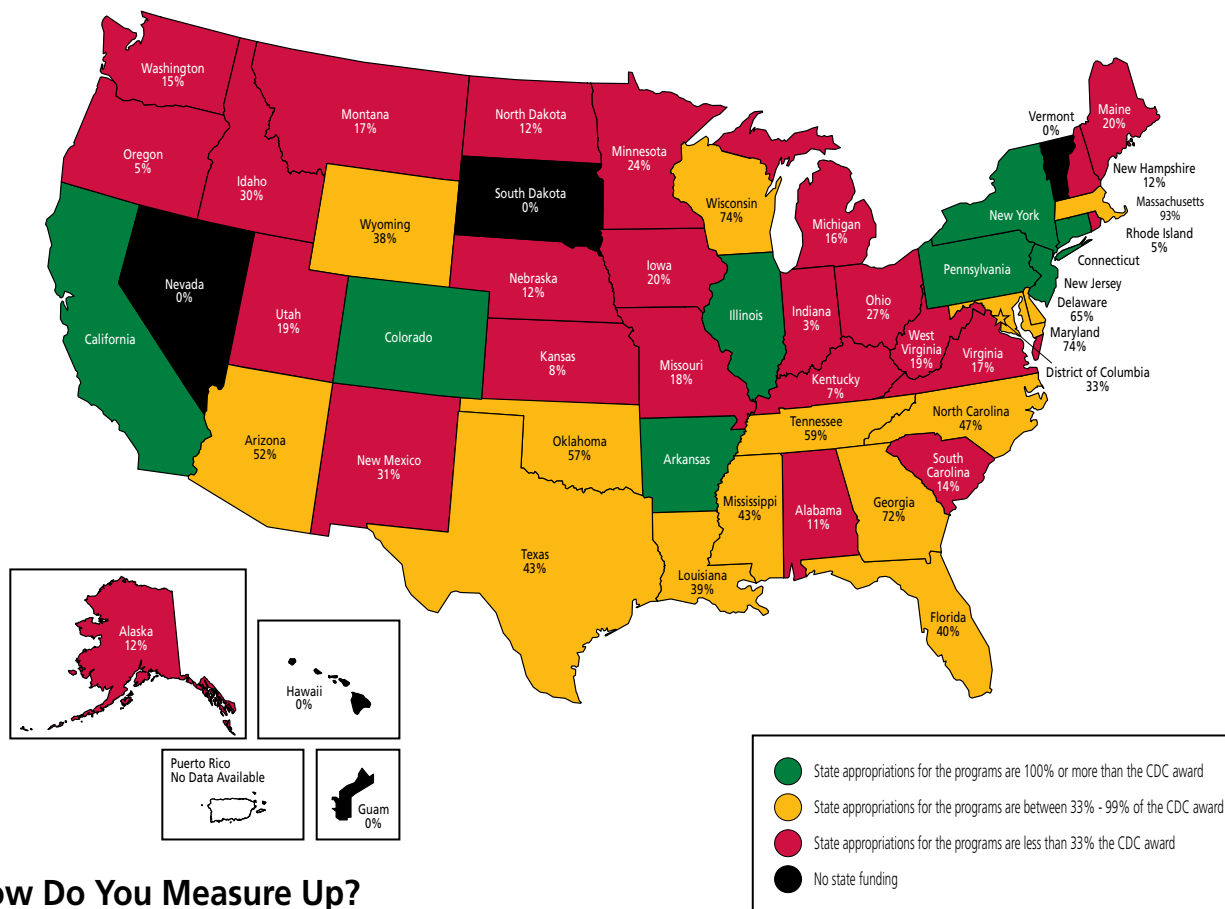


If colorectal cancer is caught at a localized stage through screening, five-year survival rates for the disease are 90 percent.<sup>7</sup> Unfortunately, only 39 percent of individuals are diagnosed at this stage, partly due to the underutilization of and inadequate access to screening.<sup>8</sup>

# FUNDING FOR BREAST AND CERVICAL CANCER SCREENING

44

## State Appropriations for Breast and Cervical Cancer Screening Programs - Fiscal Year 2015-2016



### How Do You Measure Up?

Source: 2015-2016 data from the Centers for Disease Control and Prevention and unpublished data collected from ACS CAN and ACS Divisions, including input from NBCCEDP directors.

## The Challenge

Evidence-based screenings are the most important tools for detecting breast and cervical cancer early and improving survival rates. Breast cancer is the second leading cause of cancer deaths among women. In 2016, breast cancer is expected to be diagnosed in more than 246,600 women in the United States and 40,000 women are expected die from the disease.<sup>1</sup> If detected early, the five-year survival rate is 99 percent.<sup>2</sup> When it is diagnosed at a later stage, however, the survival rate drops to only 26 percent.<sup>3</sup>

In 2016, nearly 13,000 cases of cervical cancer will be diagnosed and more than 4,000 women will lose their lives from the disease.<sup>4</sup> Cervical cancer can be prevented altogether by detecting precancerous lesions during screenings so many deaths could be avoided if cervical cancer screening rates increased among women at risk. When the cancer is diagnosed at a later stage, the survival rate drops to only 17 percent.<sup>5</sup>



Despite the effectiveness of screening in detecting cancer early and improving survival, screening rates are still not as high as they need to be. In fact, of the women who fall under the recommended screening guidelines, only 66 percent have received a mammogram in the past two years and 81 percent have had a Pap test in the past three years.<sup>6</sup> These rates are even lower among low-income, uninsured and minority women, with only 37 percent receiving mammograms and 61 percent having Pap tests.<sup>7</sup>

In 1990, Congress established the National Breast and Cervical Cancer Early Detection Program (NBCCEDP) to address

the problem of low screening rates and access issues among uninsured and underinsured, low-income women. Available in all 50 states, the District of Columbia, five U.S. territories and 11 American Indian/Alaskan Native organizations, the program has served more than 4.8 million women, detecting nearly 70,000 breast cancers, more than 3,700 cervical cancers and more than 174,000 premalignant cervical lesions.<sup>8</sup>

The NBCCEDP is more than a screening program for low-income women. Through cooperative agreements with states, territories and tribes, the program provides a range

## Impact of the Affordable Care Act on NBCCEDP

With the introduction of the Affordable Care Act, many women will be able to receive breast and cervical cancer screenings through newly acquired insurance. With this in mind, the NBCCEDP is able to work synergistically with communities in need to put a heavier emphasis on education and outreach about the importance of screening as well as monitoring screening rates, and organizing screening systems.





of important services to lower-income women with cancer, including public education and outreach; case management and patient navigation; and diagnostic and follow-up services. In addition, the NBCCEDP strives to provide quality care to the women it serves through nationally established program quality standards that evaluate quality assurance, data management and professional development.

The NBCCEDP remains an important tool in the fight against cancer. The program raises awareness among at-risk women about the importance of getting screened, it provides timely access to screening and diagnostic services and affords women diagnosed through the program access to comprehensive treatment services. The outcome of the NBCCEDP is that more women will be screened at earlier stages, when cancer survival rates are highest and costs of treatment are lowest. Unfortunately, limited federal and state funding has forced the program to turn away women in need and reduce many of the outreach and educational services provided through the program.

## The Solution

One of the most important factors for ensuring that women have access to breast and cervical cancer screenings is adequate funding of state cancer screening programs. The Affordable Care Act (ACA) has improved women's access to potentially lifesaving cancer screenings and diagnostic and treatment services, but there continues to be a critical need for the NBCCEDP. Many women with or without insurance will continue to face barriers to care and will rely on the NBCCEDP to help them get needed breast and cervical cancer screenings. A study released by the American Cancer Society Cancer Action Network (ACS CAN) and the National Colorectal Cancer Roundtable (NCCRT) estimates that in 2017 roughly 2.6 million low-income women aged 40-64 will remain uninsured and be eligible for the NBCCEDP.<sup>9</sup> Similarly, an estimated 5.7 million low-income women age 21-64 are eligible for cervical cancer screenings and services through NBCCEDP.<sup>10</sup> These women include those with geographic isolation, limited health literacy or ability to self-advocate, lack of provider recommendation, inconvenient times to access services and language barriers.

## Volunteer Story



In 2014, at the age of 50, I was without insurance coverage and told that I needed a mammogram and a follow-up ultrasound for a lump in one of my breasts. After making a trip to my local Social Services office, I was put into contact with Missouri's Show Me Healthy Women (SMHW)\* program. Through this program, I was able to get screened and was ultimately diagnosed with stage 2 breast cancer for which I am currently going through treatment.

This program saved my life. Since my diagnosis, I have met several women in the same position as me and I remind them that early screening is key and regular checkups are a must. I tell women who are putting off their screening exams for financial reasons SMHW is there to help.

I've shared my story with Missouri policy makers, urging them to support increased funding for SMHW, to preserve a critical safety net for Missouri women who lack access to essential screening, diagnostic and treatment services this year. SMHW was the ultimate gift because they said, 'We got this. Go get better.' And that's what I am doing. The stress that comes from those three words, 'you have cancer,' is incomparable to anything else. Eliminating stress is one of the most important things you can do for a cancer patient and that's what SMHW did for me.

*Margery Tomain, Missouri*

\*SMHW provides uninsured or low-income women aged 50 to 64 access to free mammograms, breast exams, pelvic exams and Pap tests which gives Missouri women access to lifesaving screening, diagnostic and treatment services.

Under the ACA, states have the opportunity to increase access to health care coverage through state Medicaid programs for Americans earning less than 138 percent of the federal poverty level. However, not all states have chosen to take advantage of this opportunity, leaving millions of low-income individuals without any affordable, comprehensive health care coverage options. In the states that have not extended eligibility for Medicaid, the NBCCEDP will remain a lifeline for low-income and uninsured women. Notably, by 2017, women in these states will be more than three times as likely to be uninsured (23.3 percent) as women in states that

have increased access to Medicaid (8 percent).<sup>11</sup> Adequate funding is necessary to continue providing benefits and services to women who have historically accessed the program for cancer screenings, but the program will also provide educational outreach and potentially lifesaving screening services to women who continue to lack an affordable health care coverage option and remain uninsured. Failure to achieve adequate funding levels will leave millions of women vulnerable to cancer diagnoses at later stages, where survival is less likely and more costly.

**Many women with or without insurance will continue to face barriers to care and will rely on the NBCCEDP to help them get needed breast and cervical cancer screenings.**

# PALLIATIVE CARE:

## QUALITY OF LIFE-FOCUSED CARE

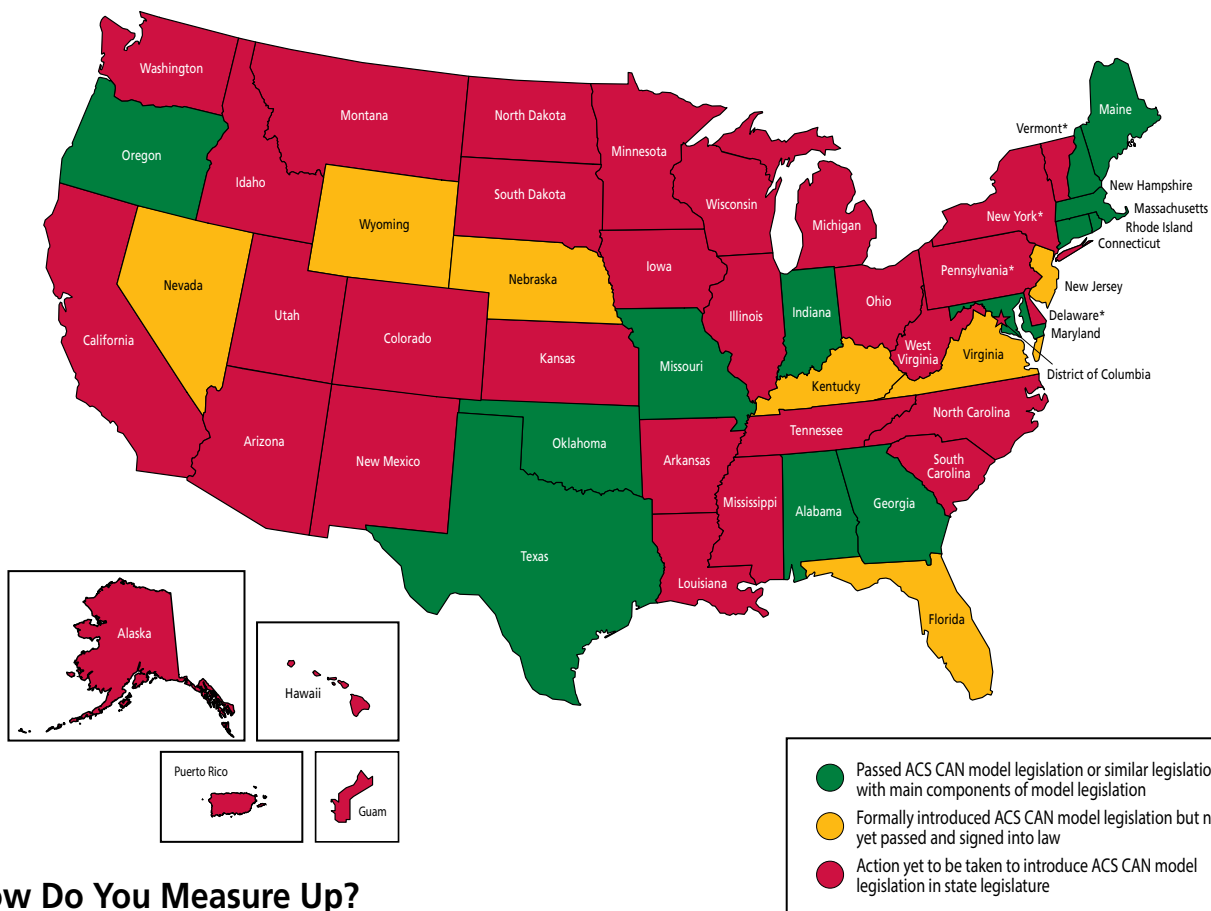
48

### The Challenge

Advances in cancer research continue to provide new and more effective treatments for cancer, but therapies do not meet all the needs of cancer patients. Focusing exclusively on treating a patient's disease can result in a failure to address the full spectrum of issues that arise as part of a cancer diagnosis and treatment. These issues include emotional distress and physical symptoms such as pain, fatigue and nausea. Fatigue, for

example, is one of the leading reasons for cancer patients to skip follow-up medical appointments, and patients suffering from side effects find it much harder to return to the workforce or engage in family activities. However, patients often do not know to ask for this type of quality-of-life-focused care, and/or have trouble accessing this care.

### Establishing a Palliative Statewide Expert Advisory Council



### How Do You Measure Up?

Source: ACS CAN  
As of May 31, 2016

\*DE, NY, PA, VT have not passed the model legislation but have statewide programs in place that closely align with the main tenets of the model legislation



## Volunteer Story



I am a two-year, triple-negative breast cancer survivor. I received two rounds of chemotherapy, radiation, a mastectomy and reconstruction surgery and I am thankful to be a survivor. But now I am living with the side effects from my cancer treatments. Following chemotherapy and my mastectomy, I was left with severe neuropathy in my hands and feet and lymphoedema in my left arm. After reconstructive surgery, I faced chronic pain and radiation left me with a great deal of fatigue.

As a mom of two daughters and a full-time pastor, the side effects of treatment made my life more difficult. Thankfully, my radiation oncologist believed in a palliative care model and during my treatment I was able to undergo acupuncture to help lessen my neuropathy and control my lymphedema, as well as massage therapy to relieve some of the chronic pain and scar tissue from the reconstructive surgery.

Unfortunately, these palliative care services were only available to me while I was undergoing treatment. Since completing my treatment, I have struggled to find the support I need to continue to live an active and productive life. It's hard to find doctors who understand how difficult these side effects can become and to find solutions that don't involve pain medication. One medication I was prescribed for my neuropathy left me barely able to function and stay awake. I refuse to survive cancer only to find myself unable to fully live out my life. For now, I live with the pain and hope that the advancement of palliative care education will allow doctors to help people like me receive palliative care throughout survivorship and therefore be able to live their lives more fully and manage their side effects.

*Jill Henning, Georgia*

## The Solution

Palliative care is specialized medical care that can provide the best possible quality of life for a patient and his or her family by offering relief from the symptoms, pain and stress of a serious illness. Palliative care is essential to achieving the goal of comprehensive, cost-effective care that improves patient satisfaction and health outcomes. Contrary to some misconceptions, palliative care is not end-of-life care – it is appropriate at any age and any stage of disease and can be provided along with curative treatment as an extra layer of support for patients.

Palliative care provides a coordinated, team-based approach among medical professionals to help meet a patient's needs during and after treatment.

The pillars of palliative care involve:

- **Time** to devote to intensive family meetings and patient/family counseling
- **Expertise** in managing complex physical and emotional symptoms such as pain, shortness of breath, depression and nausea
- **Communication and support** for resolving family/patient/physician questions concerning goals of care
- **Coordination** of care transitions across health care settings



Palliative care helps patients complete treatments, including rehabilitation to address impairments, and improves quality of life for patients, survivors and caregivers. Studies show cancer patients receiving palliative care during chemotherapy are more likely to complete their cycle of treatment, stay in clinical trials and report a higher quality of life than similar patients who do not receive palliative care.<sup>1</sup>

Palliative care is clearly in the best interest of patients, but barriers remain to the widespread adoption of such care. It is often assumed that adding services leads to increased cost. However, a large body of research has demonstrated that when palliative care is used to proactively address many of the side effects of serious illness, patients are more satisfied and overall patient care costs actually go down. A 2016 study showed that giving cancer patients a palliative care consultation within two

days of hospital admission reduced costs 22 to 32 percent.<sup>2</sup> Other studies have confirmed these cost savings, including one looking at Medicaid patients in New York state hospitals, which found an average savings of \$6,900 per patient when palliative care was provided. The study concluded that if the assumed 2 to 6 percent of Medicaid patients in need of palliative care received it, the New York Medicaid program could save between \$84 million and \$252 million per year.<sup>3,4</sup>

To benefit from palliative care, patients and families must be aware of these services, and be able to access them in their local hospital or other care settings. In addition, health professionals in training must learn from direct experience at the bedside with high-quality palliative care teams. The American Cancer Society Cancer Action Network (ACS CAN) supports policy initiatives that:

## *Success Story*

Recognizing the need for more coordination, education and access to palliative care, the states of Connecticut and Rhode Island passed model palliative care legislation in 2013. As specified in legislation, an advisory council was created in each state, and these councils have already gotten to work.

- Connecticut's Palliative Care Advisory Council gathered data on the types of palliative care being provided in different settings including hospitals, home health and hospice and long-term care facilities. Three sub-committees were established to explore the state of palliative care for each of the provider types. In 2016 the Council published a set of recommendations regarding (1) standardization of palliative care practices, (2) reimbursement and access barriers and (3) education and awareness. These recommendations include: (1) palliative and hospice care in the State Innovation Model and other payment reforms, (2) mandate standardized education for non-physician providers to ensure understanding of palliative vs. hospice care and (3) provide standardized education on palliative and hospice care across all health care settings.<sup>5</sup>
- The Rhode Island Palliative Care and Quality of Life Interdisciplinary Advisory Council published a report in 2015 summarizing their first two years of work. The Council conducted a survey of hospital-based palliative care, which found that most hospitals in the state offered palliative care services, but there is still work to be done. The report published recommendations and action steps in the areas of access to palliative care, advance care planning and access to opioids; including (1) adding advance care planning questions to the Continuity of Care form, (2) develop a website to educate patients about palliative care and (3) consider mandatory continuing education for the appropriate prescribing of opioids.<sup>6</sup>

- 1. Educate the public about palliative care.** In partnership with state departments of health and community stakeholders, provide palliative care information online and through other channels to help consumers and clinicians understand palliative care and the benefits of integrating it with disease-directed treatment for all seriously ill adults and children.
- 2. Improve access to palliative care services.** Encourage policies requiring routine screening of patients for palliative care needs and facilitating access to palliative care services in all health care settings serving seriously ill adults and children (e.g., hospitals, cancer centers, nursing homes, assisted living facilities, home care agencies).
- 3. Boost palliative care clinical skills.** Foster training in palliative care for all practicing health professionals and students of medicine, nursing and other professions. This would be done by aligning educational requirements and professional practices with current evidence demonstrating the importance of integrating palliative care alongside disease-directed treatment.

- 4. Preserve access to pain therapies for people in pain.** Implement balanced policies that promote the delivery of integrated pain care for all people facing pain, including preserving access to prescription medications and other therapies, as well as improving workforce training in pain assessment, management, responsible prescribing and use of prescription monitoring programs.

ACS CAN has created model state legislation that establishes a Palliative Care Advisory Council comprised of state experts and that also empowers the state health department to provide palliative care information through their website and through other channels for medical professionals, patients, families, caregivers and the general public. ACS CAN urges lawmakers to adopt this, or similar legislation, in their state. This legislation has consistently received bipartisan support and in just four years, ACS CAN model language or similar bills have been passed in 13 states.

### Did you know?



A recent study showed that more money is saved when palliative care is provided earlier in a patient's disease progression, and that it is especially cost-efficient for patients with multiple diseases. These results further emphasize the importance that patients have access to palliative care when they need it.<sup>2</sup>



# STATE APPROPRIATIONS FOR CANCER RESEARCH FUNDING

52



The past two decades have seen significant improvements in the way we diagnose and treat cancer. Through scientific discovery, we have also learned how to more effectively reduce our cancer risk or prevent it altogether. But our work is far from over, and sustained investment in cancer research and prevention is critical to ensuring the next breakthroughs reach those who need them.

The federal government is by far the largest funder of cancer research and the American Cancer Society is the largest non-profit entity providing funding for cancer research. However, state governments also play an important role investing in lifesaving research. Many states have committed funding to support cancer prevention and early detection programs, and scientific research on cutting-edge treatments. Below are examples of states that have provided significant investments in cancer research funding. American Cancer Society Cancer

Action Network (ACS CAN) urges state legislatures to consider investing in lifesaving cancer research.

## Texas

Created by the Texas legislature and authorized by Texas voters in 2007, the Cancer Prevention and Research Institute of Texas (CPRIT) began in 2009 to award grants to Texas-based organizations and institutions for cancer-related research and product development. In addition, 10 percent of CPRIT's funding is used for the delivery of cancer prevention programs and services. CPRIT is charged to:

- Create and expedite innovation in the area of cancer research and enhance the potential for a medical or scientific breakthrough in the prevention of and treatment for cancer;



- Attract, create or expand research capabilities of public or private institutions of higher education and other public or private entities that will promote a substantial increase in cancer research and in the creation of high-quality new jobs in this state; and
- Develop and implement the Texas Cancer Plan – a statewide call to action for cancer research, prevention and control. The intent of the Plan is to provide a coordinated, prioritized and actionable framework that will help guide efforts to fight the human and economic burden of cancer in Texas. CPRIT's current funding is nearly \$300 million for FY 2016.

## Florida

In 1999, the legislature created the Florida Biomedical Research Program, now known as the James and Esther King Biomedical Research Program, to award peer-reviewed competitive grants to researchers studying tobacco-related diseases. In 2006, the Bankhead-Coley Cancer Research Program was established, employing the same methodology to fund the best science in all cancers. Between 2006 and 2010, the programs were funded with a scheduled sunset date of January 1, 2011, subject to legislative review in 2010. The legislature reauthorized the programs during the 2010 session and dedicated \$20 million annually for each program from tobacco surcharge revenues. In 2011, faced with a budget deficit, the legislature recognized the importance of maintaining the James and Esther King Program and the Bankhead-Coley Program, but they were funded at reduced levels.

Fortunately, lawmakers have continued to see these programs as priorities, increasing their funding to \$10 million each (\$20 million total) in the past few fiscal years.

## California

The California Breast Cancer Research Program (CBCRP) is the largest state-funded breast cancer research effort in the nation, administered by the Research Grants Program Office within the

University of California's Office of the President. CBCRP is funded through a tobacco tax, voluntary tax contributions on personal California income tax forms and individual donations. CBCRP funds California investigators to solve questions about basic breast cancer biology, causes and prevention of breast cancer, innovative treatments and ways to protect a patient's quality of life following a breast cancer diagnosis. The program involves advocates and scientists in every aspect of CBCRP decision-making, including program planning and grant application review. Since 1994, more than \$250 million in research funds has been awarded to 128 institutions across California.

FY 2016 funding for this important research program is \$9,964,868.

California also has a robust Tobacco-Related Disease Research Program (TRDRP) that is funded through the tobacco tax (Proposition 99) and individual contributions. The program supports critical new priorities that represent gaps in funding by other agencies or areas where other agencies are reluctant or unable to provide support. Since TRDRP's inception, more than 1,600 research grants on tobacco-related studies have been funded, totaling more than \$475 million in funding. TRDRP revenue is used to make grants for California scientists and community researchers to find better ways to prevent and reduce tobacco use and its related diseases; 322 grants totaling \$84,137,289 have been awarded in the cancer field.

The FY 2016 funding level for TRDRP is \$10,133,000.

## Did You Know?



- Nearly 4,000 jobs have been created by Florida's biomedical research programs, with an estimated 2,376 from the King Program and approximately 1,600 from the Bankhead-Coley Program.<sup>1</sup>
- Ongoing state investments in cancer research will stimulate a state's economy while also saving precious lives. Not only do these dollars create jobs, but they allow grantees to leverage additional dollars from outside the state.

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