



# Welcome to NY Volunteer Training

**February 1, 2025**



Please introduce yourself by putting your name and where you are from in the chat!





Who is The American Cancer Society Cancer Action Network (ACS CAN)?

ACS CAN was founded in 2001 as the nonpartisan, nonprofit advocacy affiliate of the American Cancer Society (ACS). Although they are separate organizations, the Society and ACS CAN have a shared vision to end cancer as we know it, for everyone.

ACS CAN makes cancer a top priority for policymakers at the local, state and federal levels of government.





# Volunteer Structure

State volunteer team lead by State Lead Ambassador (SLA) and

Vice State Lead Ambassador (VSLA)

26 Congressional teams lead by an ACT Lead

Legislative Ambassador

Action Takers



# Agenda for Today

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**Grassroots Tactics:** Rachel Mayo, Director of Grassroots Organizing

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**2025 NYS & NYC Legislative Priorities Overview:** Michael Davoli, Senior Government Relations Director

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**Deep Dive into our Campaign Priorities:** Michael Davoli, Senior Government Relations Director

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**Media in Campaigns:** Casey O'Neill, Senior Regional Media Advocacy Manager

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**The Power of Your Story:** Casey O'Neill, Senior Regional Media Advocacy Manager & Grace Charrier, ACS CAN Lead volunteer



# Grassroots Tactics

**Rachel Mayo**

**Director Grassroots Organizing**



- Grassroots advocacy
- The power of your voice.
- How to and the importance of forging strong relationships with our lawmakers to advance our policy
- Tips for building your relationships with lawmakers

# What Is Grassroots Advocacy?

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- In-Person Grassroots Advocacy
- Digital Grassroots Advocacy





Your Voice is

**POWER**

# Tips for Building Your Relationship with Your Lawmakers



1. Crafting your cancer story
2. Participating in key opportunities to interact with lawmakers
3. Getting to know your district

# Which of the activities below can help you form a strong relationship with your lawmaker?

- A. Sharing your cancer story as it relates to our legislative priorities
- B. Participating in lawmaker meetings
- C. Meeting follow-up and thank you's
- D. All of the above



# Overview of our 2025 State & NYC Legislative Priorities

**Michael Davoli**

# 2025 State Legislative Priorities



## Improving Patient Outcomes

- **Expand Patient Navigation Services:** ACS CAN seeks to improve cancer outcomes for patients and reduce health payer costs by increasing community-based patient navigation services for everyone at risk of cancer, those diagnosed with cancer, and cancer survivors. Patient navigators have been shown to help increase cancer screenings rates, help patients better understand treatment options after diagnosis and help ensure patients receive the post treatment care they need in survivorship. In 2025 ACS CAN will advocate for the following:
  - **Require Reimbursement For Patient Navigation Services:** ACS CAN will advocate for legislation that will require all state regulated health plans in New York State, including Medicaid, to reimburse for patient navigation services.
  - **Direct Funding For Patient Navigation:** ACS CAN will advocate for New York State to appropriate **\$3,000,000** in funding for oncological patient navigation services to be awarded via a competitive grant process to nonprofit organizations working in the counties with the lowest screening rates and/or highest cancer mortality rates as determined by the New York State Department of Health, and with experience providing community-based navigation or similar services.
- **Paid Family and Medical Leave:** ACS CAN will advocate for legislation that ensures all working cancer patients, survivors, and caregivers have access to paid family and medical leave that allows them to take time off work to deal with their own or a loved one's care without losing their job or income.

## Cancer Prevention and Early Detection



- **Breast, Cervical and Colorectal Cancer:** ACS CAN will advocate for a restoration of **\$2.5 million** in funding for the New York State Cancer Services Program, the state breast, cervical and colorectal cancer screening and treatment program for low-income uninsured and underinsured women and men administered by the New York State Department of Health. The increase would bring the total annualized appropriation to **\$22,325,000**.
- **Lung Cancer:** Despite the effectiveness of lung cancer screening, uptake has been low, with only about 6.5% of the 8.5 million eligible individuals nationwide getting screened. Research shows that barriers to screening for individuals who need preventive services are contributing to lung cancer being the number one cause of cancer deaths.
  - ACS CAN will advocate for the passage of legislation to require all insurance plans, including traditional Medicaid, to provide a comprehensive benefit for lung cancer screening including all follow-up testing according to recommended guidelines, without enrollee cost sharing or other barriers.
  - ACS CAN will advocate for legislation to add lung cancer to the list of cancers for which treatment can be provided by the NYS Medicaid Cancer Treatment Program. Currently only breast, cervical, colorectal, and prostate cancer are included.
- **HPV:** ACS CAN will advocate for legislation to increase the uptake of the HPV vaccine including strengthening school vaccination requirements and appropriating funding for HPV vaccine education and administration focused on the importance of vaccination for all New Yorkers and combatting disinformation efforts.

## Reducing the Toll of Tobacco

- **Tobacco Prevention and Cessation Funding:** ACS CAN will advocate for a restoration of **\$7.5 million** in funding for fact-based, statewide tobacco prevention and cessation programs to bring the annualized total to **\$46.658 million**. Increasing the annualized funding to \$46.658 million will allow the program to increase outreach to communities where tobacco use continues to have a troubling impact.
- **Tobacco Tax Parity:** ACS CAN will advocate for legislation to ensure that all other tobacco products are taxed at the same rate as cigarettes to encourage people who use tobacco to quit rather than switching to lower-priced alternatives and help prevent youth from starting any tobacco product.
- **Menthol Cigarettes and All Other Flavored Tobacco Products:** ACS CAN will advocate for legislation to end the sale of menthol cigarettes and all other flavored tobacco products including all tobacco products, all flavors, and all tobacco retailers.
- **Improve Medicaid Coverage For Smoking Cessation Services:** ACS CAN will advocate for Medicaid to cover phone counseling so that enrollees have access to comprehensive cessation benefits. While all FDA-approved cessation medications as well as individual and group cessation counseling are covered, phone cessation counseling remains uncovered. People respond differently to different interventions; therefore, coverage for a range of counseling types and medications is essential.



# 2025 NYC Legislative Priorities



## Improving Patient Outcomes

- **Improve Access to Patient Navigation Services:** ACS CAN seeks to improve cancer outcomes for patients and reduce health payer costs by increasing community-based patient navigation services for everyone at risk of cancer, those diagnosed with cancer, and cancer survivors. Patient navigators have been shown to help increase cancer screenings rates, help patients better understand treatment options after diagnosis and help ensure patients receive the post treatment care they need in survivorship.
  - ACS CAN is advocating for New York City to appropriate \$1,000,000 in Fiscal Year 2025-2026 and in each of the four subsequent fiscal years to the NYC DOHMH for community-based patient navigation services provided to individuals who are eligible for cancer screening, follow-up, or treatment services in the neighborhoods with the highest cancer mortality rates. Investing in patient navigation would help improve cancer screening rates and reach the HealthyNYC goal of reducing deaths from cancers that can be detected early through routine screening by 20% by 2030.
- **Expand Paid Time Off For Cancer Screening:** The availability of paid leave from work for cancer screenings alleviates a significant barrier that will increase the rate of cancers detected at an early stage, when they can be more easily treated. Unfortunately, not all New Yorkers have equal access to paid time off from work for cancer screening. ACS CAN seeks to ensure that every New Yorker has a guaranteed right to paid time off from work for cancer screening.

## Reducing the Toll of Tobacco

### **Ending the Sale of Menthol Cigarettes and Reforming How Tobacco Laws are Enforced:**

Smoking remains the number one cause of preventable death and disease in New York City. 27.3% of all cancer deaths in New York are smoking-related and smoking results in more than 12,000 deaths from all types of disease in New York City annually. Menthol cigarettes are the most popular type of cigarette with surveys showing that half of youth (ages 12-17) who had ever tried smoking started with menthol cigarettes, and 42.3% of high school students who smoke reported using menthol cigarettes in 2023.

The City Council must prioritize the health of our kids, and communities who have been targeted by the tobacco industry. **Intro 1152-2024** will end the sale of menthol cigarettes by the more than 5,000 licensed cigarette dealers in New York City. Furthermore, this legislation will reform how our tobacco laws are enforced by specifying in the law for the first time that it is not illegal to purchase, use or possess these products.



# Who Is Who In State & NYC Policy Making

**Michael Davoli**

# New York State

Legislature in session from January-June

- 213 members
- Assembly
  - Speaker-Carl Heastie (Bronx)
  - Health Chair-Amy Paulin (Westchester)
  - Ways & Means Chair –Gary Pretlow (Westchester)
  - Black, Puerto Rican, Hispanic & Asian Legislative Caucus Chair - Michaëlle C. Solages (Long Island)
  - Insurance Chair-David Weprin (Queens)
- Senate
  - Majority Leader-Andrea Stewart-Cousins (Yonkers/Bronx)
  - Health Chair –Gustavo Rivera (Bronx)
  - Finance Chair – Liz Krueger (Brooklyn)
  - Insurance Chair—Jamaal Bailey (Bronx/Yonkers)

# New York City

City Council in session year-round with the budget deadline July 1<sup>st</sup>.

- 51 members
  - Speaker-Adrienne Adams (Queens)
  - Health Chair-Lynn Schulman (Queens)
  - Finance Chair –Justin Brannan (Brooklyn)
  - Black, Latino & Asian Legislative Caucus –Co-Chairs - Kevin C. Riley & Crystal Hudson

# Q&A



# Break time!

**10 minutes**





# Deep Dive into our Priorities

**Michael Davoli**

# Patient Navigation New York Campaign 2025

# What is Patient Navigation?

**Patient navigation is the individualized assistance offered to patients, families, and caregivers to help overcome health care system barriers and facilitate timely access to quality health and psychosocial care**



## Access across Cancer Care Continuum

Patient navigators have been shown to help increase cancer screenings rates, help patients better understand treatment options after diagnosis and can help ensure patients receive the post treatment care they need in survivorship.



## Advances Health Equity

Culturally appropriate patient navigation services can improve health outcomes for diverse populations through community outreach and targeted care coordination.



## Cost Savings & Treatment Adherence

Patient navigator programs help identify diagnosis at earlier stages when less invasive and less costly treatment options are available to patients, often resulting in better outcomes and reduced overall costs.



## Patient & Provider Satisfaction

Patient navigation offers tailored patient-centred cancer care and the opportunity to prioritize unique patient needs. Patient navigation has also been shown to increase patient retention and reduce provider administrative burdens.

# Current Landscape & ACS CAN Policy Position

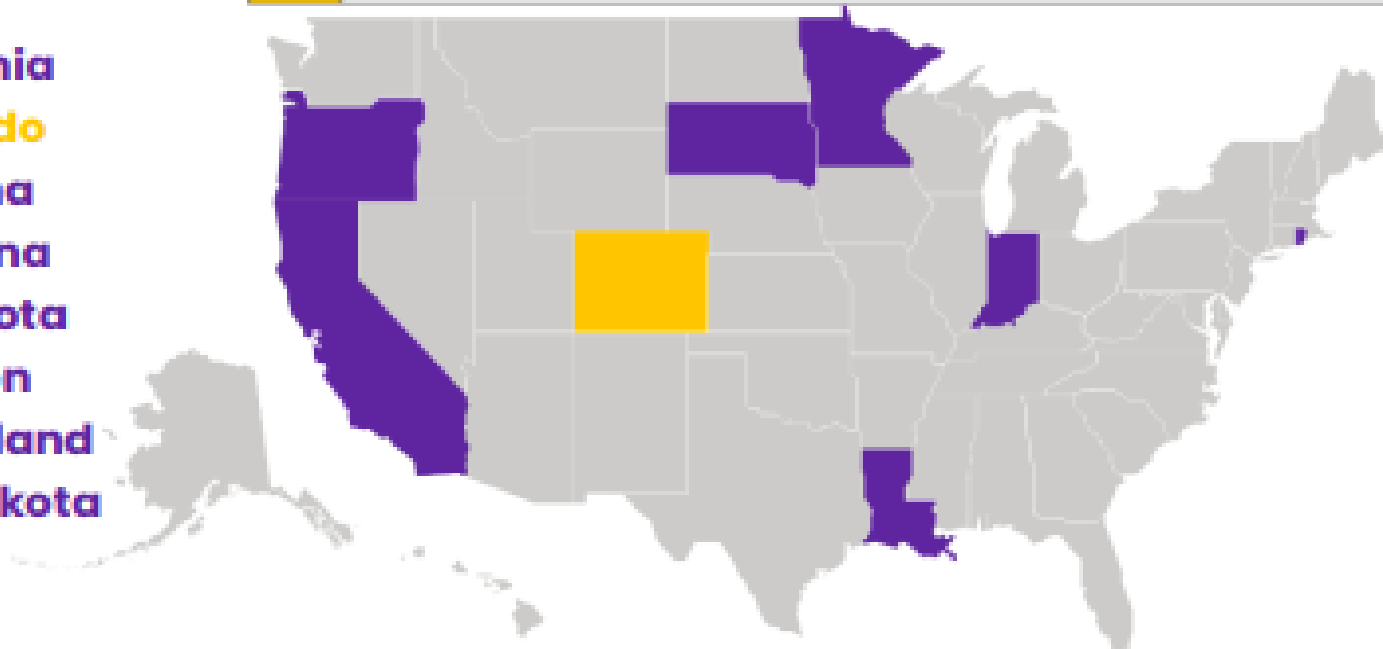


## Current Reimbursement Landscape

Patient navigation is still absent or limited in many cancer programs and hospital settings due to cost concerns and lack of clinical reimbursement. However, some states currently allow Medicaid payment for services provided by CHWs through State Plan Amendments.

- California
- Colorado
- Indiana
- Louisiana
- Minnesota
- Oregon
- Rhode Island
- South Dakota

	Medicaid State Plan Amendment
	Medicaid State Plan Amendment Pending



# 2025 ACS CAN Patient Navigation New York Policy Agenda

- New York State Patient Navigation Sustainability Act
- New York State Patient Navigation Appropriation Request for Fiscal Year 2025–2026
- New York City Patient Navigation Appropriation Request for Fiscal Year 2025–2026

# New York State Patient Navigation Sustainability Act



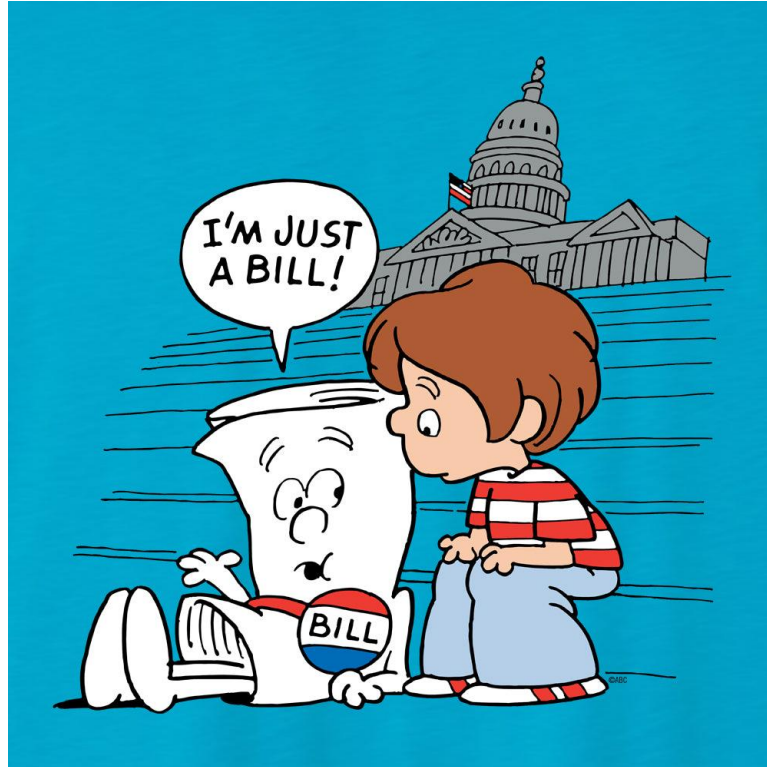
- Requires all state regulated health plans, including Medicaid, in New York State to reimburse for patient navigation services provided to patients experiencing serious illnesses like, but **not limited** to, cancer
- NYS Department of Health's definition of patient navigation services
- Medicare's reimbursement rules

## New York State Patient Navigation Sustainability Act



- Patient navigation services shall include but not be limited to:
  - screening for nonclinical and social needs that do not require a licensed healthcare provider to complete;
  - referrals and follow-up to connect individuals to services including, but not limited to transportation, employment, job training, food insecurity, childcare, housing, language or health literacy support;
  - help with enrollment or maintaining enrollment in government programs or other assistance programs;
  - arranging for and accompaniment to in-person and virtual healthcare visits; or
  - other prevention, screening and treatment health education, health navigation, health advocacy, or individual supports including transition of care supports.

# New York State Patient Navigation Sustainability Act



Goal:  
Passage by  
June 2026



# **New York State Patient Navigation Appropriation Request**

## **Fiscal Year 2025–2026**



- Request to appropriate \$3,000,000 in Fiscal Year 2025-2026 and in each of the four subsequent fiscal years to the New York State Department of Health for community-based oncology patient navigation services.
- The appropriated funds could then be awarded via a competitive grant process to Federally Qualified Health Centers, cancer centers or other nonprofit organizations working in the counties with the lowest screening rates and/or highest cancer mortality rates as determined by the New York State Department of Health, and with experience providing community-based navigation or similar services.

# **New York City Patient Navigation Appropriation Request**

## **Fiscal Year 2025–2026**



- Request to appropriate \$1,000,000 in Fiscal Year 2025-2026 and in each of the four subsequent fiscal years to the New York City Department of Health and Mental Hygiene for community-based oncology patient navigation services.
- The appropriated funds could then be awarded via a competitive grant process to Federally Qualified Health Centers, cancer centers or other nonprofit organizations working in the community districts with the lowest screening rates and/or highest cancer mortality rates as determined by the New York City Department of Health, and with experience providing community-based navigation or similar services.

# Q&A



# Media in Campaigns

Casey O'Neill

# What is media advocacy



“Media advocacy is the strategic use of mass media to support community organizing and advance healthy public policies. It is a tactic for community groups and others to communicate their own story in their own words to promote social change.”

# What does media advocacy look like in action?



**Cancer advocates push for more funding for research as deadline looms**

by WRGB Staff | Tue, September 19th 2023 at 6:58 AM



**NEW THIS MORNING**  
**CANCER ADVOCATES ASKING FOR RESEARCH FUNDING**

Cancer advocates push for more funding for research as deadline looms. (FILE)

**NEWS**

## New law to improve access to biomarker testing

by: **Jamie DeLine**  
Posted: Dec 27, 2023 / 04:14 PM EST  
Updated: Dec 27, 2023 / 04:14 PM EST



**New paid leave bill fails to pass N.Y. Assembly, advocacy group expresses disappointment**

by Leyi Huang | Tue, June 11th 2024 at 6:25 PM  
Updated Tue, June 11th 2024 at 11:00 PM



On Jun. 8, 2024, a cancer advocacy organization expressed its disappointment that the New York Assembly did not pass a new bill designed to extend employees' access to paid family and medical leave. (WRGB)

**Opinion**

## Op-Ed | New York City needs a council that will act on menthol

By **Balazs Halmos, MD** Posted on February 6, 2023




Photo via Getty Images

New York Public News Network

## Young cancer survivor lobbies Hochul on a bill that would require biomarker testing coverage

WXXI News | By **Karen DeWitt**  
Published August 1, 2022 at 2:50 PM EDT

**LISTEN** • 3:48



Karen DeWitt / New York State Public Radio

Charlotte Carlin holds a picture that accompanied her letter to Gov. Kathy Hochul, asking her to sign the biomarker testing bill. Her mother, Mary Carlin, is at left.



# The Power of your Story

**Casey O'Neill & Grace Charrier**

**What is your unique  
perspective on or  
connection to  
our issues?**





# Patient Navigation



- Did you or someone you love ever receive assistance navigating the health care system from an oncology patient navigator, social worker, or nurse?
  
- If you aren't sure, did you or your loved one have someone help with:
  - understanding medical jargon,
  - addressing any mental health issues,
  - navigating insurance claims or financial issues,
  - getting enrolled in Medicaid or Medicare coverage, or
  - facilitating treatment, including for side effects?
  
- If not, do you think it'd have made you or your loved one's experience easier?
  
- Caregivers, did you find yourself, in supporting your loved one, administering to paperwork and insurance needs more than physical and emotional needs?

# Paid Leave



- Were you able to take paid time off during some or most of your cancer treatment or that of a loved one?
- Was work—attending to it or getting back to it—a stressor for you during your cancer treatment or that of a loved one?
- Have you had an employer who was understanding of your limited work capacity following your diagnosis or that of a loved one? Did you have an employer who was not understanding?
- If you took unpaid leave time, did you ever feel like your job or health insurance were at risk?

# Lung Cancer Screening



- Have you or a loved one been screened for lung cancer?
- Did you or your loved one ever use tobacco and worry about its impact on your/their lung cancer risk?
- Have you or a loved one benefitted from tobacco prevention and cessation resources?
- Do you love someone who smokes or previously smoked and is between the ages of 50–80 years old?
- Have you or a loved one benefitted from other forms of cancer screening, such as breast, cervical or colorectal?

# Questions/Discussion

# Cancer Action Day!





**Register for  
Cancer  
Action Day!**



**THANK YOU for  
being here today!**