



ACS CAN Pennsylvania Cancer Action Day

TUESDAY, MAY 7, 2024

What we'll cover today

- 1 **Agenda: Timeline of Events**
- 2 **Legislative Overview + Our Asks**
- 3 **Meeting with Your Lawmakers**
- 4 **Social Media**
- 5 **Reminders for Cancer Action Day**



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Where, When, How

When: Day of Timeline

8:00 AM

Registration and Networking

Main Rotunda

9:00 AM – End

Lawmaker/Advocate Meetings

Capitol Building – Locations vary

11:00 AM

Press Conference

***Your lawmaker meetings take priority.

Capitol Steps – Main Rotunda

11:30 AM

Group photo

***Your lawmaker meetings take priority.

Capitol Steps – Main Rotunda

Meals are on your own

You will be provided with vouchers for breakfast/snack and lunch to be used at the cafeteria around your lawmaker meeting schedule.

How: Navigating the Capitol

1 **Parking**

There's an abundance of parking around the Capitol including street parking and lots. We will reimburse for paid parking. A full list is available: <http://parkharrisburg.com/garages-and-lots/>

2 **Entrances**

The public entrances are the East Wing Entrance at the Fountain on Commonwealth Avenue, which is also the most accessible entrance, and the Main Rotunda Entrance at Third and State Streets.

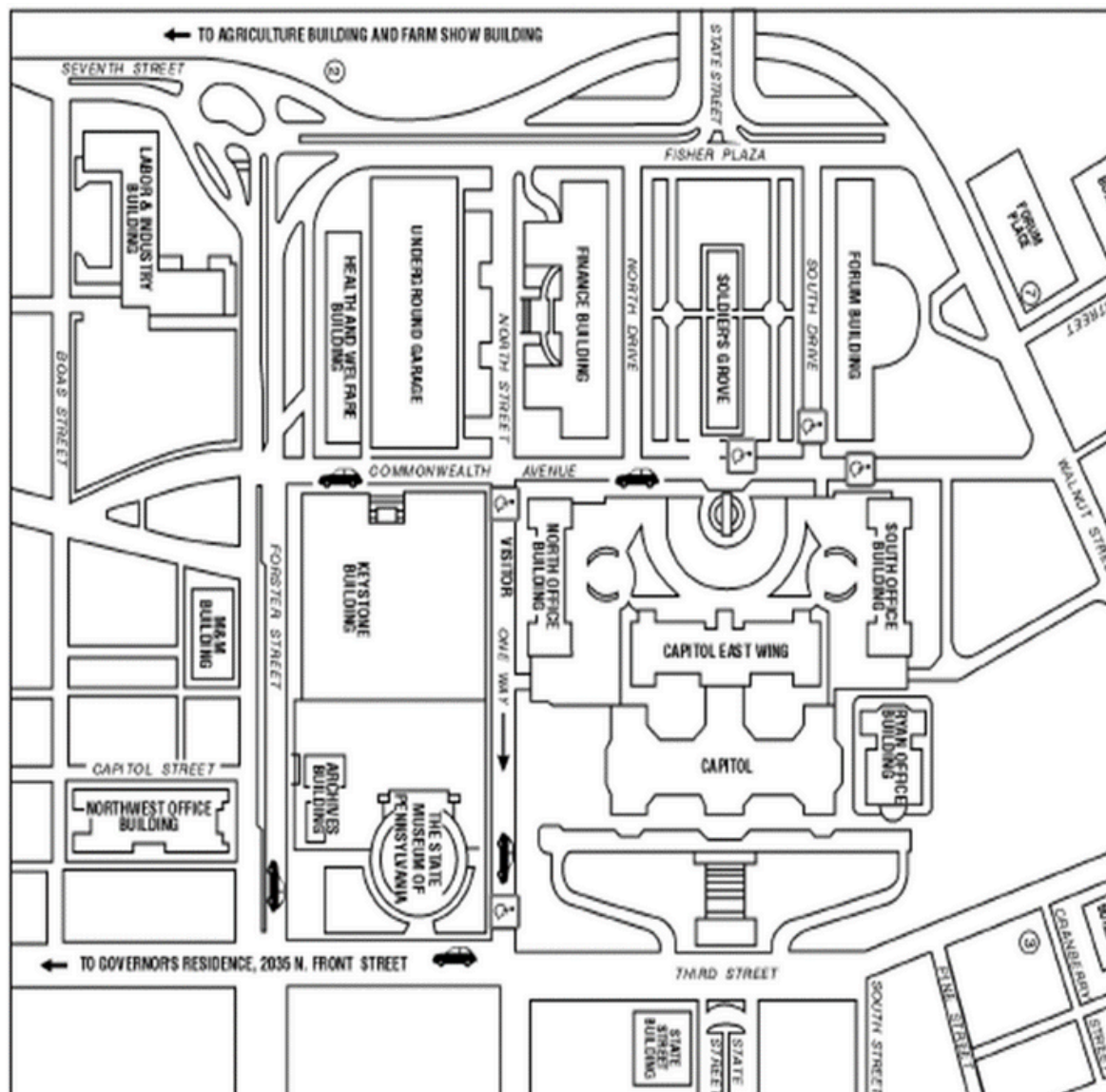
3 **Registration + Event Hub**

Event registration and our event hub open at 8 a.m. in the Main Rotunda of the Capitol Building and will be available throughout the day.



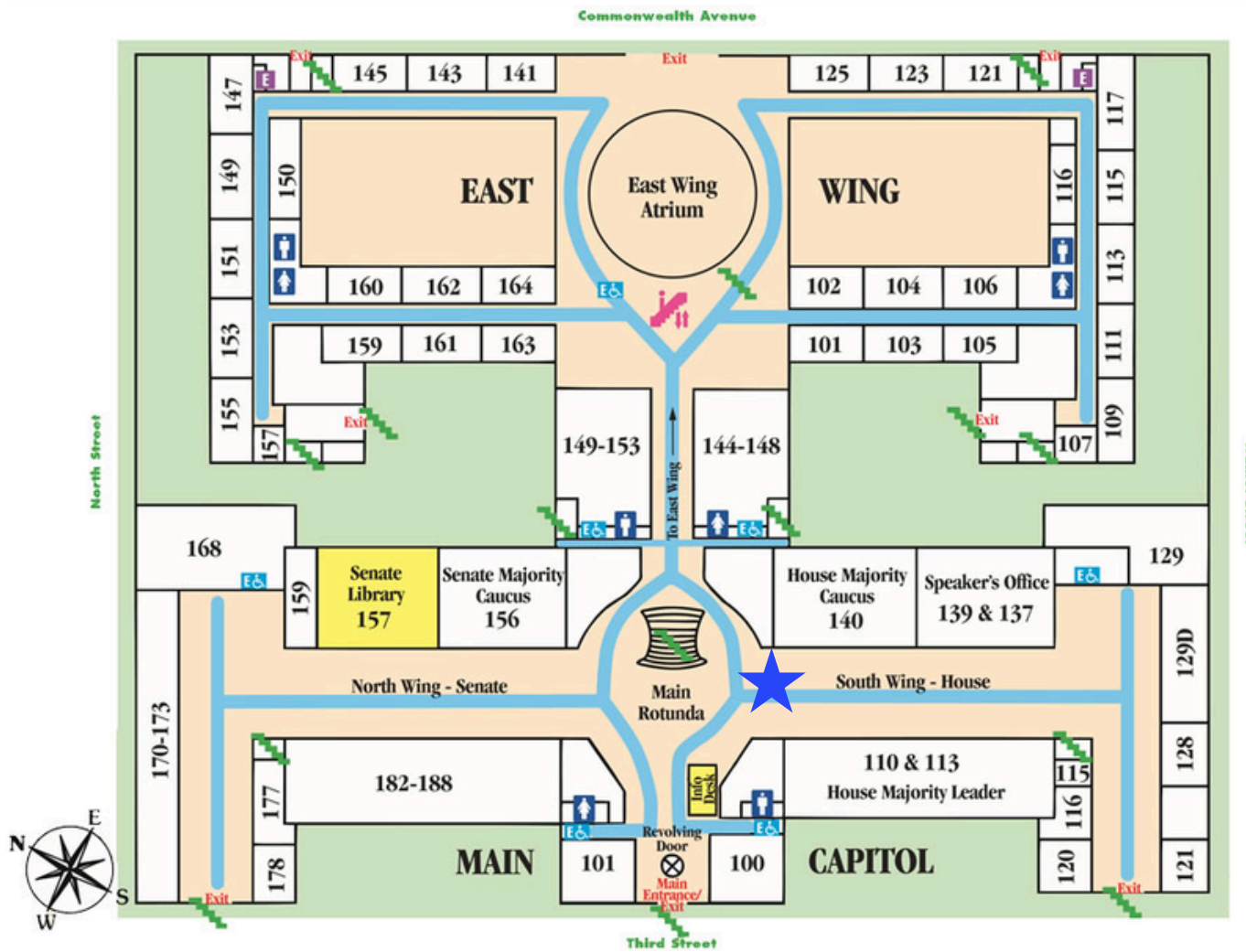
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Where: Capitol Grounds



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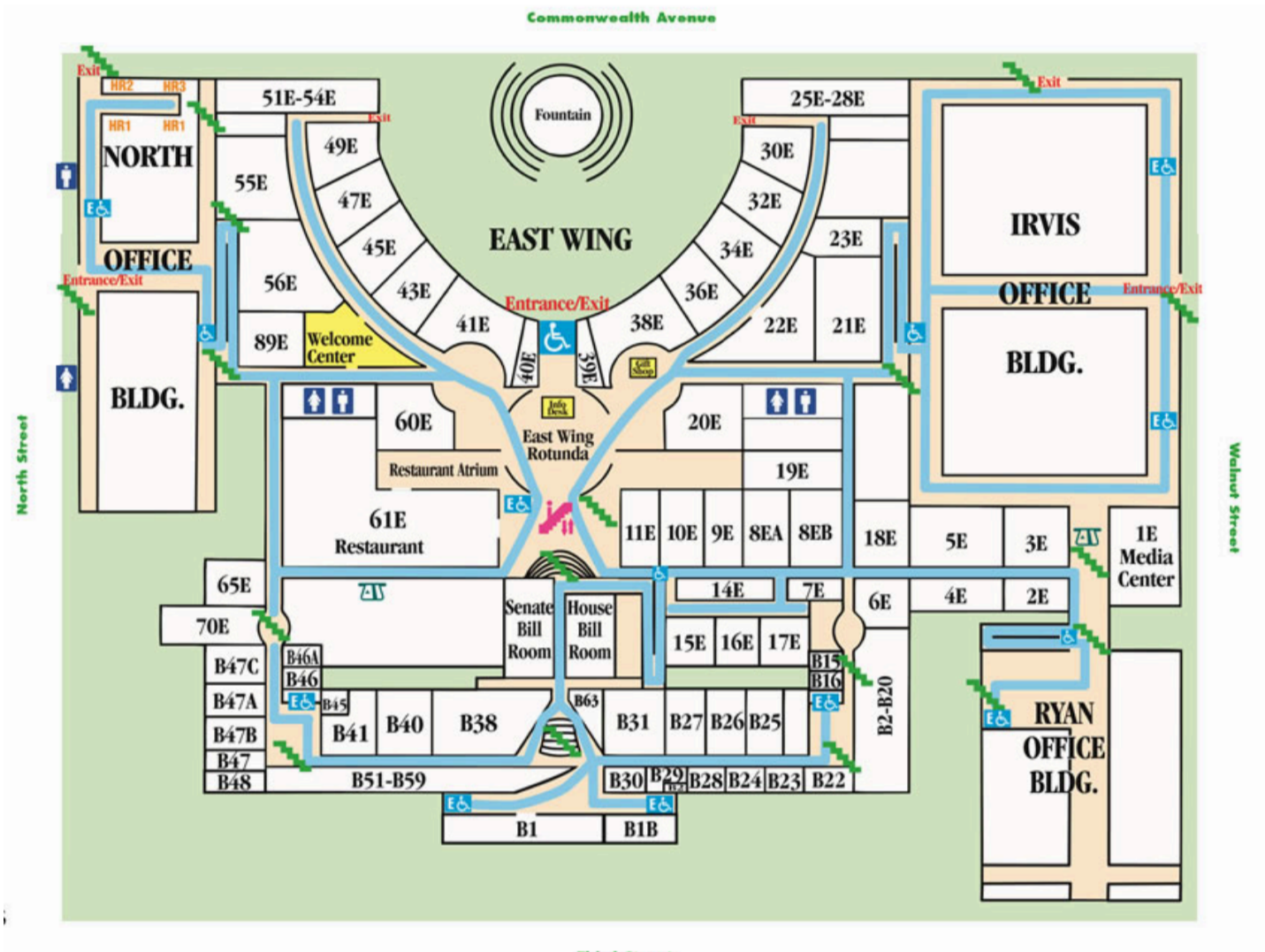
Where: Capitol First Floor + Upper Level East Wing



Our registration/event hub will be around here next to the rotunda

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Where: Capitol Basement + Lower Level East Wing



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Scope of our advocacy



Vision: End cancer as we know it, for everyone.

Mission: Improve the lives of people with cancer and their families through advocacy, research, and patient support, to ensure everyone has an opportunity to prevent, detect, treat, and survive cancer.

Patient
Support



Action
through
advocacy



Advancing
discovery



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What we advocate for

Access to Care



Accelerating Cures



Prevention, including Tobacco Control



Eliminating Disparities + Building Health Equity

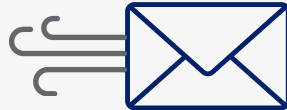


Advocacy works!

Public policy is an extremely powerful tool in the fight against cancer.

Consider

Volunteer Engagement



ACS CAN volunteers have sent

4 MILLION

messages to lawmakers to fight for cancer legislation

Research & Innovation

OneDegree Campaign

120K petition signatures to increase cancer research funding

- **26M social media impressions**
- **+\$6 billion NIH funding**
- **+\$1 billion NCI funding**

Tobacco Control

61.1%

of U.S. population covered by comprehensive smoke-free laws

UP from 2.6% in 2001

Reducing exposure to secondhand smoke

Equitable Access to Care

Affordable Care Act

20M

nonelderly people gained coverage through ACA

13M*

parents and adults gained coverage through medicaid expansion

**as of July 2021*

Millions of lives saved!

ACS CAN Championed Prior Authorization

- In 2022, after 4+ years of hard work, ACS CAN helped make Act 146 a reality, curbing restrictive prior authorization and step therapy practices.
- These insurance practices were leading to delayed treatment and often resulted in negative outcomes for patients.
- Act 146 makes the authorization process more efficient and implements guidelines that make exceptions to step therapy more straightforward and the process more time-sensitive.



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This year, Pennsylvania wins would mean

Biomarker Testing

Expanded access to biomarker testing leading to targeted treatment

Paid Family + Medical Leave

No risk of losing a job or missing a paycheck due to treatment

Medical Debt Relief

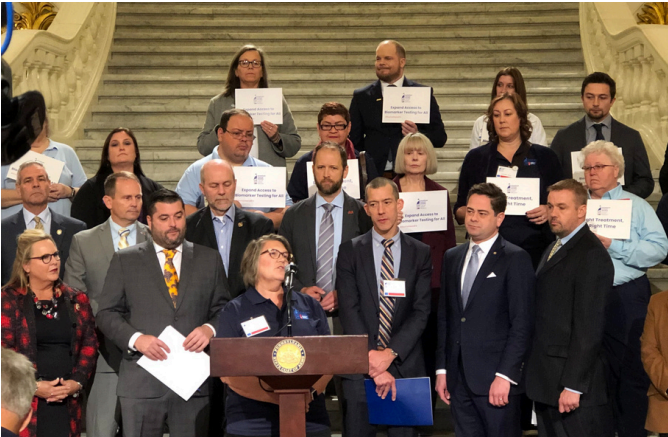
Remove economic barriers to access

Prevention Programs

Over 29k women will continue to access breast + cervical cancer screenings

Continue to prevent young people from starting to use tobacco

...And volunteers make all the difference



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Legislative Asks

The Asks

- **Establish Biomarker Testing as a covered benefit: SB 954/HB 1754**
 - Senators: Vote YES in Banking & Insurance Committee and on the Senate floor; Thank co-sponsors
 - Representatives: Vote YES in Insurance Committee and on the House floor; Thank co-sponsors
- **Establish a Paid Family and Medical Leave Program: HB 181/SB 580**
 - Senators: Vote YES in Labor and Industry Committee and on the Senate floor; Thank co-sponsors
 - Representatives: Vote YES on third consideration on the House floor; Thank co-sponsors
- **Create a Medical Debt Relief Program: HB 78/Governor's Executive Budget**
 - Senators: Advance HB 78 in Health & Human Services Committee and on the Senate floor; Support State dollars to wipe out medical debt in the 2024 Budget
 - Representatives: Thank you for advancing HB 78 out of the House; Support State dollars to wipe out medical debt in the 2024 Budget
- **Protect Funding for Critical Statewide Prevention Programs: 2024-25 Budget**
 - Breast and Cervical Cancer Early Detection Program
 - PA Tobacco Prevention and Control Program

Issue Overview: Biomarker Testing

- **Biomarker testing can help patients get the right treatment, at the right time.**
 - Leads to improved survivorship, quality of life, and possible cost savings.
 - Disease agnostic, treating cancer, autoimmune, arthritis, preeclampsia rare diseases, and others.
 - Future implications for heart disease, ALS, Alzheimer's, infectious diseases, respiratory illnesses, and others
 - 50+ partners comprise PA Biomarker Testing Coalition
- **Lack of consistent, comprehensive insurance coverage is a significant barrier.**
 - Nationally, 66% of oncology providers reported that insurance coverage is a significant or moderate barrier to biomarker testing for their patients.
 - In PA, 32% of policies are more restrictive than the National Comprehensive Cancer Network biomarker testing guidelines for advanced breast, lung, melanoma, and prostate cancers.
- **Access to biomarker testing is not equal for all populations.**
 - Patients who are older, Black, uninsured or on Medicaid, living in rural areas, or seeking care in non-academic medical centers are less likely to be tested for certain guideline-indicated biomarkers.
 - SB 954/HB 1754 would expand access to biomarker testing as a covered benefit in PA-regulated plans, including Medicaid.

Biomarker Testing Asks

Senate Ask*: Will you vote Yes on Senate Bill 954/House Bill 1754 when it comes to the Senate Floor to ensure that Pennsylvanians covered by state-regulated insurance plans, including Medicaid, have coverage for biomarker testing when medically appropriate?

*For Banking & Insurance Committee members, will you vote Yes when it is considered in Committee?

Senate Ask to Cosponsors: Thank you for cosponsoring Senate Bill 954 to ensure that Pennsylvanians covered by state-regulated insurance plans have coverage for biomarker testing. Will you encourage your colleagues to vote Yes when it comes to the Senate Floor?

House Ask*: Will vote Yes on House Bill 1754/Senate Bill 954 when it comes to the House Floor to ensure that Pennsylvanians covered by state-regulated insurance plans, including Medicaid, have coverage for biomarker testing when medically appropriate?

*For House Insurance Committee members, will you vote Yes when it is considered in Committee?

House Ask to Cosponsors: Thank you for cosponsoring House Bill 1754 to ensure that Pennsylvanians covered by state-regulated insurance plans have coverage for biomarker testing. Will you encourage your colleagues to vote Yes when it comes to the House Floor?

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Issue Overview: Paid Family and Medical Leave

- **About 62%, or 4 million workers in PA do not have access to paid family leave through their jobs**, which means they may have to make impossible choices between work and caring for themselves or their family.
- **89,400 Pennsylvanians will be diagnosed with cancer in 2024.** Cancer treatment is time consuming, often requiring time off from work for doctor's visits, surgery, chemotherapy/radiation, and recovery.
- **This is a health equity issue** – biggest impact on lower income households, those with lower levels of education, younger, and those working in smaller companies.
- **Access to paid family and medical leave contributes to positive outcomes such as being able to complete treatment, manage symptoms, and afford treatment while maintaining employment and economic stability.** This makes an important difference for patients, survivors, and their caregivers

House Ask: *Will you support House Bill 181 on third consideration to establish a Paid Family and Medical Leave program and ensure that no one has to risk employment to care for themselves or a loved one?*

Senate Ask: *Will you support Senate Bill 580 to establish a Paid Family and Medical Leave program and ensure that no one has to risk employment to care for themselves or a loved one?*

Issue Overview: Wipe Out Medical Debt

- **Approximately 1 million Pennsylvanians struggle with medical debt.**
 - According to a recent study by ACS CAN, over 50% of cancer survivors identified medical debt as a top concern.
- **73% of cancer survivors said they are worried about affording the cost of their current or future cancer care** (2022 ACS CAN study)
- **Medical debt can have a direct effect on cancer care: high costs can lead to delayed or lack of treatment.**
 - Delaying or forgoing care because of cost is more common among people with medical debt and is associated with increased mortality risk among cancer survivors.
- **Medical debt has negative health impacts:** poor physical and mental health, more years of life lost, and higher mortality rates (according to ACS research)

Senate Ask: Will you support House Bill 78 to establish the Medical Debt Relief Program and the Governor's budget proposal of investing \$4 million to wipe out nearly \$400 million in medical debt?

House Ask: We are grateful that the House has already passed HB 78, thank you! Will you support the Governor's budget proposal of investing \$4 million to wipe out nearly \$400 million in medical debt?

Issue Overview: Protect Funding for Critical Prevention Programs

- The PA-BCCEDP provides low-income, uninsured, and underinsured women access to breast and cervical cancer screenings and diagnostic services
- **From 2015–2020, over 29,600 PA women were served by the program.** Over 360 breast cancers and 779 cervical cancers or precancerous lesions have been detected by the program.
- **It is simple, screening saves lives.** Cancers that are found at an early stage are easier to treat and lead to greater survival.
- **Over 30% of cancer deaths are caused by smoking.** Across the state, 14.9% of adults smoke cigarettes and about 20% of high school students use tobacco products.
- **Current program funding falls woefully short of the \$140 million recommended by the CDC**
- Evidence-based, statewide tobacco control programs have been shown to:
 - reduce tobacco use rates
 - reduce tobacco-related diseases + deaths
 - prevent young people from smoking

House and Senate Ask: Will you protect funding for these vital cancer prevention programs -- continue funding the Pennsylvania Breast and Cervical Cancer Early Detection Program at \$2.563 million and funding the State Tobacco Control Program at the current rate of 4.5% or approximately \$16 million?



Lawmaker Meetings

Hook, Line (x2), Sinker

Hook

Who You Are

Line

**Explain the
need**

Line

**Share your
story**

Sinker

Make the ask

Hook

Introductions

- Meeting leader starts, volunteers from ACS CAN
- Go around to all constituents, quick intros

Who you are, where you're from

- State your neighborhood rather than city (esp. for Senate meetings)



Line

Explain the need:

- What is the purpose of the meeting, what issues will be covered
- Why do we need these specific policies?

Tell your personal story:

- Connect your story to one of the ASKS
- What impact would this policy have made for you/someone you know?
- What impact will it have for our state?



Sinker

Make the ASKS

- Refer to language provided
 - will vary depending on whether your lawmaker is a cosponsor already (thank you)
- Go through each policy ask

Secure a response from the lawmaker

- We are looking for a clear indication of support

Thank them for their time and support



Crafting your personal story



Your connection to cancer / your WHY

How does your experience relate to the ASKS

- Have you had biomarker testing/know someone that has?
 - What could treatment have been like if this testing was available?
- What affect would Paid Family + Medical Leave have had on your care or care for your family/friends?
- Are you or someone you know impacted by medical debt?
- Have you benefited from breast or cervical cancer screenings?

What impact will it have for our state?

Group Meeting Logistics

Due to the size of our Senate districts, most meetings will have 3+ constituents present -- which means it is important to split up the ASKS.

Meeting Captain

- Each group will have a Meeting Captain, they will reach out to the group members and coordinate roles ahead of time

Determining who shares

- It is important to highlight individuals that have a connection to the asks
- In order to keep things organized, and to maximize time, there will be no more than four speakers

Breaking up the asks

- There are four asks, so each person will be responsible for making one ask
 - Connect to your personal story
 - Be precise, keep story to to 1-2 minutes

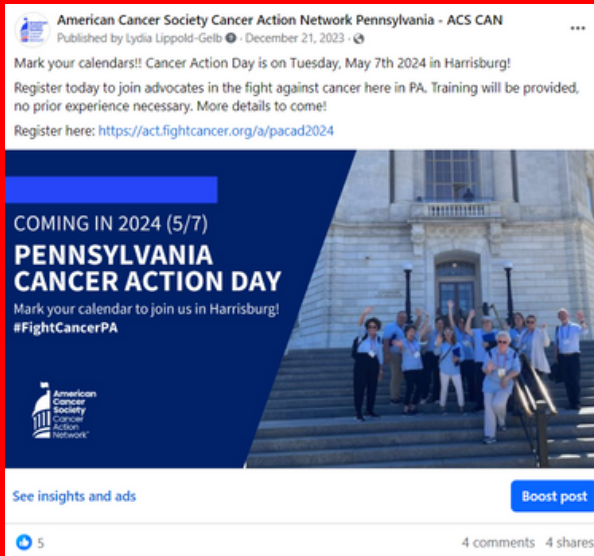


Report Back

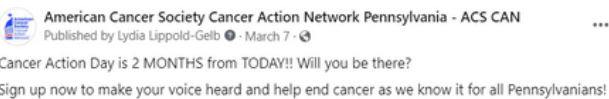
We want to know how your meeting went and any lawmaker that would like more information -- so after your meeting, complete the report back form (QR code provided in materials)

- Complete one report for each lawmaker/staff you interact with
 - Include their full name
- Please be as specific as possible, where does the lawmaker/staff stand on each ask
- Details on the report back form:
 - For Issue, please select all that apply -- Access and Tobacco
 - For "Type of Action" please select all that apply, including "office meeting with lawmaker" for any meetings you had in-person.

Let's Takeover Social Media



- **@ACSCANPA**
- **Tag your specific lawmaker**
- **#PACAD2024**
- **#FightCancerPA**
- **Share your experience & the Ask**
 - **Include photos**
- **Don't forget to engage with others**



Reminders

Logistics Reminder:



- **Date:** Tuesday, May 7th
- **Time to Arrive:** Between 8am and 9am
- **Parking:** Street and lots located around the Capitol
- **Entrance Locations:**
 - Main Rotunda at Third + State Streets
 - East Wing Entrance at the Fountain on Commonwealth Ave – ADA
- **Meeting Location:** Main rotunda of the Capitol building
- **What to wear:**
 - You will be given a ACS CAN shirt
 - Long sleeve underneath
 - Business casual
 - Good walking shoes

Reminder to:



- **Meet with your team and practice**
 - Meeting lead will reach out to schedule time to connect
 - Find your group info (and resources) here:
<https://www.fightcancer.org/pennsylvania-cancer-action-day>
- **Research your lawmakers**
 - What committees do they sit on?
 - What is their social media handle
 - Visit: <https://www.legis.state.pa.us/>
- **Your story is your strongest tool when advocating and no one knows it better than you**
- **Have FUN!**

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Want to practice your personal story?

- **Office Hours with Lydia via Teams**
 - Thursday, May 2nd
 - 12:00–1:00 pm
 - 4:30–5:30 pm
- Come with questions or to practice, open to anyone!



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Q&A



Thank You