Pennsylvania Cancer Action Day

Training Manual



Tuesday, May 7, 2024





Welcome to Cancer Action Day 2024

Dear Cancer Advocate,

Thank you for your willingness to participate in our 2024 Cancer Action Day. We are looking forward to hosting you at the capitol building on Tuesday, May 7, 2024!

As the leading cancer advocacy organization, ACS CAN works every day to encourage elected officials to make cancer a top priority. We support evidence-based solutions designed to eliminate major health problems. We bring together ordinary people with extraordinary power to fight cancer with the training and tools they need to make their voices heard.

This annual event is the best opportunity for new and experienced volunteers to add their voices to the lifesaving mission of ACS CAN. Cancer Action Day is a chance to come together to ask our elected officials to actively support the fight against cancer. You are bound to leave feeling energized, excited, and personally rewarded.

To make the absolute most of your day at the capitol, please read through this guide for important updates and attend the virtual Cancer Action Day training. This is when you will have the opportunity to learn more about our issues and ask questions.

We truly appreciate your commitment to advocacy and look forward to the great accomplishments we will achieve together.

Keep fighting!

Donna Greco ACS CAN Pennsylvania Government Relations Director Lydia Lippold-Gelb ACS CAN Pennsylvania Grassroots Manager Donna Kemberling ACS CAN Pennsylvania State Lead Ambassador





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Staff Contact Information

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2024 PA CANCER ACTION DAY Training Details

Virtual Training

Mark your calendar and attend one of our virtual training sessions

Our Cancer Action Day training will review event-day logistics and policy issues in detail. It will be a great opportunity for volunteers to get their questions answered. Your participation is required, and we believe that you will find it informative and helpful. If for any reason you are unable to participate in one of the sessions, please contact Lydia Lippold-Gelb at lydia.lippoldgelb@cancer.org.

Training dates and times - *Note: You only need to attend ONE training. Training links are available on the event site at <u>https://www.fightcancer.org/pennsylvania-cancer-action-day</u>

The training will take place in Microsoft Teams, please join on your computer or mobile app with the link provided

- Training option 1: Tuesday, April 23rd from 7:00-8:00pm
- Training option 2: Thursday, April 25th from 12:00-1:00pm
- Training option 3: Tuesday, April 30th from 7:00-8:00pm

The more prepared you are for your ACS CAN Cancer Action Day event, the more comfortable you'll be in your meetings with lawmakers. Our policy materials are on the next several pages. Please take the time to review them to be prepared for your meetings. We'll have time on the training call to answer your questions.

Nervous?

Whether it is your first time, or you are a seasoned advocate, we will walk you through what to expect on our Cancer Action Day training session.





2024 PA CANCER ACTION DAY AGENDA

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

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





2024 PA CANCER ACTION DAY Meeting Logistics

Lawmaker Meetings

ACS CAN will organize all teams and schedule all meetings. To avoid confusion with lawmakers' scheduling staff, please do NOT schedule separate meetings. All attempts will be made to schedule meetings with your specific lawmakers. Your final schedule will be provided on Monday, May 6th, before the event.

An ACS CAN T-Shirt will be provided to you when you arrive in Harrisburg to wear for the day and display our solidarity and who we are! Please feel free to bring a long-sleeved shirt to wear under it if it is chilly.

Report Back Form

Don't forget to fill out your report back form after your legislative meetings. See page 15 for QR Code

https://act.fightcancer.org/a/acs-can-report-back-form

Sharing your story

Please contact Casey O'Neill at Casey.Oniell@cancer.org if you would like to share your story, particularly if you have ever had a positive experience with biomarker testing, the tobacco cessation program, or the BCCED-PA program.





We have 4 ASKS that we will be making during our lawmaker meetings! Here is an overview of the asks. There is more information on the following pages and we will cover each ask during our training. The specific language is subject to change, given where the bill is in the process.

1. Expand Access to Biomarker Testing by Supporting SB 954/HB 1754

2. Establish a Paid Family and Medical Leave Program by Supporting HB 191/SB 580

3. Help Provide Medical Debt Relief by Supporting HB 78 / Governor's Executive Budget

4. Protect Funding for Critical Prevention Programs - PA's Breast and Cervical Cancer Early Detection Program and Tobacco Prevention and Cessation Programs





Expand Access to Biomarker Testing

- Biomarker testing can help patients get the right treatment, at the right time.
 - Used to determine the most effective treatment for the individual's specific cancer
 - Can lead to targeted therapies that may result in:
 - improved survivorship
 - better quality of life
 - potential cost savings
- 66% of oncology providers reported that insurance coverage is a significant or moderate barrier to appropriate biomarker testing for their patients
 - In PA, 32% of policies are more restrictive than the National Comprehensive Caner Network guidelines for biomarker testing in advanced breast, lung, melanoma, and prostate cancers
- Insurance coverage is not equal -- we want to change this!
 - Patients who are older, Black, insured by 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
- Disease Agnostic: used to inform the treatment of conditions outside of oncology including arthritis and other autoimmune conditions, preeclampsia, and rare diseases
 - Research is underway for implications on heart disease, ALS, Alzheimer's disease, infectious diseases, respiratory illnesses, among others.
 - 50+ partners make up the PA Biomarker Testing Coalition





Support our Biomarker Bills: SB 954/HB 1754

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 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?





Pass HB 181 / SB 580 to establish a Paid Family and Medical Leave Program

- 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. 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?





Help Provide Medical Debt Relief

- 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.
- In a 2022 ACS CAN survey, **73% of cancer survivors said they are worried about affording the cost of their current or future cancer care**
- Medical debt may have a direct effect on cancer care: high costs can lead to delayed 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.
- According to ACS research, **medical debt has negative health impacts**: a recent study found shows medical debt is associated with worse physical and mental health, more years of life lost, and higher mortality rates

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 relieve 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 relieve nearly \$400 million in medical debt?





<u>Protect Funding for the PA Breast</u> <u>& Cervical Cancer Early</u> <u>Detection Program</u>

- The PA-BCCEDP provides lowincome, 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.

<u>Protect Funding for the State</u> <u>Tobacco Control Program</u>

- 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:
 - $\circ~$ 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 Tobacco Control Program at the current rate of 4.5% or approximately \$16 million?



2024 PA CANCER ACTION DAY Hook, Line, and Sinker

All issues have many details and no one should ever feel expected to know everything- but it is important to understand why we are having a meeting and what needs to be addressed. So, what should one say in a meeting with a lawmaker? That is not as difficult as it seems if you follow the Hook, Line, and Sinker method.

Hook: Who You Are

Tell them who you are and where you are from + a very brief sentence stating the purpose of the meeting. Remember, you are a voter, a survivor/caregiver/advocate and their constituent.

Line: Share Your Stories

Be informative, be thorough, and be concise. Provide your lawmaker with personal stories. They will appreciate real-life examples that put a human face on the issue. Discuss how the legislation will directly affect you, your family, and your community. **Personal stories truly make an impact and achieve results.**

Quantify the Problem Using Facts

Share a few facts during either the 'Line', or when doing the 'Sinker'.

Sinker: The Request (include statistics as relevant)

Make a clear request of the legislator or staff and ask their position on the issue. Be polite, direct and specific. Wait for their response.

Answer any questions to the best of your ability. If you do not know the answer, it is OK to say, "That's a good question, I'm not positive on the answer, and I'll need to get back to you." Don't answer any questions you're not 100% sure you know the answer to – make sure to list them on your report back forms.

Leave on a positive note. As you wrap up the conversation, repeat one last time what action you hope the lawmaker will support. Make sure your lawmaker and/or their staff member receives a copy of the leave-behind folder. Thank them for their time and offer to be an ongoing resource.



2024 PA CANCER ACTION DAY Lawmaker Meetings

"Thank you, Representative/Senator _____, for taking the time to meet with your cancer-fighting constituents today.

My name is _____ from hometown and I am an ACS CAN volunteer. With me are constituents and advocates from around your district to talk about their cancer stories. **Constituents introduce themselves- name and hometown.**

We are here to discuss and ask for your support on four items

- Access to biomarker testing
- Paid Family and Medical Leave
- Wiping out medical debt
- Funding for key prevention programs

This year, Pennsylvania is expected to see 89,410 new cases of cancer. With this in mind, we are working hard to ensure that every resident has the ability to detect, treat, and survive cancer. This starts with supporting key policies and budget items to ensure equitable access to prevention programs and life-saving treatment, as well as helping all Pennsylvanians cover the cost of care through paid family and medical leave and wiping out medical debt.

This is especially important to me because (share your personal story and connect it to the importance of [biomarker testing/paid family leave/medical debt/prevention programs]. If another volunteer has a personal story that has a strong connection, please introduce them and have them speak. Keep it brief.)



2024 PA CANCER ACTION DAY Lawmaker Meetings

The ASKS:

- Will you vote Yes on Senate Bill 954/House Bill 1754 when it comes to the Senate/House Floor to ensure that Pennsylvanians covered by state-regulated insurance plans, including Medicaid, have coverage for biomarker testing when medically appropriate?
- Will you support House Bill 181/ 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?
- 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? (For House members, Gov. budget ask only)
- 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 Tobacco Control Program at the current rate of 4.5% or approximately \$16 million?

Remember, we want to hear a yes or no answer.

- If your elected official answers yes to this question that is great! Thank him/her for their support.
- If your member answers no, ask why and if there is further information you can provide after the meeting. Include that information on your report back form.
- If your member doesn't give a direct yes or no answer, ask for clarification.
- You should plan to follow-up with your House Representative 1-2 weeks after your meeting (by phone or email) to ensure their questions are answered and check on their level of support.

<u>Please note:</u> this script is a framework for your conversation. Please feel free to elaborate and share your personal cancer story and use information from the fact sheet and talking points.



2024 PA CANCER ACTION DAY Lawmaker Meetings

Do:

Look and act professional

Introduce yourself and tell the legislator where you are from

Stay on message

Be prepared to wait

Know the asks and something about it

Be efficient and articulate; the meeting should be brief and concise

Ask for your legislator's support for the issue

Stop discussing the issue if you get a "Yes"

Leave a one-pager about the issue

Turn off your cell phone

Thank the lawmaker (be sure to also send a thank-you note)

Don't:

Attempt to answer questions you don't know the answer to or commit to anything you aren't certain of

Get angry or hostile

Get distracted by small talk

Mention your political affiliation

Leave behind materials that aren't provided in this packet

Lobby on other issues

Get defensive if an elected official doesn't support our legislation



2024 PA CANCER ACTION DAY **Report Back Form**

How was your lawmaker meeting? Report back and let us know!



Scan the QR code Tips for completing your report back:

- Please complete a separate report for each lawmaker you interact with.
- For Issue, please select all that apply,
 - Access (or Biomarkers Paid Family and Medical Leave, and the BCCEDP funding ask
 - Tobacco for the Tobacco Cessation Program funding ask .
- For "Type of Action" please select all that apply, including "office meeting with lawmaker" for any meetings you had inperson.
- Please include the full name of your lawmaker or their staff and where they stand on each ask.
- Please be as specific as possible when completing the form to allow for follow up by your ACS CAN Staff partners.
- Questions, please connect with Lydia Lippold-Gelb at lydia.lippoldgelb@cancer.org



2024 PA CANCER ACTION DAY Social Media

Please promote your participation in Cancer Action Day on social media! Follow us at @ACSCANPA and share our posts throughout the week -- and post your own!

Pre-event Sample Post

On May 7, I will be spending the day at the Pennsylvania State Capitol Building with the American Cancer Society Cancer Action Network asking lawmakers to expand access to biomarker testing, help ensure that care is affordable for all by passing paid family and medical leave and reducing medical debt, and funding life saving cancer screening and tobacco prevention programs! Follow along! #FightCancerPA #PACAD2024

Event Day Samples

Do a Facebook live or record a video to post on social media. Below are sample scripts to use.

1. Good morning! Today, I am so excited to be participating in ACS CAN's Pennsylvania Cancer Action Day to meet with **LAWMAKERS NAMES**. Follow along as I join PA advocates from around the commonwealth in calling on our state lawmakers to make fighting cancer a priority in PA. Check in today for updates and opportunities to join me in the fight!

2. Hey everyone! I just met with *LAWMAKERS NAMES* and it was awesome! We are making our voices heard and fighting to expand access to biomarker testing, help ensure care is affordable and accessible via paid family leave and wiping out medical debt, and protecting prevention programs. Want to fight with me? It's easy and rewarding. (Post on your page with your video, sign up to be a volunteer with ACS CAN at https://www.fightcancer.org/volunteer-for-acs-can)

Posts:

Today, I am so excited to be participating in @ACSCANPA Cancer Action Day to meet with **tag your** *lawmakers*. Follow along as I join PA advocates from around the PA in calling on our state lawmakers to make fighting cancer a priority #FightCancerPA #PACAD2024

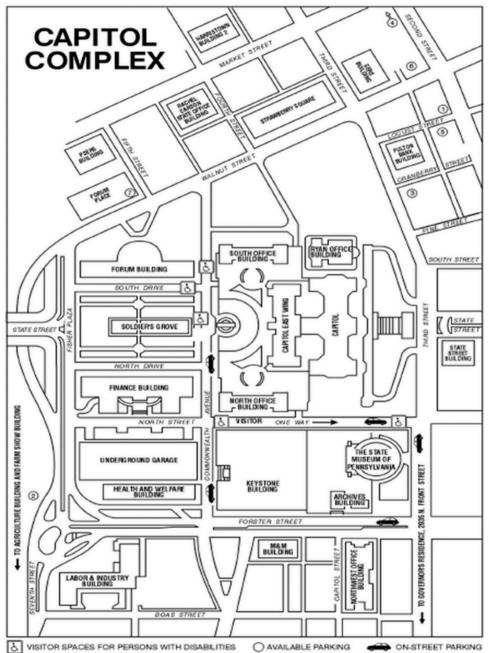
I am happy to participate @ACSCANPA Cancer Action Day at the State Capitol. I'm calling on @tag your lawmakers to expand access to biomarker testing, help ensure care is affordable and accessible, and fund key prevention programs #FightCancerPA #PACAD2024

Today I am joining @ACSCAN advocates in Harrisburg to call on **@tag your lawmakers** to ensure that all Pennsylvanians can detect, treat, and survive cancer #FightCancerPA #PACAD2024





2024 PA CANCER ACTION DAY Capitol Complex Map



Parking: There's an abundance of parking around the Capitol. We will reimburse for paid parking. A full list is available at <u>http://parkharrisburg.com/ga</u> <u>rages-and-lots/</u>

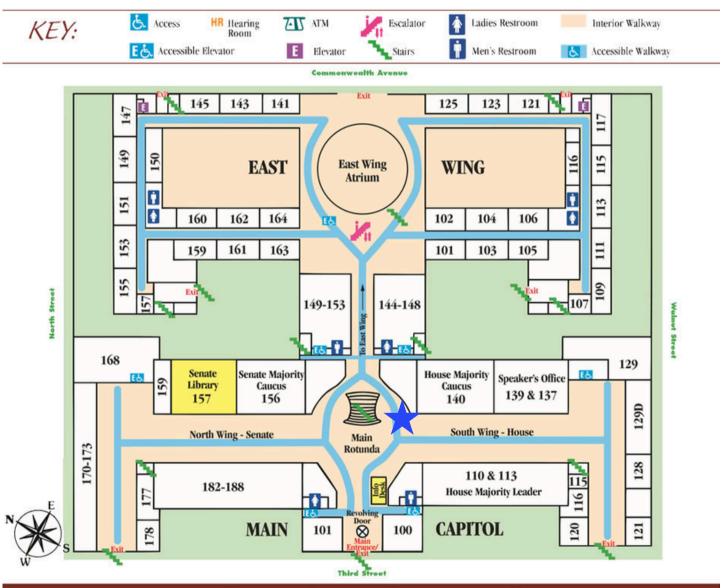
Entrances: The public entrances are the East Wing Entrance at the Fountain on Commonwealth Avenue (also the handicapped entrance) and the Main Rotunda Entrance at Third and State Streets.

All visitors to the PA State Capitol will be processed through metal detectors. All bags and packages will be xrayed, and are subject to hand inspection.

Registration/Check in: 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.



2024 PA CANCER ACTION DAY Capitol Complex Map



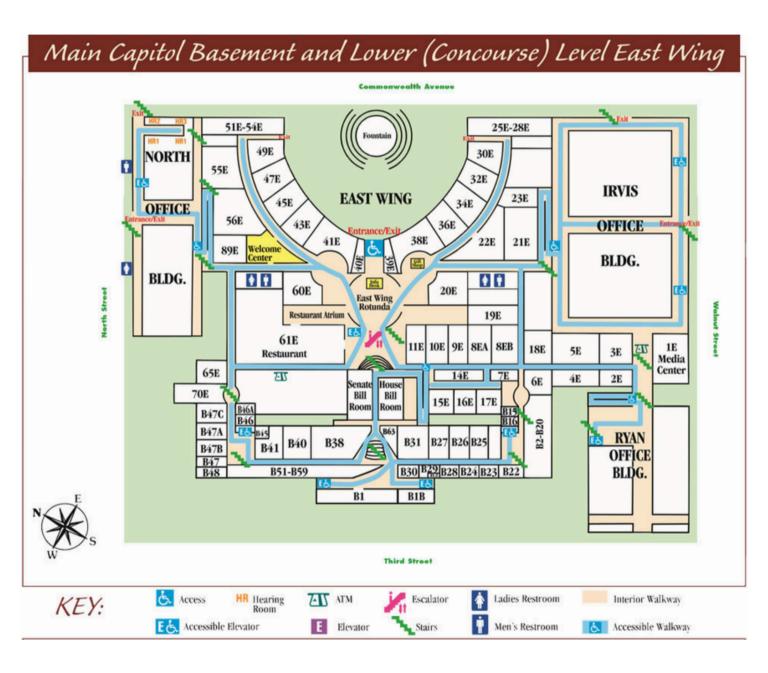
Main Capitol First Floor and Upper Level East Wing



Our registration/event hub will be around here



2024 PA CANCER ACTION DAY Capitol Complex Map





2024 PA CANCER ACTION DAY **Next Steps**

Congratulations!

Cancer Action Day is completed! You should feel proud of the effort and the impact of your meetings.

Follow the steps below to properly wrap up your experience and tie any loose ends.

Social Media Posts:

Thank you @[legislator handle] for meeting with @ACSCANPA volunteers today to hear our stories and policy priorities. Together we can #FightCancer #PACAD2024

Sorry we missed you, @[Legislator handle], during @ACSCANPA Cancer Action Day. We hope you will prioritize cancer patients in your policy positions this session. #PACAD2024

That's a wrap for PA Cancer Action Day! It was amazing to stand alongside fellow advocates in calling on the PA legislature to make fighting cancer a priority! XX meetings in one day! Want to learn how you can join us in future events? Find out more at www.fightcancer.org/volunteer-for-acs-can.

Hand-Written Notes:

Use the cards in your packet and write a note for any legislators who you wanted to speak to, but weren't able. Just a quick "sorry we missed you".

Also write brief thank you notes for all legislators who took the time to meet with you.

Turn in these note cards to Lydia, your Grassroots Manager, at the event hub in the Main Rotunda.

Stay Involved:

Join our volunteer team and advocate for life-saving policies year-round! Keep an eye on your email for actions to take and ways to make an impact as an ACS CAN Legislative Ambassador.

Sign up for more info at: https://act.fightcancer.org/a/pavolunteer





Contact:

For questions about this information, please contact Lydia Lippold-Gelb, Grassroots Manager lydia.lippoldgelb@cancer.org 206-818-1573

