

# New York Cancer Action Day Tuesday, May 7, 2024 Training Manual

ACS CAN is the nation's leading cancer advocacy organization that is working to make cancer a top priority. For over 20 years, we've worked together with our volunteers to pass legislation and advance policy changes at every level of government to end cancer as we know it, for everyone.



## New York Cancer Action Day Tuesday, May 7, 2024

Dear Advocate,

It's almost here...we are looking forward to our American Cancer Society Cancer Action Network (ACS CAN) Cancer Action Day on Tuesday, May 7, 2024!

This day is focused on meeting with your Senators and Assemblymembers in the Legislative Office Building (LOB) and Capitol in Albany with the goal to discuss our cancer fighting priorities in New York State; while demonstrating our power through telling your story. Our lawmakers need to know that cancer affects real people, their constituents, and is not just statistics on paper.

This annual event is energizing, exciting and personally rewarding. Whether you are joining us for the first time or are a seasoned advocate, please read through this guide for important information. We will be hosting virtual office hours on **Friday, May 3 from 4:30-6 PM** to answer any additional questions that may come up or to practice.

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

Keep fighting,

Rebecca Oechsner Senior Grassroots Manager, ACS CAN NY

Anthony Sandusky
Grassroots Manager, ACS CAN NYC



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## **Training & Scheduling**

## **Training**

Our Cancer Action Day training reviewed event-day logistics and policy issues in detail.

#### **Training**

If you missed the live training, please watch one of the recordings below.

\*Note: You only need to watch ONE training:

Thursday, May 2 at 12 PM

Thursday, May 2 at 7 PM

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 call.

### **Office Hours**

We will hold open Office Hours on <u>Friday, May 3, 2024, from 4:30-6 PM</u>

Join us at any point during the session to ask questions or practice your hook, line, sinker.

The link will be provided to you prior to the date.



## Lawmaker Meetings

Each participant will be placed with a team of others from your region, **led by a team leader**. ACS CAN will organize all teams and schedule all meetings. To avoid confusion with lawmakers' scheduling staff, please do NOT schedule your own meetings. All attempts will be made to schedule meetings with your specific lawmakers. Your final schedule will be provided on **Monday, May 6**, before the event.

### **Attire**

An ACS CAN shirt will be provided to you when you arrive in Albany 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 or something over it if it is chilly.

### **Report Back Form**

Don't forget to fill out your report back form after your legislative meetings. The link will also be emailed to you after the event.

### **Contact information**

If an emergency arises or you become sick and are unable to attend, please text or call: Rebecca Oechsner: (518) 275-1587 \* Anthony Sandusky: (718) 514-0527

## **Parking Near the Capitol**

The parking garage that has more availability is the MVP Arena parking garage located at 100 Beaver Street, Albany and is adjacent to the Empire State Plaza and accessed via the walkway that connects the plaza concourse to the garage. The cost is \$8 per day. Please save your receipt to submit for reimbursement if traveling from the Capital Region.

Alternative parking: There is metered parking on State Street in front of the Legislative Office Building or Washington Avenue across the park from State Street. This is more expensive and requires you to download an app to pay and is not always available. There is the visitor's parking lot under the plaza but it is usually sold out by 8:30 AM.



**Travel to Albany** - There will be transportation provided from several points, please check the schedule in this manual to see which will be closest to you. Those coming from the Capital District will be reimbursed for parking.

Once you have arrived at the Empire State Plaza Concourse, you will go through security to the Legislative Office Building (LOB). Travel lightly as to avoid hold ups going through security. Do not bring weapons of any kind, pocketknives included. Once through, you can move back and forth between the LOB and Capitol. If you go outside or on the concourse, you will have to get back in through security. There will be an ACS CAN sign at the entrance of the LOB. Take elevators to the 3rd floor.

There will be coffee, water and grab and go snacks provided upon your arrival. Boxed lunches will also be provided.

#### 11:30am - 12:00pm - Event Kick-off and Speaker Program

You will find your team number located on the back of the chairs to sit with your assigned group when you arrive on the terrace. We will share any instructions before your meetings and hear from a speaker or two.

#### 12:00pm - 4:00pm - Meetings with Elected Officials

A printed copy of your FINAL schedule will be in your packet handed out when you arrive at the registration table on the 3rd floor terrace. Your team leader will help guide your team throughout the day to your scheduled meetings.

### 4:00pm - 4:30pm - Cancer Action Day Debrief

We will all gather back on the 3rd floor terrace to share final thoughts and head back home. Pizza will be provided for attendees.

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## Travel - BUS ROUTE - Western/Central NY

Buffalo/Rochester/Geneva/Syracuse

Please arrive 10-15 minutes prior to the departure of the bus at your stop considering there is a very tight time schedule.

#### **Buffalo**

Wegmans 675 Alberta Dr Amherst, NY 14226

Departure: 6:00am

#### **Rochester**

Leroy Park and Ride 7797 S Lake Rd Bergen, NY 14416

Departure: 7:00am

This lot is located on Route 19 at Interstate 490 in the Town of LeRoy, Genesee County. It has a total of 108 spaces, four of which are reserved for motorists with handicap tags. To get to the lot from the New York State Thruway, take Exit 47 (I-490). Take Exit 1 on I-490 and continue straight onto Vallance Road. Continue straight onto Lake Road (State Route 19). The parking lot is on the left.

#### Geneva

Geneva Exit Park & Ride 1610 NY-14 Phelps, NY 14532

Departure: 8:00am



# Travel - BUS ROUTE - Western/Central NY Continued

### Buffalo/Rochester/Geneva/Syracuse

Pick up - This lot is located on Route 14 at the New York State Thruway, Exit 42 in the Town of Phelps, Ontario County. To get to the lot from the New York State Thruway, take Exit 42 (Geneva-Lyons). Turn left onto Route 14 North (Lyons Road). The driveway to the parking lot is on the left.

#### **Syracuse**

Exit 38 - County Route 57 County Route 57 Salina, NY 13088

Departure: 8:45am

The Thruway Park and Ride located near Exit 38 on the New York State Thruway (I-90) is situated in Liverpool, New York. Here are the details:

Address: County Route 57, Liverpool, NY

End Location Empire State Plaza, Madison Avenue

222 Madison Avenue, Albany, NY 12210, USA

Estimated arrival: 11:25 AM EDT



## Travel - BUS ROUTE - LI/Queens/Bronx

Please arrive 10-15 minutes prior to the departure of the bus at your stop considering there is a very tight time schedule.

Long Island
Park and Ride

395 N Service Rd Melville, NY 11747

Departure: 6:30am

Queens Little Neck Plaza

25427 Horace Harding Expy Little Neck, NY 11362

Departure: 7:00am

**Bronx** 

**Barreto Point Park & Drive** 

1724 Hunt Ave Bronx, NY 10462

Departure. 7:45am

222 Madison Ave Albany, NY 12202

Estimated arrival: 10:45am



## Travel - BUS ROUTE - Manhattan/Hudson Valley

Please arrive 10-15 minutes prior to the departure of the bus at your stop considering there is a very tight time schedule.

**Manhattan** 

American Cancer Society Hope Lodge, New York

132 W 32nd St

New York, NY 10001

Departure: 6:30am

Hudson Valley - Newburgh Short Line Transportation Center

60 NY-17K

Newburgh, NY 12550

Departure: 8:15am

222 Madison Ave Albany, NY 12210

**Estimated Arrival: 10am** 



## **Legislative Asks**

fightcancer.org

#### **Ask #1**

**Co-sponsor S2821B/A4053B** improving access to paid medical leave. All working cancer patients, survivors, and caregivers should have access to paid family and medical leave that allows them to take time off work to attend to their own or a loved one's care without losing their job or income. Please cosponsor this legislation and ask your Conference to support it and pass it before adjourning in June.

#### **Ask #2**

**Co-sponsor S8553-A/AXYZ** improving access to lung cancer screening by eliminating patient cost-sharing for follow up screening. Out-of-pocket costs for individuals lead to delayed or missed lung cancer screenings. Delayed or missed screenings can lead to delays in follow-up testing and treatment, which ultimately impacts a person's survival. Please co-sponsor the legislation and ask your Conference to support it.

#### **Ask #3**

Co-sponsor S1208/A7451 and S5415-A/A2083-A prohibiting genetic testing results from being shared by anyone other than patients and health care providers and prohibiting medical, life, accident, health, disability, or longterm health insurance plans from conditioning insurance rates, renewals, or any other coverage on the agreement of an individual to undergo genetic testing. Please co-sponsor this legislation and ask your Conference to support it and pass it before adjourning in June.

#### **Ask #4**

Co-sponsor S1531/A7154 requiring health care providers who administer any vaccines to a person 19 years of age or older to report all such vaccinations to the New York State Department of Health. Having accurate information on adult vaccinations is important to protecting both the health of individual New Yorkers and the public. Please co-sponsor this legislation and ask your Conference to support it and pass it before adjourning in June.



#### Introductions (2 min total so introductions need to be brief)

- Team leader introduces themselves sharing who they are, where they are from and if they are a survivor, caregiver, patient, etc
- Starting with any constituents in the room, each group member shares who they are, where they are from and if they are a survivor, caregiver, patient, etc. Rotate survivor story from meeting to meeting.

#### Team leader introduces the issue to the lawmaker.

- We are here today to speak with you about three critical issues that impacts millions of New Yorkers—improving access to lung cancer screening, protecting patient privacy, and improving adult vaccination records.
- I'd like to ask a few of my team members to go over the basics of why these issues are important and our policy requests.



#### ·Ask #1 Improving Access To Paid Medical Leave

- All working cancer patients, survivors, and caregivers should have access to paid family
  and medical leave that allows them to take time off work to attend to their own or a loved
  one's care without losing their job or income. This includes intermittent leave.
- Yet not all cancer patients, survivors and caregivers who work have access to paid leave, and without it they risk losing employment or not getting the care they need.
- While NY's Paid Family Leave (PFL) and Temporary Disability Insurance (TDI) programs
  ensure that a patient can take time for theirs or a loved one's treatment, the shortest
  duration that a patient may take time under PFL is one day at a time, and TDI does not
  cover any intermittent leave.
- Conditions like cancer (or treatment of cancer) are often sporadic or intermittent lasting
  weeks or months. That's why it is so important to give employees the right to take a few
  hours or days of leave at a time, if necessary, for their own serious health conditions or to
  care for family members with serious health conditions.
- Equally alarming is the fact that the amount a person can receive has not been raised since in 1989.
- ACS CAN supports legislation which strengthens NY's Paid Family and Medical Leave Programs by increase the amount a person can receive, protects patients from losing their job during leave, ensures that intermittent leave is included in coverage and more.
- Will you co-sponsor S2821B/A4053B and ask your Conference to support the legislation?

## Paid Medical Leave Background Information A recent survey of cancer patients showed that:

- 74% of cancer patients and survivors say they missed work due to their illness; most of whom (69%) reported missing more than four weeks of work.
- One-third of those who missed work did not receive any pay for at least part of the time they needed to be out due to illness, and more than 1 in 10 lost or quit their jobs.
- A nationwide survey of cancer patients showed that of those cancer patients who had to take unpaid leave from work during their treatment 37% took either hours or days at a time, which is considered intermittent, and 11% had a mix of increments of time taken. For those who benefitted from paid medical leave, 30% took time in increments of hours or days.



#### Ask #2 Improving Access To Lung Cancer Screening

- Despite the effectiveness of lung cancer screening, uptake has been low, with only about 6.5% of the eligible individuals nationwide getting screened.
- Only 31.0% of lung cancer cases are caught at an early stage in New York and significant disparities exist between different racial and ethnic groups.
- Research shows that required cost sharing including co-pays, co-insurance, and deductibles – can be a significant barrier for individuals who need preventive services.
- Out-of-pocket costs for individuals lead to delayed or missed lung cancer screenings. Delayed or missed screenings can lead to delays in follow-up testing and treatment, which ultimately impacts a person's survival.
- Cancer screening is a continuum of testing rather than a single recommended screening test and is a process that includes a recommended screening test and all follow-up tests.
- ACS CAN supports S8553-A / AXYZ which ensure comprehensive insurance coverage and the elimination of cost sharing for recommended lung cancer screening and follow-up testing for individuals by all payers in New York, including Medicaid.
- Will you co-sponsor S8553-A / AXYZ and ask your Conference to support the legislation?

#### **Lung Cancer Screening Background Information**

- Lung cancer screening has been proven to reduce mortality from lung cancer by detecting it earlier when it is more likely to be treated successfully.
- Significant disparities exist between different racial and ethnic groups for 5-year survival and early diagnosis.
- One study found the patient out-of-pocket costs for follow-up screening tests among individuals whose insurance covered initial lung cancer screening averaged \$424.05.



#### Ask #3 Prevent Genetic Information Discrimination.

- Certain variations or mutations in a patient's genetic code can either cause disease or make the development of a disease highly likely. For example, mutations in the BRCA1 and BRCA2 genes are associated with a predisposition towards developing breast, cervical, and prostate cancers.
- While this information can help individuals mitigate the onset of disease or better plan for the management of a condition (e.g. starting mammograms at an earlier age or elective mastectomy), this same information could be used by insurers to discriminate against such individuals through denial of coverage or charging higher premiums.
- In 2008, the Genetic Information Nondiscrimination Act (GINA), a bill supported by ACS CAN, was passed, barring discrimination in health insurance and employment based on genetic information.
- However, discrimination in long-term care, disability or life insurance based on genetic information is still legal.
- \$1208/A7451 prohibits genetic testing results from being shared by anyone other than
  patients and health care providers and that health insurance companies may only
  receive information on the fact that a genetic test was done but not the findings of the
  test.
- **\$5415-A/A2083-A** prohibits medical, life, accident, health, disability, or long-term health insurance plans from conditioning insurance rates, renewals, or any other coverage on the agreement of an individual to undergo genetic testing.
- Will you co-sponsor \$1208/A7451 and \$5415-A/A2083-A and ask your Conference to support the legislation?

#### Preventing Genetic Information Discrimination Background Information

- 2/3 of patients surveyed reported being either somewhat or very worried about life insurance companies using their genetic information to set rates.
- 28% of patients who declined to participate in a genome sequencing study said that a fear of insurance discrimination was their primary reason for not participating.
- At least seven states have already curtailed the use of genetic information by life, longterm, and/or disability insurers.



#### Ask #4 Improving Adult Vaccination Records.

- Under current law, all immunizations administered to children less than nineteen years old must be entered into the state health database.
- Expanding this requirement to adult vaccinations will ensure that providers continue to have a reliable record of immunization information from multiple providers for children and adults alike.
- Only 6 states, including New York, don't require adult vaccination reporting.
- ACS CAN encourages passage of this legislation because having accurate information on adult vaccinations is important to protecting both the health of individual New Yorkers and the public.
- Will you co-sponsor \$1531/A7154 and ask your Conference to support the legislation?

#### **Adult Vaccination Reporting Background Information**

- Vaccines save lives and are safe and effective at preventing deadly, communicable diseases.
- This legislation does not in any way mandate adult vaccinations.
- All this legislation would do is have vaccine providers report adult vaccinations to the NYS or NYC registries unless an adult requests that it not be reported. It is supported by physicians, nurses, pharmacists, public health & social/health equity organizations.



Please promote your participation in Cancer Action Day on social media!

#### Social Media Best Practices:

- Use @ to tag your lawmakers (post must be "public" on Facebook)
- Include the hashtag #FightCancerNY in camel case (Capital letters starting each word)
- Include pictures in your posts
- Share and like your fellow and our ACS CAN posts and tweets

ACS CAN NY handles: Facebook @acscanofNY \* Instagram: @acscan\_NY \* X: @acscan\_NY

#### **Pre-event Samples**

PLEASE NOTE: You may see all caps and xxx in some of the sample posts, that is where you will fill in the pertinent information to you and tag your lawmakers.

I am so excited to travel to Albany and join my fellow advocates in meeting with our lawmakers for Cancer Action Day to ask for more access to lung cancer screening, improving adult vaccination records and preventing genetic information discrimination. #FightCancerNY

Looking forward to meeting YOURLAWMAKER and ask them to make fighting cancer a priority during @acscan\_NY's Cancer Action Day in Albany! #FightCancerNY

#### **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 Cancer Action Day to meet with YOUR LAWMAKERS NAMES. Follow along as I join over 75 NY volunteers in calling on our state lawmakers to make fighting cancer a priority in NY. Check in today for updates and opportunities to join me in the fight!
- 2. Hey everyone! I just met with YOURLAWMAKER and it was awesome! We are making our voices heard and fighting to XXX. 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)



## **Social Media Continued**

### **Event Day Samples (Continued)**

3. Hello! NY Cancer Action Day is a wrap. What an amazing day! So fun and fulfilling to stand with fellow advocates in calling on the NY legislature to make fighting cancer a priority! XX meetings in one day! Want to learn how you can join us in future events? Message me. (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)

I am in Albany today with over 75 advocates calling on our lawmakers to ask for better access to lung cancer screening, improving adult vaccination records and preventing genetic information discrimination.#FightCancerNY

- Thank you @INSERT LAWMAKER NAME for meeting with ACS CAN today and listening to our asks to reduce barriers to lung cancer screening, prevent patient discrimination, and improve adult vaccination use. #FightCancerNY
- Despite the effectiveness of lung cancer screening, only a small % of those who should get screened are doing so. Out of pocket costs are a significant barrier to screening. S8553-A/AXYZ eliminates patient cost sharing for lung cancer screening and follow-up testing. #FightCancerNY
- No patient should have to worry about being discriminated against based on a genetic test. S1208/A7451 & S5415-A/A2083 will prevent genetic testing results from being shared with health insurers and prevent insurers from discriminating against patients #FightCancerNY



## **Glossary of Terms**

**Ask/Asks:** The legislative actions we want our lawmakers to take to support the fight against cancer.

**Concourse:** The underground area where all of the Empire State Plaza buildings are connected. Security is also located in the concourse, as well as eateries, banks and the NYS gift shop.

**Hook-Line-Sinker:** Mnemonic for the key steps for an effective lawmaker meeting: the Hook is who you are (a constituent), the Line connects your personal story to the Asks, and the Sinker is when you make the Ask.

**LOB:** Acronym for Legislative Office Building – the location in Albany where our senators and assemblymembers and staff have offices where we meet with them on Cancer Action Day.

**Off the Floor:** A type of meeting where a constituent is escorted to an area outside of the legislative chamber (in the Capitol building, across the street from the LOB, accessed through concourse) where they meet with their lawmaker (rather than meeting with a lawmaker in their office in the LOB).

**Well:** An area of the LOB with an enormous staircase (in past years we have based our Cancer Action Day activities in the Well, but this year we're using the 3rd floor terrace).

# **THANK YOU!**

We can't wait to see you at Cancer Action Day Tuesday, May 7, 2024!

### **Staff Contact Information**

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