



Welcome to ACS CAN Lawmaker Meeting Training

Cancer Action Day

at the New York State Capitol.



May 7, 2024

Agenda for Today

- **The Asks**
- **Deeper Dive into the Asks**
- **Flow of the Meeting**
- **Hook, Line, Sinker**
- **Example of Meeting**
- **Schedule of Events for the day**
- **Social Media**
- **Event Reminders**
- **Questions?**



Legislative Ask #1

Improve 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 co-sponsor S2821B/A4053B and ask your Conference to support it and pass it before adjourning in June.



Ask #1 Pt 1



- 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 New York's Paid Family Leave Program covers a portion of income lost due to time taken to care for a loved one, workers who need to take time for their own cancer diagnosis are not included.
- No increase since 1989

Ask #1 Pt 2



- Paid Family Leave Covers caregivers one day at a time
- Temporary Disability Insurance does not cover any intermittent leave for patients
- ACS CAN supports A4053A/S2821A which would expand eligibility for temporary disability insurance and paid family leave benefits. The bill will modernize the paid family and medical leave program to meet the needs of today's New Yorkers.
- Request - Please co-sponsor S2821B/A4053B and ask your Conference to support it and pass it before adjourning in June

Deeper Dive into the Asks

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.**

Legislative Ask #2

**Eliminate patient cost-sharing
for lung cancer screening**



Ask #2 Pt 1

- ✓ **Only about 6.5% of the eligible individuals nationwide getting screened for lung cancer**
- ✓ **Only 31.0% of lung cancer cases are caught at an early stage**
- ✓ **Black (24.5%) and Latino (27.4%) New Yorkers are diagnosed at an early stage of lung cancer at a lower rate than white (32.2%) New Yorkers.**
- ✓ **Cost sharing is a significant barrier to care**

Ask #2 Pt 2



- **Out-of-pocket costs for individuals lead impacts a person's chance of survival.**
- **Cancer screening is a continuum of testing rather than a single recommended screening test**
- **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 it?**

Deeper Dive into the Asks

- Significant disparities exist between different racial and ethnic groups for 5-year survival and early diagnosis
- Average cost of \$424.05 per individual with a range of \$0 to \$7,498.74
- Lung cancer screening is recommended only for adults who are at high risk for developing the disease because of their smoking history and age, and who do not have a health problem that substantially limits their life expectancy or their ability or willingness to have lung surgery, if needed.

Legislative Ask #3

Prevent genetic testing discrimination



Ask #3 Pt 1

- **Certain variations or mutations in a patient's genetic code can either cause disease or make the development of a disease highly likely.**
- **Genetic testing results could be used by insurers to discriminate against such individuals**
- **Genetic Information Nondiscrimination Act bars discrimination in health insurance and employment based on genetic information.**

Ask #3 Pt 2



- **S1208/A7451 prohibits genetic testing results from being shared by anyone other than patients and health care providers**
- **S5415-A/A2083-A prohibits medical, life, accident, health, disability, or long-term health insurance plans from requiring testing**
- **Will you co-sponsor S1208/A7451 and S5415-A/A2083-A and ask your Conference to support the legislation?**

Deeper Dive into the Asks

Preventing Genetic Information Discrimination

- 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, long-term, and/or disability insurers

Legislative Ask #4

Require adult vaccination reporting



Ask #4 Pt 1

- **Child vaccinations must be reported but not adults**
- **Requiring adult vaccination reporting is good for an individual's health and public health**
- **All vaccines including HPV vaccine**
- **HPV vaccination can help prevent nearly 90% of HPV cancers**

Ask 4 Pt 2



- **All vaccines including HPV vaccine**
- **HPV vaccination can help prevent nearly 90% of HPV cancers**
- **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 S1531/A7154 and ask your conference to support it?**

Deeper Dive into the Asks

Adult Vaccination Reporting

- 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.

Flow of the Meeting

HOOK - Meeting leader introduces the group (name + geography).

I am here as a volunteer for ACS CAN. We are meeting with Members of the New York Legislature.

LINE - Explain the need.

Why this is needed/impact on state/why important for cancer etc.

Tell your personal story: Connect your personal story to the importance of the ask/issue.

SINKER - Make the ask.

Will you support...



**Breaking it down:
The Hook**

- # Introductions
- **Who you are,
where you're
from**
 - **Who else is in
your group**



Start your story:
You know your passion
You know your cancer connection

- **You know the asks**
- **You have your talking points**

Tell your personal story:

- **Connect your story to the importance of the asks**

**Breaking it down:
The Line**

Make the asks:

1. **Help improve access to paid medical leave by co-sponsoring S2821B/A4053B and asking your conference to support it.**
2. **Help improve access to lung cancer screening by please co-sponsoring S8553-A / A.XYZ and ask your conference to support it.**
3. **Help protect patients from genetic testing discrimination by co-sponsor S1208/A7451 and S5415-A/A2083-A - and ask your conference to support it.**
4. **Help improve access to vaccinations by please co-sponsoring S1531/A7154 and ask your conference to support it.**



**Breaking it down:
The Sinker**

Example of a Legislative Meeting

Listen for:

- **Introductions (Hook)**
- **Personal connection to cancer (Line)**
- **A request for support (Sink)**

**Key
Takeaways
and don't
forget to
Practice!**



Telling Your Story

- Your story will be different.
- You don't have to be perfect.
- If your story doesn't align to the asks, you can say:

I know what it's like to hear the words "you have cancer" or I know the impact that a cancer diagnosis can have on a family. Let me tell you about my friend/relative/coworker.....



Social Media



- Follow ACS CAN NY and share/retweet our posts.
- Our handles: Facebook: @acscanofNY
Instagram: @acscan_NY Twitter:@acscan_NY
- Follow your state Assembly member and Senator's social media pages
- Post tagging your lawmakers, use #FightCancerNY
- Post selfies or videos
- Take group pictures with permission from legislator or staff member

Agenda for the Day

Tuesday, May 7, 2024



6:00 AM – 10:30 AM – Travel

10:00 AM – 11:30 AM – Check in – 3rd Floor Terrace, Leg Office Bldg.

11 AM – Press Conference, LCA Room 130, Leg Office Building

11:30 AM – 12:00 PM – Event Kick-off and Speaker Program

12:00 PM – 4:00 PM – Meetings with Elected Officials

3 PM – Pizza and salad delivered

4:00–4:30 PM – Cancer Action Day Debrief/Departure



Event Reminders

Tuesday, May 7

- Dress Code – ACS CAN T-Shirt (given out at registration) no ripped jeans or shorts, bring a cardigan or sweater if you get cold, wear comfortable shoes.
- Buses will drop off in front of the NYS Museum on Madison Avenue. There will be greeters on the concourse to direct you. (Wheelchairs will be available for those with impaired mobility).
- We will be gathering on the 3rd Floor Terrace of the Legislative Office Building (LOB).
- You will need to go through security, be sure you have your ID with you. If parked underneath the Empire Plaza, enter security from the concourse, go to your left to the LOB take the elevators to the 3rd Floor.
- Coffee, water and grab and go snacks will be available upon your arrival.
- Boxed lunches will be available from 11–1:30 PM, stop by and grab them when your schedule allows. Pizza and salad at 3 PM.
- We will hand out t-shirts, volunteer packets and leave behind packets when you arrive.



**Want to practice
or have questions?**

**Join us for Virtual Open Office
Hours on Friday, May 3, 4:30 – 6 PM**

Questions?





Thank You