

Sample Meeting Agenda With Talking Points

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 four 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?

• 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.
- Cancer screening is a continuum of testing rather than a single recommended screening test and is a process that includes a recommended screening test <u>and all follow-up tests</u>.
- 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?

• 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 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.
- **S1208/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.
- **S5415-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 S1208/A7451 and S5415-A/A2083-A and ask your Conference to support the legislation?

• 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 S1531/A7154 and ask your Conference to support the legislation?

30 second pitch

On behalf of the 130,000 New Yorkers who will be diagnosed with cancer in 2024 and the 1.7 million cancer survivors living in New York, we have four asks of you today:

- Strengthen NY's Paid Family and Medical Leave Programs;
- Improve access to lung cancer screening by eliminating patient cost sharing when follow up testing is needed;
- Prevent genetic information discrimination by health insurers; and
- Help protect both the health of individual New Yorkers and the public by requiring the reporting of adult vaccinations
- Here is a packet with all of the information, including bill numbers that we are asking you to support.