

Hill Day Preparation

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Two Legislative Asks

- **Comprehensive Cancer Survivorship Act (HR 4363 / S 2213)**
- **Cancer Care Planning & Communications Act (HR 5183)**

► Comprehensive Cancer Survivorship Act (HR 4363 / S 2213)

- Bipartisan legislation first introduced December 2022 and again in June 2023
- Introduced by Representatives Debbie Wasserman Schultz (D-FL), Brian Fitzpatrick (R-PA), and Mark DeSaulnier (D-CA) and Senators Amy Klobuchar (D-MN) and Ben Cardin (D-MD)
- Seeking additional cosponsors in the House
- Seeking Senate Republican to lead in the Senate



▶ What Does the CCSA Do?

- Addresses the health of cancer survivors throughout the entire continuum of care – from diagnosis to active treatment and post-treatment
- Aims to close many of the gaps survivors face to improve survivorship, treatment, and transition for all cancer survivors.

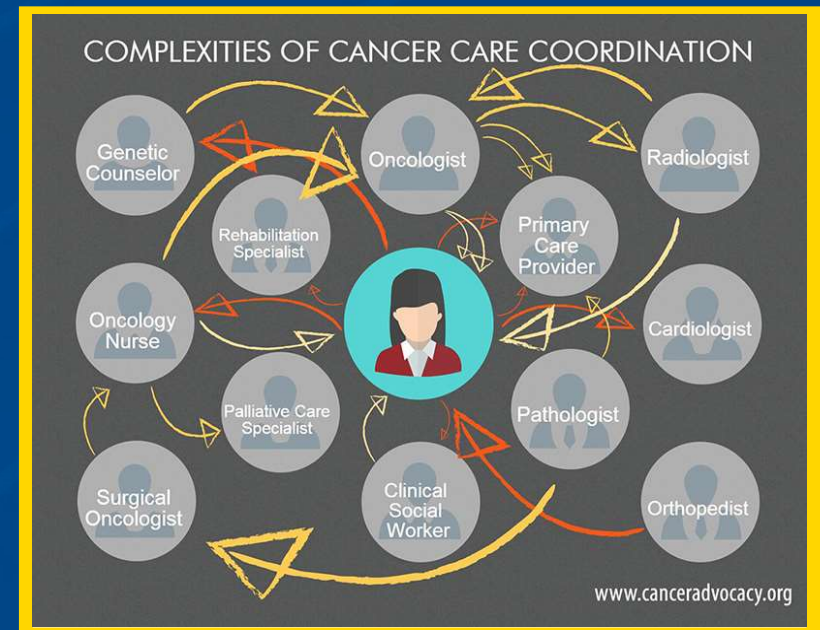


What's in the CCSA?

- Coverage cancer care planning and communication
- Survivorship transition tools
- Alternative payment model
- Survivorship navigation
- Survivorship care demonstration program
- Employment assistance program
- Adult cancer survivorship study
- Survivorship progress report
- Easing transition to primary care for children with cancer
- Childhood cancer demonstration model and standard of care
- Medicaid coverage of fertility preservation

► Cancer Care Planning and Communication

- Creates Medicare service and payment for care planning and coordination services to help improve coordination of care and transition to primary care.
- Cancer care planning has been identified as an element of quality cancer care.
- In the NCCS 2020 State of Survivorship Survey, only 17% of survivors said they received a survivorship care plan.
- Without a written plan, survivors are left to navigate their cancer diagnosis without clear direction.



► Cancer Care Planning and Communication

- Will help cancer patients by supplying them a tangible plan or roadmap.
- Will promote shared decision-making between patients and their cancer care teams so patients are not left in the dark.
- Will empower patients with information necessary to help manage and coordinate their care.
- Will help providers deliver the right care at the right time, better coordinate a patient's care, and use resources effectively.



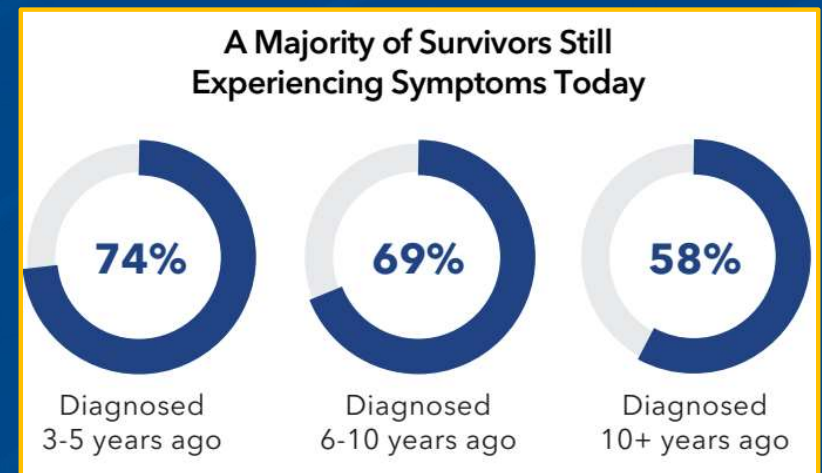
Majority of cancer patients say they discussed what to expect post-treatment with their provider (62%), but far fewer got information about exercise and nutrition (39%), long-term side effects (39%), or mental health support (24%). Only 17% report getting a post-treatment survivorship plan.

Adult Cancer Survivorship Study

- Requires an analysis to assess the benefits of creating an adult version of the Childhood Cancer Survivor Study.
- The study would collect information about late and long-term effects of cancer to:
 - Help better understand these effects
 - Improve treatments and interventions to increase survival, minimize harmful health effects, and improve quality of life

▶ Adult Cancer Survivorship Study

- Survivors are at risk of developing future health problems due to their cancer treatment, often decades after completing treatment.
- This study would provide data and insights to help survivors and their health care providers make informed decisions about their care.
- It would help ensure future cancer survivors have access to the best possible care.



▶ Cancer Care Planning & Communications Act (HR 5183)

- Introduced by Congressman Mark DeSaulnier (D-CA) in August 2023
- NCCS has advocated for cancer care planning for many years
- Seeking additional cosponsors in the House
- Seeking champions to introduce in the Senate



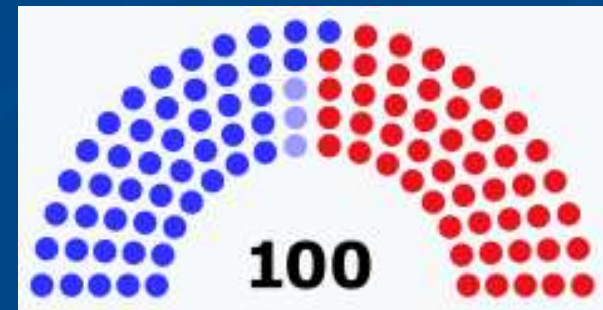
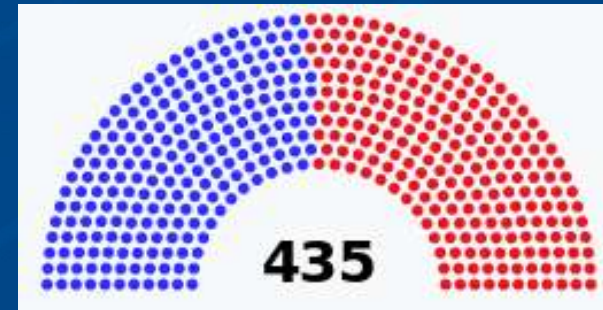
▶ 118th Congress

House of Representatives

- 435 representatives
 - 218 Republicans
 - 213 Democrats
 - 4 vacant seats
 - 6 non-voting members (e.g. PR, DC, Guam)

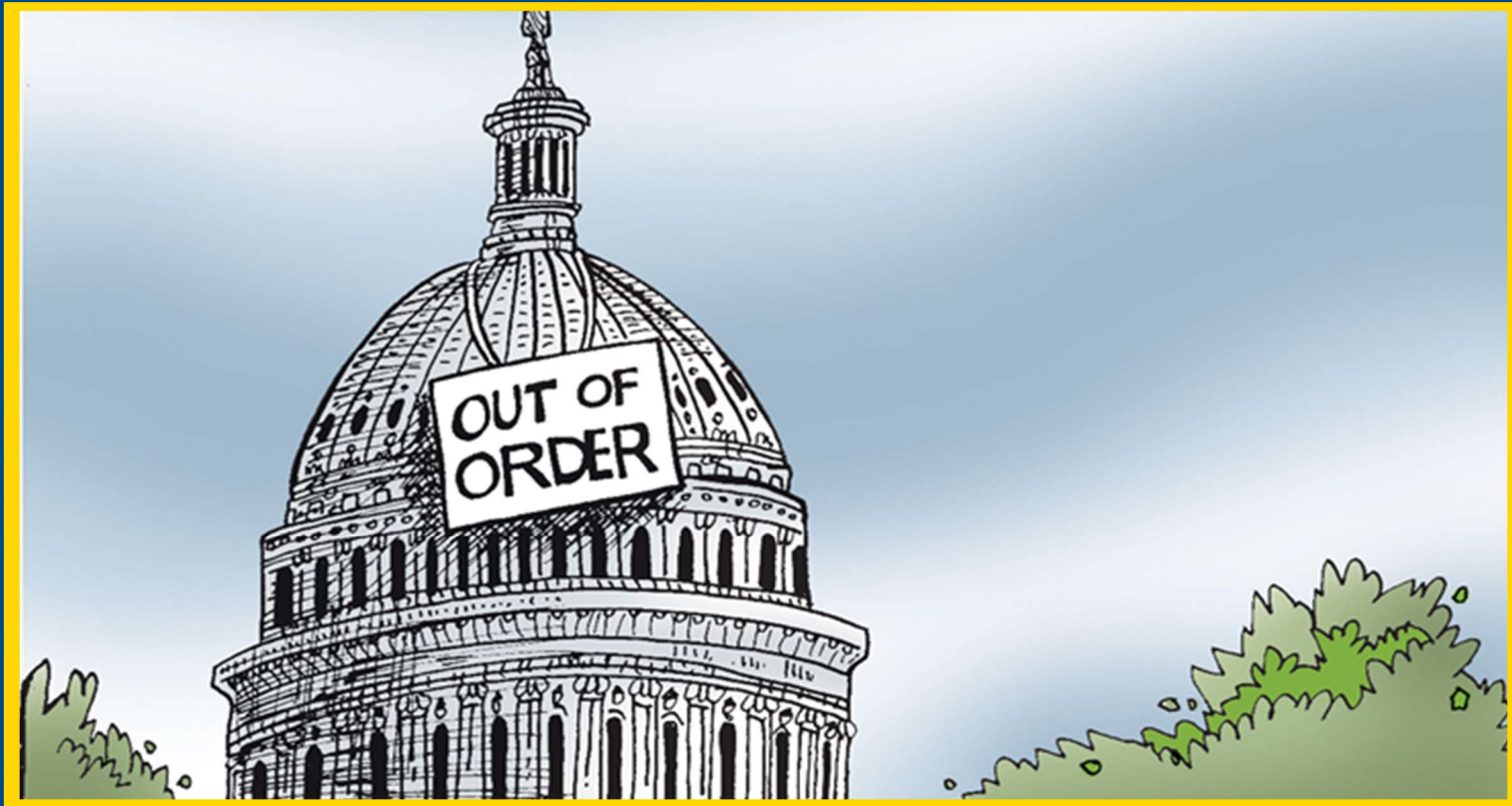
Senate

- 100 senators
 - 48 Democrats
 - 3 Independents (caucus with Ds)
 - 49 Republicans
 - VP Harris casts tie-breaking votes



▶ How Congress Works





▶ Who will you meet with in Legislative Offices?

- Member
- Chief of Staff
- Legislative Director (LD)
- Health Legislative Assistant (HLA)
- Fellow
- Legislative Assistant (LA)
- Legislative Correspondent (LC)
- Staff Assistant



▶ The Meeting

- Brief introductions (name, city, connection to cancer, NCCS advocate)
- State the purpose of the meeting
- Share your story
- **Make the ask OR** thank them if they are already cosponsor
 - House: Will you cosponsor the CCSA and the CCPCA?
 - Senate: Will you cosponsor the CCSA and introduce the CCPCA?



Telling Your Story

NCCS' Telling Your Story Worksheet can help you identify the key pieces of your story while also keeping your story concise and compelling.



**Comprehensive Cancer Survivorship Act
Telling Your Story: A Step-by-Step Worksheet**

People have been telling stories since human beings first sat around campfires. We are hard-wired to take in new information through stories.

Statistics reach people in the head. Stories hit people in the heart. Sharing your personal experience is a powerful way to establish a connection and drive your listener to action. Your audience (e.g. elected officials, donors, the media, other volunteers) may disagree with your facts or arguments, but they cannot argue with your unique personal experience.

The steps below are based on research in effective storytelling, but you should tailor them to your own circumstances.

1. Hi. I'm [name] from [place].
If meeting with a member of Congress, identify yourself as living in their district.

2. My life changed when [describe your diagnosis or a loved one's].
Example: I had to undergo multiple surgeries and rounds of chemotherapy, which took a physical and mental toll on me. Despite having a good relationship with my doctors, it was difficult to coordinate my care between them, leading to confusion and frustration.
Example: As my father's primary caregiver when he was diagnosed with cancer, I had to navigate a complex health care system that I knew little about. I was constantly worried about whether I was making the right decisions for his care and felt like I had to advocate for him at every turn.

▶ How to End the Meeting

- Share that NCCS will follow up to answer any policy questions they may have.
- Thank the staff member(s) for their time.
- Ask if they are willing to take a photo with the group.



DOs for Hill Meetings

- Be prepared
- Be on time
- Be flexible
- Be respectful
- Be concise
- Share the spotlight
- Be responsive
- Be appreciative
- Use social media
- Follow up

DON'Ts for Hill Meetings

- Overload the Hill visit with other issues
- Expect your legislator or staffer to be an expert on the issue
- Be afraid to say “I don’t know”
- Be offended if your legislator is unable to meet with you
- Confront, threaten, or pressure

Questions you may get asked?

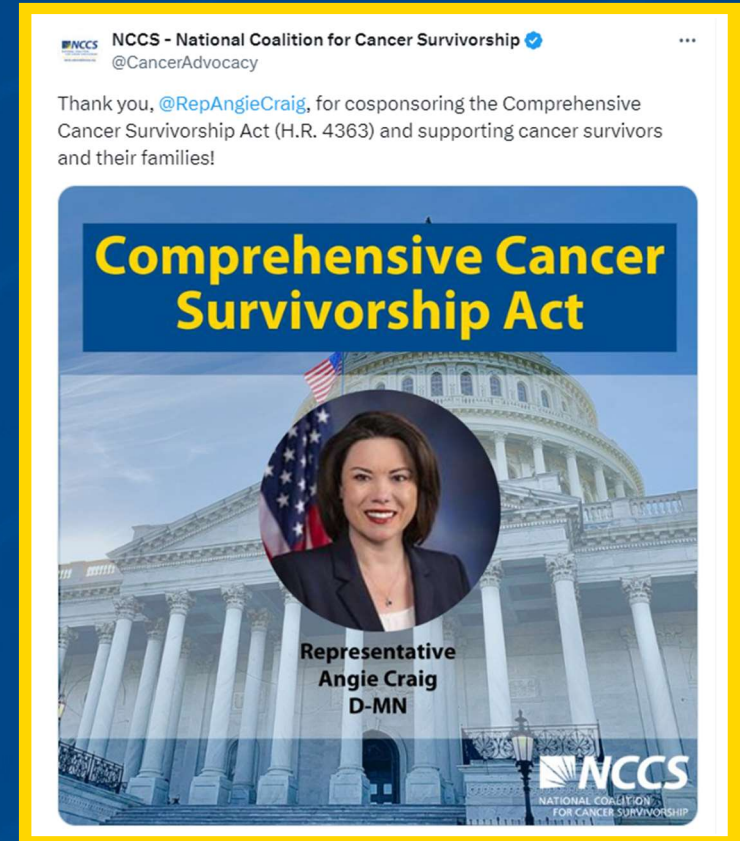
- What is the difference between Survivorship Navigation and the new patient navigation codes implemented this year?
- What is the CBO Score?

Reforms of Medicare Payment to Encourage Patient Navigation

- Beginning January 1, 2024, the Medicare physician fee schedule includes codes for patient navigation and community health integration (to address social determinants of health)
- Payment is made to physicians or other qualified Medicare providers, but services may be provided by lay navigators with appropriate training
- These new payment codes, advanced by President Biden, hold the promise of addressing certain needs of cancer patients during treatment and improving quality of care
- Implementation of new codes is always challenging, and NCCS is engaging in patient and provider education to enhance code utilization
- There are limits to the use of the new codes for survivorship care, and there remains a need for planning and coordination services for cancer survivors

▶ After the Meeting

- Tweet to thank your legislator for the meeting and restate the ask
- Send thank-you emails
- Follow up with Hill and NCCS staff on action items, if any
- If your member takes action, thank them and their staff
- Complete Surveys in Soapbox Portal
- Upload Photos in Soapbox Portal



Logistics

- Buses
- One-Pagers
- Getting around
- If you have a 4:30 meeting, text Elena (978-618-3032)



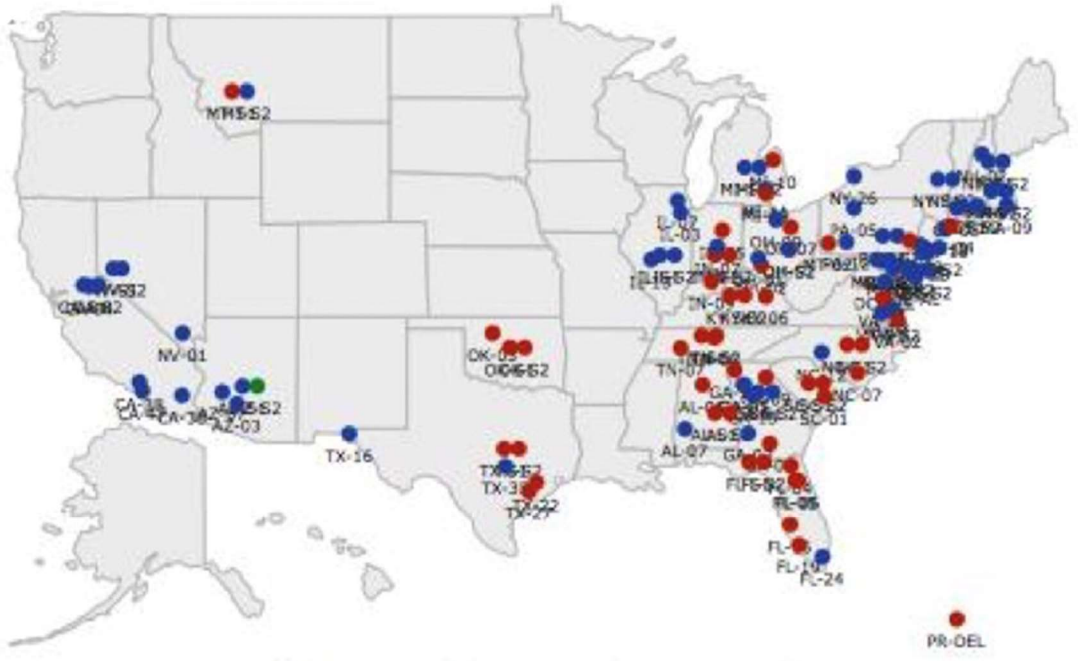
LOGISTICS **2024**

118th U.S. Congress
2nd Session

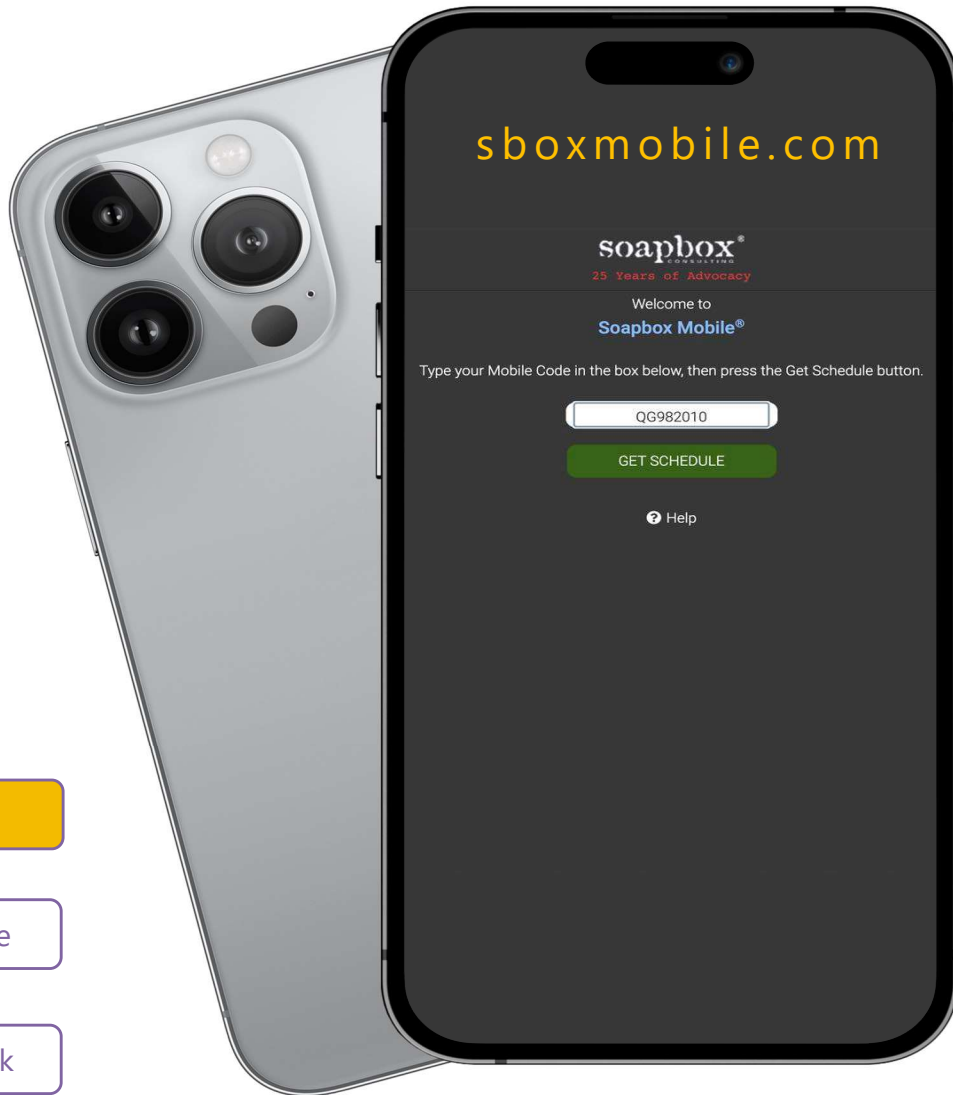
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STRATEGIC MAP

Strategic Map: Political Parties
National Coalition for Cancer Survivorship (NCCS)



Legend:
Blue square: Democrat
Red square: Republican
Green square: Independent



Soapbox Mobile Tool®

- ✓ Nothing to download or install
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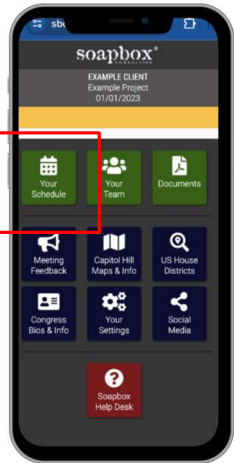




Log-In

Schedule

Feedback



soapbox[®]
EXAMPLE CLIENT
Example Project
01/01/2023

HOME > SCHEDULE LEGEND

Your individual schedule is below.

11:30 AM (ET) – Sen. Tom Cotton (with Alex Hanson, LA) AR-S (R)
Room: SR-326 [CAU]

Feedback Meeting Roster

12:00 PM (ET) – Sen. John Boozman (with Member) AR-S (R)
Room: SD-555 [S.Approps] (HlthPro) [S. 345]

Feedback Meeting Roster

2:00 PM (ET) – Rep. Steve Womack (with Jessica Powell, LD) AR-03 (R)
Room: RHOB-2412 [H.Approps]

Feedback Meeting Roster

Rep. or Sen. | (w/ Member or Staff & Title)

Building & Room Number

Bill Co-Sponsors / Caucus Members / Etc.

Key Committee Members

Log-In

Schedule

Feedback

soapbox
CONSULTING

EXAMPLE CLIENT
Example Project
01/01/2023

HOME > SCHEDULE > FEEDBACK

MEETING: 10:00 AM (ET) -- Sen. Amy Klobuchar (MN-S-D) [S.Leadership]

Did the Member (or staff) agree to our request(s)? (please explain)

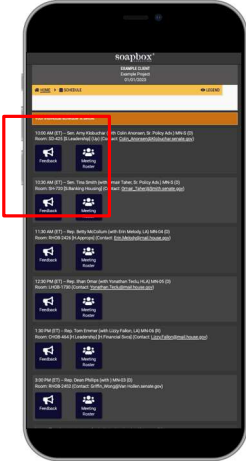
Additional details you would like to share about your meeting:

Was any additional follow-up or information requested?

Upload a photo of the meeting (optional):
Choose File No file chosen

SUBMIT

Cancel



YOUR SCHEDULE

Association Example
Advocacy Day

Lisa Jones
New City, GA
Primary district: GA-01
All district (if applicable): NA-00

Mobile Tool Code
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(www.sboxmobile.com)

Help Desk
Soapbox Help Desk
(202) 362-5910

Your Team
GA Team 01
Lisa Jones (GA-01)
Louis Rodriguez (GA-01)
Brian Smith (Group Lead) (GA-01)

Sunday, January 1, 2019 #RapidHillDay

10:30 AM – Sen. David Perdue Jr. (with Member & Daniel Hale, LA) GA-S (R)
Room: SR-455 (Up) *S-123*

11:30 AM – Sen. Johnny Isakson (with Allie White, LA) GA-S (R)
Room: SR-131

1:30 PM – Rep. Buddy Carter (with Member) GA-01 (R)
Room: RHOB-2432 [H.Edu-Full] *HR45S* [CAU]
Note: Rep. Carter will now join meeting at the new time.

2:30 PM – Rep. Sanford Bishop (with Jonathan Halpern, LD) GA-02 (D)
Room: RHOR-2407 [H.Appr-Full]
Note: This Representative may be late due to votes.

Key Committees
[S.Appr-Full] - Appropriations
[H.Appr-Full] - Appropriations
[H.Edu-Full] - Education and Labor
[Ldr] - H. Leadership
[Ldr] - S. Leadership

(Printed 1/10/2019 12:15:50 PM)

Staff Titles:	Additional Info:	Office Numbers:	Co-Sponsor/Caucus:
COS: Chief of Staff LD: Legis. Director Cmte./Staff: Committee Staff LA/HIA: Legis. Assistant LC: Legis. Correspondent	[New] – New to 116th Congress [Up] – Senator up for re-election [Ret.] – Not running for re-election	SH-xxx Hart SD-xxx Dirksen SR-xxx Russell CHOB-xxx Cannon LHOB-1xxx Longworth RHOB-2xxx Rayburn	[H.R.0000] – House bill co-sponsor [S.0000] – Senate bill co-sponsor [Cau] – Caucus member [LTR] – Signed Dear Colleague Letter

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Name | District

Mobile Tool® code | Help Desk phone number





Team (for all House meetings)

Meeting times | Location | Staffing | Co-Sponsors

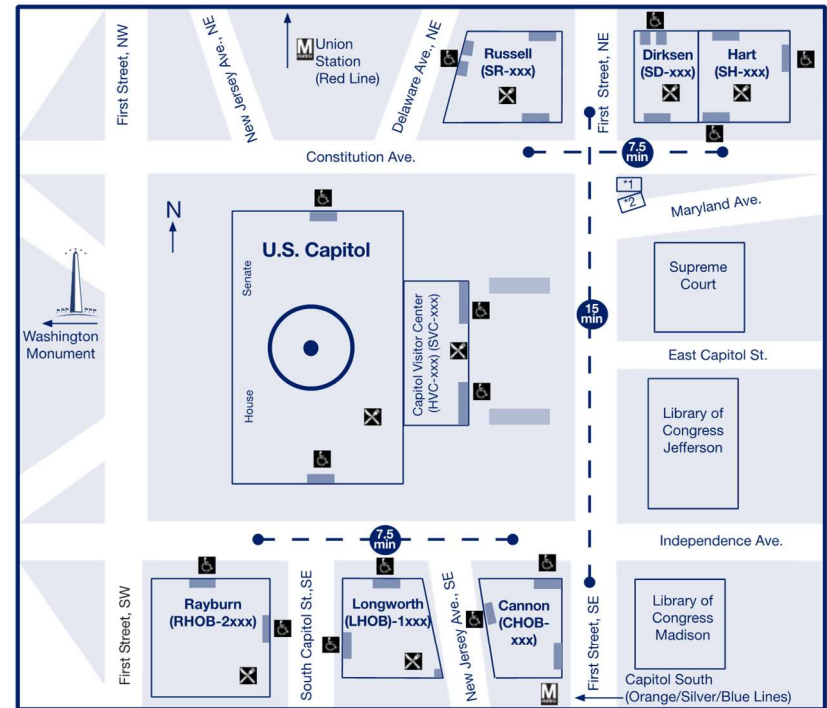
Key Committees

Other Abbreviations

CAPITOL HILL MAP

-  Entrance
-  Accessible
-  Food/Drink
-  Est. Walking Time

Map of Capitol Hill



Senate Office Buildings	House Office Buildings	Capitol Visitor Center	
SH-xxx Hart	CHOB-xxx Cannon	HVC-xxx House Side	*1 Reserve Officers Building
SD-xxx Dirksen	LHOB-1xxx Longworth	SVC-xxx Senate Side	*2 United Methodist Building
SR-xxx Russell	RHOB-2xxx Rayburn		
			Estimated walking times

-  Entrance
-  Wheelchair Access
-  Food/Dining

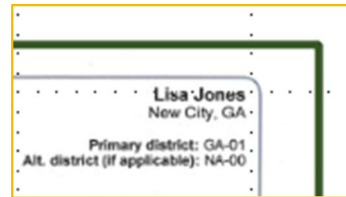
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SCHEDULE DISTRIBUTION

A.

Pull schedules out of envelope and distribute by name.



B.

1. Put unclaimed schedules back in envelope..
2. Drop a business card from anyone who didn't get a schedule in the envelope.
3. Gather any other questions or needs from your state (especially any meetings nobody will attend.)

C.

Bring your envelope back to the Help Desk to check in (even if it is empty)

& TEAM CHECK-IN



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