

Effective Advocacy:
Making Your Capitol Hill Visit
Fun and Successful

Ovarian Cancer Survivors Capitol Hill Day

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Washington, DC

Ilisa Halpern Paul, MPP

Managing Government Relations Director

Drinker Biddle & Reath

ADVOCACY

- Patient
- Legislative
- Regulatory
- Media
- Legal



Who Am I To Lobby Congress?

I am "just" a patient/affected family member.

- The Constitution grants you the right "to petition the government for a redress of grievances."
- Members of Congress play a huge role in cancer research & health care – they need your expertise.
- Their decisions affect you!
- They work for YOU!



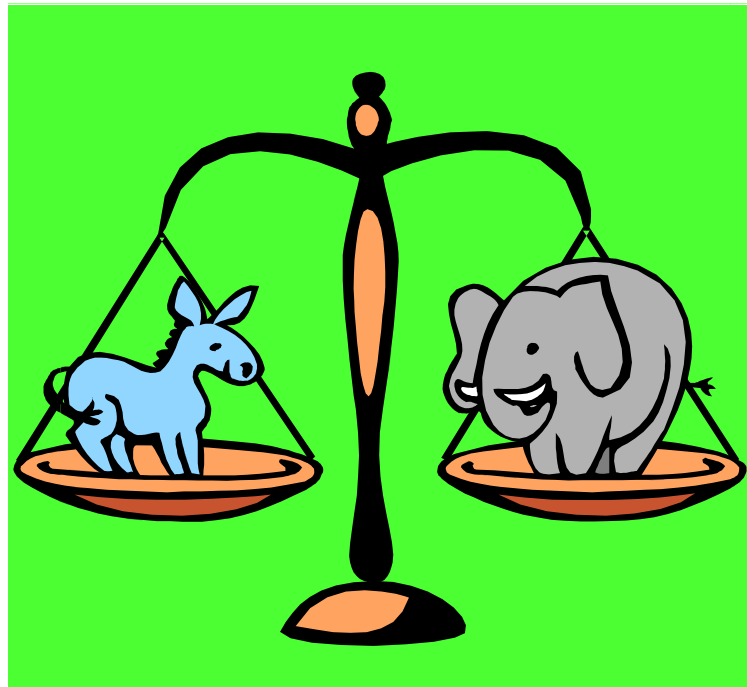
What Counts?

- All emails, faxes, letters, calls, postcards, petitions, etc. are counted.
- Personal, handwritten letters suggest a high level of priority and importance (send by fax or to staffer's personal e-mail address).
- Phone calls and e-mails allow you to weigh-in quickly on an urgent matter.
- In-person meetings are powerful **IF** you follow-up after you return home with a thank you letter and subsequent phone call.



Cancer Affects Everyone

It is a Bipartisan Issue



Congress: The Basics

House

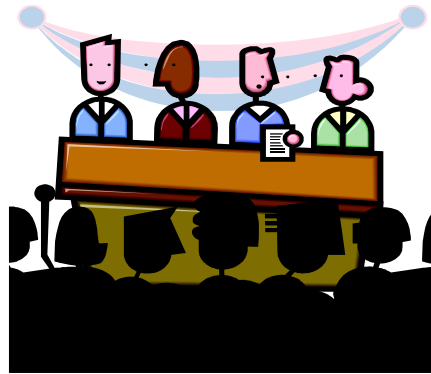
- 435 members
- Population-Based: A Member Represents a Local District
- Two-Year Terms: Every Member up for Election Every Two Years
- 255 (D) – 178 (R) (Two vacancies)



Senate

- 100 members
- Two Per State: Senators serve entire state.
- Six-Year Terms: 1/3 of Members are up for Election Every Two Years
- 58 (D) – 40 (R) – Two Independents

KEY CONGRESSIONAL COMMITTEES



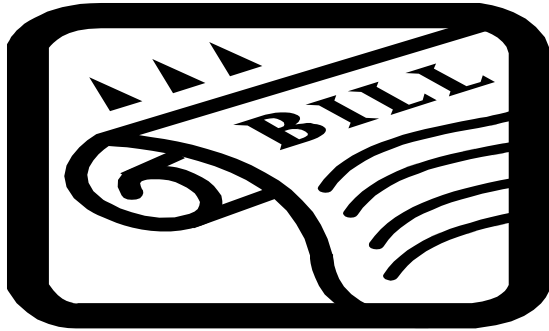
House

- Appropriations
 - LHHS
 - Dept. of Defense
- Energy & Commerce
- House Cancer Caucus

Senate

- Appropriations
 - LHHS
 - Dept. of Defense
- Health Education, Labor, and Pensions
- Senate Cancer Coalition

Two Key Types of Legislation: Authorization vs. Appropriations



Authorization
(From/Until a Certain Date)



Expands and Creates Programs
(e.g. Johanna's Law)



Needs To Be Reauthorized
(Every # years)



Appropriations
(Each Year)



Funds Agencies/Programs
*(e.g. DoD Ovarian Cancer Research
Program, Johanna's Law)*



Sept. 30th/Oct. 1st
New Fiscal Year

Capitol Hill: The Real Deal

- Congress Legislates by Anecdote
 - Compelling Stories Prompt Action
- Members Need to “Hear from Home”
 - Constituents Have An Impact
- Congress is Run by 20 and 30 Year Olds
 - Young Staffers Have Power and Influence, But Need Your Expertise



What to Expect on the Hill

- Meeting space is tight - you could meet with staff in the hallway, or be asked to go down to the cafeteria.
- Members or staff may be late or cancel – it is important to be flexible and understanding.
- There will be very little time for the meeting – it's important to get your key points out early and often. Be clear, concise, and compelling!
- Staffers are distracted and may give “insensitive” responses to your requests – be patient and prepared to explain why your “ask” is important.

What's going on up on "The Hill?"

- Congress just returned from a week of "recess" – staff may be distracted or stressed out.
- The Labor-Health and Human Services-Education (LHHS) appropriations bill is scheduled to be considered by the subcommittee in the House on Friday, and by the full committee on July 14th, although these dates are subject to change. The Senate is moving more slowly, and has not yet acted on the LHHS bill or announced when it will do so.
- The House is scheduled to consider the Department of Defense appropriations bill at the subcommittee level on July 13th, and at the full committee level on July 21st. These dates are also subject to change. The Senate has not yet moved its version.

Basic Points to Keep Handy

- Ovarian cancer is the deadliest of the gynecologic cancers and the fifth leading cause of cancer death among women in America.
- Although there are known signs and symptoms of the disease, there is no effective screening test for ovarian cancer.
- Less than 20 percent of ovarian cancer patients are diagnosed early, when survival rates are higher.
- Ovarian cancer mortality rates have remained virtually unchanged over the last 20 years.
- The nation has seen the power of early detection tests with the use of mammography for breast cancer, PSA blood tests for prostate cancer, Pap Smears for cervical cancer, and colonoscopy for colon cancer. We need such a test for ovarian cancer.

Our Funding “Asks”

Expand critical federal ovarian cancer research, prevention, early detection, and education programs by providing in FY 2010 the following:

1. \$10 million in the Labor-Health and Human Services-Education (LHHS) Appropriations measure, for implementation of Johanna’s Law: the Gynecologic Education and Awareness Act;
2. \$10 million in the LHHS Appropriations measure, for the Ovarian Cancer Control Initiative at the CDC; and
3. \$30 million for the Department of Defense Ovarian Cancer Research Program.

Our Authorizing “Asks”

Support ovarian cancer research and awareness by cosponsoring and enacting:

Johanna’s Law: The Gynecologic Cancer Education and Awareness Act of 2009 (H.R. 2941), which will:

- reauthorize the current programs at the CDC to increase awareness among women and health professionals, and
- expand other efforts, including supporting public-private partnerships to leverage community-based initiatives focused on education of target populations and audiences.

Our Easy “Ask”

- Submit a statement into the Congressional Record Statement about the signs and symptoms of ovarian cancer to help increase awareness and promote early detection.

(We even are providing them with a template to make it really easy!)

#1 Ask: \$10 million in FY 2010 for Implementation of Johanna's Law

Talking Points

- Johanna's Law created a national campaign housed at the Centers for Disease Control and Prevention (CDC) to increase awareness of the symptoms of ovarian and other gynecologic cancers among women and health professionals.
- For ovarian and other gynecologic cancers there are no screening tests, so early detection through recognition of symptoms currently is our best hope to reduce mortality.
- Increased funding will help ensure that women and health professionals are aware of the signs and symptoms of ovarian and other gynecologic cancers.

#2 Ask: \$10 million for the Ovarian Cancer Control Initiative (OCCI) at the CDC

Talking Points

- The CDC's OCCI enhances the growing knowledge about ovarian cancer by initiating research projects with external partners to help identify factors related to early detection of the disease, treatment, and survivorship.
- With additional funding, CDC would be have the resources to:
 - (1) implement recommendations from previous CDC workshops on ovarian cancer,
 - (2) launch community-based health initiatives that educate and target those at greatest risk for ovarian cancer, and
 - (3) continue to make progress in increasing early detection of ovarian cancer, improving treatment practices for women with ovarian cancer, and enhancing survivorship of those women.

#3 Ask: \$30 million for the Ovarian Cancer Research Program at the Department of Defense (DoD)

Talking Points

- Research holds the key to identifying better treatments for ovarian cancer, as well as the development of a screening test.
- The DoD Ovarian Cancer Research Program plays a key role in supporting unique ovarian cancer research.
- Increased funding will allow the program to maintain current research and expand innovative investigations into much-needed early detection and screening tools.

#4 Ask: Cosponsor and Enact Johanna's Law (H.R.2941)

Talking Points

- Johanna's Law created a national campaign housed at the Centers for Disease Control and Prevention (CDC) to increase awareness of the symptoms of ovarian and other gynecologic cancers among women and health professionals.
- For ovarian and other gynecologic cancers there are no screening tests, so early detection through recognition of symptoms currently is our best hope.
- The addition of the grant program supports public-private partnerships, leverages resources, and builds upon existing local targeted awareness and education work.

#5 Ask: Congressional Record Statement

Talking Points

- Too many women and health professionals remain unaware of the signs and symptoms of ovarian cancer.
- Members of Congress are uniquely positioned to help increase awareness among their colleagues, staff, and the public.
- Increasing understanding and awareness of the signs and symptoms of ovarian cancer is our best hope until an early detection or screening tool is developed.
- Early detection is key to long term survival.

How Your Capitol Hill Meetings Should Go – The Opening

1. Introduce yourself – full name and city you are from, and explain your connection to ovarian cancer. Express thanks for the meeting and any previous support.

- My name is Ilisa Halpern Paul. I am from Silver Spring, MD and I am here because a close family friend died from ovarian cancer. Thank you for your time today and your previous support of our issues.

2. Ask the staffer up-front approximately how much time he/she has, and then adjust your discussion.

How Your Capitol Hill Meetings Should Go – The Opening

3. Ask if the staffer knows anyone with ovarian cancer and then provide a brief overview of your personal experience with ovarian cancer.
4. Give some perspective on local impact of ovarian cancer – reference your state data sheet for details. Use the “handy points” to set up the “asks.”
5. Make the “asks.”

How Your Capitol Hill Meetings Should Go – The “Asks” Part One

To help reduce ovarian cancer mortality, I respectfully request three specific funding allocations in fiscal year 2009:

- \$10 million for implementation of Johanna’s Law;
- \$10 million for the Centers for Disease Control and Prevention’s Ovarian Cancer Control Initiative; and
- \$30 million for the Department of Defense (DoD) Ovarian Cancer Research Program.

Use your talking points to explain the programs and make the case.

How Your Capitol Hill Meetings Should Go – The “Asks” Part Two

I also would appreciate your support of two additional items that will make a difference for the ovarian cancer community:

- Reauthorization of Johanna’s Law (H.R. 2941)
- Congressional Record Statement

Use your talking points to explain the bills and make the case.

How Your Capitol Hill Meetings Should Go – The Closing

6. Answer questions as best you can. If you do not know an answer, ask the Alliance to follow-up and note the issue on your **Green Report Back Form**.
7. Ask for a commitment – if the staffer cannot answer, try to nail down a commitment for the best time for you to follow-up when he/she may have an answer on your requests. Ask the staffer for his/her preferred mode of communication.

How Your Capitol Hill Meetings Should Go – The Closing

8. Say thanks and express appreciation for the staffer's consideration of your views, and give him/her the leave-behind packet and your contact information.
9. Complete a [Green Report Back Form](#) for the Alliance, and turn it in at the end of the day. Be sure to note any specific questions you could not answer or information that the staff may have requested. Cara Tenenbaum will follow-up with the office directly.

How Your Capitol Hill Meetings Should Go – The Follow-up

10. Using the materials from the Alliance, please send a thank-you note to the Congressional office – addressed to the Member and copied to the staff.
11. Call on the day that you decided with the staffer that it would be appropriate for you to check on the status of your requests. If you cannot reach the staffer and do not hear from him/her within a week of your call, call again – being polite and persistent is the key to getting a response.
12. Inform the Alliance of your communications with staff and any commitments you are able to secure.

Capitol Hill Visits: Top 10 Tips

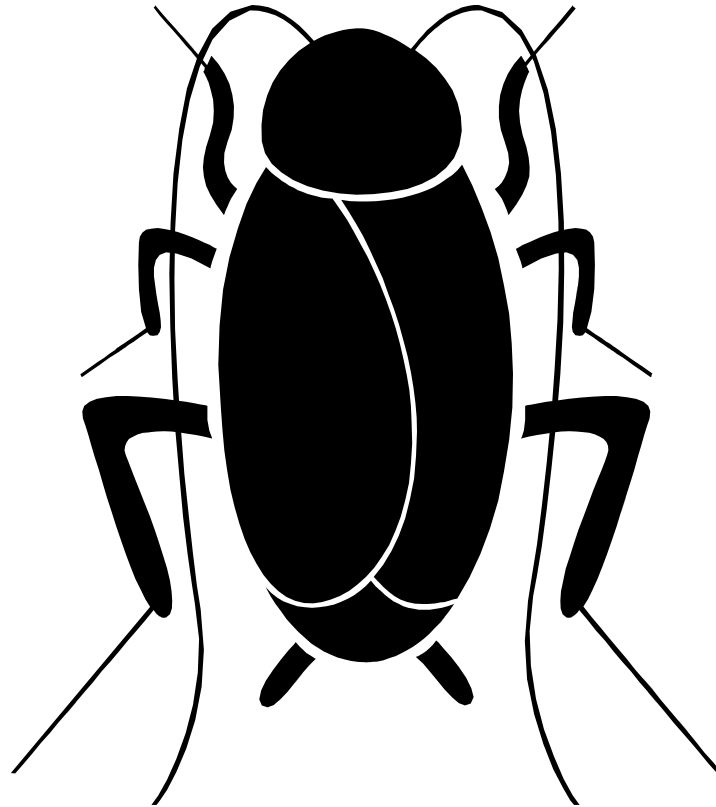


1. Be Organized – Arrange Speaking Roles Ahead of Time and Deliver Your “Asks” Up-Front and Clearly
2. Be Brief and Mindful of the Time
3. Give Evidence and Rationale – **Local Data**
4. Include a Personal Example, Not Too Many Details
5. Listen Carefully and Be Courteous

Capitol Hill Visits: Top 10 Tips

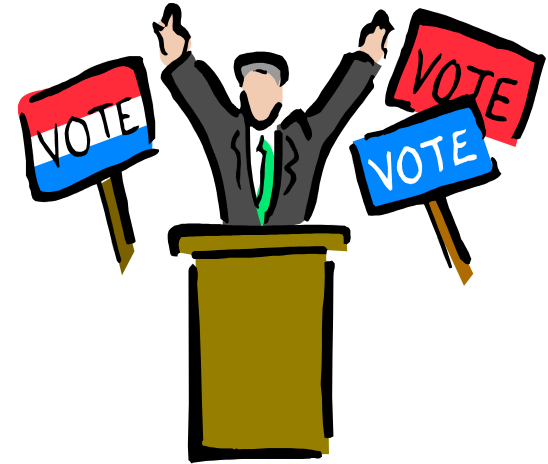
6. Discuss Positive Effects of Taking Action/Consequences of Not Taking Action
7. Be Sure to Get a Response – In a Nice Way
8. Leave the Background Materials, Your Contact Information, and Summarize Your Requests
9. Be a Resource, Offer to Help, and Express Thanks and Appreciation
10. Report Back to the Alliance, and Follow-Up with the Congressional Office with a Thank-You Letter and a Call

Cockroach



Theory

Advocacy In Action



- Know Who Represents You
- Vote
- Sign up for Ovarian Cancer Action Network
- Visit the Alliance's Advocacy website regularly - www.ovariancancer.org/advocacy
- Call, Fax, E-mail Your Policymakers
- Visit Local Offices of Your Members of Congress – AUGUST!
- Get to know the Congressional Staff
- Invite Policymakers to Visit Your Local Events
- **HAVE FUN!!**

Ovarian Cancer National Alliance Public Policy Resources

Cara Tenenbaum, Esq.
Ovarian Cancer National Alliance
Senior Policy Director

ctenenbaum@ovariancancer.org

(202) 331-1332, ext. 300

www.ovariancancer.org/advocacy