

ADVOCACY

FROM YOUR TOWN TO THE

NATION'S CAPITOL

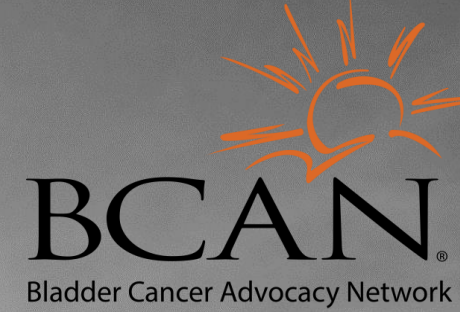
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BCAN[®]

Bladder Cancer Advocacy Network

OVERVIEW



- What is advocacy and How Can I Get Involved?
- Federal and State Government Structure and the Lawmaking Process
- How YOU can be an effective advocate
- Common Questions and Concerns



WHAT IS ADVOCACY?

- Def: “Public support for, or recommendation of, a particular cause or policy”
- Simple Definition: “**Speaking Out**”
- An opportunity to affect change that directly improves people’s lives
- Allows you to work *individually, or with like-minded people*, to affect positive change
- Incremental in nature – each interaction brings success closer

WHO IS AN ADVOCATE?

➤ YOU ARE

- “Citizen Advocates” – Anyone who speaks up and looks for a solution to a public problem
- Organizations like BCAN are an informational and organizational clearinghouse for the bladder cancer community
- Lobbyists
 - ❑ Professional representation before public officials
 - ❑ Named after the Lobby of the Willard Hotel

LEVELS OF ADVOCACY

There are multiple opportunities to advocate effectively to your community's decision makers


- **Individual** – Tell your story and ask to fix the problem
- **Community** – Problem affects you, and a broader community. Together, we represent the Bladder Cancer Community
- **State** – Affecting change at the state level
- **Federal** – Affecting change at the state level

SUCCESSFUL ADVOCACY

- Identifies a problem
- Identifies a solution
- Links it to a broader issue
- Identifies who can address the problem
- Develops relationships and enlist allies
- Is PERSISTENT



SUCCESSFUL ADVOCACY

- ▶ Prolonged, consistent contact with officials
 - ▶ Building an active base of supporters
 - ▶ Identifies not only the problem and solution, but addresses obstacles in the way
 - ▶ Tools - letter writing, marches, meetings, media, voter registration, etc.
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SUCCESSFUL ADVOCACY

- ▶ Unites a community around a single goal
 - ▶ Leads to a solution
 - ▶ Real people get real benefits
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CAN ADVOCACY REALLY LEAD TO CHANGE?

- YES Decision makers listen to constituents
- Frequent contact builds trust
- Educates the community, as well as the officials, about your issues
- The more energy behind a problem, the higher likelihood of success

Decisions are made by those who show up!

CAN YOU BE AN ADVOCATE?

YOU ALREADY ARE!

➤ Your personal story is more powerful than you know

- ❑ YOU are the face of bladder cancer, not a statistic
- ❑ YOU are more credible than you know
- ❑ YOU are an antidote to cynicism
- ❑ YOU are united with the bladder cancer community
- ❑ YOU have strength in numbers



WHAT IS YOUR STORY?

- How has bladder cancer touched you? Your family? Your community?
- What is your experience with the healthcare system?
- What issues do you face as a result of bladder cancer?
- How can we improve care for bladder cancer patients?
- What tools have been helpful to you? What tools do you wish you had access to?
- What barriers have you faced?
- What is the future for treatment? How do we get there?

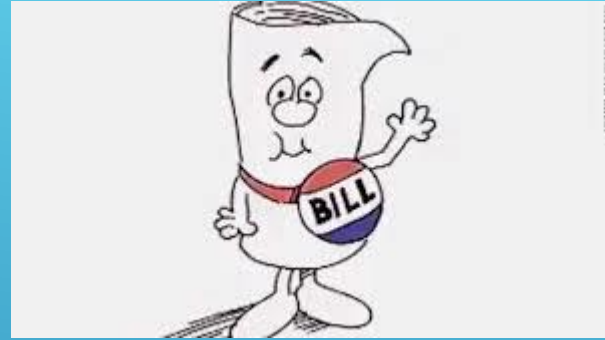
There is no wrong answer

WHAT CAN YOU DO?

TELL YOUR STORY

Don't be intimidated by what you don't know – [Your Story is Powerful](#)

- Call and write your elected officials
- Meet with elected officials and invite them to your events
- Sign petitions, post on social media
- Write Letters to the Editor and Op-eds for your local newspapers
- Ask family and friends to join your efforts
- Join advocacy organizations like BCAN and respond to action alerts
- Tell your personal story at a community forum or campaign event



The State and Federal Government Structure and Lawmaking Process

1 FEDERAL + 50 STATE GOVERNMENTS

- Every State and the Federal Government uses our 3 branch system
 - ❑ Legislative – Writes and Passes the Laws
 - ❑ Executive – Enforces the Laws
 - ❑ Judicial – Interprets the Laws
- 535 Federal Legislators, with 8,200 staffers and 7,500 State Legislators with over 35,000 staffers in State Capitols
- State Governments pass on average of 80 laws for every Federal law
- State governments are considered incubators for the development of federal law
- State governments play an increasingly active role in day-to-day governing of the country

STATE GOVERNMENT

- Many similarities but variations between how every state runs itself
- 49 States have a Bi-Cameral, or 2-Chamber, legislature with the “Upper Chamber” while the “Lower Chamber” will have a larger membership
- Legislative Sessions vary from state to state and year to year
 - ❑ Some as short as 30 days and others take place over a 2-year period
 - ❑ Some states only meet on odd or even numbered years
- The Governor is the Chief Executive of a state
 - ❑ Governors have the right to call for a special legislative session
 - ❑ Governors can sign/veto laws, set a budget, control the National Guard, and direct/oversee state agencies

FEDERAL GOVERNMENT

Legislative branch

- Congress has 2 Chambers, the House of Representatives and the Senate
- The Senate has 100 members, 2 per state
- The House has 435 members, based on population (CA-53, WY-1)
 - ❑ Seats are reapportioned every 10 years
 - ❑ Representatives serve 2-year terms, Senators 6-year terms

FEDERAL GOVERNMENT

Executive Branch

- ▶ Consists of the President and the departments of the Federal Government
- ▶ Each Department is led by a Secretary, who is part of the President's Cabinet and advises the President on issues before their department

FEDERAL GOVERNMENT

Judicial Branch

- ▶ Led by the 9-member, life-time appointed, Supreme Court
- ▶ 13 Appellate Courts
- ▶ 94 federal judicial districts organized into 12 regional circuits

HOW LAWS ARE MADE

In every step of this process there are chances to affect the outcome and direction of law

- Bills are drafted, introduced and referred to committee
 - ▣ In the current US Congress (2017-2018) 7,030 bills introduced – 254 laws passed
- Committees and Subcommittees hold hearings, debate, offer amendments and then vote on the bill.
- Bills that survive this far go to the full chamber for a vote. If passed each Chamber's bill goes to a Conference Committee
- If the President signs the bill, it becomes law. If vetoed, the Congress may override the veto with 2/3rds vote in both chambers



Helpful Tips for Becoming an Effective Bladder Cancer Advocate

ADVOCACY DOESN'T TAKE ALL DAY

Less than One Hour Per Month

- ▶ Vote
- ▶ Call, Email, Write a Letter, Social Media posts
- ▶ Draft and Submit your story to BCAN – Sign up for BCAN legislative Action Alerts
- ▶ Contribute to a campaign or non-profit
- ▶ Sign up for advocacy email and informational lists
- ▶ Support businesses that support your cause



ADVOCACY DOESN'T TAKE ALL DAY

One Hour Per Month

- ▶ Cultivate a Relationship with a decision maker in your community
- ▶ Write a Letter to the Editor or Op-Ed to your local newspaper
- ▶ Invite a decision maker to visit an event or tour of a facility
- ▶ Attend a community forum or campaign rally and speak up
- ▶ Talk to others and ask them to join the cause



ADVOCACY DOESN'T TAKE ALL DAY

More Than 1 Hour Per Month

- ▶ Testify before a State Legislature or Congress
- ▶ Start a BCAN Chapter, or join a Board at your local BCAN Chapter
- ▶ Set up an Advisory/Educational Booth at a community event
- ▶ Apply for Community Advocacy Grants
- ▶ Serve as a local spokesperson and help generate media interest in the cause



HOW TO MAKE “YOUR ASK”

“Your ASK” is the direct action you are requesting

Make your ask, repeat your ask, get feedback and always close any by restating your ask

- **Connect** – Tie your ask to the lawmaker’s self-interest
- **Importance** – Why is it to important for them and their constituency?
- **Specific and Direct** – “Can you commit to.....” – If not, ask why
- **Relate** – Link your request to the bigger issue
- **Pause** – This is very important – Give the lawmaker a chance to respond
- **Appreciate** – Thank the lawmaker for their time and representation
- **Follow Up** – Follow up with a request for a response in writing

MEETING TIP SHEET

- Whether staff or elected official, be Prepared, respectful, concise and make **your ASK** crystal clear several times
- Open by discussing commonality between you both
- Officials will try to control the discussion and turn it to their accomplishments –steer it back to **your ASK**
- Know your Audience – Tailor **your ASK** using terms that resonate with the official
- Try to get a direct answer to **your ASK** – “Will you commit to.....”
- Carefully listen to, and try to address the officials concerns with **your ASK**
- Leave Behind – Have a document that backs up **your ASK**
- Follow Up – During the meeting, ask if you can follow up and do so – Get the response to **your ASK** in writing

BEFORE YOUR MEETING

- Plan what you will say and how you will say it. Ensure **your ASK** is very clear and that your personal story is told in as concise a way as possible
- Research the official so you know a little about their background and broad position on your issue; personal data could help build rapport
- Draft a leave behind document that adds gravitas to your position

DURING YOUR MEETING

- ▶ Expect the meeting to last 15-30 minutes so make a personal connection quickly
- ▶ Remind them you are a constituent, that you vote, and why you are there
- ▶ Tell your personal story and offer to be a resource to the official
- ▶ Relate your experience to the official's constituency,
- ▶ Stay on Topic – avoid unrelated issues to **your ASK** and leave party politics out of the discussion
- ▶ Listen to what the official has to say and try to address any opposition
- ▶ Tell them you will follow up and [get the lead staffer's direct contact information](#)
- ▶ Thank the official for their time

AFTER YOUR MEETING

- ▶ Follow up, Follow up, Follow up
- ▶ Contact the official's office to get a written response regarding **your ASK**
- ▶ Let them know you will be following the issue closely and reiterate offers to be a resource.
- ▶ Send any additional materials that help your cause.

TIPS FOR CALLING YOUR ELECTED OFFICIAL

Quick and Easy to do ---- you'll probably get a staffer rather than the official



- **Plan** what you want to say and how you want to say it
- **Identify** yourself as a constituent and give your contact information
- **Tell** your personal story and why the issue matters to you.
- **Your ASK** – Stay on Message and make sure **your ASK** is clear
- **Question** – Find out if the official has a position on **your ASK** – request it in writing
- **Find Out** the name and contact information for the staffer that handles the issue
- **Recruit** – Ask family and friends to do the same
- **Call Again** – You may want to call semi-daily/weekly

TIPS FOR WRITING YOUR ELECTED OFFICIALS

- **The Good** – Handwritten letters have the most impact
- **The Bad** – Letters are often irradiated, leading to 2-3 week delays
- Write legibly. Be sure your full address is on the letter.
- State that you are a constituent and vote.
- State **your ASK**
- Tell your personal story
- Highlight the local nature of the issue, and its affect on other constituents
- Be brief – No more than 1-1.5 pages in length
- Ask for a response in writing
- Encourage others to write as well
- Follow up and write again if there is any movement in your issue



TIPS FOR EMAILING YOUR OFFICIALS

- **The Good** – Easiest, fastest way to communicate with a legislator
- **The Bad** – Less personal than a letter, and carries less weight
- Subject Line – State you are a constituent and your issue
- Personalize – Tell your personal story; if forwarding, personalize it to your official and ensure all he/she pronouns are correct.
- State **your ASK** clearly
- Provide local context for how your issue affect other constituents
- Ask for a response, in writing
 - ▶ Ask others to send similar emails to their officials
- Follow up your email if you don't get a response in writing
- Follow up with a new email any time there is movement with your issue.

STRENGTH IN NUMBERS

“An orchestra is much louder than a soloist”

- Being on “the right side,” or having the supportive facts does not guarantee success – **BE PERSISTANT**
- Reach out to family and friends, and through social media to help recruit volunteers and raise funds for the bladder cancer community.
- Provide information and means to get involved as easily as possible
- Invite politicians and the media to any event you host and **give them a reason to join you**
- Note those who are supportive but don't help this time, they may help next time



COMMON QUESTIONS AND FREQUENT CONCERNS WITH ADVOCACY



WHAT IF I “GET STUCK WITH” STAFF RATHER THAN THE OFFICIAL - ON THE PHONE OR IN A MEETING?

- Staffers can become your single strongest advocate – they represent their boss and are trusted by them
- Treat with the same respect you would treat the official
- Staff often have a much deeper policy understanding than do officials
- Ask the staffer to fully explain their boss’ position on your issue
- Offer to be a resource to the staffer – everyone likes people who make their job easier on them
- Be sure to get their direct contact information
- Follow up directly with the staff on all future correspondence

HOW DO OFFICIALS REGISTER THEIR CONSTITUENT'S VIEWS – DO THEY READ THEIR OWN MAIL?

- **Yes and No** – Officials don't read the bulk of what is sent to their offices – but their staff do and report to them. Snail Mail often has the biggest impact and is much more likely to be directly read by the official than is an email
- **Busy Times** – When the phones are “blowing up”, staffers will only take your name and address and register if you are a yes or a no
- **Slow Times** – Staff have more time to talk
- **Mass Mailings** – Such as postcard campaigns and mass emails have the least amount of swaying power – unless they are on an immense scale
- **Personal Letters** – Most effective but slowest way to start a dialogue
- **Always** ask for a response in writing in any correspondence

DO I HAVE TO FULLY UNDERSTAND THE LEGISLATIVE PROCESS TO BE EFFECTIVE?

- **No** – Anyone can be an advocate – you need passion and a willingness to **Speak Up**
- *Your Personal Story is very powerful*
- Rely on your national organizations, such as BCAN, to provide the who, when and how information you need to ensure your contacts are done when the timing is right.
- “All Politics is Local” – Build interest in your community
- Doctors and patients – the nature of your experience gives you natural credibility

WHEN DO I HAVE THE BEST CHANCE TO TALK DIRECTLY TO A DECISION MAKER?

Ongoing, consistent communication is best

- In Session – They are actively legislating at the Capitol. Votes may be pending and issues are at their hottest – but time is the shortest
- Out of Session – when legislators are in their districts and not actively legislating, but they never stop representing you
- Town Hall Meetings – Take the opportunity to Speak Up
- Campaign Season – Politicians listen to everyone and try to please everyone so make sure they are hearing **YOU**
- Public Events – Officials regularly publicize attendance at upcoming public events – attend those events and question the official

WHAT IF MY OFFICIAL IS THE OPPOSITE PARTY OR OPPOSES MY VIEWS?

- Today's opponent can be tomorrow's champion so be respectful while agreeing to disagree
- While party affiliation colors an issue, the issue itself and its importance "back home" is the most important concern for any legislator.
- Listen to the officials views and try to address them on the facts
- Keep calm – don't let other issues cloud your communication
- Offer constructive dialogue and seek common ground where you can
- Consider every contact an opportunity to move them to your side, even if the move is only an inch
- Ask for their position in writing



CHANGE TAKES SO LONG – AM I MOVING THE ISSUE FORWARD OR WASTING MY TIME?

- Passing or Changing a law, especially at the federal level is not easy and requires a sustained effort over time
- “Best things come to those who wait”.....and push for change
- Advocacy is incremental in nature so every step forward should be celebrated
- Break down your larger goal into smaller steps and celebrate passing those landmarks on the way to your bigger goal
- Count the new relationships you have established/strengthened
- Tally the number of advocates who were engaged
- Celebrate earned media or visits from officials
- Count the materials developed that strengthen your cause



FINAL THOUGHTS

You are already an advocate

With a small commitment of time, you can make a big difference

Your Personal Story is powerful

Always be clear what your ASK is – and make it several times

Rely on BCAN to keep you informed – And take action when action alerts are sent out

The more you participate the more you know you aren't alone

Advocacy is a cure to cynicism

