

My Advocacy Journey : The Path from Adversity to Action to Accomplishments

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Disclosures

I have no financial disclosure or conflicts of interest with the material in this presentation.

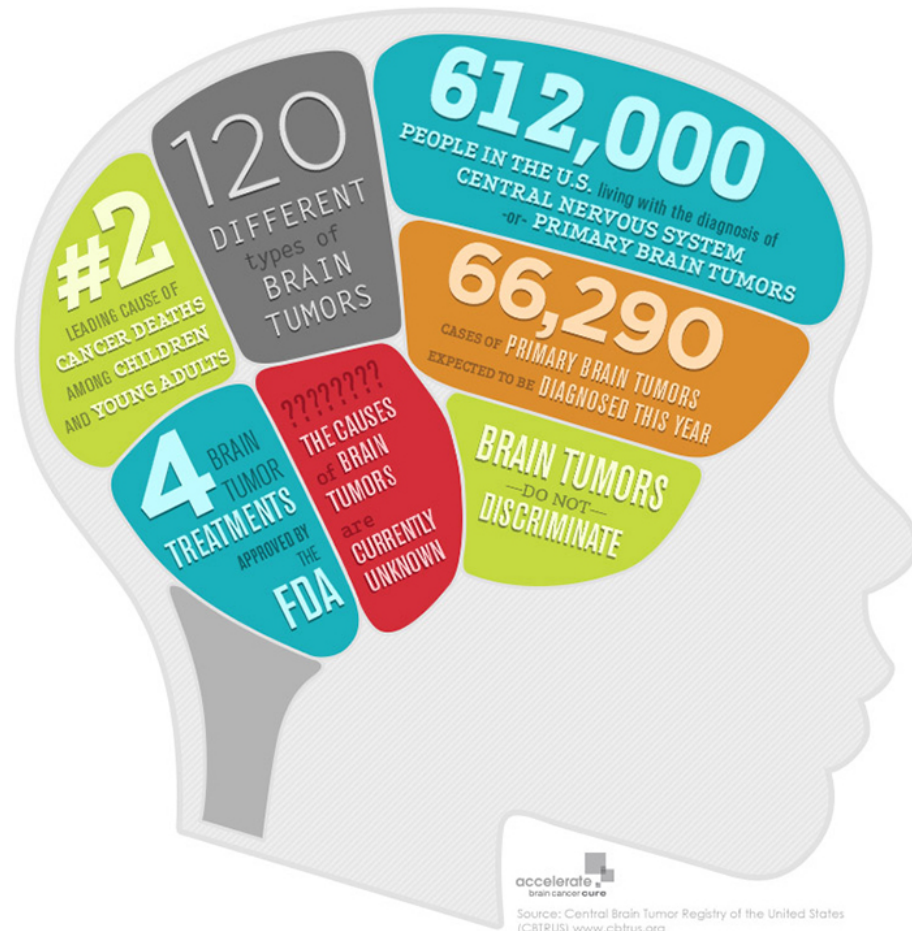


Background

- 40+ years of experience as small business owner
- 10+ years of experience as non-profit professional
- National Patient Advocate
- Founder, The Brain Tumor Awareness Organization
- Regional Coordinating Director, Region 1 North NCI CRCHD GMaP
- Field Instructor, College of Social Work, University of South Carolina
- Administrative Coordinator, SC Cancer Prevention and Control Program
- Chief Operations Officer, Connecting Health Innovations LLC



The Launch into Advocacy



**‘You have a brain tumor.
You have 6 months to live.
Go home and get your affairs in order.’**

Adversity: Issues of Concern

Loss of Income and Employer Benefits: Life insurance; health insurance; and retirement

Access to Care: Affordability; lack of insurance; and specialty care;

Disability: Claim initiation; 6 months to 2 years waiting period to Medicare coverage;

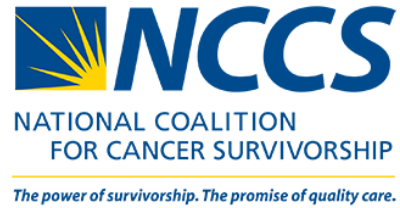
Caregiver challenges: health education; work-life balance; respite; and self-care;

Survivorship: quality of life; and patient navigation;

Research: 'gold standard' vs. clinical trials; and funding;



Strength in Numbers



Accomplishments

- **The Brain Tumor Awareness Organization:** provides those affected in SC with patient support backpacks distributed at Hollings Cancer Center (NCI) and throughout the state
- **LIVESTRONG/Lance Armstrong Foundation:** Passage of 'The Cancer Screening, Treatment, and Survivorship Act of 2007'
- **National Patient Advocate Foundation:** Passage of 'The Patient Protection and Affordable Care Act of 2010'
- **Social Security Administration:** Compassionate Allowances Conditions inclusion of brain tumors
- **Local, National and International Awareness:** May is National Brain Tumor Awareness Month; Go Grey in May Campaigns branded and launched



ADVOCACY

- the act or process of supporting a cause or proposal : the act or process of advocating
- Types of advocacy
 - Self-advocacy: an individual's ability to effectively communicate his or her own interests, desires, needs and rights.
 - Citizen: aims to involve people in their local community by enabling them to have a voice and to make decisions about the things that affect their lives.
 - Grassroots: originates among concerned citizens
 - Individual: advocate concentrates their efforts on one or two people
 - Patient: preserves a patient's rights to health care.
 - Professional: Paid independent advocates support and enable people to speak up and represent their views, usually during times of major change or crisis.

Each of these are **AGENTS OF CHANGE!**
STRENGTH IN NUMBERS!





116th United States Congress



Convened January 3, 2019 and will adjourn January 3, 2021

Senate President: Mike Pence (R)
Senate President pro tem: Chuck Grassley (R)
Senate Majority: Republican

Majority (Republican) Leadership

Majority Leader: Mitch McConnell (KY)
Majority Whip: John Thune (SD)

Minority (Democratic) Leadership

Minority Leader/Caucus Chair: Chuck Schumer (NY)
Minority Whip: Dick Durbin (IL)

Speaker: Nancy Pelosi (D)

Majority (Democratic) Leadership

Majority Leader: Steny Hoyer (MD-5)
Majority Whip: Jim Clyburn (SC-6)
Caucus Chair: Hakeem Jeffries (NY-8)

Minority (Republican) Leadership

Minority Leader: Kevin McCarthy (CA-23)
Minority Whip: Steve Scalise (LA-1)

U.S. Senate website:

<https://www.senate.gov/>

U.S. House of Representatives website:

<https://www.house.gov/>



How a bill becomes a law

435

Representatives

Each state is represented in proportion to its population, entitling it to at least one Representative. Each representative serves for a two-year term. The House was granted exclusive powers: initiation of bills, impeachment powers and election powers of President during electoral college deadlocks.



The bill is introduced in the Senate or House of Representatives

The bill is sent to committee for debate and approval

The bill is sent on to the full Senate or House for consideration

Passage of the bill is debated and voted upon

Upon approval by one chamber, the bill is sent to the other chamber and the process is repeated

If approved, the bill is signed by the Speaker of the House, the Senate Pro Tem, and sent to the President to be signed (or vetoed). Bill can still pass with 2/3rds vote by House and Senate.

100

Senators

Each U.S. state is represented by 2 Senators, regardless of population. This ensures equal representation of each state in the Senate. Senators serve staggered six-year terms.

Before the Meeting

Get to know your Senators and Representatives!

- As you begin your advocacy journey, becoming familiar with your Member and their committee role(s) will assist you with your meeting. Visit their webpage to learn more.
- Note your Member office location(s).
- Identify if your Member has sponsored or co-sponsored a bill you are discussing.
- Review 'leave' packet and fact sheets included.

Plan your visit

- Take your business card(s).
- Be sure to take brief notes during the meeting. Have a notepad or tablet on hand.
- Decide order of advocate team member introductions, sharing of stories and how each will focus on problem to be addressed.
- STAY ON MESSAGE! As you and others meet in Congressional Member offices, the message needs to be consistent so the focus is on the 'ask'.
- Remember that your 'leave' packet contains all the information for the Member and their staff to refer to-during and after the meeting.
- Determine who will 'close' the meeting with the 'ask'.
- Include debriefing sessions for the team to share notes and impressions. These are invaluable to your advocacy leader as follow-ups are held with Congressional Member offices.



Your Congressional Meeting

Introduce yourself

- State where you live! Your Congressional office wants to HEAR where you reside (district-specific); assessing your geography.
- State what you do and where you work
- State what other organizations you are affiliated with (if relevant)

Congressional member or staff?

- You may meet with a staff member
- Congressional member may join the meeting; be prepared!

Opportunity

- To tell your story
- To share a clear message
- To put forth the 'ask'
- To provide the 'leave behind'
- Exchange business cards: establishing the relationship



During the meeting

RELAX! You advocate on a daily basis-this is who you are and what you do!

➤ **Remember to speak simply and keep it brief:**

- Introduce yourself, where you live, what you do and why you are there.
- Share your story, the issue of concern, your experience and how the Member's support of the proposed legislation will address the issue. Conclude your individual session with the 'ask'.
- Thank the Member and/or staff member for their consideration and for allowing you to share your story.

➤ **Leave behind packet:**

- Provides all background information for Congressional office members' review
- Reflects Congressional members that sponsored or co-sponsored the bill
- Guides you to 'stay on message'
- Supports your 'ask'

➤ **Tips for success:**

- Provides all background information for Congressional office members' review
- Bi-partisanship = Sponsorship: advocacy goals reached benefits everyone! Avoid discussing along party lines.
- If you don't know an answer, tell them you will get back to them—and be sure to do so
- Take a picture if possible. Share it with your advocacy leader.

➤ **Afterwards: send a thank you note**



After the Meeting

Debrief:

- Share your observations and notes among the team.
- Summarize your debriefing notes with your advocacy leader.
- Determine follow-up strategy and delegate specific tasks and timelines for each.

Follow-up:

- Send your thank-you notes! Reiterate your message and 'ask'.
- Coordinate next steps with your advocacy leader.

Track the legislation:

- Visit <https://www.congress.gov/> to track the legislation.
- Continue advocates' team meetings to assure responsiveness during bill journey.



NAVREF Advocacy Agenda

NAVREF coordinates its funding advocacy efforts with the **Friends of VA Medical Care and Health Research (FOVA)**, a coalition of more than 80 medical specialty, patient advocacy, scientific and academic organizations committed to high quality care for veterans.

NAVREF believes it is time to update our enabling legislation to clarify areas of confusion and/or misinterpretation. We believe these changes will improve the ability of VA-affiliated nonprofit corporations (NPCs) to satisfy Congressional intent to support VA research and education activities and bring greater benefit to Veterans.

- **Flexible Funding Mechanism:** “The Secretary may authorize the establishment at any Department medical center of a nonprofit corporation to provide *a flexible funding mechanism* for the conduct of approved research and education at the medical center.” This statute should be updated to specify that transferring funds from VA to NPC by MOA has the force of a contract in the eyes of the Economy Act for purposes of obligating funds.
- **Independence** – the statute states that a NPC is not “...owned or controlled by the United States” or “an agency or instrumentality of the United States.” The statute should be updated to specify that while NPCs are clearly related to VA medical centers and designed to support research and education activities at VA medical centers, they remain independent and autonomous nonprofit corporations.
- **Administration of federal awards-** the NPCs should be given the **right of first refusal** for administration of federal awards when the majority of work is being performed at the VA. Administering non-VA research funds is one of the primary reasons NPCs were created. NPC administration of research empowers the VA medical center to garner the greatest benefits for Veterans while ensuring the sustainability of the NPC.

Learn more:

<https://navref.wildapricot.org/Advocacy>



In Conclusion

NAVREF Members are integral to the advocacy efforts within the **Friends of VA Medical Care and Health Research (FOVA)** to ensure a consistent focus on the delivery of high quality care for veterans.

Contact information:

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Dorn Research Institute

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Phone: 803-776-4000 x 4199

THANK YOU!



Effectively Advocating Elected Officials: What to do and what not to do.

PRESENTER: JON ARNOLD, MGPS MSW

DIRECTOR OF CONSTITUENT SERVICES

THE OFFICE OF THE HONORABLE WILL HURD: TEXAS 23RD CONGRESSIONAL DISTRICT

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Background

- 5+ years of experience as a Congressional Staffer
- 10+ years of experience advocating for veterans
- Former Army Wounded Warrior Advocate
- Appointed to the Texas Department of Adaptive and Rehabilitative Services (DARS) Advisory Council by Governor Rick Perry
- 10 Year Army Intelligence Veteran



Topics Covered

What to do During meeting: Highlighted from the elective officials perspective

Dos and Don'ts Discussion: Focusing on Selecting the correct audience, Timing/Scheduling the meeting, Leave behind materials

Interactive Question/Answer Session

Conclusion



During the meeting

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- Afterwards: send a thank you note



Dos and Don'ts: Target Audience

Target Audience: Understand the levels of government (Federal, State, County, City, etc.) and who has authority of what;

DO

- Select Officials at the correct level of government
- Build relationships with staff members who can help you get a meeting with the official
- Explain how your proposed legislation affects their constituents
- Understand the member's point of view and their constituency

DON'T

- Address the wrong level of government, it is a waste of your time and their time
- Assume the member has a strong understanding of your issue
- Use jargon or industry specific language
- Be overly partisan or political

Dos and Don'ts: Timing

Timing your meeting: Timing your meeting is extremely important when dealing with legislative bodies;

DO

- Check the legislative calendar prior to contacting your members office.
- Understand when the budgeting cycle is if your request involves funding
- Always try to connect your meeting with a current event or themed month (i.e.. September is Cancer Awareness Month, 9/11 Day of Service, Labor Day, World Alzheimer's Day etc.)

DON'T

- **Try to schedule a meeting in a members district office during session or vice versa**
- Advocate for a cause “off cycle” as your cause will be lost in the noise



Dos and Don'ts: Leave Behind Materials

Leave Behind Materials: The goal should be to provide a quick synopsis of your issue, the ASK, and friendly members

DO

- Start with a clear ASK
- List Sponsors and Cosponsors starting with the member's state
- Provide data and graphs/charts when available
- Provide links to additional information and sources

DON'T

- Overthink this
- Blow your budget on leave behind materials, a black and white one pager is fine
- Provide excessive information
- Forget to put your ASK and contact information in the material



QUESTIONS?

I KNOW YOU HAVE SOME, DON'T BE SHY

In Conclusion

NAVREF Members are integral to the advocacy efforts within the **Friends of VA Medical Care and Health Research (FOVA)** to ensure a consistent focus on the delivery of high quality care for veterans.

Contact information:

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US House of Representatives

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THANK YOU!

