ICA Virtual Advocacy Day
April 21, 2020

How to Best Prepare
Speakers

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About ICA

• The Interstitial Cystitis Association is the only nonprofit charitable organization dedicated solely to improving the quality of healthcare and lives of people living with interstitial cystitis.

• ICA’s Mission: Early diagnosis and optimal care with dignity for people affected by IC...
  – Advocacy, Research, Education
History of ICA Advocacy Efforts

• The ICA has been advocating on Capitol Hill on behalf of IC patients for over 35 years.
  – Department of Defense (DoD) Peer-Reviewed Medical Research Program (PRMRP)
    • IC is again listed as a condition eligible for study and has consistently been listed since FY2010.
    • To date, 12 IC-related grants have been funded through the PRMRP since IC has been included as a condition eligible for study totaling over $19 million
  – National Institutes of Health (NIH)
    • After years of stagnant funding levels, NIH has received continuous increases since FY2016. In FY2015 NIH was funded at $30.3 billion but has grown to the current FY2020 level of $41.7 billion.
    • ICA along with the larger patient community is responsible for these increases as a result of advocacy efforts on Capitol Hill demonstrating the importance of robust NIH funding.
  – Centers for Disease Control (CDC)
    • The IC Education and Awareness Program has grown from around $650,000 to $1.1 million currently within the last 10 years.
History of ICA Advocacy Efforts

• ICA Advocacy Day is going virtual in 2020!
How to Participate in ICA's Virtual Advocacy Day
April 21, 2020

- Email or call your Senators/Member of the House of Representatives
- Be sure to share the story of how IC/BPS has affected you!
- Post on social media using the hashtag #ICAAdvocacyDay -- you can even tag your Congresspeople on Facebook, Twitter, or Instagram!
- Be sure to thank them!
Thank you for your participation!

- Sharing your personal story is a big deal
- You are helping our legislators better understand interstitial cystitis
- You are giving voice for the interstitial cystitis community
Our Agenda Today

• How Congress works

• How can you contact your legislators

• Legislative issue review

• Questions
Quick Overview

3 Branches of Government

• Executive Branch (the Administration)-enforces laws

• Judicial Branch (the Courts)-interprets laws

• Legislative Branch (Congress)-creates and enacts laws
Congressional Authority

- The power of the purse
- Creating policy
- Oversight of federal agencies
The Senate

- Elected to 6 year terms
- 2 Senators from every state
- 100 Senators Total
The House of Representatives

- Elected to 2 year terms
- 1 Representative from each district
- 435 Representatives Total
Key Senate Committees

• Appropriations

• Health, Education, Labor, and Pensions

• Finance
Key House Committees

- Appropriations
- Energy & Commerce
- Ways & Means
Key Federal Healthcare Agencies

- National Institutes of Health (NIH)
- Food and Drug Administration (FDA)
- Centers for Medicare and Medicaid Services (CMS)
- Centers for Disease Control and Prevention (CDC)
A “Critical Mass” of Support

• A coordinated nationwide effort by grassroots advocates can help advance research, increase research funding, and improve overall health and healthcare.

• Individual advocates work together with one voice to influence enough legislators to create meaningful change.
Make Your Story Personal

• Keep it simple and concise

• Share your experience

• What has your journey been?

• What challenges have you faced?
Contacting Congress

To contact your Senators and Representative:

1. Prepare for the discussion with materials provided at www.ichelp.org/advocacyday.

2. Call your representative’s district office.

3. Ask to speak with a staffer who handles health policy as well as the email address of the DC based health staffer.

4. Follow-up with the staffer you spoke with via email and continue to stay in touch with them throughout the year by sending them updates on interstitial cystitis.
Finding Your Senators

To find and contact your U.S. Senator:

• Visit the Senate website ([www.senate.gov](http://www.senate.gov)).
• Conduct a search using the **Find Your Senators** pull-down menu at the top of your screen.
• On the results page is a link to the Senators’ website, contact information, and links to an online contact form (forms vary by Senator).
• Follow your Senator on Twitter and Facebook.
Finding Your Representatives

To find and contact your U.S. Representative:

• Visit the House of Representatives website (www.house.gov).
• Conduct a search using the Find Your Representative zip code search box at the top of your screen.
• On the results page is a photo of your Representative(s), links to the Representative’s personal website and online contact form, and a local map.
• In the event your zip code overlaps with multiple congressional districts, the results page will include boxes for you to enter your zip code+4 or mailing address to find the correct Representative.
• Follow your Representative on Twitter and Facebook.
How do I prepare?

• Read the materials you receive via email or on the ICA website at www.ichern.org/advocacyday.
• Make a note any questions you have for the staffer.
• **Prepare your IC story** – how has IC changed your life?
• Write down your story. Keep it to 3-4 minutes.
• Practice – saying it aloud many times will help you manage nerves & time pressures.
• Follow the call and email script that was provided in your prep packet.
Email and Phone Script

• The script can be found on the ICA website at www.ichelp.org/advocacyday.

• Please familiarize yourself with the script and the issue briefs preceding.
Following your Contact with Congress

Send ICA your feedback:

- How did the conversation go?
- Let us know of any questions asked by the staff. Do we need to follow-up?
- Who did you speak with?
- Who did you email?
- Did you receive a reply?
- Email us at advocacy@ichelp.org.
Following your Contact with Congress

• Send the congressional staff person a follow up thank you e-mail (provided next week).
Washington Update

• 2nd Session of the 116th Congress

• Annual Budget and Appropriations Activity

• Continued congressional focus on healthcare policy, including medical research and patient access
Legislative Issue Review

1. Medical Research

2. Responsible Pain Management

3. IC Education and Awareness
Medical Research

• Please provide the National Institutes of Health (NIH) with at least $44.7 billion in fiscal year (FY) 2021. NIH supports interstitial cystitis research through the National Institute of Diabetes and Digestive and Kidney Diseases (NIDDK), National Institute of Neurological Disorders and Stroke (NINDS), and other relevant institutes and centers.

• Please continue to include “interstitial cystitis” in the Department of Defense Peer-Reviewed Medical Research Program (PRMRP) for FY 2021. IC is becoming increasingly prevalent among veterans and is associated with post-traumatic stress disorder.
Maintain access to chronic pain care medication and protect the patient/doctor relationship with regards to prescriptions

• Please accommodate the needs of patients who rely chronic pain medication. ICA fully supports educating providers with the full spectrum of pain management regarding effective treatment for all patients. We understand the current epidemic with prescription misuse, abuse and overdoses, however we represent patients who rely on responsible use to live a normal life. Pain management is wide reaching and does not only include prescribing health providers but also physical therapists who assist patients working on their pelvic floor to alleviate and manage pain. These practices can lead to a patient moving away from prescription usage while maintaining the same quality and results of care.
IC Education and Awareness Program

• Please provide $1,100,000 for the IC Education and Awareness Program at the Centers for Disease Control and Prevention’s (CDC). The CDC IC Education and Awareness Program provides patient support that empowers patients to self-advocate for their care. For this reason, it is especially critical for the IC program to provide patients with information about what they can do to manage this painful condition and lead a normal life. ICA urges Congress to provide $1,100,000 for the IC Education and Awareness Program with recommended increased education and awareness activities in FY 2021.
Virtual Advocacy Day
Communication and Resource Tools

Find the following communication tools on the ICA website at www.ichelp.org/advocacyday:

• How to Contact Your Two Senators
• How to Contact Your Member of House of Representative
• Phone Script
• Social Media Post
  – Use #ICAAdvocacyDay
  – Tag your representatives in your social media posts
• ICA Advocacy Facebook Frame
• 2020 Funding Priorities and Background Detail for Reference
Questions?

If we don’t get to your question today, please email us at advocacy@ichelp.org and we will follow up via email!