

BE A CHAMPION FOR PEOPLE WITH AN OSTOMY OR CONTINENT DIVERSION

Awareness and Advocacy
on Capitol Hill & Beyond



ABOUT UOAA



United Ostomy Associations of America, Inc. (UOAA) is a 501(c)(3) nonprofit organization that supports, empowers, and advocates for people who have had or who will have ostomy or continent diversion surgery. There are approximately 725,000 to 1 million Americans living with an ostomy or continent diversion, and approximately 100,000 new life-saving ostomy surgeries occur in America yearly.

We make it our mission to promote quality of life for people with ostomies and continent diversions through information, support, advocacy and collaboration.

For more information about UOAA visit www.ostomy.org

UOAA'S ADVOCACY COMMITTEE

The Advocacy Committee is a standing committee with goals of advancing UOAA's Advocacy Agenda. It is led by a Chairperson appointed by UOAA's Management Board of Directors (MBoD) and includes UOAA's Advocacy Manager and volunteers. UOAA's President and Executive Director are ex officio members. Driven by the energy and experiences of the committee members, they provide ostomates with the tools necessary to become effective advocates to improve a continuum of quality ostomy care.

UOAA'S ADVOCACY AGENDA

UOAA is the leading organization proactively advocating on behalf of the people living with an ostomy or continent diversion. Our Advocacy Agenda is grounded in the core values that form UOAA's vision:

A society where people with ostomies or continent diversions are universally accepted and supported socially, economically, medically, and psychologically.

TO THIS END, UOAA STRIVES TO:

- Ensure public and private health insurance options, including those under the Affordable Care Act, Medicare, Children's Health Programs, and Medicaid, provide affordable coverage and access to high quality healthcare services, technology, and products to meet the needs of people living with an ostomy or continent diversion so that they may participate fully in society

- Protect the rights of people with an ostomy or continent diversion and eliminate discrimination at school, work, and elsewhere in their lives to ensure they are accepted as normal, healthy individuals
- Dispel the fear about undergoing this life-saving and life-restoring surgery and erase the myths, stigma and embarrassment that are sometimes associated with having an ostomy

TO ACHIEVE THIS VISION UOAA WILL EXECUTE THE FOLLOWING STRATEGIES:

- Promote alliances, identify and partner with coalitions and organizations that will take collective action and achieve one strong voice before key decision-makers, thereby advancing UOAA's advocacy goals.
- Advocate for policies and legislation that ensure people living with an ostomy or continent diversion receive quality health care that meets their needs
- Develop a comprehensive advocacy program to reach and engage constituents
- Provide resources and information about access to quality care and ostomy supplies to educate various audiences including but not limited to UOAA constituents, families, public policymakers, insurance decision-makers and the public at large
- Increase public understanding of "ostomy"

UOAA ADVOCATES ON EVERY FRONT FOR THE ISSUES OUR CONSTITUENTS CARE ABOUT MOST. WE REGULARLY REACH OUT TO:

- Congress
- Federal Regulators such as the Centers for Medicare and Medicaid Services (CMS) and
- Other healthcare organizations and coalitions including partnering with the Digestive Diseases National Coalition (DDNC) and the Access&Care Coalition and their member organizations such as the Crohns and Colitis Foundation (CCF), as well as the American College of Surgeons (ACS) and the Wound, Ostomy and Continent Nurses (WOCN) Society.

WHY BE AN OSTOMY CHAMPION?



You play the most important role! No one knows better than you what living with an ostomy is like, and you have the power to improve the quality of life not only for yourself, but also for thousands of people living with an ostomy or continent diversion. The most convincing advocate for people living with an ostomy or continent diversion is the individual who can speak from firsthand experience.

By sharing your story, and offering opinions and suggestions for how to make things better you can make a real impact on decision-makers, and be a catalyst for change whether it is to improve your own personal quality of life or change a national policy.

A person does not need formal “advocacy training” to be an advocate. Advocacy can be as simple as getting involved with growing and strengthening your local UOAA Affiliated Support Group. Participate by being a role model or visitor. Inform other community groups such as the cancer survivor groups or a Crohn’s and colitis association about your UOAA Affiliated Support Group and what you do for someone with an ostomy.

Moreover, as it relates to governmental advocating, it’s a fact that legislators want to hear from their constituents, the very people they were elected to work for, about the issues that affect them and the communities they serve. They want to work with you to try to address your concerns much more than any paid lobbyist. By lending your voice you put a face on the issues confronting people with an ostomy or continent diversion. Otherwise, public policymakers will fail to address your concerns and not understand the potential ramifications to their solutions or policy changes. Instead they will focus on the issues and concerns that have been brought to their attention by other constituents.

You are UOAA’s greatest resource for making positive changes across the country thus we can expand our educational and advocacy outreach to not only elected officials but other decision-makers that affect the ostomy population’s ability to live a full normal life such as employers, insurance providers, Medical Directors at the Centers for Medicare/Medicaid Services, state regulatory governance, or management at health care facilities.

This toolkit will help educate, engage, and empower you to make your voice heard by decision-makers and elected officials, and raise broader awareness on the matters of importance to you. Ensuring ongoing gold standard of ostomy care or protecting rights doesn’t merely happen. Together with your passion and dedication we hope this will help you become a powerful force to drive change in the ostomy and continent diversion communities.

“People living with an ostomy can lend their voices to help others. We all know how much adjustment can be required and for those of us who are living well with an ostomy it’s important to help those who come after. Thank you for your unique voice.”

UOAA President Susan Burns, 2017

Now That You Have Decided To Be An **Ostomy Advocacy Champion** What Are The Different Ways To Advocate?

ADVOCACY is promoting what is important to you, and persuading others to support your cause. Here are some of the different ways you can get involved in advocacy:



SELF-ADVOCACY Represent and speak up for yourself as a person living with an ostomy or continent diversion. Be informed (e.g., Check out all the information at ostomy.org; subscribe to The Phoenix magazine.) and stay connected (e.g., Sign up for UOAA's monthly newsletter). Be actively involved to help make sure that necessary changes are made so you can live a healthy, productive, satisfying life (e.g., Know your rights; Utilize UOAA's Action Center.)



COMMUNITY Join with others to represent the rights and interests of the ostomy and continent diversion populations in the United States. Ostomy communities begin with UOAA Affiliated Support Groups and can include virtual ostomy and special interest ostomy support groups. Online groups expand the community to include disease specific interests, professional organizations and world wide scope.



COMMUNICATIONS Increase public awareness and influence public interest on ostomy and continent diversion issues through traditional media, social media, interviews, and other awareness opportunities.



CIVIC Reach out to elected officials at the local, state or federal level, educating and influencing them on important legislative healthcare decisions or by raising awareness through formal proclamations.



POLICY-MAKING Influence regulations and rules that have an impact on your well-being for example, getting your employer or insurer to cover your ostomy supplies. Educate the decision-makers. Share your story.

Unless someone like you cares a whole awful lot, nothing is going to get better. It's not. **Dr. Seuss, The Lorax**

It's imperative our constituents are informed and understand the TSA rules when traveling. Visit TSA.gov to read the section on disabilities and medical conditions where they explain the requirements for individuals with an ostomy. UOAA has also written [Ostomy Travel Tips](#) and a downloadable [Travel Communication Card](#) to help educate TSA agents. **George Salamy, UOAA Treasurer & TSA Liaison, 2017**

A FEW WORDS ON SELF-ADVOCACY

More often than not, this is the type of advocacy that you will be doing as you take the initiative to speak or act on your own behalf to encourage change that will bring about improvements in your life. UOAA has created a separate self-advocacy checklist specifically as it relates to a person living with an ostomy or continent diversion, which is available at ostomy.org.

TO ENSURE SUCCESS AS A SELF-ADVOCATE HERE ARE A FEW TIPS:

Learn your rights such as the American Hospital Association's Patient Care Partnership (patient rights) because you are entitled to quality healthcare and being involved in your care decisions in the hospital. In addition, UOAA has created a set of expectations that you should be aware of as it relates specifically to your unique medical needs entitled "You Matter! Know What to Expect and Know Your Rights: Ostomy and Continent Diversion Patient Bill of Rights". Print the wallet card and keep these handy. You need to play a very active role in assuring you receive proper care.

Know the laws such as the American with Disabilities Act that protect a person living with an ostomy for example when you are in your workplace or swimming with an ostomy. Be aware of any federal or state law or regulation that affects ostomy care or access to care (e.g., Assisted Living Facility admission requirements).

Work with the resources available to you such as your workplace human resources department (and/or union, if applicable), advocacy organizations such as UOAA or the Patient Advocate Foundation (patientadvocate.org), or your elected officials (if applicable). For ostomy-related situations or issues seek input and get help on UOAA's discussion board, or your local ostomy Affiliated Support Group and see if anyone else has faced a similar

experience. Ask questions and get reliable information by calling UOAA's information line at 1-800-826-0826.

When you need to make a change in your community or workplace get the contact information of the person in charge or in a position to address the issue and make a change. If this person can't help you with your concerns, ask for someone who can.

Build your case. Gather accurate facts and relevant information so that you can educate the person in charge to assist them and persuade him/her in making the proper change. Assert yourself clearly and firmly.

Always be polite. Do not make demands. Medical professionals and healthcare facilities value patient satisfaction. A well-communicated complaint should get their attention.

Always keep a paper trail. Whenever you need to make a request to ask for what you need or make a complaint, put it in writing. Meanwhile keep copies of all correspondence. On the other hand if someone tells you something, ask the individual to put it in writing. If they tell you something is a law, policy or procedure, ask for a copy of the document.

You must be proactive. Stay on top of the issue. Follow-up as necessary. Depending on the situation or type of issue it can help to keep it alive by raising awareness (See awareness page with tips on this.).

Depending on the change you are trying to make and who you are dealing with (e.g., employer, government agency), if you believe a decision is wrong, inquire about dispute resolution processes and your right to appeal a decision. Make sure you understand your responsibilities and know any applicable deadlines.

The more you self-advocate, the more you will gain confidence in making your concerns known. Always believe in yourself.

REMEMBER YOU MATTER AND ARE WORTH THE EFFORT.

Ostomy-related Self-Advocacy Examples

EXAMPLE	LAW (IF APPLICABLE)	SELF-ADVOCACY RESOURCE
<p>My town won't let me swim in the public pool or my healthcare facility won't let me participate in water aerobics for my therapy because I have an ostomy.</p>	<ul style="list-style-type: none"> American with Disabilities Act (ADA) Fair Housing Act 	<p>Swimming with an Ostomy Toolkit: The Facts and Your Rights</p>
<p>On a recent travel trip during a routine airport security screening I was intrusively patted down, within the waistband of my pants, and firmly along my ostomy bag. Afterwards I had to go to a private screening area where the supervisor needed to see that my ostomy appliance was truly attached to my body.</p>	<ul style="list-style-type: none"> American with Disabilities Act (ADA) 	<ul style="list-style-type: none"> Transportation Security Administration (TSA) CARES Program UOAA's Travel TSA Toolkit UOAA's Travel Communication Card
<p>My supervisor treated me differently as he/she made ignorant remarks about my ostomy during a conversation among other employees.</p>	<ul style="list-style-type: none"> American with Disabilities Act (ADA) Rehabilitation Act of 1973 	<p>Employment-Based Workplace Discrimination</p>



FINAL THOUGHTS WHEN ADVOCATING AGAINST DISCRIMINATION: The ultimate goal is to change or improve a situation not take someone to court. If you have exhausted all courses of action or appeals, then legal remedies might be considered as a last recourse.

AWARENESS FUELS ADVOCACY

In 2015, the CDC negative anti-smoking ad that exploited the fear of living with an ostomy was a wake-up call for our organization that broader awareness efforts were needed as well as a staff to react to misinformation in a timely and professional manner.

To be truly effective in our advocacy efforts we need to expand awareness and when necessary keep advocacy-related issues alive in the public's mind and on the

radar of key influencers (and legislators, if applicable). The growth of ostomy awareness is realized each time a person living with an ostomy shares his/her story and advocates. You can speak up where you are most comfortable. This can be anywhere including digitally in the comfort of your own home or submitting public testimony all the way on Capitol Hill.

ON THE NEXT PAGE ARE THINGS YOU CAN DO TO DRIVE TRAFFIC TO THE CAUSES IMPORTANT TO YOU.

HOW WILL YOU RAISE OSTOMY AWARENESS?



GET THE WORD OUT!

Prepare visual handouts to catch people's interest like an informational flyer or brochure, the more professional looking the better. Present the facts and why people should pay attention to your cause. Include your contact information. The World Wide Web has been a boom for ostomy communities online to connect, but false information is also more easily spread. UOAA's website www.ostomy.org is a go-to trusted source for information where there are downloadable one-page fact sheets with ostomy-related issues such as our position statements on Federal legislation, "Swimming with an Ostomy: The Facts and Your Rights" discrimination toolkit or the Ostomy Infographic with easily digestible ostomy facts that can be used as handouts in certain efforts. Any time you can educate someone it will strengthen your case and lead to a positive step in the right direction. Perhaps maybe not today but down the road for the next person.



BUILD YOUR TEAM!

Recruit and build a network of supporters from your family, friends, neighbors, schools, co-workers, medical professionals, etc. to help spread the word.



GOT STOMA?

Use effective memory joggers. Get creative with the use of clever slogans, acronyms or original symbols such as UOAA's "stoma" pin.



FREEBIES!

Design giveaways that you can handout like wallet cards, pin buttons or stickers or magnets. This can give you some mileage to help people recognize your cause. For example UOAA encourages people to use our self-advocacy wallet cards such as the Travel TSA Communication Card or the Ostomy and Continent Diversion Patient Bill of Rights for these important ostomy-related issues.



LEAVE BEHIND MATERIALS.

Distribute your handout materials to professional offices such as hospitals, surgeon and medical doctor offices, legislator offices or ostomy support groups to help spread awareness.



USE YOUR FREEDOM OF SPEECH TO YOUR ADVANTAGE.

Write letters to the editors of local newspapers, and share your ostomy-related human-interest story with your local TV and radio news stations. UOAA provides sample templates to Affiliated Support Groups and individuals to encourage people to write letters for Colon Cancer and Ostomy Awareness Day. Create a Public Service Announcement (PSA) or you can use the PSA available on our website. Contact UOAA's Communication Manager for questions or assistance.



PUT A FACE TO THE ISSUE!

Be sure to include a photo or video to help increase your human-interest story getting featured. If your story gets picked up locally, it could lead to a nationally broadcast segment, which will catch the eye of more people who might want to support your cause. Increased exposure means more press.



ATTEND TOWN HALL MEETINGS.

These are great opportunities where you can meet your Members of Congress and share your concerns with policymakers. Encourage other advocates and your “team” to join you. Position yourself and UOAA as the experts on the ostomy-related issue. Bring your handouts for distribution. You might attract more people to the cause and build your network!



LET'S GET THIS PARTY STARTED!

Organize a fun social event that would be popular in your town, staff a table at a local fair or work with UOAA to plan a Run for Resilience (www.ostomy5k.org) in your community to raise funds for UOAA's education programs. Whatever type of event you plan it is another opportunity to share your materials to raise awareness about your specific campaign/cause. Contact UOAA at 1-800-826-0826 for materials to help raise ostomy awareness.



VOCALIZE YOUR OPINION.

Give public testimony at state and federal levels of government. Provide written copies of your statements to the elected officials and press.



REACH PEOPLE WHERE THEY ARE.

In today's world the greatest tool to drive change and raise awareness is social media. Follow UOAA on its' social media accounts such Facebook and Twitter. Twitter has proven a valuable way for people to contact us and for us to use hashtags to spread a more positive message about living with an ostomy. Together we can share and retweet the specific ostomy-related advocacy campaign. Special hashtags related to the cause can also be created to engage people. Always tag UOAA on posts in any social media platform in case we can help or spread the word. On Instagram accounts' photos of people showing their pouch and doing great things or being honest in their struggles help to smash stigmas. Send us photos or tag us on your public posts there as well. Spark conversations with the people in your online communities, discussion boards and network of friends. Post comments on related blogs.



DON'T HOLD YOUR TONGUE.

An easy way to advocate at the local community level is to speak at civic groups, or with medical students, nurses, and others to educate them about living with an ostomy or continent diversion and the issues you face in your ongoing ostomy care. Or host a panel discussion with fellow ostomates, policymakers and physicians at your local hospital or community center. By doing so you help to eradicate stigma, drive change and might have an impact on someone else who is wrestling with the same problems.



YOUR EXPERIENCES MATTER.

Contribute to the body of knowledge about living a quality life with an ostomy or continent diversion by participating in studies, focus groups or surveys from medical researchers or manufacturers of ostomy supplies.

OSTOMY AWARENESS DAY

Our greatest national effort to raise ostomy awareness is Ostomy Awareness Day. In the United States national Ostomy Awareness Day began in 2010. It is held annually on the first Saturday of October. UOAA continues to celebrate this day by spreading awareness and increasing national visibility of those living with ostomies. While focusing on different inspiring themes, each year through our collective voice we will reach out to the general public, carry on breaking the silence and shining a positive light on what has saved so many lives. Visit www.ostomy.org during late summer for information about the events and activity plans for the current year. Be sure to promote Ostomy Awareness Day on your social media accounts and customize your profile with UOAA logos for that year.

Each year we organize [Run for Resilience Ostomy 5ks](#), which reach broad swaths of local communities. Route signage and runner packets including basic ostomy facts for those unfamiliar with what an ostomy is are provided. Visit www.ostomy5k.org for more details on how you can support, join or cheer an organized run or have your own virtual run/walk in your favorite place to walk.

In addition, Ostomy Awareness Day is a great way to introduce yourself to your legislator and help build those relationships. It's a first step to positively address the policies that can impact the ostomy community. In addition, you can contact your elected official to request a proclamation for this special day (sample proclamation available on our website).

Not only does Ostomy Awareness Day provide an opportunity to raise ostomy awareness, it can also provide an opportunity for you to raise awareness about your particular issue (or pending legislation), by writing a letter to the editor of your local newspaper. You could simply write:

Dear Editor,

This October, as our nation celebrates Ostomy Awareness Day, I want to let your readers know about (issue or bill number, title and brief description). This is important to persons living with an ostomy because _____. (If a bill: Please ask your Senator/ Representative to support (or oppose, if applicable) this bill when it comes up for a vote.)

Thank you!

Lastly, you can find a sample letter to the editor on our webpage specifically for Ostomy Awareness Day.

Do you want to change the public perception about this life-saving surgery? Join us annually for this special day and all year long. Awareness doesn't happen overnight or just in one day.

START SPREADING THE WORD!

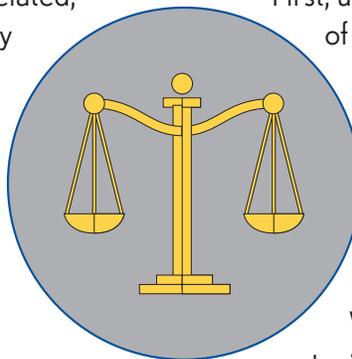


For me as long as I stay involved and am able to tell my story to other ostomates it helps me to accept the person I have become. It's a new me just carrying a little more extra baggage in a good way. **Roxanne C.**

UNITED STATES LEGISLATIVE PROCESS

Not every advocacy initiative is legislative-related; however, there are times when it is necessary to introduce new legislation or support (or oppose) a specific piece of legislation that affects persons with an ostomy or continent diversion. Your elected officials are determined by where you live. There are three levels of government you can engage with: Federal, State or Local.

As a citizen of the United States it is your civic right and duty to take an active role in our government. *Joining UOAA's Advocacy Network will give you the opportunity to do so.*



First, understanding the fundamental process of how a bill becomes a law in our Federal government can be helpful to ensure an effective legislative effort. The next page shows an infographic with a brief snapshot of this process.

Don't be fooled by the short list of steps. The legislative process is a long one. When a bill gets referred to a committee, typically no action is ever taken and it dies there.

The wheels of government move slowly. It can be frustrating and discouraging. Be patient. Keep pushing and asking for answers.

State legislatures follow a similar process and each state has its own website where you can find bill status information, calendars, committee members, and more. On some websites you can even listen to proceedings in real-time.

Examples of successful state legislative campaigns that resulted in a positive change for people with an ostomy are Ally's Law (aka The Restroom Access Act) passed in several states. Also CT, MD and NY all now have state health insurance mandates for ostomy supply coverage by commercial health plans.

To find your Federal or State legislators look up your legislator on UOAA's Advocacy Action Center.

If your advocacy effort is indeed getting a law passed, it could take many years to accomplish. There are many factors that can affect how and when a bill will pass. It helps to work together with other individuals and organizations to advance a cause. Most of all it takes commitment and dedication.

“Never doubt that a small group of thoughtful, committed citizens can change the world. Indeed, it is the only thing that ever has. **Margaret Mead**”

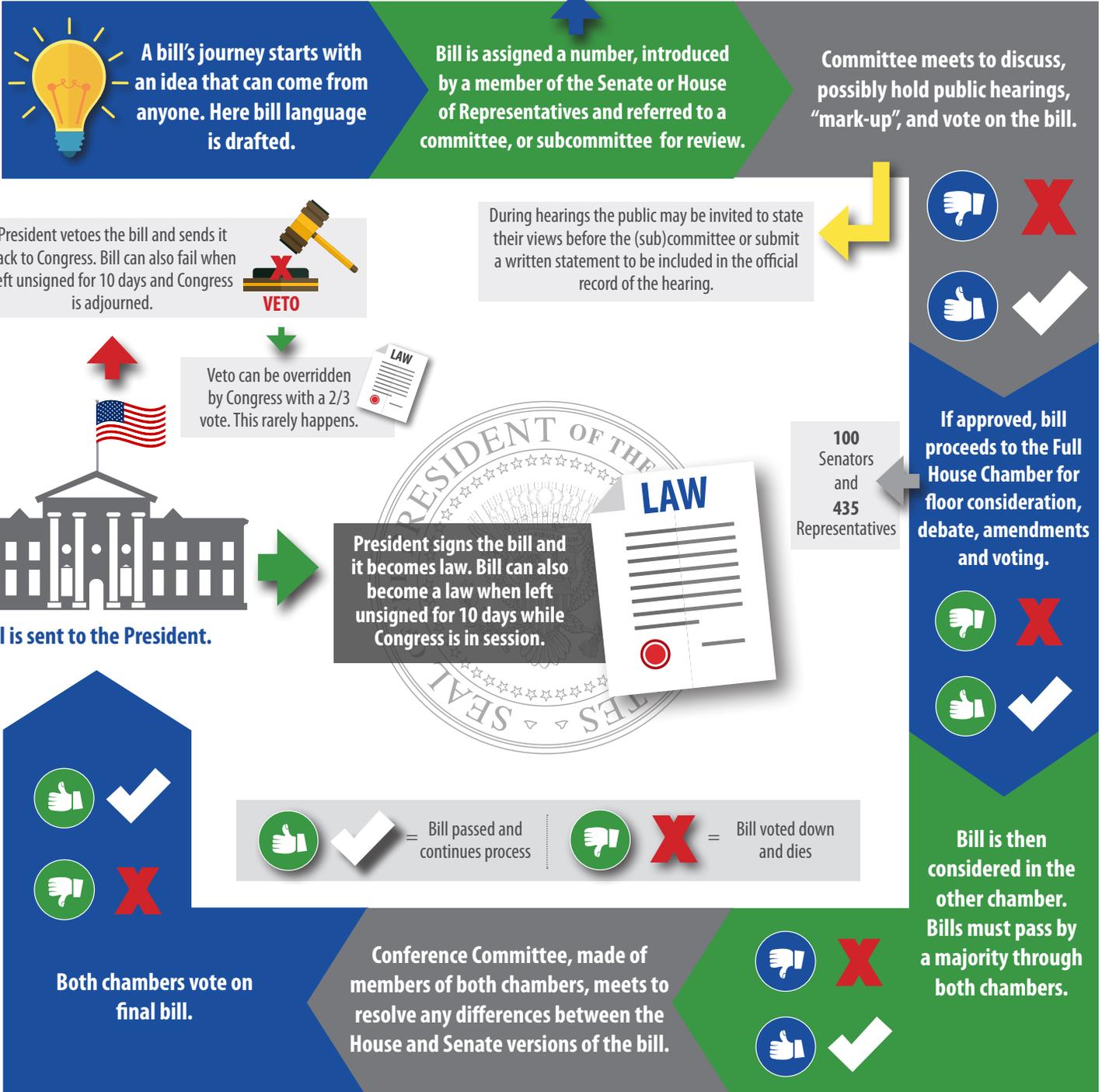
A BILL'S JOURNEY TO LAW

The US Legislative Process



It's a long journey for a bill to become a law. Thousands of bills are introduced yearly in Congress (Senate and House of Representative chambers), but only about 4% reach their final destination of becoming a law. If a bill does not complete the process that year, it expires and can only come back through reintroduction and the whole process starts over again. **This example shows the steps when a bill's path starts in the House of Representatives.**

NUMBER CODE OF A BILL: H.R. 284 [115] = House of Representatives
in which bill was received / Congressional Session



Join UOAA's Advocacy Network to get involved and be updated on legislative issues that may affect the ostomy and continent diversion populations.

CONTACTING CONGRESS

Most Federal ostomy-related legislative initiatives will be spearheaded by UOAA. For us to be truly effective we need grassroots advocates. We encourage you to participate in these advocacy campaigns because we are louder and stronger together. UOAA's Advocacy Action Center provides tools to help you easily find your elected officials, sample advocacy messages and a simple click of a button to send your messages for these Federal campaigns.

Communicating with Members of Congress is one of the easiest and most effective ways for advocates to build a relationship with policymakers on the issues that are of importance to you. By writing postal letters, calling, emailing, and posting on social media, you can make your opinions and views known. Your ostomy story and experiences can influence decisions our elected officials and other decision-makers make every single day.

“Don't think of ostomy supplies as you would for an oxygen tank or a crutch. It is not 'one size fits all.' Ostomy appliances are critical to a person living a normal life but the appliance has to work for each person's body chemistry, shape, size and life style. The availability of a wide range of choices and manufacturers of products has been the greatest single advance for those with ostomies in the last fifty years. **Gary S.**

Follow these effective tips to help you gain confidence as you engage in conversations or correspondence with your legislators and help make your views known.

Regardless of the level of government you are trying to influence or the form of communication you use with your legislators, the following are some important guidelines to keep in mind:

- 1.** Research your issue. Make sure you have the most up-to-date and accurate facts. Never assume that the person you contact is knowledgeable on your topic or issue. If you are advocating with UOAA on our top priorities, read our position statements, action alerts and follow our guidelines on our website's Action Center. Sign-up for UOAA's monthly newsletter to read about our advocacy efforts.
- 2.** Learn what legislation is a priority for your legislator. Sign-up for your elected official's email newsletters and follow them on social media. If an office has historically never supported an issue, you might want to reconsider taking it to them. However, some legislators have been known to change their minds and that's where your own story comes in play to make a difference.
- 3.** Identify yourself as a constituent ("voter") and an advocate for United Ostomy Associations of America.
- 4.** Grab their attention with a thought-provoking statement using clever, attention-grabbing wording or personal anecdotes versus standard template messages. For example in the above quote Gary, who has an ostomy, had that direct sentiment for legislators from a past ostomy supply issue with regards to Medicare's Competitive Bidding Program.
- 5.** Educate them on how the issue or particular bill will affect you, your loved ones and the community with a touching story or persuasive reason. When they are speaking on the House/Senate floor, they may even use your story as an anecdotal example. Try to make the issue relevant so they can understand the local impact. Whenever possible use our prepared advocacy materials to help you have the strongest message possible.
- 6.** Network. You never know who might know someone influential such as a staffer in a legislative office. They can provide valuable information or open doors that might not have been accessible.
- 7.** Use your personal contact information and computer or telephone versus your workplace.

8. Develop relationships with the legislative aides, and they can be your greatest ally in reaching legislators and persuading the legislators to take notice of your bill or request. Some day the aide may be Chief-of-Staff!
9. Be realistic. Identify a reasonable solution and offer yourself as a resource for assistance and available to answer any questions.
10. There may be a time where you have an opportunity to testify in front of a committee hearing. To avoid unnecessary stress, learn ahead of time what to expect or the process at the US Capitol or your own state capitol. For example, where do you park? Do you need a photo id?

11. No matter how you reach out to your legislator always say "Thank you," and express your gratitude for their time and consideration. Furthermore, if your elected officials vote your way, send a thank you note.
12. Hold your elected official accountable. This is your right. Ask for a written response or call-back.



Remember when communicating with elected officials or staff members whether in-person, mail or phone that they work for you!

YOUR TAXES PAY THEIR SALARIES!

Writing your legislators:

There's a reason why they say, "The pen is mightier than the sword." Writing is a highly effective and important means of communication. For elected officials the letters they receive are used as a barometer of public opinion, and if they receive a lot of letters on a subject, then this reflects strong voter sentiment. In addition, it is a personal poignant letter rather than a standard form letter that will catch the eye of a staffer or legislator.

Mail takes a few days to arrive. For a quickly moving issue a phone call is best.

Whether it is a postal letter or email message the following guidelines can be applied to improve your effectiveness:

- Do not write legislators who do not represent you - they will not respond.
- In the opening paragraph identify the issue and your position. If writing about a specific legislation, remember to include the bill number.
- Write what you are specifically asking for and the outcome you want from the legislator.
- End your letter with closing statement: "Looking forward to your response."; "Your constituent;"; signature and your address.
- Keep a copy of your letter and mark the date in your calendar. If you do not have a response in 4 weeks, call the office.

Elected officials value personal narratives more so than data and statistics.

Calling your legislators:

When you need to quickly contact a legislator - CALL. During a critical voting period, it is not uncommon for people to call everyday. A flood of calls sharing the same sentiment can sometimes change a legislator's vote. Every day the Senator or Representative and their senior staff receive a report on the 3 most-called-about topics for that day at each of their offices (in DC and local offices). Your voice does matter.

- Do not call legislators who do not represent you - they immediately look you up in the voter registration system to confirm you are in their state or district.
- Make an outline before you call, be concise and don't become argumentative. "You catch more flies with honey, than vinegar."
- Begin your call by introducing yourself and telling them you are a constituent and where you live and what you are calling about.
- Always ask for the name of the person with whom you are speaking and their job title as its best to speak with a paid staffer versus an intern.
- Then ask for the name of the person who handles your issue and if you can speak with that person if they are available (i.e., Health Legislative Assistant).
- Before you hang up the phone ask, "Can I count on his/her support?"
- Confirm the staff person has your contact information.

Write down the name of the person you spoke with and any notes you may have from the discussion. If follow-up is required, mark it in your calendar. Wait 2 weeks, then call back asking for your response.

Meeting your legislators:

The most impactful and effective means of communication is the face-to-face meeting with a legislator. It shows your dedication and commitment to your issue. However, it is not easy to get a private meeting with a legislator. If it is a Federal legislator it is very difficult to even get a meeting and it will not be with your legislator. So don't be surprised when you walk into the office to see you are actually meeting with the Chief of Staff or even a junior legislative aide. Realize this is ok and that it can still be a meaningful meeting, because these staffers have direct access to your elected official.

- Don't just show up to your legislator's District office. Schedule an appointment. For Federal legislators meetings can be held "at-home" in their district offices or in Washington, D.C. at their Congressional office. Meetings in district offices are just as effective as DC and you have a better chance of getting on that calendar. Plus more convenient for you since local to your home.
- Think of key questions to ask in advance. For example, "Can you tell me specifically why our bill hasn't moved in committee?"
- Be on time and be prepared.
- Be flexible. It is quite possible your meeting will take place in the reception area or in the building cafeteria, because office space on Capitol Hill is at a premium.
- It's ok to be nervous. It can be intimidating speaking in front of a legislator. Remember that although these are important people, at the end of the day they work for you.
- Always be polite and respectful. Don't be argumentative. Have the same expectation from the person you are meeting.
- Listen to their responses and viewpoints. Consider the opposing view. If you disagree, still be courteous.
- When you don't know an answer to a question, tell them you will follow up with the correct answer.

WANT TO MAKE A STRONG IMPRESSION?

At the close of the meeting leave behind your handouts that explain your issue and how it affects their constituents.

Social Media Communications:

Nearly every Member of Congress has some form of social media presence. So at your fingertips from your mobile smartphone or home computer you have access to a powerful, quick, and easy advocacy tool.

Benefits of using social media:

1. **Direct 2-way communication**
2. **Occurs instantly in real-time**
3. **Raises awareness in the public eye for no-cost**

Here are some tips for successful use of social media for advocacy purposes:

- Find your legislators' accounts and connect with your public officials. "Like" the Facebook pages of your Members of Congress. Follow them on Twitter. For certain UOAA advocacy initiatives thru our Action Center we will connect you and give you sample messages.
- Engage in respectful conversations. Keep your messaging civil and clean. Make your posts appropriate.
- Build social media in to all of your advocacy efforts. Announce meetings on Facebook, tweet thank you messages, post visit photos etc.

- The more people you like, friend or follow the more that will follow you and the wider your reach will become. In addition, follow UOAA @UOAA on Twitter, @UOAAinc on Facebook and @UOAA_ on Instagram to keep abreast of issues and retweet anything interesting to your followers.
- Look for trending hashtags surrounding the issue and use them to get noticed. Also use hashtags such as #ostomy, #MyAccessMatters and #UOAAChampion on your messages on Twitter and Instagram.
- Post or tweet on your legislators' accounts. Create a special hashtag for your issue.

For example:

"Can I count on your yes vote today for bill number ___?"

"Support constituents with #ostomies. Vote yes on bill #!"

If your elected official hasn't sponsored the bill yet, "@representative (Use official legislator handle) @senator please support #HR123 #S123 (insert actual bill#)"

@senator thank you for co-sponsoring #S123 #UOAAChampion This is important to me. #ostomy

Share your posts and get your followers and friends to ask for support. Build these legislator connections and make them count!

What Else You Can Do

Use our Action Center

Join our Advocacy Network

Share your ostomy access story for our #MyAccessMatters initiative

Donate to UOAA to support our advocacy efforts

Remember to utilize the educational resources and self-advocacy tools available at ostomy.org



Advocating can be challenging and intimidating. Success rarely happens overnight especially when trying to change a longstanding policy. Furthermore, the end result of your efforts may not be as you had hoped and planned. However, without your voice and that of others educating decision-makers (and/or elected officials) or sharing persuasive informative materials, they will have no way of knowing what it's like living with an ostomy or continent diversion or the challenges facing our community. The important thing is that each time a person does so it becomes one step closer to a positive change in the future.

We want to help you be the best advocate possible. If you need additional information or clarification on anything listed in this toolkit, please contact UOAA at 1-800-826-0826 or reach out to our Advocacy Manager at advocacy@ostomy.org. Let us know the issues that are important to you. Finally, we'd love to hear about your success stories or visits with your elected officials. For national issues please report back any outcomes from your efforts.



You've taken your first advocacy step just by reading this toolkit! We hope that you will take the next step in self-advocating for something important to you or get involved in UOAA's national advocacy efforts. We all have the choice to do nothing or take action. Know that whenever you take a stand to help others living with an ostomy you will have supporters and UOAA standing behind you and fighting with you. Together we are advocates for a positive change.

Jeanine Gleba, UOAA Advocacy Manager, 2017