



RAISE YOUR VOICE

Advocacy Toolkit



Prader-Willi

SYNDROME ASSOCIATION | USA
SAVING AND TRANSFORMING LIVES

PATIENTS
RISING
Delegate

This toolkit was created by Patients Rising Now with contributions from PWSA | USA. It provides tools and tips on how to be an effective advocate. Patients Rising Now is a national nonprofit organization dedicated to advocating for the rights of patients with chronic and life-threatening illnesses.

In addition to supporting reforms and legislation aimed at advancing patient access to affordable, quality healthcare, Patients Rising Now offers an Advocacy Master Class which is designed to train patients, caregivers, and citizens in the art of healthcare advocacy. The course is structured as a 15-week, immersive experience where you will learn about advocacy on and off ‘the hill’ and be provided with the tools and tactics you need to be an effective healthcare advocate.

For more information on how you apply to their Advocacy Master Class, click here: [Advocacy Master Class - Patients Rising Now](#)



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Personal visits are a highly effective way of helping elected officials understand the issue you care about and your program. Elected officials are supposed to represent you, and welcome visits from constituents. They want you involved, even though they are busy people.

Repeatedly meeting or speaking with elected officials or their staff is an excellent way to develop a strong relationship, so that you can become one of their go-to resources when a vote is coming up related to your issue.

SCHEDULING THE MEETING

- Make your appointment 3–4 weeks in advance. On your elected official's website, they will either have a contact form, or information about scheduling a meeting. If you have a contact at the official's office, try reaching out to them to assist in scheduling a meeting.
- While scheduling the meeting, inform the staff of who you are, what organization you are representing (if any), and what topic you are hoping to discuss with them.
- Be flexible! Try to make it easy for your elected official to meet with you and be prepared for delays or cancellations.
- Consider whether you might know someone - a board member or volunteer maybe—who already has a relationship with the elected official and can make an introduction for you, and possibly attend the meeting.

PREPARE

- Invite other advocates! Bringing a coalition of diverse voices and experts on the issue can communicate the scope of the issue you are meeting about. Try to include people who use your program and have personal experiences with the issue you are meeting about. Because your time at the meeting will be limited, avoid bringing more than 4–5 other people.
- Write out your talking points and practice them! You don't have to be a seasoned public speaker to convey your message but writing out the main points you are trying to get across can help you feel more prepared and get the most out of the meeting.
- If possible, send materials about your program and issue in advance, including data, stories, and fact sheets.



DURING THE MEETING

- Bring printed copies of the materials you sent in advance.
- Don't be surprised or offended if you meet with staff rather than the representative. Staff meetings are incredibly valuable - they are the people the representative goes to before a vote!
- Be on time for your appointment or even arrive five minutes prior to the start time. Be prepared, be polite, and be brief—you might only get fifteen minutes with the representative or staffer.
- At the beginning of the meeting, state who you are, who you represent, what you want to discuss, and what you want your elected official to do.
- Don't be surprised if your elected official does not know about your issue or program. Elected officials must know about many issues and may specialize in areas unrelated to your work. Avoid overwhelming the elected official with information and detail.
- If you do not know the answer to a specific question, offer to find the answer and then forward the information to the elected official after the meeting. You want to emphasize that you are a resource for the elected official.

BEFORE LEAVING

- If you feel comfortable, ask your elected official for some sort of commitment. If you are meeting before a vote, clearly ask them to vote the way you would like them to.
- Leave behind any materials about your issue or program, summarizing your points, ideally including your key points and what you are asking from them. Make sure you leave either a business card or your contact information.

AFTER MEETING

- Follow up the meeting with a thank you note or email, thanking the elected official for their time. Be sure to re-state your position in this note.
- If the elected official asks for more information, get this information to them as soon as possible.

HOSTING ELECTED OFFICIALS

Bringing an elected official to your organization or to an event can be an excellent way to show what real patient advocates in their district need and also gives others the chance to speak with their elected officials.

Here are some tips that can help to make your event a success:

Send a formal invitation letter. Even if you speak in person with a member of Congress, congressional staffer, or other elected official about visiting your program, make sure to follow-up with a formal invitation letter. Such an invitation letter should be submitted to the elected official’s scheduler in the form preferred by the office. Most congressional offices will have a separate scheduling e-mail address to which invitation letters can be sent, but don’t hesitate to call an office and ask how they prefer to receive invitations. If a board member or other community partner who knows your program well has a relationship with the elected official, ask that partner to co-sign the invitation letter or follow-up on the invitation on your behalf.

Be flexible with respect to date and time of the visit. Don’t be afraid to offer several days or a span of time during which your program would be able to welcome the elected official to visit. Elected officials, particularly members of Congress, often have busy schedules into which they try to squeeze many visits, events, and engagements. Reasonable flexibility with respect to scheduling will increase the likelihood of securing an elected official visit.

Don’t be afraid to follow-up on a pending invitation. Members of Congress and other elected officials receive far more requests of their time than they can reasonably fulfill, and sometimes invitations get lost in the shuffle. If you haven’t received a response to a

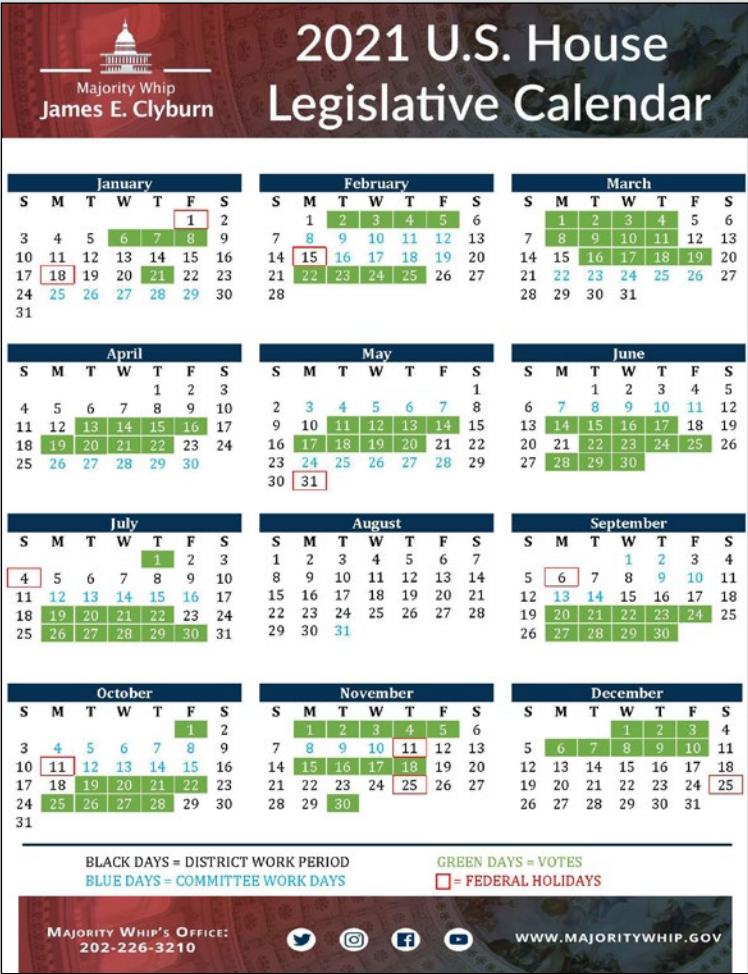
pending invitation, feel free to call the elected official’s scheduler to confirm they received the invitation.

Choose the right service location. Members of Congress and local elected officials who represent a specific geographic area will be most interested and willing to visit a service location in their congressional district or geographic jurisdiction.

Invite others. Having people representing a few different organizations present, even just to introduce themselves and show that they also care, can enhance the impact of a visit. These could be your traditional partners or other stakeholders that care about your issue but have a different perspective.

Confirm whether the visit will be open or closed to press. This will affect your preparation for the visit. If the elected official wishes to have the event open to press, a media advisory will have to be issued, in coordination with the elected official’s office, in advance of the visit.

Provide briefing material in advance of the visit. Elected officials will almost always receive a briefing memo from their staff in advance of any event or appearance. Providing a briefing memo to the elected official’s staff several days in advance of the scheduled visit will both save them time, which they will appreciate, and ensure the right message is presented to the elected official.



A sample Congressional calendar

Make an “ask.” At some point during the event, someone (typically a board member, executive director, or state commissioner) should ask the member of Congress or their staff to act in support access and affordability. Having a specific bill to refer to is a huge bonus.

Make Introductions. If there are specific attendees at the event who you know are

skilled at talking about a particular issue, or have a powerful and relevant story to share, try to introduce them to the visiting elected official. One of the biggest benefits of hosting an elected official is the opportunity for them to speak directly with people who would be impacted by legislation, rather than hear their stories indirectly.

Personal or form letters? Writing a personalized letter is significantly more impactful than signing on to or reproducing a form letter. Taking the time to write down a personal story about why you care about an issue can be much more persuasive than a form letter covering the basics, though form letters are still worth sending if that is what you have time for.

When should you write a letter? Generally, the most important time to write a letter to a legislator is before a vote on a bill, so your input can be taken into consideration. However, it is also worthwhile to write to a legislator to either thank them or express concern after a vote, depending on which way they voted.

Keep it brief. Keep your letter under one page. Your letter will most likely be read by a staff member and summarized for your legislator. Focusing on a few brief points ensures that your purpose for writing is clear.

KEY POINTS TO INCLUDE

Who are you writing to? Open your letter with a formal greeting.

- If you are writing to a Senator, “Dear Senator ____” will work.
- If you are writing to a Representative, “Dear Representative ____” will work.

Who are you? Identify yourself early in the letter as a constituent of the person you are writing to. If you are representing an organization or an agency, identify yourself in this way as well.

What are you writing about? Try to be as specific as possible. If you are writing about a specific bill or piece of legislation, include the name or bill number in the first paragraph of your letter.

Why is this important to you? How will this bill positively or negatively impact you or your community? If you can, include both data and a story.

What are you asking for? Make sure that you end your letter with a crystal-clear ASK. E.g., “Please give your support to H.R. 2525 to make sure no more patients suffer the same fate as so and so.”

SAMPLE LETTER LAYOUT

This letter can easily be customized to any kind of legislator. It is structured to fit on one side of a piece of paper, so manage words carefully and remove anything not in defense of your Ask.

Paragraph 1: Introduce yourself, any organization you represent, and introduce your Ask.

Paragraph 2: Your emotional argument. Make this personal.

Paragraph 3: Your rational argument—also emotional.

Paragraph 4: Your Ask/call-to-action. Make this the only logical thing to do to solve the problem.

For a Senator, use:
The Honorable [full name]
United States Senate
Washington, DC 20515

DATE

The Honorable [full name]
United States House of Representatives
Washington, DC 20515

Dear Representative [last name]:

I am Jim Sliney Jr, patient, caregiver, and Registered Medical Assistant living in your district since 1967. I am also the Community Outreach director of Patients Rising, a nonprofit organization representing over 150K chronically ill and disabled Americans. I’m writing to you today to ask you to support the SSI Restoration Act so you can save my son.

In 2008 my adult son was diagnosed with colon cancer. He was a successful small business owner and cherished in his community (this very district) as a purveyor of rare and out-of-print books. When he was diagnosed, he had to shutter his business to focus on getting well. But he never quite did. After many complications, he had most of his intestine removed and is now dependent on liquid food through a tube in his abdomen, and still suffers daily. Disabled, he went on Supplemental Security Income. Within 3 years he lost his business, his home, and depression stole his passion for working with his neighbors.

The SSI system (which hasn’t been updated since 1974!) only allowed him to get \$794 a month, yet the out-of-pocket costs for traveling to treatments and doctors, and the copays for his medications alone cost him \$310 a month. The remaining \$484 has to cover food, rent, and essentials of his very spartan life. Unable to amass more than \$2000 in assets meant he had to sell his business and his beloved books. Being trapped by such limited income and limited ability to save money, there was no way he could buy back his business or start a new one, much less live independently. If he were able to hold more assets, or marry without losing his meager benefits, he might be able to come back to being a pillar of the small business community in this town.

Mr. [last name], I’m asking you to give your full support and endorsement to H.R. 3824, the “SSI Restoration Act of 2021” so my son and others whose dreams were derailed by disease, have the ability to lift themselves out of this state of forced poverty and dependence.

Thank you for your time,

Jim

CALLING AN ELECTED OFFICIAL



Keep it brief. Your call should be somewhere between 30 seconds and one minute. Your goal is to state who you are, what issue you’re calling about, why you care about it, and what you would like the person you’re calling to do. Limiting yourself to one to two sentences on each of these points will help you keep the call clear and on topic.

Be kind. Most likely, you are going to be speaking with a staff member at the office who takes calls from constituents all day. Yelling or making their job unpleasant can get your call discounted. Be polite but firm with your requests.

Write out a script. Writing down what you’re planning to say, or even just a few bullet points about the subject, can be very helpful to make sure you and the staff member get the most out of your call.

SAMPLE SCRIPT WITH OFFICE OF ELECTED OFFICIAL

You: Hello, my name is [your full name], and I live at [address]. I would like to make an appointment to meet with [elected official's name] about the upcoming legislative session. Are you making in-person appointments or virtual?

Staff member: Yes/No. Please give me an idea of what you would like to address, and I will see what we’re able to work out.

Thank you. My _____ has a rare disease called Prader-Willi syndrome (PWS). I would like [elected official's name] to sponsor a resolution to bring awareness to this rare disease and help our community have a recognition day for PWS. I would like the opportunity to discuss a little bit about PWS with [elected official's name], either in person or via a virtual platform, so that [he/she] understands why this is such an important step for the PWS and rare disease community. In a perfect world, we would love for the PWS Awareness Day or Month to take place in the month of May; May 15th would be great because PWS is on the 15th chromosome, but take what you can get!

Ok. Let me look at our calendar and see when we can get you an appointment.

Thank you for all your help. Would you mind giving me your name again and an email address where I can reach you?

OP-EDS

Op-ed (“opposite the editorial page”) pieces are opinions written to grab the attention of various groups, including elected officials, business and community leaders and the public. Write about your PTA’s public policy positions and submit it as a letter to the editor of your local newspaper, inviting readers to join PTA. Newspaper editors select pieces for publication based on interest to readers, originality of thought, timeliness, freshness of viewpoint, strength of the argument and the writer’s expertise on the issue.

Tips for writing a strong op-ed:

PURPOSE

Stay relevant to your reader. If you are writing about opera but submitting to a magazine read by baseball fans, you’re going to strike out.

Stay focused. You don’t have a lot of space so you can’t afford to ramble or mix your messages, because you’ll lose your reader.

You are joining a conversation. You are not the first or last person to have an opinion on this topic. Be new and innovative, not an echo chamber. Also, anticipate what someone might use to argue against your point and acknowledge it.

ATTITUDE

Don’t show off. Elevated vocabulary and tricky sentence structures won’t win you any prizes, so ask yourself, “can my 12-year-old niece follow this?”

Establish trust and expertise. Anyone can comment on anything, so why should people listen to you and trust what you have to say? Are you experienced, educated, immersed?

Treat your reader well. Don’t talk down to your reader. Respect them. They are you. Speak how you’d like to be spoken to.

TECHNIQUE

Say nothing you cannot back up. You may not have to add your sources and citations, but have them ready for those who will challenge you.

Start with an attention grabber. Think about how you read, and how quickly you move on if you’re not interested. Get people’s attention. Short sentences work. Graphic imagery can grab people by the face and keep their eyes on you.

Have a point. Remember, you’re in a conversation. Have a point, make an argument, and end with a conclusion.

Want to go deeper? Check out [The Op-Ed Project](#).

LETTERS TO THE EDITOR

Letters to the editor are another way to reach a large audience. Letters can take a position for or against an issue, simply inform or both. To capture readers’ interest, they can include emotions and/or facts.

Tips for writing a strong letter to the editor:

- Visit the website for your local newspaper for additional guidelines for writing op-ed pieces and letters to the editor as well as submission information.
- The principles of writing a letter to the editor are much the same as writing a good op-ed. What makes letters to the editor different is that they are your attempt to join an existing conversation in that periodical. For instance, “In your May 2020 article entitled ‘Why Advocacy is Counterproductive,’ the author said...” If it’s already been in the periodical, the editor has already found that topic interesting.

PARTICIPATE IN A DRUG UTILIZATION REVIEW BOARD MEETING

While each state's process is a little bit different, here are some of the ways to make your voice heard in the DUR process.

ATTENDING A MEETING

- All DUR meetings are open to the public, whether they are occurring in person or virtually. Some states require you to register in advance to attend the meeting. For others, you can just show up!
- Check websites for links to the DUR Board/P&T Committee sites, meeting schedules, and other information for each state.
- Many states include instructions on their DUR Board site on how to register or attend the meeting. However, if that information isn't readily apparent, no problem! There is usually a secretary or other administrative person's contact information listed on the site. Don't hesitate to call or email this person and ask for more information or help getting registered.

SPEAK AT THE MEETING

- Visit the DUR Board site to see if there are instructions or requirements to speak. If you don't see the information on the site, call the administrative person and ask for help.
- Each state has a different process for allowing people to speak at the actual meeting but assume that you'll have to register in advance. Some states use a "first come, first served" approach, and others use a random lottery system to determine who will get to speak. Keep in mind that there is likely to be a deadline to register to speak that could be weeks ahead of the meeting itself, so if you want to have a chance to speak, start the process early!
- Assume you will have to fill out paperwork to speak. The most common requirement is disclosure about your interest in the proceedings. This might include who you are representing, whether you are being compensated to participate, whether you own stock or have other financial interests in the product, and/or other information showing whether you stand to gain financially from the decision. These disclosure requirements are for transparency purposes and are often required by state law or some other regulation.
- If you get the chance to speak, there are likely strict limits on how much time you have. Usually, speakers are limited to five minutes at most, and more likely far less than that, so plan accordingly! Practice your remarks and time yourself so you have a good sense of how much you'll be able to say.

SUBMIT A STATEMENT IN ADVANCE OR AFTER THE FACT

- If you are not selected to speak or aren't comfortable speaking, that's ok – you can still weigh in. Most states have a process in place to submit statements or testimony in advance of the meeting, and/or even after the fact. The window varies by state, but best to assume you must submit your statement before the meeting occurs, or within a very short time afterward. Visit the DUR Board site to see if there are instructions, and if you don't see the information on the site, call the administrative person and ask for help.
- There may be limits on the length, format, file size, and file type for written submissions, so make sure you know what those limits are and stick to them! There may also be disclosure required about who you represent and what you stand to gain, so make sure you understand the disclosure requirements as well.
- The same tips apply whether your remarks will be delivered live or in a written submission.



CRAFTING YOUR STATEMENT

To help you make the most effective and compelling case possible, here are some DOs and DON'Ts to consider when you are crafting your statement.

DO...

- ✓ **Introduce yourself and explain your connection to the disease state.** This can be brief but explain who you are and why you are there. This gives the Board members context and helps them understand how you got your insight.
- ✓ **Share your personal experience.** How would your life be enhanced or improved with a therapy that helps treat your condition? Or how has it already been improved or enhanced by that treatment? What are the consequences of NOT having access to the treatment? Include clinical benefits, but also consider including other factors, such days of work missed.
- ✓ **Discuss the treatment itself.** What experience do you have with the treatment in question? What are the other options available to treat the disease? How does this treatment differ? What personal data can you share to help the DUR Board understand the treatment's value to the patient?
- ✓ **Ask the board to support coverage for the treatment.** State clearly and directly your request that the Board supports coverage for this treatment, without any unnecessary restrictions, such as "fail first," step therapy, or invasive testing.
- ✓ **Give context.** Approximately how many people in the state could benefit from this therapy? Reach out to other organizations if you need data to come up with a reasonable estimate. Especially in cases of costly treatments, it is important for the DUR Board to understand that there is a limited number of patients in their state who would even be eligible for the treatment in question.
- ✓ **Familiarize yourself with the Board members.** Know your audience and speak to them in terms that they'll understand and be familiar with.
- ✓ **Use facts and information you can verify.** Whenever possible, use independently verifiable facts rather than generalizations or guesses. Cite your sources. This includes your personal experience and observations!
- ✓ **Make sure you understand any requirements for the statement.** This includes time or page limits, format, file size, file type, and any other style requirements. Also make sure you know the deadline by which the statement must be submitted, and how to submit it.

DON'T...

- ✗ **Assume the Board members know about your disease state.** Assume the DUR Board members are not familiar with your specific disease state – they are not experts. What is the typical disease progression? How does the treatment impact that progression? What else is important to understand about the disease state to make an informed decision about this treatment?
- ✗ **Be combative or disrespectful.** No matter how compelling your case may be, if your tone is combative or disrespectful, it takes the focus away from your message.
- ✗ **Make your statement overly emotional.** While this is a deeply personal issue for you, being overly emotional in your remarks can backfire. The Board members are more likely to respond to an earnest request based on relevant information – including your personal experience – and other data rather than an emotional appeal devoid of any evidence that the treatment merits coverage.
- ✗ **Try to tackle every single argument in your statement.** With any treatment, there are many points to argue – sometimes dozens! If you have a time or page limit for your statement, don't try to tackle every single point. Choose the points that you are the most expert on and focus on making a compelling case for those points. For example, if you are a parent of a child who was part of a clinical trial for the treatment being considered, you can discuss your first-hand experience with how effective it has been for your child, and how that tracks other clinical data.

SAMPLE DUR STATEMENT

My name is XXX and I am a [patient/caregiver/loved one] who has spent XXX years [living/working with/caring for someone] with [disease]. [If relevant, add a professional background.] I am asking you to support coverage for [treatment] without restrictions or barriers that would block access to patients who may benefit.

[Disease state] affects XXX people worldwide. According to data from [source], approximately XXX patients whose condition makes them amenable to this treatment live in our state. [Disease state] affects patients by... It is [chronic/fatal/debilitating] and typically results in... My personal experience with the disease is...

This treatment helps patients by... My personal experience with [treatment] is... It [has improved/would improve] my life by... Without access to this treatment, I would...

Clinical data shows that the treatment is effective. For example, according to [source], patients [were able to/didn't have to] ... My experience reflects... This treatment is [different from/complementary to/superior to] existing treatments because... This treatment is important to patients because...

Again, I ask that you support coverage for [treatment] according to the FDA label without requirements like ["fail first," step therapy, invasive testing, and/or other requirements] that will limit patient access to this treatment.

Thank you for your consideration.

Congress takes numerous breaks from their legislative work so that elected officials can get back to their districts and spend time with their constituents. During these recesses, they schedule various public events, including town halls. Attending town halls is an important part of being an active advocate.

HOW TO FIND A TOWN HALL

- Elected officials and government agencies will list upcoming town hall meetings on their websites. You can check their websites to find out when the meeting will happen.
- Call their district office directly and ask when their next one is.
- Another great place to look is townhallproject.com.

MEETING TYPES

Usually there are 2 types of town hall meetings:

- **General meetings**, where constituents and advocates can ask and speak freely to their elected officials.
- **Specific meetings** that mainly focus on one topic.

Make sure to check beforehand which kind of meeting it is.

WHAT HAPPENS AT A TOWN HALL MEETING?

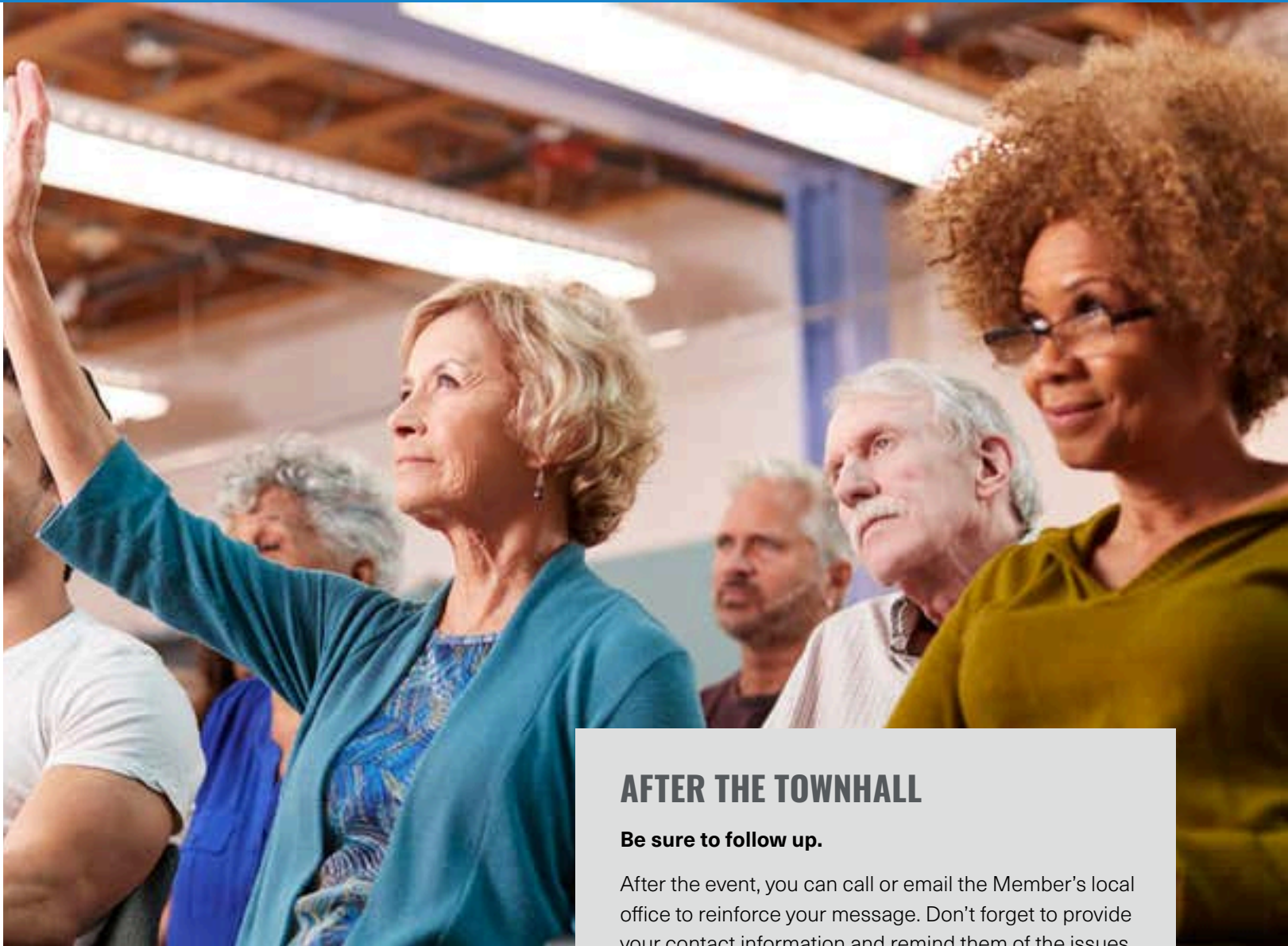
Having an elevator speech prepared for the town hall can help. An elevator speech is a short speech that you memorize in case you get a moment with a member of government.

Here is what you should include in an elevator speech:

- Your Name
- Where you live and who or what you represent. (School, Organization, Workplace.)
- The issues you care about and how/why it affects you or others you care about.
- Why you and others need the issues to get fixed and how can your elected official help.
- Thank your member for listening to you.

Try to keep your speech under a minute or so and try practicing with friends and family.

It might be beneficial to bring a written document with more information about the issues you care about. You can give the document to your member or to their staff so they can read it and learn more later. That way, you can give a short speech but still cover all the important information.



AFTER THE TOWNHALL

Be sure to follow up.

After the event, you can call or email the Member’s local office to reinforce your message. Don’t forget to provide your contact information and remind them of the issues you raised concern over. It is always good to try to make a connection with the staff because they may want to follow up with you down the road!

TESTIFY AT A COMMITTEE HEARING

- **Know the schedule.** Check the legislative website and with legislative staff to know when a bill is scheduled to be heard. Be advised- schedules can change quickly, especially in the final days of a legislative session.
- **Know the process.** Before testifying, know who is sponsoring the bill, who supports or opposes the bill and why. Be familiar with the committee chairs, committee members, and legislative staff. Let the sponsor of the bill or key legislators know beforehand you are testifying on the bill.
- **Know the purpose.** Understand why you are testifying. Are you there to persuade, dissuade, provide expertise, or delay action on a bill? Know how to separate out the important points of your testimony to ensure they are heard.

FOOL-PROOF TIPS

- Thank the committee for the opportunity to speak.
- Clearly state your position and what you support or oppose in the proposed bill.
- Refer to the bill by the bill number and be sure you are using the most recent version of the bill.
- Identify yourself and your organization.
- Summarize your recommendations first, then add explanations.
- Wrap it up with a closing statement. Ask lawmakers to vote for or against the measure.



WORKING TOGETHER

Now that you have these tools at your fingertips, go put them to the best use you can.

It's important to remember that advocacy is a team effort, so if you find yourself stuck or needing help, reach out to advocacy@pwsausa.org.

You can also reach out to our Community Engagement Coordinator:

Dorothea Lantz / dlantz@pwsausa.org



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