

Best Practices for Connecting with your Legislator

Making Phone Calls

Do not expect to reach your elected official directly when you call. You will more than likely talk with a person who works in their office (aka a staffer). Be prepared to leave a message either with the person answering the phone or on their voicemail.

Plan your call and practice a few times. The more you practice, the less nervous you will be once you pick up the phone. Write out a few notes to keep you on track.

Speak with Confidence. Open the conversation by identifying yourself. State your name, tell them where you live in their state and clarify you are one of their constituents. State that you are a member of the ITSAN/TSW/Eczema Community (whichever you prefer).

Be precise and concise. Stay on topic about your desire to meet to share your story and talk about an awareness resolution for TSW. Be courteous and respectful. Regardless of whether you agree with the legislator's politics, thank them for hearing you out on this issue and acknowledge their commitment to improving the lives of their constituents.

Before the call ends, leave your contact information with the staffer, so they can reach back out to you about setting up a meeting or to get additional information. Also, ask for the name and email of the person who you are speaking to so you can follow-up email to provide additional information and a draft of the resolution.

Sample call script

Hello, my name is (your name). I am from (city) and one of the (senator's/representative's) constituents. I am someone living with/impacted by topical steroid withdrawal syndrome which is impacting thousands of Americans. (Add one sentence or two about your personal connection to TSW.)

I am calling to ask if I could get a meeting with (X) to share my story and ask if they would consider introducing a TSW Awareness Resolution. Can you please connect with the staffer who is handing this topic? (If they say they are that person, give them a little more background – a couple sentences – about your experience with TSW. If they say that person is unavailable, ask to leave them a message.) Thank you so much for helping me with this. Can I please ask your name and email address so I can follow-up with you after this call with more information and a draft of the proposed resolution for your review? (Provide your contact information.)

Thank you so much for your time and support.

Meeting with your Legislator

A face-to-face meeting with your elected official is one of the most impactful ways to get through to them and gives you the time to focus on your story and your requests. It also provides an opportunity for your legislator to ask questions for a more meaningful back and forth conversation.

Reach out to the office of your legislator through phone or email and ask for time on their calendar to speak with them. Be prompt and professional in responding to their communications.

Do a little research on them - Before you talk with your legislator, find out what issues they care about and have been working on in your state, and what special committees they serve on. Remember, they are there to serve YOU, their constituent. They want to hear from you, to know what you are concerned about, and how they can help you. Also, see if you can find any common ground or mutual friends to bring up in your conversation - you are building a relationship with them!

Be prepared – print out a copy of your written story (and include pictures if you are comfortable with that) a copy of the draft **TSW Resolution**, and the **TSW Awareness Fact Sheet** to leave with your legislator. You can also print and bring along an **ITSAN brochure** and copy of **Lucy's Story** (about the threat many TSW caregivers face of Child Protective Services involvement).

Dress professionally – when you take yourself seriously through how you present yourself, so will they.

Be on time - maybe even 5 minutes early! If you live near the capitol and plan to meet your legislator there, remember to plan for extra time to find parking, go through security and find their office in the building.

Be patient and courteous – Keep in mind your elected official may be very busy, so be understanding and conscientious of their time. Ask up front how much time they have – if they let it spill over because of their intense interest in your story, keep going. ☺

Be respectful – don't talk over or interrupt your legislator or their staff when you are speaking with them. Be articulate and stay on the topic of TSW – stay away from other political issues you may not agree with them on.

Be Honest – Don't be afraid to be vulnerable and share the true impacts of TSW on your life. It's completely natural to get emotional when sharing how devastating this condition is. And it really is through emotion that we reach another human's heart and get them motivated to help. Just remember to keep why you are meeting front and center: TSW needs recognition and must be addressed – most of all, we need them to take action.

Take a picture – Ask if you can take a picture with your elected official to post and tag them on social media. It's great PR for them! And it will empower others to get out there and advocate too.

Follow up – Once your meeting is over, follow up with an email to thank your legislator for their time and remind them of what you would like them to do for you. If you don't hear back after a week or so, reach back out to them by email. If you still don't hear back, call their office again. Like the saying goes, "The squeaky wheel gets the grease." Just don't call and text every day and drive them crazy!

Enjoy your newfound friendship with a political figure!