

## Usher Syndrome Coalition | Government Relations Strategy: How you can be an advocate

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Hello, and welcome to the virtual Usher Connections Conference Government Relations Strategy presentation. My name is Brian Forni. I haven't had the pleasure of meeting many of you yet. I hope that changes in the near future, but obviously with COVID, we're stuck doing virtual events. But I look forward to being at the next in-person conference. Till that day, I hope everyone stays safe and healthy.

My presentation today is about how the Usher Syndrome Coalition can be a successful advocate in our efforts to accelerate a cure and achieve better treatment options. The families and supporters of the Coalition like you will play a major and critical role in this.

In my two decades' career working in Congress, government relations-- and for an executive branch federal agency, I've found that citizen lobbyists like yourselves are the most effective, persuasive, and compelling advocate for change. When somebody can really personalize the story, which we're going to get into during this presentation, that really is one of the most effective tools when you're lobbying the executive branch, members of Congress, and their staff.

But why be an advocate? It's a great question. And you might be sitting there saying, you know, what can I do? Why should I become an advocate? Well, let's start off. We are here because Usher syndrome affects as many as 25,000 people in the United States. More than 400,000 worldwide.

The recent pandemic and shelter-in-place requirements are exceptionally difficult for individuals and families suffering from deafness and vision loss. We talk about social distancing. It might be a little more difficult for the deaf-blind community to social distance. I see it in DC on the metro. It might be a little more difficult for some. There was a *Washington Post* article that hopefully a lot of people in this community saw and just get a better understanding of what the blind-deaf community is going through, people suffering from Usher syndrome, what you're going through.

Why be an advocate? The media, the public, and Congress have become aware of the challenges you face every day during the pandemic. And it's not going away soon. There is promising research going on across the country, and our goal is to help accelerate this research with increased resources, including federal funding and political leadership.

Some of the examples are at Harvard Medical School, they're partnering with Massachusetts Eye and Ear Infirmary, and they're looking to accelerate research on Usher 1F, the rarest form of Usher

syndrome. They want to augment current critical research on genetic hearing loss gene therapy project.

Another example would be the University of Washington's Retina Center. They're looking to establish regional Usher syndrome centers with excellence to combine basic translational and clinical research towards accelerating the search for a cure. Now those are just a few of the examples, but there are many research universities and centers and hospitals all across the country that are doing important work on Usher syndrome.

The best way to achieve this goal is for the Coalition to become more visible in the halls of Congress, and to educate and advocate for Usher syndrome. One of the things-- I worked in Congress for nine years, and I've lobbied them for now over a decade. So I've walked around Congress for probably about 15 years now.

And there are so many people advocating each and every day, so you have to get the attention of members. So this government relations strategy is not just a one-off. This is, we have to be persistent. We have to make sure that our message gets out. And everybody here, everybody watching can play a part.

The only way to secure the necessary funding needs is to have a constant presence in Congress with both staff and members. And I'll get into that a little more. I think maybe sometimes people get caught up in meeting with members. But I can tell you, having been a staffer myself, that a significant amount of the work is actually done at the staff level.

So moving on to the next slide. How can additional federal funding help? Now as I'm sure I don't have to tell all of you, Usher syndrome is a multifaceted disease and requires a multipronged approach that addresses hearing and vision loss.

As I mentioned in the previous slide, there is promise and research, and exciting results happen at universities, medical centers, and private labs all across the country. But we have to keep this momentum going. These places need a continuous stream of research money to achieve the necessary results for finding a cure.

We can't just get federal funding one, two, three years, and then call it a day. This has to be continuous. Members of Congress, staff, the administration, they have to know that with additional federal funding, that increases the opportunity for a cure.

And in getting the message out, particularly now with so much oxygen being taken up on COVID, will

be a challenge. That's why we're doing this presentation, and that's why we want to engage as many of you as possible.

Usher Syndrome Coalition has 2020 advocacy goals. I'll cover some of these. As I said in a previous slide, it is easy-- you are a citizen's lobbyist. It is easy to become one.

I don't know if you're familiar with the term lobbyist, but if you are, sometimes it has a negative connotation. It's unfortunate that that's the case, because people like yourself, by picking up the phone, by writing a letter, by meeting with members of Congress, staff, and state and local officials and governors, you are a citizen lobbyist. You are lobbying on your issue. It doesn't really take any other skills except dedication and persistence, which I know a lot of you have. But before we get into that, we need to develop a plan and then encourage you to become involved and to promote our shared goals.

One of the things we need to do here is we need to identify and educate members of Congress and their staff about goals. Like I said before, there are so many organizations trying to take members of Congress and their staffs' time. There's unfortunately so many other diseases that are out there that people are trying to get funding for. ALS or Huntington's disease. We really need for staffers and members and outside organizations to really focus on the needs of the Usher syndrome and the Usher Syndrome Coalition.

So we need to identify members of Congress and their staff about our goals. I'll talk more about that later on who exactly we should identify, because there are certainly key members. And while you may not live in DC, you can play a role in your state, in your community.

So first, we need to promote increased funding for Usher syndrome research. You can't do it without the money. You can't do it without the federal funding. You can't do it without working with the National Institute of Health and other organizations like that.

You need to include Usher syndrome in the expansive list of medical conditions and diseases in congressional annual spending. So aside from funding, what Congress does is when each piece of legislation, with each fiscal year appropriation, they also do a list, like an intent of Congress. This is an explanatory statement that indicates congressional intent.

Right now, Usher syndrome is not on there. So what it does is when they appropriate money, they tell these organizations, they tell the executive branch that we want to make sure that ALS is funded, and this is the intent of Congress. Well, our goal now is to make sure that Usher syndrome is listed in that

intent of Congress. That carries more weight, particularly with these executive branch agencies.

Another thing that we need to do is we need to request the Government and Accountability Office-- GAO-- to include Usher syndrome in their investigation of the cause of undiagnosed and untreated rare diseases. For many of you that might not be too familiar with the GAO, it's an independent, nonpartisan agency that works for Congress, often called a congressional watchdog. GAO examines how taxpayer dollars are spent and provides Congress and federal agencies with objective, reliable information to help the government save money and work more efficiently.

So for us to include Usher syndrome on the investigation of undiagnosed and untreated rare diseases, we need a member of Congress to write a letter to the GAO, asking them to do that. And the good thing is that any member of Congress can send a letter asking for an investigation. So that's something. That's one of our goals this year as well.

Another one of our goals would be to meet with leaders of key executive branch agencies. I gave an example of the National Institute of Health. They appropriate-- so Congress appropriates that money, and then the NIH gives a lot of money to its research centers and universities. The Coalition has met with them in the past, but we really need this year to be the focus that Usher syndrome really needs to be brought up to the level of some other genetic diseases that are getting a little bit more funding.

Also, we need to involve relevant external stakeholders in this. Consider anybody that is willing to go to bat for Usher Syndrome Coalition as an advocate, as a relevant external stakeholder. An example of this would be the National Alliance for Eye and Vision Research. We're all moving towards the same goals, so the more people that you can have on your side, advocating on your behalf, particularly, again, trying to get members' attention and staff attention is better. And we'll cover some more of this in later slides.

So how can you get involved? There's a lot of ways. Like I said, you may not live in DC. I don't know. I remember when I lived in-- I come from Massachusetts. When I lived in Massachusetts, DC felt so far away. But there's so much you can do just in your local communities.

So let's talk about what you can do at the federal level. Every member of Congress, whether serving in the Senate or the House of Representatives, they want to hear from their constituents. Whoops. Sorry. Switching sides here. This is my first virtual event-- virtual presentation, so bear with me.

So they want to hear from their constituents. And you know, I give an example. I remember each time I visit a certain member of Congress's office-- he was from Wisconsin. And if he was in his office, he'd

come out and ask which part of the district I was from. He just assumed since I was there to meet with his staff that I was in the district. And when I said I was not there, he walked away.

[LAUGH]

And he did that three or four times. And I asked the staff, what's going on? He goes, "Oh, If there's a constituent, he comes out, meets with them, takes a picture. He wants to hear what their issues are." Members of Congress and senators want to hear from their constituents, so just keep that in mind. Any letter, any phone call, it actually matters.

So at the top of the slide, I put the link to find your representative. So as you know, each state has two senators. There's a link there for the senators too. But the member of Congress might be a little more difficult. If you click on this link, you can just put in your ZIP Code, and the member of Congress will come up who to contact.

And below that is the switchboard. That way, you just call, ask for your member, and you can speak to their office. And I will tell you that if you do call, you will talk to somebody in the office. And if you do have an issue that they want to talk about, the person answering the phone will take it down, and then they will log it in, and it will go to the staffer responsible, the staffer for those issues. And then that staffer does tell the member of Congress. So don't think that a phone call won't get heard or won't get registered. They do matter.

But what I want to stress in this is make it personal if you're willing to, if you write a note to a member of Congress or an email. When I was there-- I left in 2011-- members of just the House of Representatives, each member had at least 5,000 to 8,000 emails per week.

And what a lot of these were form letters where an organization would just say, sign here. And you'd get 1,000. And the staffer would log it in and you would get a response. Sometimes the member didn't see those points.

But I can tell you, when we got the personal notes, those were taken out, highlighted, and given to the member. It's the personal touch. And you know, some people have difficult stories to tell. And you know, I understand if you might not be able to. But if you can personalize the letter or the call, it will have a bigger influence on the member of the staff. That's just from my personal-- just my personal opinion on having worked there, and now I lobby Congress.

Like I said, staff save the personal notes. If you're getting 5,000 to 8,000 emails, it's tough to read all of them. In fact, it's almost impossible. So I just, again, stress. Personalize, personalize, personalize. If

there's one thing that you take away from this-- and I hope it's more than one thing-- personalize your message.

So let's talk more about identify and encourage other congressional advocates to help. So again, if you're not in DC, talk to your state legislature. Talk to your state rep. Talk to your state senator. Talk to the governor's office or staff. They do speak to the congressional delegation.

And on this slide we have, get to know your staff. Get to know their staff. And schedule a meeting with DC or local staff. I understand it's impossible to do a meeting right now and in person.

But offices are doing virtual meetings. And having worked in the personal congressional office, go in and meet with them whenever you can. Because what they'll do is they will actually take your issue or your letter or your meeting, and then they will report that back to DC, and then they will report that to the member as well.

So even if you don't live in DC, even if you live in the furthest corner of Washington state, 3,500 miles away from DC, meet with your member of Congress in his district office or call at that office. The staff there-- they're not in DC, but they do report everything to DC.

Right now, I wouldn't say it's easy to do, but they need to hear from you that increased funding for Usher syndrome is your priority. And it should be their priority as well.

You know, there's an election coming up, and every House member, which is 435, and 35 senators are up for re-election in November. So right now, they'll be in their districts and states more often.

If you can't do an in-person meeting-- like I said, it's a little difficult. Virtual meetings with constituents are a great way for them to reach out. Again, the congressional delegation speaks to the state delegation all the time. So when you're speaking to them, I'm going to reiterate, make it personal.

So if we want to focus on funding, which is the key aspect of the strategy this year, we really need to hone our focus. There are some members of Congress who play a larger role in our efforts to secure more money and attention to Usher syndrome. These are the members in the House and Senate who sit on the Appropriations Committee.

The Appropriations Committee determines the annual funding amount for every government agency. And that full committee is divided into subcommittees that do the initial work of putting together a bill that determines the funding level for an agency like the Department of Health and Human Services.

I mentioned HHS, Health and Human Services, because that is the agency that has jurisdiction for Usher syndrome programs. If you have a member from your state serving on the House or Senate Appropriations Committee, that will be especially helpful. You'll get a little more information on that on a later slide.

But don't be discouraged if your member does not sit on the Appropriations Committee. Members always talk to each other. So your member can lobby or advocate on your behalf. So if you have a member that does not sit on the Appropriations Committee, still talk to them. Still tell them that we need increased Usher syndrome funding.

They'll talk to the Senate floor. They'll talk on the House floor. They can speak to their members while they're there. Say, hey, look. You sit on the Appropriations Committee. What are we doing about Usher syndrome funding? I need to see more.

But if you do live in a state or congressional district that is represented by a member on the Appropriations Committee and/or the-- well, and the subcommittee that funds Usher syndrome, and if you have any relationship with that member, please contact Krista. It's extremely important that they hear from as many of us as possible.

I also want to touch upon a bill the Usher Syndrome Coalition supports as another example of how you can get involved. The bill here was introduced in the House. It's called HR 2620, which just means House Resolution. It's Faster Treatments and Cures for Eye Disease Act.

And what this bill does is this bill requires the Department of Health and Human Services to establish a pilot program that provides for a partial federal guarantee of specified bonds, the sale of which will finance promising translational vision impairment research with private investment. The Government Accountability Office-- GAO again-- must study this program and consider whether similar programs should be established for other areas of biomedical research.

A link to the bill has been included on this slide. Along with the text, there is a list of members who have co-sponsored the bill once you click on that link. Check it out to see if your congressman is a co-sponsor. If they're not, ask them to be.

If they are, contact them and offer your support. Thank them for signing on to the bill. We don't want to just be a Coalition that just continuously asks for something. If a member of Congress does do something, let's call them and thank them. If your member signed on this bill, thank them for their

support. You know? Too often sometimes in DC, you only hear negative. So it's helpful to hear the positive.

So who funds the Usher syndrome? Well, this is what we were talking about in the subcommittee before. So each House and the Senate Appropriation has subcommittees. And who funds us are the Senate Appropriations, Labor, Health and Human Services, Education, and Related Agencies Subcommittee. In DC, we call that the Labor HHS Subcommittee, because as you can see, that's a lot of words to say right there.

However, the people that we have here, so the pictures are Tom Cole, who's the ranking member from Oklahoma. Rosa DeLauro is the chairwoman for Connecticut there in the House. And then the Senate is Roy Blunt, who's the chairman, and Patty Murray, who's the ranking member.

Each of these subcommittees have more members, of course. And the Senate subcommittee has 19 total members, and the House subcommittee has 13. Now additionally, the full Appropriations Committee in the Senate has 31 members and the House has 53.

So there are a lot more members that sit on this committee and subcommittee that might be in some place that you live. I am sure that there is someone and I am sure that there is someone who belongs to the Coalition in each of those members' district. Our goal is to make the connection as we move forward. These bills will be moving fast, so we need to act fast.

I'll let you know that I'm recording this on June 22 for this presentation, and we just found out today that these subcommittees will be considering their bill-- they call it marking up-- that week that the conference is taking place. So as soon as you hear this, find out who your member is, and let's move as quickly as possible. We'll be doing our part here before the conference, but these subcommittees really need to hear from as many people as possible.

So let's move on to state engagement. I covered a bit of that, but I want to go into a little more detail. There's an important role that state elected officials can play in influencing House members and senators. Most state lawmakers know and work with the federal member of Congress, even if they are from a different political party. They can be strong advocates for our program. They talk to the governors. They talk to the statehouses.

If you're a congressman from Massachusetts, you're talking to the state reps and state senators from Massachusetts, the governor's office, on a weekly basis. You're coming back to the district in the state, and you're doing meetings with local officials in there.



So the state politicians can be an advocate. And they do have a role to play too. They don't necessarily only have to be an advocate with their federal colleagues.

For example, September 19 is Usher Syndrome Awareness Day. We should use this day recognizing Usher syndrome to educate the media, the public, and lawmakers about Usher syndrome and its impact on families, the community, and government programs.

We think of this as a multipronged strategy again. You're doing things on the state. You're doing things in the local area to try and advocate also for federal funding and federal issues as well.

The more awareness that can be brought all around the country, how Usher syndrome affects at least 25,000 Americans, the more noise we make, the more we do Usher Syndrome Awareness Day or walks or things like that, the more politicians will have to take notice. So again, it's a multipronged, multistate strategy.

There's also a key component here is the media. And I put write, write, write. So whatever you do, get the message that-- find an avenue to tell your story. Is that creating a blog? Is that writing an op-ed? Is that contacting your local newspaper? Is it asking for stakeholders to partner and write newspapers? The bottom line here is we need your help.

You know, having lived in DC for over 15 years, I know the real power that comes from citizen advocates like yourself. You offer a voice that carries a significant amount of weight. Even a small act can make a difference. Especially during a time when we need to rely on the written word during COVID, and there are many and effective ways to do that.

Again, ask a friend. If you want to write more and you've already written to them, to the local newspaper, ask a friend. Ask a family. Ask an ally. Just get the message out as much as possible.

And this is where maybe something that I would need help on is-- unless you're tech savvy-- use social media. If you're like me now, I just ask my niece and nephew for help, because if I try and post a video or hashtag, I might not do it very well. So I'll ask somebody younger that might be a little more tech savvy.

But you post on Facebook, right? Write something on Facebook, Instagram, Twitter. Create a hashtag. Find like-minded people or people that will support you. Try and create a hashtag to get more people involved. Again, if you can, personalize it as much as possible

My current position, it's always amplify, amplify, amplify. Find a way to amplify what you're going

through or what you're looking for or what you need support, whether that's funding for more research. Get the message out there as much as you can.

If you go to a local event, take a picture. Post it on social media. I'm sure most of you probably could do that, maybe a little better than I can. But maybe someday I'll figure all that out. Maybe I'll become tech savvy. Maybe not. I mean, probably took me an hour to figure out how to record this, so here we go.

OK. Next slide. Grassroots engagement. So there are many people who are part of the Usher syndrome family, and we need to involve them in our efforts. Everyone is welcome and everyone can help. And if anyone's willing to help, they can be an advocate. They can help. As I've said in my previous slide, ask family, friends, local groups to write, email or phone legislators. Just ask anybody you think that can be an ally.

We need to take advantage of this time in our country when lawmakers, opinion leaders, family and friends are aware of the impacts a pandemic is having on you or your loved one. You know, we can do this working together with your personal story, your commitment, and our coordinated message.

If you don't know on this slide, participate in a Walk 4 Hearing. Find out what's going on in your community and just participate. Find out what's going on-- or maybe you want to create something in your local community. Maybe there's a Walk 4 Hearing. I didn't know that existed. Maybe I want that to happen in my town or city. Work with your local city hall, town hall. Work with your local city council member. Just work with whomever you think could be an ally.

And I encourage you certainly to visit the Usher Syndrome Coalition website to see how you can get involved more. We have a great leader there. And what I want to talk about is once you go to that, if you want, volunteer for the Coalition. Again, this is about building a community to ensure a cure becomes a reality.

Volunteer. You know? Our leader there, Krista, who I'll talk about in a second, the more the merrier for her. She wants more allies. She wants more people to help. Become an ambassador. Become a resource.

You know, if you have an experience and there's a family that just found out that their son or daughter just got diagnosed with Usher syndrome, they'll be looking for answers, or they'll be looking for people to talk to. Join. Volunteer to talk to them, or join the mailing list.

Also, if you have certain skills, again, for this volunteer outreach, utilize them. Do you have marketing skills? Are you development? Are you finance? Are you audit? You know, anything. Any skills that you bring to the table, look to see if you can help the Coalition, again, because really, everybody here that's watching, we're all one family trying to attain the same goals, and that's to find a cure.

Krista Vasi, can't say enough great things about her. She's been - I've volunteered now for two months. She's been exemplary. She's been really fantastic to work with.

If you have any questions on advocacy, government relations, you know, any issues that came up on this, contact her. She's the Executive Director of the Usher Syndrome Coalition. I'm sure most of you already know who she is. Her email is right there.

And thank you for taking the time, again, to listen to this. I really wish we could have done this in person. I'm sorry for this impersonal virtual presentation. Hopefully next year, the conference will be in person and I get to meet a lot of people that are watching this today.