

Transcription for 2022 Advocacy Day Training on February 24, 2022

Lincoln Clapper, Advocacy Associates ([00:03:21](#)):

Uh, Stephanie, I didn't know if you wanted to, uh, open up with any opening remarks before I get going. That's fine. Or otherwise, I can jump right into

Stephanie Bozarth ([00:03:27](#)):

We have been partnering with Advocacy Associates for a few years now, and are so grateful for all of your help with getting us onto the hill, um, through zoom meetings. And, um, it looks like we have a lot of advocates tonight. I'm going to hand it off to Lincoln. He's going to talk a little bit about our platform and then I'm going to follow up with an overview of the logistics of the day, go through some of our priorities. And we're going to finish up with a little bit of education on social media and how we're going to blend that into everything. Um, of course, along the way, we will definitely have opportunities for questions. So, um, that was just off the cuff. So I think

Lincoln Clapper, Advocacy Associates ([00:04:20](#)):

So good evening, everybody. My name's Lincoln clapper. I'm part of the Advocacy Associates team here in DC. And, Stephanie said we've been working with you all for a few years now. And if you participated in this event last year, virtually, a lot of what I'm going to show you is going to look pretty familiar. I'm just going to walk you through, um, just an overview of the online dashboard you'll be using for your meetings. And just some of the features that, uh, go along with that in terms of how, how to navigate that. So, um, if you were here last year, great, this will be a good refresher for you. If not, um, we'll be able to introduce you to everything right now. So that being said, um, I'm going to share my screen and we'll get going here.

Lincoln Clapper, Advocacy Associates ([00:04:59](#)):

Now, if anybody has any questions along the way, uh, just for time sake, please put them in the chat box. I'll hang on here after I'm done and answer them, um, individually with you all. Or we can ask them as a group depending on what the agenda is, but, um, put them all in the chat and I'll go through to make sure I answer them all. One more thing also before I get going, just to make sure everyone's on mute in case somebody's, you know, dog walking in or my alarm goes off in the background, but just sometimes that can happen in this day and age. So, will, will get going here now. So you should have all gotten an email from us earlier today. And if you're watching this as a recording, today is February 24th.

Lincoln Clapper, Advocacy Associates ([00:05:42](#)):

So we released these around midday. So look in your inbox for advocacy day at advocacy, associates.com. That's where that would have come from. Uh, if you don't see it in your inbox, check your spam or junk folder. It more than likely is sitting there. If you do find it there, please unmark spam, because this will be our main way of communicating with you in terms of time changes, scheduling updates, all of that's going to come through over email. We want to make sure you're getting that correspondence. Now, if you did not, uh, if you, if you don't see it in your inbox and you don't see it in your spam or junk folder, I'll be able to drop a link in the chat after this is done, where you can, um, reach out to our development team. And they'll send you new login credentials, tomorrow.

Lincoln Clapper, Advocacy Associates ([00:06:28](#)):

Now within the body of that email, it will be a link to your schedule. And so this is an example here, but you'll see a link to your schedule in the upper right corner. That is highlighted here in red and in the middle of that email will be your login credentials. So when you click on that link, you're going to need your username and password, which it'll be your email address and a temporary password that the system has generated for you. So when you click on that link, it'll take you to the login page and that's where you're going to want to enter those credentials. So go ahead and put your email in, put that temporary password in, click the sign in button, and then you'll be prompted to change that password to your own personal password. So rather than using the temporary every time, you'll be forced to make a new one, just make sure you meet all the requirements there.

Lincoln Clapper, Advocacy Associates ([00:07:11](#)):

You can see all the boxes are checked in green, here as an example, pretty standard, password creation stuff. Once you click the send button, it'll launch you into your schedule. And from there, that'll be the only time you'll be asked to log in on that device. So it will save you. It will save you logged in, it's called dropping a cookie essentially. So, you'll remain logged in, and every time you revisit this, page, you'll stay logged in like an app on your phone. Now, if at some point you become logged out, or you try to access from another device and you forgot your password, you can easily reset it, just click the forgot password link, follow the directions that come up from there. It'll be like any other standard, password reset function that you've encountered online.

Lincoln Clapper, Advocacy Associates ([00:07:58](#)):

Now, if you're still having issues getting in at that point, please, go to the contact link here and that initial email that you've gotten from us. You can reach out to our development team through this mechanism. They'll be in touch with you tomorrow or this weekend, uh, depending on when you submit this, uh, with any issues in terms of getting you logged in. Now, once you are logged into this schedule, you'll see a dashboard that'll look similar to this. All of your confirmed meetings will have a time next to them. That's how you'll know they're confirmed anything. That's still pending. We'll show as "TBD" I think we have about 10 meetings or so left in your project, um, which is pretty standard, even this close to the day of the event. What if you do see it as TBD?

Lincoln Clapper, Advocacy Associates ([00:08:41](#)):

That just means we're either working on a time, or we're still working on trying to rearrange something within your schedule to make it work. Once these meetings do become confirmed, you will get a notification email about that from our system. So you'll be very much in the loop every step of the way as they become slotted into your schedule. And don't be surprised that this happens Monday morning or even midway through the day Monday. Uh, sometimes you should come across extremely last minute. But either way you will be very much, notified of that. If, if that does occur.

Lincoln Clapper, Advocacy Associates ([00:09:13](#)):

Now, one thing that we have changed, from last year is we have our new time zone modification. So all time zones will be displayed in the time zone you're located in. So you will not need to do any time conversions. The time will adjust accordingly based on your locations. So you will not need to do any time conversions. Now, in order to get the content for each meeting, just click on any part of the module there, it'll launch you into that specific meeting dashboard, which will look something like this. You'll see the time and date again at the top, followed by who you're going to be speaking with in that office,

whether it's the staffer, the member, or both, If there's been a meeting lead assigned to your meeting by by the government affairs team here, you'll see that person or person's name displayed here. If not, then this area is going to be blank

Lincoln Clapper, Advocacy Associates ([00:10:04](#)):

In order to access the video component for your meeting, just click that green join online meeting button, you can expect to engage in the zoom platform. I would say 99% of a hundred times, there are a few offices that for whatever reason, whether it's security or their, their own per office policy, they just don't do video at all. So if that is the case, you will see a disclaimer on the button letting you know that it's an audio only meeting. I think we only have a handful of those. So some of you will see that on your schedule. Now, if you are not able to access via a video, you can, of course, dial into, there will be dial in instructions in this area here. So just follow those instructions. If you need to dial into the meeting, All of your talking points will be in the talking points module here, uh, which will be discussed later. All of your documents will be in the documents module here. Simply just click on each document. It'll open in a separate tab on your browser. You will not need to download anything. It will just simply open up in a new tab. So you can toggle back and forth between your schedule, your documents and your zoom platform all at the same time

Lincoln Clapper, Advocacy Associates ([00:11:11](#)):

Beneath that is the attendees section. You may have to scroll down a little bit to get to it, but you'll see the attendees section, uh, in this area here will show all the attendees who are going to be in that meeting with you. There may be some relevant contact information there for you to contact each other outside of the platform. You can also turn this on or off by clicking on your name in the upper right hand corner. There'll be a dropdown menu where you can hit the privacy tab, and then you can uncheck whether you want to display that information or not. You can also contact each other through our peer to peer chat function. This is a direct private messaging system between you and the other advocate that you're messaging. So you can have a private conversation through this module. If somebody messages you this way, you will get a notification about that from the portal as well. On the left hand side is our report form area. The first one is the check-in feature. So we ask everyone to check this box either before or shortly after your meeting concludes letting us know that you checked in and you were there because we'll be sending an attendance report over to the team after this event. And we want to be able to highlight that you were present.

Lincoln Clapper, Advocacy Associates ([00:12:20](#)):

Beneath that will be an option for you to send a thank you email to whoever you met with. This will pull up an automated script that's already been crafted for you by the government affairs team. It'll also pull the staffer's email for who you've met with as well. So you'll have that contact information and you can open this email in one of two ways. You can click on that blue open email button at the top, which will pull up whatever your native platform is on your computer. So for example, I have Microsoft Outlook. If I were to click that button, it would pull an outlook email for me to send, if you don't have anything like that on your computer and you, you use Gmail or Yahoo, et cetera, you can copy all of this information with those three copy clipboard buttons beneath that blue button, and then paste it over to the email client at group choice to send Beneath that will be the meeting report form. These are specific questions for you to answer after each meeting. So go through and answer those when you get to the bottom, you'll see the submit button, just make sure you click that to submit your answers. And, you'll do this for each meeting on your schedule.

Lincoln Clapper, Advocacy Associates ([00:13:25](#)):

Beneath that will be a take note section. This is essentially a blank notepad. If you want to take free hand style notes, rather than using a pen and paper, just a nice way to sort of keep everything in one place. You may also see some past notes from meetings from last year about what advocates had to say about their meeting with that office, if they use this module. So it can also serve as a nice refresher and some nice, uh, background material. Before you go into your meeting, Beneath that as an option to select, if the member of Congress was present or not present, this is just a nice data that we're able to get specifically from you. The meeting may be scheduled with a member of Congress, but they get pulled away to vote, or they're stuck at a committee hearing and they can't make it. Again, just a very useful data point at the end of the day for, for follow up perspective. So mark one of those options as well when the meeting concludes, And then lastly for you, so social media fans, you can access your Twitter, Facebook, or LinkedIn if you'd like to drop a post on any of those platforms. Once the meeting concludes as well.

Lincoln Clapper, Advocacy Associates ([00:14:31](#)):

When you click on the meeting tab, it'll take you back to the homepage and you can navigate your way to that next meeting on your schedule. The legislators tab will take you to an area where you can view bios for everyone you're meeting with such that you'll also see links to all their social media pages as well. And you can play around with that further.

Lincoln Clapper, Advocacy Associates ([00:14:49](#)):

The bills tab will highlight any relevant bills that you may be tracking for this event. It'll also show the vote history of how the member has voted on that bill previously, if it hasn't been voted on yet. If you click on the actual bill there, it'll take you to the act, that congress.gov site for it, where you can look up co-sponsors, you can read the actual text of it. You can do a lot more exploring, through that site news, the news tab will pull any relevant news articles they've been mentioned in recently online, you can read about those, um, online and the committees tab will show all the committees that they serve on. So you'll have that background information as well, going and teach meeting.

Lincoln Clapper, Advocacy Associates ([00:15:30](#)):

The messages tab, will take you to an area where you can view those direct peer top messages, just sort of a catalog of them. The directory is a master directory of everyone in the event. So you can contact people outside of your meetings. If you choose to. And the support tab will be your best friend for anything and everything support, whether it's technical support, scheduling support, you can't make a meeting, anything and everything at all, go to the support tab. This will be the fastest, most efficient way to get any question resolved. So go to support for any issues. The more tab is basically a dropdown menu of all the content I've already reviewed. You can see how that operates when you get into your portal. There may be some additional resources in there too, for you to check out so go ahead and play around with that when you get logged in as well.

Lincoln Clapper, Advocacy Associates ([00:16:19](#)):

Okay. Last slide here, again, check your spam or junk folder. If you haven't gotten that initial email from us, our domain is@advocacyassociates.com. If you want to search for that, we're asking everybody to get into the meeting, whether you're calling in or via video, 10 minutes prior to the start time on your, and this is really just to make sure you can touch base with the other attendees in your group about roles. And also just to make sure everyone's present when the office joins that way, you guys can start

right on time. All times on your schedule are going to be shown in the time zone you're located in when viewing it. So again, you will not need to do any time conversions. You're going to get a reminder email one hour prior to each meeting out the course of the day, which will also include a link to your schedule in it, which will make it really easy to get in and out of the schedule throughout the course of the day.

Lincoln Clapper, Advocacy Associates ([00:17:03](#)):

If the office does not join your meeting within 10 minutes past the start time, please contact us. There will be a help number in the support tab for you to call if a situation does come up like that members in staff are people too, and sometimes they run late. So just give them a 10 minute buffer to join before letting us know. Please recognize these meetings may go anywhere from 15 to 30 minutes. So just prepare your talking points accordingly, any changes to your schedule the day of the event is going to come through over email. So again, just make sure you're really monitoring that closely throughout the course of the day. Make sure you are in an area with good wifi connection as again, most, if not all of your meetings will have a video component to them, please meet your microphone whenever you're not speaking. And lastly, just know your audience and sure you have an appropriate background. What I mean by that, it's just nothing super politically charged because you'll be speaking with both Republicans and Democrats throughout the course of the day. So that being said, very much looking forward to next week. And, I'll turn it back over to Stephanie from here.

Madeline Schehl ([00:18:02](#)):

Hey Lincoln, you have some questions in the chat. Okay. someone asked, so if we have multiple meetings, can we plan on 30 minutes? And then afterwards, somebody asked if we have five to nine advocates in a meeting. Do you want every single one of us to fill out the meeting report for that meeting?

Lincoln Clapper, Advocacy Associates ([00:18:25](#)):

So first question, yeah, you can expect the meeting to go anywhere from 15 to 30 minutes. It's always better to prepare for it to be shorter rather than longer. So the more concise you can be the better, um, if it ends up going long, then that's great. But, uh, you always want to make sure you have enough time to get sure. Your main points across and I'm sure, uh, the rest of you and your team are going to dive into that more later. In terms of the, uh, well, sorry, what was the second part of that question?

Madeline Schehl ([00:18:56](#)):

It was about filling out -

Lincoln Clapper, Advocacy Associates ([00:18:59](#)):

Oh, the media report form. Yeah. So, I mean, I'll leave that up to you guys. Stephanie, I mean, some groups want all the data, some only want one person from each team to submit it. So, you know, I'll, leave that up to you to, to kind of tell everyone,

Stephanie Bozarth ([00:19:14](#)):

Yes. And actually just to answer that, I think what we did last time was whoever was the constituent. We just picked one person and that person would fill out the meeting notes and that just made it easier. But if everybody wants to fill it out, if it's, it's okay to do that too, if everyone wants, has something they want to put in there, but just definitely agree amongst yourself that we get at least one from every meeting.

Lincoln Clapper, Advocacy Associates ([00:19:44](#)):

Okay. Anything else, Madeline?

Madeline Schehl ([00:19:49](#)):

Nope. That seems like that was all of the questions. But if anybody has any questions now, you can feel free to ask Lincoln while he's available. But if not, we can hand it over to Stephanie.

Lincoln Clapper, Advocacy Associates ([00:19:59](#)):

Okay. Yeah. I'll hang on for a few minutes in the chat in case anybody wants to submit anything else.

Stephanie Bozarth ([00:20:04](#)):

Okay. And Lincoln, you can see the chat. So can you respond on chat as well?

Lincoln Clapper, Advocacy Associates ([00:20:09](#)):

I'll look back through it. Yep.

Stephanie Bozarth ([00:20:11](#)):

And Madeline, I know we are still trying to work on the captions.

Madeline Schehl ([00:20:18](#)):

Yes, we are looking through all the tabs and cannot seem to find the setting, but Rebecca is still searching her settings as the host. She's still trying to get it sorted out. We're trying to get it done as quickly as possible.

Stephanie Bozarth ([00:20:34](#)):

Maria, do you know how to turn on captions? Do you want to unmute and share how to turn those captions on?

Maria ([00:20:44](#)):

Well, the host has the ability in their zoom settings. Sometimes it's on the website itself, their account, and sometimes it's on the actual zoom application, whatever that platform is. It depends on which version of zoom you have and what type of paid account you have.

Sheri Wise ([00:21:08](#)):

I know when we do the adult resource committee zoom chats, we have a caption company that we use and we schedule them before that. So I don't know.

Stephanie Bozarth ([00:21:19](#)):

Well, Maria, you bring up an extremely good point, and I am sorry that we did not anticipate this better. We should have, but certainly if we can't figure it out this time, this needs to be on our list for next time to make sure we do have it.

Maria ([00:21:38](#)):

Sorry. Yeah, I'm not the only one here who's looking for captions. I'm just the one who's very vocal about it because I'm kinda annoyed about it.

Stephanie Bozarth ([00:21:45](#)):

You know, actually Annabel needs captions right here in my house. There's so many things we're trying to put together here. Sometimes you miss some of the trees in all the forest, and I'm really sorry about that. I should have known personally. So they will be looking for that. Maybe pop up if it doesn't, I'm sorry. We will get that addressed for next time. I'm going to try to share my screen.

Stephanie Bozarth ([00:22:33](#)):

Just quickly, we're going to go over some of the background here and logistics, and then really try to spend just a little bit more time on the actual legislative priorities for this year. I do always like to give a little bit of history to kind of put in context— what we have done at the MPS Society— so when you go into your meetings, you know a little bit of our history here. Prior to 2012, it was really just a small number of advocates that would go to the Hill each year. It was probably about maybe four to five, six advocates that would visit as many people as they could, representing all the states. It just happened to be maybe board members or someone that was chairing the Advocacy Committee. 2014 was our first time that we decided we gotta add a little vigor here.

Stephanie Bozarth ([00:23:31](#)):

We ended up bringing in the entire board, the staff, and we got some grant funding. We all came up, did our advocacy visits, and then we thought, wow, this is working out great. We should spread the love. And that's when we launched the Speakers Bureau in 2017. Again, we were able to do that thankfully through some generous sponsors and from writing some grants through the MPS Society to cover those costs. Now, unfortunately, we've had to revert to not actually going there, but we are doing it by zoom. But the fun thing is, we are having more advocates engaged than ever because of the accessibility of actually doing it by zoom. So it's kind of one of those situations, it seemed grim, but it turned out to be an actual plus for a lot of people to get engaged that wanted to be.

Stephanie Bozarth ([00:24:24](#)):

And as you can see this year, we've got around 66. And when I talked to Terri earlier today, she thought we had about 118 legislative visits scheduled. That's just an estimate. The number could have changed a little bit. So, the big day logistics. Of course we just talked to Advocacy Associates. The goal is to secure appointments with two senators, one house representative. Every state has two senators representing them. That's for everyone that lives in that state, same two senators, but we all have one house representative.

Stephanie Bozarth ([00:25:21](#)):

And that is a smaller division within your state. It's in your community, there's a boundary set. Sometimes that changes a little bit from year to year, but you only have one house representative. However, in the Senate there's a lot more representatives as you can imagine because it's broken down and there's many, many representatives that can come out of one state. They only represent one specific area. You will receive your personalized schedule. We've gone through that, and as Lincoln mentioned, changes can happen. It happened to me last year, and we had actually not even planned for an extra meeting at the end of the day. And we were scrambling since I was going off to do other stuff.

And then I had to change my plan because of a change in the schedule. So really try to leave your day open for these changes that they might squeeze in an appointment in the beginning, middle or end of the day, just be ready for it.

Stephanie Bozarth ([00:26:31](#)):

Know your legislators. Just as we were looking at that screen again with Lincoln, I was reminded that that is all on there. That is such a cool feature. I would definitely recommend getting on there and taking a look at that, to get to know your legislator and there's even some acts that we're going to look at. You will need to find out if your legislator is a co-sponsor and where you can see that. As Lincoln mentioned, do not talk partisan stuff. This is when we're talking about rare diseases. It doesn't matter what party you're from. Don't make assumptions about how they might react to something you're saying, and if anyone in your group accidentally is kind of veering in that direction, you know, just everyone work together to do your best to kind of steer the conversation back to why we're here today. It has nothing to do with Republican or Democrat issues, our independents or anything like that. That's not what we're here to discuss today.

Adam Cohen ([00:27:40](#)):

Stephanie, the word is democratic, not Democrat issues.

Stephanie Bozarth ([00:27:46](#)):

Okay. Thank you. So what is your story? And this is where I want to make sure that you need to take some time over the weekend. We all know our story. Sometimes we know very long, long, long, long, long versions of our stories. You need to think about that story. Think about what parts of that story really relate to the ask that we're asking today, because sometimes what might be super important to you doesn't really relate to the ask. If you can somehow build it in because you feel like it is important to share, just take some time, try to figure out what you're going to say. How are you going to say it quickly, time yourself, say it in front of the mirror, say it with some friends, get some feedback. Did they even understand what you were saying? Did you get off track? It's always good to just check back in with, what are you trying to talk about and how does it connect with why we're here today?

Stephanie Bozarth ([00:28:54](#)):

By the way, the same thing. If anyone has questions, please put it in the chat. I will have a section where we can, you know, ask questions again. Madeline, will you just make sure to not let me miss questions we have in the chat? I'm sure you'll let me know. Okay. These are guidelines for success. Some of this is already covered. Conventional wisdom, sometimes we wonder when we're getting ready for the day, what in the world do I wear? Well, it's on zoom. So really we just have to worry about the top half, but just try to, you know, just try to address that we're talking to people in a government office. So, you know, just something nice on top. You will plan for 15 minutes generally.

Stephanie Bozarth ([00:29:42](#)):

They might go over a little bit. We do have some lofty asks. Our list is a little longer than usual, so it might take a little more time. Hopefully we'll have that time. However, if you do get to a point and you have not covered an ask and all of a sudden they're like, "I gotta go, I've got another meeting," don't worry, don't freak out. Just say, "I'm going to send this to you by email. I'll let you have a copy of all this information. You can look at it on your own time." Then do a follow up email in two weeks to make sure

that they reviewed it and answer any questions they might have. Lincoln did address the difference between a member versus an aid or correspondent.

Stephanie Bozarth ([00:30:36](#)):

More likely than not, you will be meeting with a legislative aid or a health aid, a legislative correspondent. Some of them have different titles. On occasion we do get an opportunity to meet with our members, which is a huge honor. We feel really excited to actually have their attention for that short amount of time. They might just zip in to say hello, and then zip out and let the aids carry everything. It's great to actually have them in the room with you if they're able to show up, but they do have busy schedules. It's actually the aid or the correspondent that is getting in the weeds of all of this stuff, so they're really the ones you want to educate.

Stephanie Bozarth ([00:31:23](#)):

Lastly, as far as this overview, make sure that we finish right. You need to write a thank you email and/or letter ASAP. I think it is a beautiful touch to do a handwritten letter. However, emails will suffice. I've talked to some legislative folks in the office who are like, oh, just send me the email— snail mail takes so long to get to us. So either will work, but definitely please try to start with that. Thank you. Note with email right afterwards. I do mine immediately so that I don't forget about it. So now we're getting to the priorities. I'm going to quickly review all of this. First is the meeting agenda. Madeline, I'm not absolutely positive, I don't know if I actually saw this in the documents. Do they have the meeting agenda?

Madeline Schehl ([00:32:25](#)):

For their specific meetings individually or...?

Stephanie Bozarth ([00:32:28](#)):

Just in general, like this, that kind of gives you some time frames of like three minutes for introduction.

Madeline Schehl ([00:32:36](#)):

Yes. We have a mock meeting online as well as the template for the thank you email in case anyone doesn't know what to write. These are located on the advocacy page of the website.

Stephanie Bozarth ([00:32:55](#)):

Okay. And maybe we can put this out there too. This just kind of helps you work your time and to kind of figure out how much time you should be spending on each thing. You want to start out doing introductions, whoever is the constituent in the room. For some of us that might be five constituents in the room. You can't all go into a long story about your experience. So you might want to decide ahead of time. Pick one or two people, depending on if you're trying to shuffle around your different representative, who's going to talk in the meetings. We don't want to spend too much time going into a deep background. Then we do spend a little bit of time asking. This zoom thing, I've really gotten pretty used to it. It's conversational. Just try to kind of keep it easy going and ask questions. Like when you're bringing up the newborn screening reauthorization act, for example, are you familiar with this? Are they familiar with it? So then you can kind of get an idea of how deep do I need to go into this one? Our priorities are right here and I'm going to go further into those. It's probably going to be more than five minutes. So that's really a type of timeframe.

Stephanie Bozarth (00:34:22):

Okay. The first thing I wanted to talk about was the NIH appropriations. This is just to show you a little bit of background. We have for many, many years gone in and made an ask to include MPS related language into the appropriations bill that goes to NIH, the FDA, and all these different government bodies. That's what appropriations language does. It goes to the different bodies of government. It tells them what Congress would like them to focus their attention on this year. And then at the end of the year, each of these government bodies have to go back to Congress with the actions that say what they did. So there's accountability at the end of the year for what they did or didn't do. So it's really exciting for us to have MPS related language in there.

Stephanie Bozarth (00:35:19):

There's a handful of rare diseases that are actually named in the appropriations language. So this was something that our advocates pushed for long before. I was a part of the MPS Society, and we have just been able to maintain it usually year after year. You can see each year, we've never actually asked for an exact amount. We've never attached a number to it. We've left that to NIH to determine that. However, this year we are asking. As you can see, we started out in 2006, we're 10. We dipped and we are still at 10 million. There's been a lot of inflation since 2006. So we did put a suggestion that we would like to see investment in MPS related research go up to 17 million.

Stephanie Bozarth (00:36:20):

You will have a one pager on this. What we are asking is, would you champion this language in the appropriations bill? And that's the ask. Then there's an appropriations committee that will get together, and they will hash through letters from all the different representatives, all the different senators. There's a committee on the Senate side, a committee on the House side, and then they hash it out. What they're going to do, what language they're going to leave in, what they're going to kick out. Then they squish them together between the House and the Senate and do another committee. What ends up stays in there. You want them to champion your language, to make a request with their appropriations. If they're actually on that committee, which you will be able to research and find out if they're on their appropriations committee, will they champion it and make sure it stays in because it is so critically important. It is saving lives.

Stephanie Bozarth (00:37:23):

We've had these huge outcomes. This is a disease that had absolutely no treatments, cures, and barely any research not that long ago, and look where we are today. It's because of this investment that we are saving the lives of our children and adults. You will have a one pager on that, and you'll be able to get that to them. They will most likely respond, can you submit that in electronic form? And then you'll need to get instructions on how to do that. It's usually a Google sheet or an online form that you fill out and try to do yourself. If you're getting stuck, we will be there to help you.

Madeline Schehl (00:38:12):

Hey, Stephanie, there was a message in the chat that says, "Are you able to speak to why we are asking for the 17 million?"

Stephanie Bozarth (00:38:21):

We are asking for 17 million because it has flatlined for too long, and there's no reason not to, as many other disease groups at NIH have continued to go up with inflation. This investment is a good

investment. It's actually translational science as well. It will be in your one pager to show kind of how we're talking about that. So what we learn about the brain of San Filippo in some ways translates to the brain of Alzheimer's or Parkinson's. It has a lot of translational components to it.

Lynn Hopkins ([00:39:06](#)):

Stephanie, can I just clarify my question? I think that what I was leaning by my question is how did we come up with 17 million? Like, I would love to ask for 50 million.

Dr. Matthew Ellinwood ([00:39:19](#)):

I came up with that number.

Lynn Hopkins ([00:39:23](#)):

That was the gist of my question. I agree that it was at the 9 million level for a few years, and now we're at the 17 million. So I didn't know if there was some sort of formula behind it.

Dr. Matthew Ellinwood ([00:39:34](#)):

I can tell you exactly what happened there. When I was given that wonderful table by Madeline, that listed the increase in funding for spina bifida and for sickle cell, I just figured out how much we would have to add to our anticipated funding this year to get right between those as a percentage of their baseline funding. So that's how I came up with adding 7 million to what we think would've been a 10 million funding given their flat line.

Lynn Hopkins ([00:40:11](#)):

Thank you

Dr. Matthew Ellinwood ([00:40:12](#)):

Certainly

Madeline Schehl ([00:40:14](#)):

Adam, do you have a question? I see that your virtual hand is raised.

Adam Cohen ([00:40:18](#)):

I do. Um, this is basically for Stephanie, but, and anyone can chime me as well. I had a meeting with my congresswoman's office a couple of weeks ago, and if this information had been out, cause I had asked what kinds of things they wanted to, they wanted to actually lead on the letter for the appropriations. And this was one of the things I wanted to know. And two, I did send an email reply after the meeting, asking the questions at my congresswoman's office had, and I never received, I reply back on that email that I sent. So I'm wondering, was this information available prior to a couple of weeks ago? And if so, why wasn't I given another email saying this is what we wanted and B why as no one responded to my follow email?

Stephanie Bozarth ([00:41:23](#)):

Okay. Well, I do think there's a possibility our wires got crossed because I thought that the office was responding to you and maybe they thought I was, I, I thought that they had it. They were responding to

you and Adam. No, this, this information is really a lot of this is hot off the presses. Um, a lot of times we are trying to work out all these priorities. We're trying to figure it out. We had a meeting about a week and a half ago to really finalize exactly what we were going to go in with our ask. Um, the reason being is we have in the past, I've made a mistake of doing that too early and got all prepared and turned out on when we were about to go to advocacy days, what we were planning was no longer relevant. It was off target. So we do kind of wait till we're close to the date to see what, where we are and where these PRI you know, what, what should our priorities be and make sure that they are the most relevant during the time that we are going to the hill, our making these visits.

Stephanie Bozarth (00:42:25):

So I will look for your email, Madeline, will you help and see if you can find it as well? Thank you. And, and see if we can find that for you, Adam.

Adam Cohen (00:42:36):

Yeah. Cause see they wanted

Stephanie Bozarth (00:42:38):

I remember it,

Adam Cohen (00:42:40):

They wanted the questions that they asked were, is there anyone who was currently any member of the house currently leading a letter or, and what Republicans had signed in prior years? So they knew who they could work with. So, and I, that was the email I sent basically that 30 minutes after I had my meeting with

Stephanie Bozarth (00:43:04):

Them. Yeah. And Adam, that is a pretty complicated question because we don't have someone, we, in the past, we've had someone that the champion was Lindsey Graham. That's been many years since he's done that for us.

Adam Cohen (00:43:16):

Well, he's a Senator, he's not in the House.

Stephanie Bozarth (00:43:18):

I mean, Senator. Yeah. But that was someone that led it from Senate. We actually got in from the Senate side in the past. That's how we got in. Um, now we're asking both the house and the Senate. Um, so actually we don't have someone that's actually leading the letter. We're just asking. So my understanding and, and Adam different offices go about this differently. So sometimes what I understand may not be happening. What someone else's office in Idaho is doing. Um, but my understanding is that when they get an appropriations request from their constituents, they might have a huge long list that that legislator will put together their list of all the things that are important to them and their constituents. And then they submit that to the Appropriations Bill in, into the appropriations committee to review. And that's their request as a legislator, they want this considered. We do not, we do not have one person championing.

Adam Cohen ([00:44:18](#)):

I understand. And that was what they that's. They were asking that because if he didn't have a person, they were willing to be that person.

Stephanie Bozarth ([00:44:26](#)):

Oh, that's

Adam Cohen ([00:44:27](#)):

Right. They wanted confirmation that you didn't have anyone. So I told them, I will check with the NPS society. And as soon as they tell me, I will tell you, but I never heard back. So I couldn't say anything.

Stephanie Bozarth ([00:44:44](#)):

Okay. They were willing to, you have your answer tonight.

Adam Cohen ([00:44:47](#)):

Well, I'll let them know, on Monday. I'll send them any email and, and then, but also tell 'em on Monday as well.

Stephanie Bozarth ([00:44:55](#)):

Yeah. Okay. Well, thank you.

Dr. Matthew Ellinwood ([00:44:57](#)):

I wanted to say something just on a follow-up to how we got to the 17 million, um, within the portal, uh, for the advocacy platform, I believe we have preloaded documents. And I think one of those actually lists out the showing the funding levels as a percentage of, funding starting in six for spina and sickle cell. So, that should make it really abundantly clear how badly we've lagged and how what we are asking for just gets us right up to the median of other rare diseases.

Stephanie Bozarth ([00:45:31](#)):

Yeah, yeah. You you're right. Actually. Um, oh my gosh, I have it right here. And it is on the one-pager, everything out. Oh yes. Okay. So see on there, you'll see that my thing you see he's, this is way they're going to be able to show them this graph. These are the other ones and how they're comparing it. Do y'all see my picture? Did you see that? So if

Stephanie Cozine ([00:46:00](#)):

Stephanie, do we have a comparison with the incidence rates of the other two rare diseases? So if they wanted to compare how rare each of them were and what that investment looks like for like their population,

Terri Klein ([00:46:12](#)):

Not on that graph. We don't. Okay.

Stephanie Bozarth ([00:46:16](#)):

But yes, pull up, when you look at your one, your, what we call 'em one-pager, but when you pull that up, you will be able to see that it will be, be more self-explanatory on that graph. Okay. I'm going to move on because we are going to go really long. Okay. So speeding access to therapy access today, this and like the appropriations language that is going to be presented on both your house and your senators. So you're going to tell both of them about that. Along with this one, speeding access to therapy, spin has therapy access today. Wait, did I write that wrong? I feel like I put the word twice, the speeding therapy access today act. Okay. I did access my title there. Uh, so you have one page on this as well. This one is familiar to us.

Stephanie Bozarth ([00:47:19](#)):

We have advocated for this last year and possibly the year before. The purpose of this one is to improve the development of, and access to therapies for the rare disease communities by enacting targeted and impactful policy reforms at the food and drug administration, the FDA. This is hopefully the plan is to improve stakeholder engagement by creating a rare disease center of excellence. This is very similar there, like what they did with oncology five years ago and was huge for the oncology world. It also, within this act, would create a rare disease and condition advisory committee. It would fund science to treat a very small, rare disease population and enhanced communication coordination between FDA Medicaid and Medicare. And if you do receive Medicaid and Medicare, Medicare, you probably have seen the gaps, the problems between rare disease becoming available and them actually covering it. It's a problem. So this is, this is one of those acts to help fix that.

Stephanie Bozarth ([00:48:35](#)):

Just one more thing. So this is one of those acts that we will see for a few years in a row because it takes a while for it to get some legs. Um, one day it might actually morph into another bigger bill, but right now this is really about educating. This is about putting it on the table. This is very important to us along with many other rare disease groups. So they will most likely it's a good chance. Your representative has seen this before. So I would ask, okay, this one newborn screening saves lives. Authorization act is only on the Senate side. The house has already passed their portion. We are just now waiting for senators to get on board and pass their side. And what we are asking them to do is just to co-sponsor it. Um, this one is most likely whoever you speak with is going to be familiar with newborns screening saves lives, reauthorization act.

Stephanie Bozarth ([00:49:35](#)):

again, in the one page, it's going to really explain in more detail what this is about. Anytime we do a reauthorization of newborn screening and other things we're always asking to kind of modernize it, like let's update it, like let's fill the gaps, the voids that we had before that weren't working. And again, this one is hopefully going to do that. The purpose of its diagnosis through newborn screening saves lives, improves healthcare outcomes, and reduces long-term healthcare costs by allowing detection at the earliest moment possible. I think for most of us, um, this one is an easy one to connect to your story of earlier treatment, better outcomes. Um, and, and, and better outcomes means a lot of times less visits to the doctor, less medical interventions, if you have a better outcome. Um, I did put down the current co-sponsors that I looked@uptodayoncongress.gov. You will have a link through that through advocate advocacy associates. So I would take another look because there might be more signing on that from when I even just did it earlier today that it might get updated again. And so your Senator might end up

there. If your Senator is already there, this is not an ask. It's a thank you. Thank you. Thank you very much.

Stephanie Bozarth ([00:51:03](#)):

Okay. I'm even on the next one. Okay. Now we are going to the Senate. Now we're going to the house side. I don't know why the house is over there for me, but this is co-sponsored cures 2.0, it's HR 6,000. It is not in the Senate yet. It is legislation for some of us that have been advocating for a while. This, you probably remember as 21st-century cures. That was a huge feat achievement for the rare disease community. And we advocated for 21st-century cures for years, until it finally became a thing. It finally happened. Um, gosh, I don't have the date of when that happened. I think it was like 2016 maybe. And now we are cures 2.0 is modernizing because we've even advanced since then, but it's really modernizing that concept and growing upon filling in the gaps of, yes, we've had huge success with 21st-century cures, but this is the next step.

Stephanie Bozarth ([00:52:14](#)):

We need to take another step in this one. And as you can see, like some of the words revolutionize, it's all about inclusion, it's equity for rare disease community, rare disease patients, and their disease groups. I'm going to have Terri speak on and I've got a slide for that, Terri, so I'll get to it right next, but it's going to create in this bill, it talks about creating an agency for advanced research projects for health, which is the H at the end of it. So ARPA-H is within the, I got a slide on that. Also talks about telehealth. It talks about streamlining the payer process for equity of those receiving Medicaid and Medicare. I've already mentioned that before is such a problem that we have right now. Um, people that have Medicaid and Medicare can probably speak to that. Um, also more programs, um, to train and educate those that are home caregivers, uh, more, um, encouraging more diversity in clinical trials and more access and education to education about illness and treatment options.

Stephanie Bozarth ([00:53:21](#)):

Um, this bill has a ton of co-sponsors. it was so many, I couldn't put it on a slide. So your homework is to see if your Senators have signed this. if they already signed to this, this is a thank you. Thank you so much for signing on this. If you go to congress.gov and you're going to pull up HR 6,000 and then it's going to pull up here's 2.0, and then they're going to be these little tabs and you can kind of get more information on the bill and then there's going to be, co-sponsors you hit that. And then you gotta scroll through cuz it's not alphabetical order. It's and it's, it's by the date that they signed on, it should be alphabetical, but you know, that's me. Okay. Terry, I'm giving this one to Terry, cuz she's really excited about this

Terri Klein ([00:54:29](#)):

I'm super excited about this and the ARPA H first of all, is a program that President Biden has put in place last year. So this program actually is implemented, but there are some issues with it. And when we've begun addressing what those issues were in a deep dive, we began working with the coalition of other foundations and what we've done is put together this one pager for you. So let me break it down a little bit because this is a talking point for you, but we also want you to recognize it's not a standalone Bill in the House yet, but it is addressed under Cures 2.0, it's also a dressed under the HELP legislative act

in which we've been in contact with both of the Senate side and the House side body of legislators that are championing behind these bills. So, this is why it is important.

Terri Klein ([00:55:26](#)):

The ARPA-H program came together and really quickly groups came together, like the Society, Every Life Foundation, Global Genes, NCATS, Dr. Chris Austin, and we began to address what were the gaps for rare diseases and the ARPA H program that was being launched last year by President Biden. And so these are the asks. We're asking for the ARPA-H program to include the rare disease community in a more prominent role as representatives of the rare disease community. Our goal is to ensure that ARPA-H is structured in a way that prioritizes and reflects the unique circumstances and needs of the rare disease patient community. We're looking for the incorporation of a stronger tie between the FDA and ARPA-H for clear language of duties between both of them, so that we can understand the formal mechanisms that they're going to use to implement clinical trial design, drug approval, and know who's supposed to own which part so that they're not overlapping duties. Because right now, their language in ARPA-H says that they're going to "collaborate" and they're going to "consult" with the FDA, but those contexts are not strong enough.

Terri Klein ([00:56:52](#)):

And we just don't think that that is strong enough language for our timelines, for the rare disease communities. We want them to clean that up, the communication and the coordination that takes place between ARPA-H and the FDA is really critical. And this is the reason why the coalition was formed. We do not want ARPA-H to skirt around our rare diseases at all. We would like to see a more concise delineation of the duties between both of them to make sure that the program's successful for us. And right now, the way the language is written under ARPA-H they're not saying enough about rare diseases. And we're really worried. They're going to put things into motion that are going to miss these 7,000 rare diseases. And, so that was the quickest way for me to kind of pair it down, but I will tell you why I'm excited about this.

Terri Klein ([00:57:37](#)):

I'm excited because there are groups and foundations like the Society that are strong that say we have found an unmet need. We need to address it right away. And if Cures 2.0, doesn't address it, and if it doesn't get addressed under the HELP Bill, then we recognize we're going to be moving forward to create legislation, and it will become a Bill in the future. So in the meantime, you're going to have this in your takeaway packets. I mean, the legislators, your representatives, and your senators will have this as a takeaway. And if you feel confident enough to talk to it, just land on the language about ARPA-H needing to include more rare disease language. And we'd like to see more division of duties that are understandable between the FDA and ARPA H so we're not building gridlocks for drug development in the rare disease patient community. And that's it.

Stephanie Bozarth ([00:58:36](#)):

Thank you, Terry. Okay. All right. Questions and any tips that you feel I might have missed first, let me talk with Madeline. Do you see anything in a chat box that we need to address?

Madeline Schehl ([00:59:04](#)):

Questions?

Stephanie Bozarth ([00:59:13](#)):

Okay. Well, I'm thinking of something. Lincoln did talk about this for a second, uh, in his presentation, but yes, I do highly recommend everyone get on the, your platform, uh, online and get in there at least 10 minutes early so that you can work out with the other advocates that are going to be in the meeting with you. What each of you are going to cover. It doesn't have to be one person doing all of it, cuz that's a constituent it's, it's a time when you can, you know, you hit this and then I'll go and then you hit this and then just kind of work out a plan. Like how are we going to say, you know, someone, if we need to kind move, move along, is there like a signal we want to do to kind of help each other out? So that is really important. Precious time that I please take advantage of, um, to coordinate with your advocates. I would also suggest if you don't know who they are, try to reach out to 'em over the weekend, um, or on tomorrow or over the weekend prior to your meeting, that could be someone you can role play with as well as share your story with that would be able to provide probably pretty good feedback. Okay. Madeline, did you have,

Madeline Schehl ([01:00:38](#)):

Um, yes. Uh, would you like me to do the social media section now? I know we're running short on time, so I just want to be cognizant of that as well.

Stephanie Bozarth ([01:00:47](#)):

Yes, you jump in, I'm handing it over to you. Thank

Madeline Schehl ([01:00:50](#)):

You. Alrighty. I will share my screen. All right.

Stephanie Bozarth ([01:00:57](#)):

Do I have to unshare? I still see my screen-stop sharing. Okay. I'm stopping. Share

Madeline Schehl ([01:01:03](#)):

The social media screens.

Stephanie Bozarth ([01:01:05](#)):

There we go. Yeah.

Madeline Schehl ([01:01:07](#)):

Okay, awesome. So I'll try to run through this quickly, but if you have any questions afterwards, please just let me know. Um, so for advocacy, we primarily used Facebook and Twitter to, um, share with members of Congress and others. Um, so social media can be used to make, uh, people aware of the problems that we and our community are facing. Um, thank representatives for the actions that they've taken in the past, whether that be co-sponsoring a bill voting in a certain way or other certain ways that we ask them to, and also to make them aware of how pieces of legislation would affect you and the community. So that's what we'll be doing now is having our asks for our representatives in our meetings.

So anyway, before we know how to create a post, we need to know how do we mention someone on Twitter?

Madeline Schehl ([01:02:01](#)):

So this is pretty straightforward. Uh, when you mention someone, they will be able to see the post directly. Um, and that's very easy. All you do is the app symbol and then their name. Um, and if you don't know the members' Twitter name, it can easily be found by a quick Google search or checking on their official website. Um, so that way you can directly thank them after the meeting or contact them about something that you really thought was interesting during the meeting and things of that nature. Um, so in terms of hashtags, um, hashtags, if, if anyone doesn't know are to make searchable links, um, so anything that we have a hashtag on we'll be able to search afterward. Um, so it also brings awareness to the cause that we're doing. So our hashtags that we've used in the past and that we would like you guys to use this year are hashtag national NPS society, hashtag cure support advocate, and hashtag NPS advocacy 2022.

Madeline Schehl ([01:03:05](#)):

But if you have any hashtags that you really enjoy using as well, um, just make sure that they're professional and okay to be shared with Congress people, but yes, anyways, so how to a, so we ask that during your meeting, you ask your representative if you're able to take a picture, um, so this can easily be done with the print screen function of, on your computer and it can also be done with the snipping tool. So if you go into the little search bar on the bottom of their taskbar, you or snipping tool and it should pop up, um, but also if you have any questions on how to use that I can help with that as well. Um, so you can post the picture with the member and just thank them for their time. Um, because obviously, we want to make a good impression. So yes, anyway, and then here is a sample post of, you know, a post that has been done in the past. So as you can see, they have the at, to the Senator and then thanking them for joining them. And also what they had talked about in the meeting and as well as a hashtag. So that's just a really quick overview of social media. Um, but like I said, if you guys have any questions, I would be more than happy to, um, speak individually or through email. So thank you so much for your time.

Terri Klein ([01:04:37](#)):

Awesome.

Terri Klein ([01:04:37](#)):

Thank you, Madeline. That was terrific. Well, Stephanie, what do you think? I, I want to end the meeting though with an apology to Adam because Adam, it was with me that I should have emailed you back. And, I did start the draft email, but I didn't because we had two other people that reached out to me about the appropriations language. And I hadn't had a confirmed answer yet from them. And the answer is we have no one that's championing that bill yet. So I just looked back at my emails now and we're grateful for all you do, cuz you're a superstar, Adam, you always have been you're on top of it. And we would be so grateful if you could move forward to ask if, if your representative would carry that appropriations language and it, it would mean a great deal to us.

Adam Cohen ([01:05:20](#)):

Be happy to do that.

Terri Klein ([01:05:22](#)):

Thank you, Adam.

Stephanie Bozarth ([01:05:25](#)):

Okay. I do see a question on here. Did we answer this? Is there a list of all the people in the meeting? All I have seen is the government official. Okay. When you go further in and you click on the person like mine's, you know, representative Tim Kane or Senator Tim Kane, excuse me. He's not representative. If I click on that, it will show me who else is in the meeting with me. I'm pretty sure, I tried it earlier. So, the first thing you'll see is your list of all your meetings, but then you have to click on it to see who's in it with you. And if no one else is assigned with you yet and you can't see it, that's when he said he's got that little help thing that you can ask questions. So in it directly back to them, they are coordinating all of that for us. So they are the right person, the right people to ask.

Terri Klein ([01:06:26](#)):

And that's a really good point because if you do see yourself alone, we don't want that either. And the team like myself or Madeline or, or anyone else on the society team, we'll jump into that meeting with you. So you're not alone. I just want you to know that. Okay.

Stephanie Bozarth ([01:06:40](#)):

Yeah. Right. Stephanie,

Speaker 12 ([01:06:42](#)):

I appreciate that. And I looked, I don't know, maybe I'm Louisiana, I would have that many, but I looked and I didn't see where that was and I'm looking at it again and I'll try, I don't mind talking about, or our situation as a family, but I just, I didn't know if I was talking over to somebody else.

Stephanie Bozarth ([01:07:06](#)):

I think we specifically have tried and asked to pair people together. So I mean, even me who I've done this for years and years and a long time, I still love to go someone else in my meeting. It just adds, um, a little bit of depth, someone else's, it just adds to the whole experience. It's really exciting. Um, so if you are in your meeting alone and you do not see anyone else, and you're not going to anyone, else's like, I'm going to my meetings in some meetings for Delaware. Um, if you don't see any other people on there, then you need to go ahead and let advocacy associates know through their little, uh, help portal. And like Terry said, anyone from the Society will be happy to jump in with you. It definitely makes it more fun.

Speaker 12 ([01:07:57](#)):

Hundred percent. Stephanie. I mean, we've all been, I don't know I've been at this since my daughter, I was diagnosed, you know, since she was three she's now 16. So I have no problem talking about her.

Stephanie Bozarth ([01:08:11](#)):

Okay,

Terri Klein ([01:08:12](#)):

Wonderful. Thank you.

Stephanie Bozarth (01:08:15):

Uh, any other questions? I think there are some questions about the leave behind cards and I Madeline can you answer that?

Madeline Schehl (01:08:23):

Yeah. Um, Leslie answered in the chat, but she said that, um, leave Behar behind cards will be sent by the individual advocate after the meeting.

Stephanie Bozarth (01:08:35):

Anything else that anyone has you want to just throw out there?

Madeline Schehl (01:08:40):

There was one message that just came in. Um, did we already receive the email with the software link?

Stephanie Bozarth (01:08:48):

To get on the advocacy associates? Yes. That came out around noon today. Check your spam. If you still don't see it. I will have to get on it first thing tomorrow morning and make sure that we let advocacy associates know you, you want to contact the office. I'm not going to be as available tomorrow. So contact the office to make sure that we get you all linked up and make sure you get that link again. I got on, it was really easy to do. It's like five seconds. Stephanie Cozine (01:09:19):

Stephanie, um, do we have a copy or an example for a follow-up email? Um, I know in the past we've had an example and I didn't know if that was uploaded as well.

Stephanie Bozarth (01:09:29):

Oh, and yes. Lincoln did talk about that. So there will be a thank you email that you can either have it linked to your outlook account, but if you have like Yahoo, which I have, or Google, or one of those other things, it, it will have where you can copy the email and, and then paste it into your, like your whatever email account. Okay. Directly to them, their email addresses. It should. That's how I did it last year. It was pretty easy.

Stephanie Cozine (01:09:57):

Okay, great.

Stephanie Bozarth (01:09:58):

So it's already, and you can go in there and add in whatever you want. I usually, you know, add in a few little tidbits to make it more personal.

Terri Klein (01:10:07):

Also, Stephanie, um, Madeline wrote a thank you email template, a really good one. And it's on the downloads on the advocacy page with the bills.

Stephanie Bozarth (01:10:16):

So you can a different one.

Madeline Schehl ([01:10:19](#)):

I believe that they'll be putting the same email on the advocacy associates' website. It's in multiple places in case, you know, for some reason if the email function on advocacy, associates isn't working or anything like that,

Stephanie Bozarth ([01:10:32](#)):

You got it, you got it in two places. Okay. All right. Does anyone have a question, cause I'm about to let, y'all go. I love seeing your faces. This is so exciting. One day, I hope we might all be running around on the hill together again, but I don't think we should ever give this up. This really gives everybody an opportunity. So I don't know, maybe we're going to have like a hybrid of going to the hill and doing, um, zoom meetings so everyone can be involved, cuz it's really exciting to go. But this is also a great opportunity. Thank you each and every one of you for being a part of this for all the years, you put into it for those that are brand new, and this is your first year, I'm so excited for you, to be a part of what makes our country tick and kind of get on the inside track and realize we actually do have a voice is kind of cool. So thank you everyone for being on here tonight and, and listening to me for like a bazillion times. Talk about advocacy. Okay.

Terri Klein ([01:11:45](#)):

Never gets old. Stephanie never gets old.

Stephanie Bozarth ([01:11:49](#)):

All right. Thanks. Is she talking? Is someone talking? Oh, Heidi, are you talking or no, she's not talking to us. Okay. All right. I think we're done. Thanks. Y'all

Stephanie Cozine ([01:12:01](#)):

Hello. Hi everyone.

Madeline Schehl ([01:12:03](#)):

Thank you guys so much.