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>> Hello. You've reached the webinar, tired of feeling the world is not set out for you? Find out how to make the world listen. Giving folks a couple minutes to dial in and we'll get started very shortly. Thank you. If folks have just dialed in, we're giving folks a couple more minutes and we'll start momentarily. Thanks so much.

>> Hello again. Just a reminder that this webinar is entitled tired of feeling the world is not set up for you. How to make the world listen. And we're going to be starting any second now. Thank you.

>> Well, welcome, everyone. My name is Ann Eubank. I work with the United Spinal Association with program users first, which is a grassroots program for United Spinal, and you'll learn more about that later. And today I am speaking with Alex Bennewith, the VP of government relations for United Spinal Association. Alex, thanks for talking about me today.

>> Welcome. Glad to be here.

>> Wonderful. So today's webinar is set up sort of like a talk show host, radio show. So if you have questions throughout, you can put your questions into the question box. We'll talk more about that, too. And Alex and I are going to have a discussion about some of the most important policies that are happening and that we follow and what we're doing about it and what you can do to be more involved, and as your questions come in, I will try to get right to them and if we do not get to your question, our personal e-mails will be up soon and you can feel free to stay in contact. We'd love for you to stay connected. All right.

Oh, also, I'd like to introduce our leader, president Paul Tobin. He's not on the phone with us today. Hopefully he's watching. He's our president and CEO of United Spinal Association. And thank you to our sponsors: Allergan, our pursuit, life's potential. And Permobil, the power of mobility. For you make this go webinar possible.

So the United Spinal Association is one of the largest and oldest consumer or disability organizations in the United States. And it's the parent company and has a variety of programs. Two of the programs that

we're going to talk most about today are users first, little green guy down on the left, and NSCIA, which is national spinal court injury association.

United Spinal started in 1946 after World War II. Is he vans shut down union station in New York City, because they weren't being treated as well as they thought they should be in the VA system. So it started as a vet organization. And some of our employees now were the authors and helps with Title II of the ADA. United Spinal has 60 years of policy experience in DC, so United Spinal is one of the main organizations that watch for any policy that may affect the lives of people with disabilities. One of those ideas you're going to talk about today, you'll be able to ask questions and learn more about.

NSCIA is the chapter network. There's 35 chapters nationwide and five in the works and over 200 support groups. So if you want to be connected, we're going to show websites and ways that you can be all over the country, be connected to our organization that goes from grassroots up to DC, following policy, along with many other services that I'll show in just a second.

There's an active list of 44,000 members all over the country. And we field about 500 consumer calls each month through our resource center, not to mention the various websites where people are able to log on and receive information. Our help line, or resource center has a few social workers there that will be with you and follow you through any process that you may be going through.

This is a map of the United States, as you can see how vast our network and how many members are in different parts of the country. If you see yourself in one state, you can see if there's a chapter there. If you see that it's not, feel free to call us and contact us. You can start a chapter or even a support group.

These are all the programs of United Spinal, but today we are focusing on users first and NFCIA. So there are a wide variety that you can learn about later and log on and see on the website.

So united spine's mission, it's really important to know who's giving this webinar and some of the history. Our mission is to improve the quality of life of all people living with spinal cord injure toys any reason. Today, United Spinal is the largest nonprofit dedicated to helping people living with spinal cord injury for any reason. We are committed to providing active lifestyle information, peer support, and advocacy that empowers all ever us to achieve our highest potential in all aspects of our life, and that's a little bit of what we're going to talk about today is the advocacy part.

Users first is a program of United Spinal. One of the newer programs is to empower and amplify the voice of the world chair consumer. So regardless of why someone uses a wheelchair, all-wheel chair users, to maximize our independence in the community. So users first rejects the

one size fits all perception of wheelchairs. If you use a wheelchair or love someone that uses a wheelchair, you probably know what I mean when I say the right wheelchair is essential to live the life we choose. And that's users first.

NSCIA is the chapter network, which is right until providing support and resources and opportunities right in your own community. You can contact NSCIA through spinalcord.org. That will not be the first time or the last time it will be up there. We'll have those websites up throughout this presentation.

So this is a great slide where it shows NSCIA and users first are the programs on the grounds. We work with people personally and locally and United Spinal Association, Alex Spinowith is going to be speaking very soon, is the DC based department. So Alex monitors every policy that may affect the disability community negatively or positively and makes sure we know about it, and these two programs push that information out to all of our members, not just our members, but other disability groups. Some disability groups work on different types of issues than we do. Some work on raising money for cures and things like that. So some of the policies that we're showing today, United Spinal leads the country on, like wheelchairs and things like that. We'll get more into that. I made that slide. I'm pretty proud of it. So thank you for watching.

Alex is going to talk about really exciting thing that's coming up this month on June 16th. We're going to be in Capitol Hill. All scene of the accident

>> That's right. Thanks, Ann. Yes, we have our second roll on capitol hill, our annual policy conference June 16th through the 19th. We're really excited about it. We're going to have over 80 people coming to do around 200 visits with their members of Congress and it's we canning with the chapters -- working with the chapters and also the grassroots folks, the users first folks that Ann was talking about. We have a whole day on the 17th of June on education and helping people get ready for their visits on the hill. Tuesday will be the hill day and we'll have a really great reception in the evening, and you'll see more photos about that, but last year we had some great people come. Senator harken was one of the folks we awarded with all these great work for the disabilities community. And we can say more about that for the upcoming awards reception. Senator McCain will be there for this year, which is really great. He's been very supportive of some of our issues that I can address later.

>> I know. I'm very excited to get my picture taken with him.

>> That's exciting. So yes, it's our second time. I know some of you who are on will be coming and some of you haven't come before, so love you to take a look at it for next year, but don't forget, it's not just a one-time event. There's ways that you can get involved all the way through

the year, and Ann will continue to tell you and I can tell you about how to do that.

>> All right. Thank you, Alex.

>> Yes.

>> So that website goes right to everything that we're doing, and I don't know if you said this, but we will be pushing out lots of information through social media the users first Facebook, NCSIA Facebook, and I'm sure we'll have pictures throughout the day of what we're doing. And we have some pictures from last year up here, as Alex said.

>> Yeah. And I would love folks to use their cameras when they hear and take pictures and post them. Absolutely. It will be great.

>> Our upcoming webinar, to celebrate the 23rd anniversary of the ADA, United Spinal's counsel and very vice president James Weisman, who was one of the authors of the Title II ADA has been a disability attorney partnering with DC for many, many years. I won't tell you how many. He might get mad at me. But be sure to tune in to that, because you're hearing it right from someone who's experienced many landmark things.

So to ask a question, there's a question box. Some of you already have. Someone said roach is going to be awesome. Thank you, Ernie. Little going to be great. Roach is roll on Capitol Hill, for us inside people, because it's hard to say that all the time. To ask a question, you can type it in the questions box and it pops right up here on my computer. There's my e-mail, aeubank@users.first.org and Alex's.

So why are we here today. Go ahead, Alex.

I'm sorry, Ann. Just on the slide that we just had about the webinar one slide back where they can access this webinar as well, it would be posted there in a few days. So if they need to get all this information, they're welcome to do it there.

>> That's right. Thank you for reminding me. It's all archived and all of our other webinars, correct, are archived at spinal.cord.org.

>> That's right. That's right.

>> And they're amazing webinars. So there's a question again. So this slide is about challenges. Sort of why are we here today and what does United Spinal focus on? And I've said that a few times of policies that affect our lives, things like, you know, is it easy to get the right equipment and services to live the life you choose? Not for everyone. It's not easy. There is often very difficult insurance issues, Medicare issues. Lots of hoops to jump through, and I would assume 100% of the people on the call would probably agree. And also, are you able to access everywhere you want and need to be? Access meetings hit anything to employment to a parking lot, church, school, work, everywhere. And United Spinal focus on his those types of issues, too. Actually, one of those departments on that

fly was all the departments is an accessibility department. So there is a question that someone asked about how I do help the school put down paint to warn wheelchair users? There's temperatures. That's something that I don't know the exact answer to that, but our accessibility departments will. Please e-mail me and I will shoot you right over to them so that you get the laws and the type of paint and things like that so I can definitely find that resource.

Today we're going to talk about some important policy issues. Alex thinks the eagle is scary. I think it's striking.

>> It looks very scary, Ann.

>> It got my attention. So we're going to talk about issues that affect everyday lives. Why are they important? You know, there's so much politics on TV and radio. Why these are important. Don't need to remember each detail of every policy. There's about six or seven we'll go through. But if something catches your ear or you have a question about it, just make note of it, because we will not be able to go through each policy in the background, because it's politics and it can get maybe complicated. I think convolute school district a better word. And we'll talk about how you can participate, the more people that participate and join with an organization like United Spinal users first, the more leverage we have. When Alex is in meetings with Medicare, with Medicaid, with Senators and Congress people, they want to know, how big are you? How many people care about competitive bidding? How many people don't have the right wheelchair? The more people that just say I use a wheelchair, I love someone that uses a wheelchair, I want to join, very, very important.

Our first issue, I know a little bit about this one. I'll talk a little bit and Alex can add to it and also make sure I don't say anything incorrect from a Washington standpoint. This will, there's two: HR 942/S and 948. There's always two bills. One in the Senate and one in the house. It's called complex rehab tech knowledge. I'm not going to read even what it says up there. Complex rehab technology or CRT is what you're seek on the green, Nick Labosi over there on the left, that's when he was chatting with the push girls, mind you. All three people are using CRTs. That is a piece of equipment that's unique and can be adjusted to your body, to our bodies, unlike over to the right top, like a wheelchair that you would see in an airport. Imagine pushing that wheelchair with a sling seat, slingback. That chair in the airport is meant for transportation of it's not meant for everyday life. It's got big wheels. It's heavy. It's got fabric. The difference between complex rehab technology and the airport chair, it's very important Medicare knows the difference. Right now they think what Nick and the push girls are using and Mark and Renee down on the bottom, that's all adjustable equipment they think that's the same as what you would

see in the airport. That's the crazy, isn't it? We want this bill to go through to separate, you know, wheelchairs that actually work and for everyday use versus a transport wheelchair or something you'd see in a hospital hallway. Did I get most of that right, Alex?

>> Yes. That's exactly right. Thank you, Ann. United Spinal has been extremely active on this issue. We've been working really closely with mean stakeholders and working for a couple of years now to get this legislation that Ann mentioned earlier, the H bill and the F bill, that's the house bill and the Senate Bill, into Congress. We did finally get it introduced last year by a New York congressman, congressman Crowley, and then we were able to get it reintroduced again this year by congressman Crowley again, along with Congressman Sensenbrenner, who is the Republican. Crowley is the Democrat and Sensenbrenner is the Republican. It's good to have people who support bills, what we call sponsor bills from both parties to get more people to sign on, to sign on as sponsors, to be a cosponsor on a bill. So we're making really good progress. Right now we have 47 or so sponsors on the house bill and the Senate Bill did just get reintroduced, so that's pretty much breaking news for you guys. It happened just a couple weeks ago. Senator Schumer out of New York introduced the Senate Bill. We'll be working very closely with the disabilities caucus, and I can talk about that a little bit more further down in the slides, but they will be helping us put on a congressional briefing on this very important issue later this summer. . Ann, I'll let you move on from here and we can always go back if there are questions.

>> Yeah. On all of the policies, something like this looks like wow, it's a bill. It's in Congress. The wade Renee has done, and maybe other people, you can visit your Congress person or senator in your state if you live close to the capital or you can write a letter. Huge impact. Huge impact. If you use a wheelchair and say you e-mail us, we will give you a little pamphlet about this, amazing. It helps a lot.

>> Ann, can I add one quick thing? I'm sorry. Before we go on to the next slide. I just realized, as I was talking about it, people may not have heard about this bill, so let me just do a quick, quick description what have it really means and then we can move on.

So what it means is that Medicare, the folks that reimburse people that provide the equipment and the services that you need will have a separate benefit, a specific benefit under Medicare for these types of wheelchairs for people. Right now it's not separated. It's all combined and all the other equipment that folks use, and it's very difficult for folks to get what they need, especially when they're not being evaluated properly in their homes with an occupational therapist and a physical therapist and a physician. And that's part of this bill. There's a home evaluation with all -- you know, with a team, a medical team and a social team approach to make

sure people get what they need. So that's just a quick and dirty description of it. And of course there's plenty more where that came from. Thank you, Ann. Thank you for letting me explain that a little bit more.

>> Oh, no problem. We just got a question in about how to e-mail to get your members of Congress. Later in the slides, there will be a website where you can find your senator and Congress person, and if you're going to do that, we'll shoot our e-mail up there. We call them talking points so we're able to get some bullet points about what Alex and I just talked about. Thank you for the question. Alex, this is let us know why Medicaid matters.

>> Yes. Medicaid does matter. It's what you need in your state, in your home, providing the services that you need to get around in your community. And as you know, United Spinal is all about integrating everyone into the community and making sure they're able to do what they want to do at home and at work and wherever. So basically, this is an issue that we're very focused on. The main issue about being involved is you have to be involved. You have to raise these issues with members of Congress. There's a colleague of mine that says this phrase to me one time. She said, if you're not at the table, you're on the menu. And that's a very funny way to say it. When it comes to politics, that's so true, because you have to keep building the relationship. Keep talking to folks about these issues, and you guys are the experts in what matters to you. So when they hear from their own constituents, they're going to listen to you.

>> I like that.

>> So this is one of our big issues, and there's a lot more where that came from, but the link there, and I know Ann and colleagues of mine, other colleagues of mine have been working up hard on the survey, take a look at that survey and say what kind of services you're getting, you're not getting, what you like, what you don't like, what's available in your community, and what would really help us as we're tracking how we need to help you get the things you need. So that's for that slide, Ann.

>> Okay.

>> Next one of the CRPD. If you know anything about DC, everyone is shortened to letters, lots of acronyms. That's convention on the right, persons with disabilities. What that means is the international version of the ADA. The ADA is the Americans With Disabilities Act. So, it's really making what we already have in the United States, you know, Jim Wiseman has been really de-making a lot of those changes here in the states. So it's really just the same thing. On a national basis. And we were working very hard on this issue last year and we got so Lewis working with the U.S. and the national council on disabilities, and we were five votes away from getting it. All we needed was five votes. So seen at this McCain, as we mentioned before, was really helpful in all of his support

and we really see that we can make that go through this time. So what that is, it's a treaty that has -- the president has signed. He signed the treaty back in 2009, but we just need it to become formal law and we need the Senate to get those extra five votes to get it passed. So that's what we're pushing again this year, and we're really confident that we can be successful with your help, so that's what CRPD is.

>> And Alex, because it's a treaty, wait I understand it, it doesn't bind any country. There's no law in a country. So if it's another country, no one will go for jail if they don't do it. It's a suggestion as a treaty.

>> That's right.

>> So it doesn't affect us as Americans that much, so it's just something that we watch, something that probably anyone on this call would support, and one of the examples that is kind of hard to hear, some babies are born with disabilities. They're not even names. That's just in countries, you would be surprised. And so that's one of the many unfortunately inequalities that happens in different countries that doesn't typically happen in the U.S. But it's one of the things that we watch out for, but it's -- it does not necessarily affect the Americans since we have the ADA.

>> Right.

>> An improved quality of life.

>> Yes. Support the able act, achieving a better life act. We have a lot of folks introduce this go bill over and over again, so we're great to feel that, but what this is, this really enables individuals to save some funds that are not subject to tack for his whatever we need to use it for related to education, housing, transportation, employment support, health issues, assistive technology, personal support service, which is, of course, very important for our community. So this really helps that. Just helps you have a savings account separate from being taxed, and that's what that is.

>> Alex, does this help for people that are on disability benefits where they can have a bank account and not lose their benefits?

>> Yeah.

>> Because they have some?

>> Yeah.

>> Okay.

>> Yeah. Which is a good point, Ann. Yes. So you can have this and it's not counted against you if you are on Medicaid or have, you know, SSI benefits. So that's a really important point.

>> That's very, very important. So again, another policy that, you know n your everyday life you're not going to know that it's out there in Washington, but we're watching for it. That's very important. Thank you, Alex.

>> Yeah. You're welcome.

>> This is exciting.

>> This is good. This is the congressional bipartisan disabilities caucus. And we have one of those. I mean, there are different caucuses in Congress on different issues and it's great that we have one on disabilities issues. There are I'd say around 40 members. All that are considered friends of the disability community. There are co-chairs of the caucus. One is congressman Langevin, who is a Democrat out of Rhode Island, and he actually is a wheelchair user himself. And congressman Lee Terry, who is a Republican out of Nebraska, is really supportive of lifespan care, lifespan respite care issues. Congressman Langevin, we gave Haim Ward last year in the roll on Capitol Hill, because he's been very supportive of all of our issues. So he's the lead co-chair with congressman Kerry, and we work with them on a lot of issues, and sometimes they'll come to me to ask my input, my advice on things, representing the United Spinal Association. So it's a really good focus to have, and I really encourage everyone on this call do reach out to members of the caucus and to reach out to other members who aren't members yet, to encourage them to join, because it's really a good way to put different meetings and briefings on, you know, about different issues to educate more people about what we need to educate them on. And we are, as I said, we are going to have a briefing in July. It's scheduled for July 15th here in DC on Capitol Hill, and Paul Tobin, our president, will be speaking at that event about complex rehab technology to educate other members of Congress. So I just wanted to make sure people knew about the caucus, because it's a very important group of people.

>> So in regular terms, is the caucus where we have an opportunity to speak literally directly to senators and Congress people in the same room?

>> Yes. Well, you can reach out to them in all the different ways that we do usually: By phone, by e-mail. That's usually the two best ways. And you can ask to meet with them in person in the DC office or you can meet with them in your local what we call a district office where you live. Various members of Congress usually have, obviously, a DC office and several offices in their home state. So usually sometimes in higher populated areas. They may have three or four different offices in some other state. There may be one or two that you can go visit them. So yeah, you can speak with them directly. You could talk with them. You can meet with them at various, you know, coffee sessions they have in their home state. All kinds of things you could do.

>> But the caucus is for people like you, different leaders of disability organizations get to meet in Washington with these politicians?

>> Yes, but also advocates. Also --

>> Okay.

>> People that are dialing in. You can talk to anyone, you know? You can pick up the phone and talk to them.

>> All right.

>> They usually will be talking to one of their staffers, you know, but you can schedule a meeting to meet with them, meet with the members themselves. So it's obviously -- they are voted in by us, by you. So that's who they listen to.

>> All right. Thank you.

>> Yeah.

>> So, this is very important and it's happening right now.

>> Yes. This is a very big issue. Some of you may have heard about it already. This is something that we've been focused on a lot. It's introduced by Dr. Price, congressman Price who is a congressman out of Georgia. And he introduced this. We have, I believe, 115 cosponsors on the bill now, which is great. It really is a way to fix how Medicare provides services right now. They plan specifics. Their bidding program, they plan -- it started January 2011 in just a few areas, in nine areas. And it's going to expand, as they call it, in Round Two in July to another 91 additional areas, which may have a huge impact on folks. And I don't know where all the states that they're pulling in from, but probably will be impacted by Round Two. What it is, it's a program that sets prices on products and Medicare award sets the price and then providers and equipment have to stick to that pricing or go low we are that pricing, and you're stuck with the providers that Medicare says you could use, which shouldn't be right. You should have your choice of provider, depending on, you know, who you like and which service, which provider service you like. So we are definitely opposed to this program. It really impacts wheelchairs, breathing devices, oxygen equipment. A whole host of things. So we are supportive of this bill, H.R. 1717, which really makes it a lot better as far as how the pricing is set up. It really is more of a competitive price. Not so low where providers can not provide services you need. So that's what we definitely support on moving forward and, you know, the big time frame now is July 1 when this Round Two is going to go into effect, and they really don't want that to happen. They really wouldn't want them to change, to change the program so it better helps our members.

>> Yes. Out in the world I've heard people say that, you know, of course Medicare and the government and, you know, in these times, we want to save money, but the way they save money is probably going to cost more in the end.

>> That's right.

>> Imagine if you can't get diabetes medication or oxygen. People will just get sick. It's a really crazy program. Basically, what Medicare this program, the competitive bidding part is trying to do, it picks the

lowest bidder for the company that's willing to just provide equipment and supplies and service for the lowest cost. And what do you think you're going to end up with? Probably, can't say for sure, but probably the cheapest products and the worst service. And that's what we see happening. So competitive bidding like they have done it is very frightening.

>> Yes, that's right, Ann. And we don't want people to not get what they need or get the wrong equipment and then unfortunately, perhaps, they might need to end up going into hospital because they're not getting the right equipment. So this is definitely a very important issue.

>> Very important. So as we go on in the webinar, there will be more slides of where to find this information, and of course this will be archived. So you can see how you can take action. All right. Social Security?

>> Yeah. Social Security benefits. So what is that? Well, that's people that are eligible based on disability for benefits. And there's two kinds. There's supplemental security income and Social Security disability insurance. One of them is through Medicaid and one of them is through Medicare, and one of them is because you put into the system, you've worked, and so you've learned a certain amount of money, and the other one is because you have -- you're categorized as having a disability status. So you've got the money that way. It's really helpful for people to really bolster what their income is and cover essential needs such as food, medicine, and shelter. And we really want to make sure that these benefits aren't cut. There's been a lot of discussion with, you know, with the budget discussions and cutting funding, but we really have been pushing hard on making sure that these programs are not cut. Folks can not afford to have any more cuts to their services, and I have an example for you on the type of coverage that people need. A typical person with Social Security may have \$878 a month. Rent may with \$450. Gas is \$40 a month. Food is \$450 a month. That doesn't include medical. There's also bus fair, then totals up to around 10.85. And that's over, you know, that's more than the 878 a month that she's getting from Social Security. So you can see how tight money is and how important and critical it is for people that really do need it. So we've been pushing really hard on making sure that these benefits do not get cut. And congressman Bisara, who is going to be given an award at our roll on Capitol Hill reception at the end of this month, a couple weeks from now, he has been really vocal, really helpful in making sure that these programs are protected. So we have various bills that we're going to be supportive of. We don't know how to go into that detail, so there's a few of them that we'll be highlighting at our roll on Capitol Hill event. And of course, happy to give you some more info on this if anyone has any questions.

>> Alex, thank you. We have a couple questions about one of the

last slides where private insurance, which is not necessarily part of the competitive bidding program, but they do the same thing where a private insurance company will get the lowest bidder for products and services, so whether you go to, like, a wheelchair clinic and you're ready for your next wheelchair, they will say, you can only go to this vendor. And there's a couple questions about that.

>> Sure.

>> That is something that we work on from a grassroots level. So I absolutely want to know about it. You can find, if you just go users first.org, there's an e-mail on there that you can push, because what we can do in situations like that, because we have such a fantastic lawyer like Jim Weisman, there's a lot of people having a lot of difficulty with one particular insurance company, we politely talk to them, so it ends up as a grass roots level. But unless we know about it, you're going to know, of course, before I do if that's happening. Sometimes I hear about it from different sources and we might send an alert out to people in just that area to say, hey, are you having trouble with such and such insurance company? And a lot of people are like, hey, yah, I have actually. Once again, we need numbers. We need more than one person. We need lots of people, even 10 that are having issues not getting equipment that keeps you healthy and active.

>> That's right. Go ahead. I'm sorry. I didn't know cut you off.

>> Oh, no, no. That's all right.

>> Yeah, no, that's great. That's really important. And just to know about the private insurance. Necessity do copy, they do copy what's going on in Medicare and Medicaid, and as Ann said, we do get involved at the state level and we continue to do that to make sure that they are aware that they really can't cut those prices so low.

>> And when they cut them low like that is correct the reason sort of they, quote, get away with it is because who can fight big organizations? It's difficult. There's lots of members that used to use, for instance, a lightweight manual rigid wheelchair, and they go back for maybe their second or maybe they've been using a chair for awhile, third chair. Third chair, now we can't get the lightweight anymore. They're like, wow, my chair is 5 pounds heavier on something something like that. Those kind of things we want to know about, because those things will affect people in the long run. Okay. So get involved and make a difference. This is a great slide. If you're jotting all this down, if you're on your computer, you could do a screen capture. Don't worry. We can give you all this information via our e-mail and just on the website. You can push the e-mail there. But you can become a member of united final. United final has a team advocacy, the action center has all of the issues that we're working on, that Alex works on. She has great papers up there with lots of information on them.

They're position papers. But those are pretty official and that's what's used in Washington to show where United Spinal, where we stand on each issue. You can join a chapter at spinal.cord.org. You can start a chapter at spinal.cord.org or just a support group even. We have quite a few support groups that are not necessarily right near a chapter, but just a group of people getting together, supporting each other in a variety of ways, and then just being connected with the national organization you support, like a social worker or people to talk to, you know, guidance that, kind of thing. And a grassroots advocate that's for anyone that uses a wheelchair, insane cares, people that don't use wheelchairs, we've been pretty successful when something happens like at a state level to literally organize, what just happened in Illinois. Uses first, along with a lot of disability organizations in Illinois, came together to challenge some of the policies of Illinois Medicaid. And we stayed together and stayed communicating. It was wonderful. E-mails go together in all different types of organizations, so that's what we do.

More ways to get involved. This is a picture senator Harkin, and I have some friends in Iowa. I know they visit his office a few times. It is an amazing champion for the disability community and the ADA is his main piece of legislation in his career. Is that right, Alex?

>> He's worked on a lot of issues, a lot of issues, including he had other indication for people with disabilities. His own brother was deaf, and so he really has a personal issue, personal connection to these issues. Yes, ADA issues, education issues that affect people with disabilities, all kinds of things.

>> And someone asked I think on a question where you could find your Senators and governors and Congress people, I mean, and that's where they are. It's Senate.gov and house.gov. You put in I think your zip code and your representatives will pop up.

>> That's right. For your representatives, obviously, you know, for some of the higher populated states, that's more than one. So you put in your zip code. But for Senators, you just need to find your state and they'll pop up. But that's easy to find on those two websites.

>> And one reason to be connected and get all your friends to be connected with us is when there's another issue, we'll send out an action alert. We don't bombard your e-mail box for sure. The last thing we want to you do is drop. We want to be useful to you. An action alert will say, hey, something's going on. This is what it is. Would you like to click here and send your representative an e-mail? And we make it easy. So we do have action alerts and we do send them out. All right? And there's the switchboard. You can call the capital. You can e-mail. You can call and you can visit either locally or in DC.

>> Right.

>> I love this slide. This is the Oklahoma City chapter. The guy on the left, the man on the left is Willis, and Willis will be with us in roll on Capitol Hill. And this is a local chapter, and they started, if you can see their banner, it's called wheels of change, and this chapter, one chapter in Oklahoma City covers the state. Was able to change some significant legislation in Oklahoma. They went to the capital. They gathered as a group. I think it was about Medicaid.

>> Catheter. It was increasing the use of the number of catheters.

>> Right. They decreased from whatever, five a day or six a day down to two. I mean, that's a little crazy. People will definitely get sick. But it took this group going there and the politicians going, oh, okay, now I understand it. It's a great group and I love that photo. I was there last year at their expo. It was raining that day, but it was a great expo. So advocating in Washington, D.C. Another great photo. When you get there, for people that are going to be with us and roll on Capitol Hill from the airport to the hotel, there will be accessible vans that United Spinal has contracted with, and also super shuttle has accessible bands and you can call them. And that picture on the left is of Paul using one of those vans. I guess it was a smooth ride since he still has his coffee cup in his hands. And this time we're using battle transportations for some people on this call. It is a prep call for our visit to Washington DY in June. So it's battle transportation. All of this information is on the link for roll on Capitol Hill. You can literally Google roll on Capitol Hill, United Spinal, and the link will pop up. And so it shows thousand get from the airport to the hotel and back. The DC buses, the DC subway is very accessible. The buses, if you're going to use them, these are all different websites you can use. If you're coming with us to roll on Capitol Hill and you have any questions, that last contact there, Carol Tyson, so cytson --

>> It's spelled wrong.

>> Oh, see. The first typo of the slide. It's so by the last letter of her first name. She's organizing our transportation, which is mazing. I think we've taken upper accessible no a three block radius of it, so it's pretty exciting. Once we're at the hotel, this is what it looks like. People are registering on the top there. Getting those orange lanyards, which looked great, so when we're on the hill, people have those orange lanyards and they know where they're from. Gained lots of respect. Over on the left, I think that's Josh Anderson, a friend of mine, and he's study to go get a packet like that. Has a map in it, where the accessible entrances are, what kind of sort of what we went over today. Policies. And when we go to meetings with our representatives, you pick the policy that you feel most comfortable talking about. So if it's wheelchairs, it's wheelchairs or competitive bidding. If it's CRPD, you choose what that is. We'll get into small groups and talk about it so you can kind of practice what you're going to say. And

while we're in our education class, we will also show what a visit looks like. And I think we have some slides. Here's some pictures of the metro. I took these pictures on purpose to show that the elevators are a bit small, but they are there. And they're better than many cities, but often some of the elevators do not work, so we'll always be in groups. We have to be prepared to maybe go to the next station up above to get to the next elevator. And also, the elevators don't always smell the best, but that's typical. The metro, you buy tickets. It's accessible. It's pretty self-explanatory. I'm glad Paul did it for me. But you put your money and outcomes the ticket and when you get ready, the, the turnstiles, that's Nick flying through there. Orange lanyard, tie, very nice looking, and Paul and a whole bunch of us, a whole bunch of members getting ready to go. In the picture on the right, it's a very nice subway system, getting ready for the train to come. And that takes us to the hill. We find that to be the easiest way versus buses and taxis and things like that. One time one of the elevators was out, so we had to -- if you notice, we're moving pretty quickly, so we're trying to get quickly to the next station where we can take an elevator down to the subway. And here's Paul outside. DC is beautiful. It might be a little warm in June. Be prepared for that. You want to look business like, which is not too fancy. I find Washington people, usually a gray suit, not too flashy, and that works well, or using a chair, a lot of guys wear the vest with a tie, because the jacket gets kind of bulky.

Oh, Alex put all kinds of things up here. These are accessible entrances. She actually gave you all the different accessible entrances, which you might not think it sounds important now, but when you've just pushed or walked or gone a quarter of a mile around a building only to find that he know stance not accessible, it's frustrating. We have a map to find where the accessible entrances are. Sometimes it doesn't look accessible, but then the ramp ask way over to the other side, also. And there's some maps available here. You can find all this online and you can also get the archive of it. Is there will be a few buildings that we will be visiting, and these are the buildings, and they are, if you're above ground, they can be far away. If there's weather of any kind, it can be frustrating. So Alex was able to get us permission, which is very exciting, to use the tunnels.

>> Yes.

>> And so we have to get permission once you get there. There will be a certain protocol, but if you're with our group, you're able to use the tunnels that are only available to members of Congress, and so that's, like, wonderful.

>> That's right. Yes. Mechanics of Congress use that only. You can get special permission to use the tunnel. So we'll do that.

>> As you can see, the buildings are not right next to each other. If it's raining, it's wonderful to have that. And once you're at the security, it's

very similar to the airport. We try to go on time. There's a line out the door for security. Everyone has to go through it. Even the members of Congress have to go. So is it about the same as the airport, Al scene of the accident

>> Yes. You may have to take your coat off, things like that as you go through, but they'll let you know. And just to the end of this slide there, the gentleman that's standing up, he's putting his property on the conveyor belt like you see in the airport, and that goes through and they look at it, and then when they give you the signal, you'll go through that little screening thing right there, just like an airport. Yep.

>> And if you see the officer looking my way, I was told to put my camera away. It's illegal to take pictures of the security area. But I didn't know that and he didn't ask me to delete it, so I don't think it shows much, but keep that to yourself. This is a typical elevator, and this is what the tunnels will sort of look like. It's in the basement format. And so they're nothing special, except that they go underground, and Paul is waiting for an elevator.

This is a typical congressional hallway. So the hallways are rather wide and each office has its seal of the state and the person's name there. So it's kind of exciting to be in the hallway and see. And I don't think they're in alphabetical order. They're random. You'll see Iowa, Rhode Island.

>> Yeah. How that works is people basically get their offices by seniority, you know? Over time, people move out, move in. Some of the high level offices are more senior offices that people like to get if they can. So that's the kind of -- that's how people get different offices.

>> So they office with probably someone that has more authority?

>> Exactly. Yeah.

>> So a successful visit? Alex, would you like to talk about when you actually meet with the representative?

>> Sure. We definitely do want to do that. So all of this talk around how to do it and what to talk about and how to get there, this is why you're all here. This is why you've come to roll on capitol hill is to talk to the members of Congress and their staff. And even if it's not the member of Congress, staff do all the work anyway, so sometimes it's better when you're talking to a staff member instead of the senator or representative. But everything is good. It's all good. You just want to get your voice heard. So usually a visit is about 30 minutes, and as I said before, you are your own expert as to how things are affecting you. So you just need to tell your story and tell them what's important to you and they'll listen and maybe they'll disagree with you. Maybe they'll agree with you. But always be respectful, of course, because you never know. The next time you go in there, they may support you on something or they may say, well, I'm sorry. We can't do anything on this issue, but I really, you know, I support you,

but I can't do something. You say, well, that's okay. I'll just keep talking with you about it, because this is important. And maybe they'll change their mind, you know? You just have to continue to reach out to them, tell them what your issues are. They may have questions that they don't know the answers to. And if you don't know the answers, you can say, oh, well, I don't know that. That's a good question. I'll make sure to get back to you. And you follow up with them or you ask somebody in the policy department like me or Ann or Paul or Jim or any of the united final staff can help you get the information you need. So that's really it. It's not intimidating. You're just there to chat with people. Sometimes many of the staffers on the hill, they're in their twenties, their thirties. They're young kids, you know? Sometimes they'll be interested in what you have to say. Sometimes they won't be. Just like anybody. Sometimes they'll be having a good day. Sometimes they won't be. But that's what it's like and it's just an opportunity to be there and tell your story, which is really important. And as you saw in the hallway picture just before that Ann showed you, sometimes some of those meetings will actually occur in the hallway and I have done meetings like that myself with others just in the hallway. So the bottom picture on the left there. Don't take that as a light by any means. Really, they have tons of people coming in all the time. You might be one of seven people speaking on a specific issue that day. They'll have lots of people in different office and they won't have any space.

It's a little bit more room on the Senate side than there is on the house side, by these are old buildings. Bear that in mind. And just go with it. Experience it. It's a fun day. You'll get to experience a lot of good stuff. So that's really my quick summary of the visit. And Ann, do you have any questions?

>> No. I want to make sure we hit it on time. The top right photo, we were in the Illinois representative's office and Paul had a power wheelchair. If there's a piece of furniture in his way, he just moves it, and it's really wonderful to watch the staffers sort of, you know, scurry around and he's like, oh, no problem. And he'll just move the table or whatever with his chair. But don't be offended. Some of the offices are quite tight, but we've always been able to figure it out some way. And this is autumn grant. She'll be attend this go year, also, and she's leaning in, discussing her wheelchair and complex rehab and how it works and why it works best for her in her life. And that's a staffer. Right, Alex? ?

>> Yeah, on the right side, yes, it's a staffer. And then over in the far corner there's a clinician there that definitely works very closely with us. And was at roll on Capitol Hill earlier, Jenny Leiberman.

>> Yes. And the awards reception. This is like the highlights.

>> It was great.

>> Senator Harkin is up there speaking with Ian ruder, the editor of

life in action, the magazine that comes to all the members. And then on the right is congressman Langevin using the I bought, the wheelchair that kind of stands up. And in the middle, Jim Weisman is standing with the tan coat, and I think those are all members from the New York chapter. Right?

>> Yes. That's Jason did he sill variety on the left there. I don't know if you know who he is, by -- De silva but he does his own film work. He has multiple sclerosis and he submitted a film. It got picked up as a finalist at the Sundance competition, which is really great.

>> Oh, wow.

>> He did film some of our roll on capital till last year on our website. And George Giago on the right was this year's winner of the Paul Hearne award, which is a great honor to be given that award. So he used to be the head of our New York chapter, so that's that group there on the bottom.

>> All right. And this is a great picture. Paul Tobin is on the right. Jennifer wolf is a citizen of Iowa, and she's giving senator Harkin an award that he got last year, and Jim Weisman is all the way to the left. I am pretty excited about this year. I was very impressed. It wasn't just those representatives. There were representatives from all different states, and then staffers, too. So there's people, a lot of people attended from quite a few offices.

>> Yeah. Yes.

>> This is our last picture. I took this of Nick. Nick, I know you're on the line. And this is, you know, we have a little fun, too, while we're in DC. We were at a little cafe and he wanted me to take his pictured and looking very regal there. Wonderful. And I see some stories, I mean some questions, and the ones I didn't get to, you will think our e-mails are coming up right now. There's some accessibility questions, and I think there's enough questions I will suggest to the accessibility department to have a webinar about what are your rights? How do you ask for what you need without jeopardizing your employment? What about blue parking? What do you do if a restaurant is not accessible? And what steps do you snake so I wrote that down. Thank you very much. And those are our e-mails that you can contact us. It does end at 3:00. Right?

>> Yes.

>> Okay.

>> And I wanted to make sure we didn't go over. We're right on time. Please take those down if you have any questions. We would be more than happy. And take those action steps. We'd love everyone to sign up and have your friends and family sign up. Disability or no disability. It's people. It's Americans that care about these issues. Alex, any final words?

>> Just to make sure folks know that all the questions that have

been coming in during the webinar, we will definitely be sure to follow up with all of you. And thanks for dialing in and look forward to see all of you again soon, hearing from you soon. Thanks, Ann.

>> Thank you so much. We'll end the webinar now.

Some of the end of event.)

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