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>>CART PROVIDER: On standby. (recording: The Webinar will begin shortly, please remain on the line)

>> Thank you for joining us today for United Spinal Association Webinar, finding the right wheelchair that works for you. Today's four distinguished presenters are Alex Bennewith, MPA, United Spinal Association Vice-President of Government Relations, Erin Michael, DPT, ATP, SMS, manager, patient advocacy and special programs, Seating and Mobility Specialist at the International Center for Spinal Cord Injury at Kennedy Krieger institute. Tangita Adams Daramola, competitive Ombudsman, center for Medicare and Medicaid services, Jennifer Wolff OP, manager United Spinal Advocacy Alliance. This is Bill director of resource center, I'll be your moderator for today's presentation. Today's Webinar is one of a continuing series of United Spinal Association Webinars, all are archived at spinalcord.org, we will have time at the end of today's presentations for your questions. Please use the chat window for questions on your control panel to pose your question and we'll try to do our best to get to them at the end of today's presentation. For any questions remaining unanswered, please e-mail directly to the presenters, e-mail addresses are displayed upon that last slide. Alex Bennewith, Vice-President, Government Relations at United Spinal Association directs advocacy for legislation and regulations regarding disability policy at both the federal and state level and works closely with a range of stakeholders in medical equipment and supplies, prescription drug, public health, employment, Social Security and disability advocacy committees. Alex, would you like to forward your PowerPoint to slide that please for the photos? There we go and then one more forward to you Alex, thank you. Erin Michael, DPT, APT, SMS, I don't actually know the acronym for that last one, is manager of patient advocacy and special programs for seating and mobility at the International Center for Spinal Cord Injury at Kennedy Krieger Institute in Baltimore Maryland, a certified Assistive Technology practitioner and Seating and Mobility Specialist and serves as the coordinator of seating and mobility clinic at the international MCI center. Tangita was named Ombudsman for CNS in October of 2011, after as serving

as active CAO since June of 2009. Her core tasks, as mandated by section 154 (b) of the Medicare Improvements for Patients and Providers Act of 2008, are to respond to complaints and inquiries made by suppliers and individuals related to the application of the durable medical equipment, prosthetics orthotics and supplies, you may have seen this acronym many times. The competitive bid willing program, and to submit Angela: Objective you'll report to Congress. The CAO works with the local competitive bidding contractor representatives, a contracted source for local assistance to respond to complaints from suppliers and Ben fishers. Miss Daramola holds a Bachelor of Science degree from Howard University and masters from University of Maryland and College Park. Erin Michael, is manager of patient and advocacy services. I just read that one twice for which I apologize. Jennifer Wolff, OT, is the manager of United Spinal Association Advocacy Alliance, a grassroots organization that provides guidance to the greater community to United Spinal and ultimately to a governmental authorities for the needs and interests of those who are wheelchair, other mobility device user. Now we're going to be in our presentation with Alex Bennewith, Government Relations, director for United Spinal Association, Alex?

>>Alex: Hi Bill, thank you very much. Thanks everyone for joining. We have a good number here joining with us today. So thanks a lot. We're going to go over, as you can see on the slide, getting the right wheelchair and supplies that work for you, photos from previous rolls on capitol hill and Congressional events. Thank you Bill for those introductions, I want to do a quick thank you for all of our sponsors for Roll on Capitol Hill so far and our partners. Just quickly I want to go into some of the details about this, for this Webinar and then we have a lot of other good information coming up as you can see from the other speakers. So United Spinal, we're dedicated to enhancing the quality of life of all people living with spinal cord injuries and disorders, including veterans and providing support to loved ones, care providers and professionals. So everything we do focuses on that, making that person, person's life better. Be it health care, be it transportation, you name it. That's what our goal is, that's what our mission is. So we're all, we all work towards that for this population. I just wanted to say a quick word to the advocate down on the screen, with the hat, unfortunately he passed away in January and I wanted to acknowledge his great advocacy and his strong partnership with United Spinal for many years. Quickly, Roll on Capitol Hill, that's our annual policy conference we have every June. Members of United Spinal are welcome to attend and just wanted to make sure everyone has those dates on their calendars.

And going into the meat of the topic, durable medical equipment, complex and standard, manual and power wheelchairs. So I'm going to go over a little bit describing what these are and what the differences are and unfortunately this, this picture isn't the best picture, because it is in black and white, but it hopefully gives you a good idea and then there are some other Web links on our website that you can go to, to see more information and I'll share that with you. But complex chairs are customized, individually configured chairs that have seating and positioning systems that are functional specific to that individual and it could be different from one individual to the next.

And there are, what we call manual chairs and power chairs that are both complex, meaning both customized for that individual. You can see from the descriptions there, the left column is the two types of complex chairs that you can have and the standard chair, very different. So there is no, as you can see from some of the description, no pressure management on the top right screen, top right corner, it really looks like one of those chairs that you would see at an airport. Whereas on the left, the top left corner you can see, maybe not as well in this picture, but there is a descent thick cushion on the right

side of that box, with wheels that are slightly angled for better maneuverability and usually that's a lighter frame, which makes it a complex chair.

And then as you can see very clearly with the multiple movement, with the Chair next to it, the tilt and recline feature is definitely for individuals with specific needs and helps with positioning and pressure management issues. You can see an option for moving the Chair up at the bottom, with moveable seating positioning. So obviously these are complex and it's really a small percentage of Medicare, as you can see the percentages there and it is really critical that people do get what they need to avoid, avoid pressure sores, skin issues, you name it, all kinds of problems that could occur if people didn't get the right chairs. So I'm going to go to the neck slide and I know that other presenters will be going into this in more detail. But I wanted to just give you a quick heads up on the issues that we're focusing on at United Spinal for you guys. We have been very active and taking a leading roll on these issues for several years now. H. R. 1516/S. 1013 that's a Bill that creates a separate benefit to rehab technology, which means customized technology you saw in the previous slide has a specific designation under Medicare so that everything is categorized as CRT instead of the bucket, which is very broad, includes a lot of different things and that's the problem sometimes and I know I've spoken to Tangita and others about this very often, so much variation in the types of chairs across the board. , if they are not specifically designated as CRT. It does make it very difficult for individuals to get what they need and with Medicare for coverage or other insurances. That is really key we have been pushing that and we have a lot of good bipartisan support on that Bill. We got some success at the end of last year where the third Bill on the slide, S. 2425, by the President, December 18, which was great, gives us a one year delay of basically excluding those customized power wheelchairs and accessories from Medicare competitive bidding program. Specifically the payment applied, the reduced payment applied to those items, which is good for us, for consumers.

And we will continue to push for that Bill for an extended delay or permanent exemption from SRT for Medicare. We have met about with government office, GAO, which is in the habit of producing reports on various government programs and they are with putting a report together they will be submitting to Congress in June, early June, to look more closely at the coding issues and the coverage issues related to the complex power.

And as I mentioned United Spinal has met with GAO to make sure they understand important differences and why CRT does need to be excluded. 3229 is another Bill, we are very happy with all of these senators and members of Congress that have taken the lead on these issues, which eliminates permanently complex wheelchairs and accessories from competitive bidding program. Just to explain just briefly, I know Tangita will touch quite a bit on this too, it is a program that CNS provides payment options, payment single payment amounts for different products within different Regions of the country and awards contracts to various providers of durable medical equipment.

And sometimes it may not be the one that you are used to using or you would like to use or maybe they don't have the features, they don't offer the features that you would like and for United Spinal perspective we think it is restrictive for that, for that reason.

And so that's why we have been vocal in opposing the program at least looking at reforming the program. I know Tangita has been helpful in relaying some of those concerns and making some tweaks around the information. For more information you can go to our website and there a really good link

there, you can look at additional components that may be impacted by this program, this competitive program.

And just quickly, there's a lot of people that we work with across the spectrum, not just with the, within the consumer advocacy phase, but also providers, American Association For Homecare and national coalition for Assistive Technology and rehab technology and there are others. We work together, we did, had a really good campaign at the end of last year and we continue that throughout the year.

And with your help and other groups, you know, we can continue to be successful.

And I just quickly wanted to address urology supplies, very key for our area. This came out in February with this as a provision, that expands this program to urological supplies, as you see at the end there. Could include inhalation drugs, orthotics, and urological, and tracheostomy, in the same way because these types of supplies are specific for the individual. We really feel that the government shouldn't, shouldn't be restricting that access. So you can find out more about that um at the urology coalition, which is what United Spinal facilitates, a group of consumer and provider and manufacturer groups working together on that issue as well. So you'll be seeing more of that, and we will be highlighting that, highlighting the issue at capitol hill along with CRT issue. But I just wanted to bring that to everyone's attention. I think, actually, it is a good time now to do our first poll and IT director is on, on hand to do that.

And the first poll that you all can take part in as we speak, a live poll question, it should come up any second, right, and I see some action on the screen. Do you have the correct chair for your needs? And all you have to say is yes or no, an easy poll to answer. If you can just take a second to answer that poll right now and we'll see immediate results on the screen and Bill will have to tell me what those results are and then we can go into our next presenter, Erin Michael, in a second.

>> Bill: Sure the results will be up in just a moment. Usually we like to allow about 30 seconds to allow people to vote and then we'll see the results, also this is a point at which we can remind people to ask their questions in the chat window for the panelist to answer at the end of the presentation. And the results are in and they are mixed. Do you have the correct chair for your needs? Yes, 29%, only 29. No, 32%, not sure 38. So yes 29, no 32, not sure, 38%. So there is a lot of concern there for having ones wheelchair be the correct chair.

>>Alex: Okay thank you Bill, hopefully those saying not sure will learn a lot now from the next upcoming slides and I'm going to segue over to Erin to start her part of the presentation.

>>Erin: Hello everybody. So as a coordinator of a seating clinic I of course have to advocate a little bit for seating clinics. Because in a seating clinic you get the interdisciplinary team approach. So there's usually a seating specialist and then the vendor or supplier of the equipment and the, those two people can coordinate with your physicians, your treating therapists, if you happen to be in therapy and any case manager. So it gives a nice well-rounded approach to providing you with a wheelchair.

And where you can find seating clinics, generally they are located in larger hospital systems. Sometimes I couldn't find a list um of every seating clinic that there is in the country, but typically around the major cities there is at least one and a quick search will pull up clinics in your area online or if you aren't sure you could always reach out to a vendor, supplier for wheelchairs in your area and they may be able to

direct you to a seating clinic. Generally at some point they are working in those clinics, so they know where they are.

And if you are not in an area where a seating clinic is convenient to you we can talk a little bit about that as I move forward. So we'll go to the next slide. Okay.

And so what happens during a seating evaluation? So there should be, to really ensure that you are getting the seating system that's most appropriate for you, one that is customized to your needs in that realm of CRT that we've been talking about, you want to participate in this type of thorough eval. So you are going to have a subjective component where the therapist doing the evaluation is going to ask you what, what about your current chair, if you have a chair, meets your needs, what doesn't meet your needs and then if you don't have a chair, you know, what the reason is that you are coming in for the seating appointment and then any other information that you might be able to provide them. Then there is going to be an objective component where they actually take specific measurements. They will use objective measures and different tests that they can actually document in that eval to show that you meet the needs for that piece of equipment. They'll look at a functional skills assessment, so transfers, sitting balance, bed mobility, different things that they can use, ability to do pressure which is a huge one for seating systems. They will look at that and be able to document that enthusiasm thoroughly in write-up, they will look thoroughly at that chair and try to determine what about it meets your needs and what about it could use some improvement. A good seating evaluation, they'll get you on the mat and actually take a close look at joint range of motion, your posture and that will help them determine what equipment is going to be best for you and if there is any limitations in your range of motion or any postural deformities they need to accommodate for or they need to correct.

And then you'll, you'll go through some equipment trials. So if it is something where they are going to be recommending new equipment or they will actually have you trial that and you can get a feel for it. Then we can determine which piece of equipment will be best.

And it will involve a lot of discussion and education. When I see a patient in my seating clinic, I spend a lot of time talking and the reason I spend so much time talking is because this is a very complicated process and there is a lot of different equipment, there are a lot of choices and there are a lot of reasons that you could or could not qualify for something. I like to talk my patients through that and make sure they really, really understand where we are going in the process and why we're recommending each piece of equipment we're recommending. Then as we go through that end the appointment with a selection of equipment that we think best meets your needs and again this may take more than one appointment. I've had patients come for one or two follow-up appointments because we weren't able to get everything done in one session. So this process, like the equipment, the process is very, very person dependent and very individualized. So next slide please.

And I just wanted to touch a little bit about why your seating and positioning really matters. As most of you know, what the equipment you are using can make a big impact on your independence in your home, in the community, to attend work or any of the other special interests that you have. There's a component of safety within your home or even in the community. So someone with a history of falls and if there's a functional status that, you know, independence is declining and your balance is worsening, safety becomes a big concern. So that can be, that can make seating and positioning important. Instrumental ADLs, activities of daily living that, grocery shopping, banking, those types of

things where you need to be able to access the community to perform those activities. and then overall community and work access. So being able to get out of your home and participate in the environment.

And then again participation, so just getting, getting out of your home, getting you into the community activities that you enjoy and then also prevention of further injury. If that is an injury from a fall or if it's arm pain, when you are using a wheelchair, especially manual wheelchair, upper extremity injury is a significant risk. The shoulder joint and the other upper extremity joints are not meant to be the primary weight bearing joints of your body. When you are doing transfers, when you are rolling your wheelchair, when you are getting in and out of bed, when you are driving a car, all those things are very, very stressful on your body and they are highly repetitive tasks.

And so it may be that the equipment that you have right now is contributing to that pain or the setup of that equipment is contributing to that pain so we can make adjustments to your manual wheelchair setup, to reduce your pain or we can actually make recommendations for other types of equipment that you could qualify for that would eliminate pain. Next slide please. Yep, there we go. Another reason that we're concerned about your seating and positioning um are they can lead to Orthopedic deformities, poor sitting support, when you have a deficit in trunk control, resulting from a spinal cord injury, you need to rely on that seating system to provide you upright posture and to reduce the effects of gravity. If it is not doing that efficiently, then you may end up with a more permanent deformity like a scoliosis, as we see in this picture. We're worried about altered pressure distributions, which could lead to skin breakdowns, so we know a huge, huge issue is development of a wound. So that not only does it take you out of your regular activities and but they are highly costly and they take a long time to heal. So we really want to try to prevent those before they happen. Also overall organ function, the body is not meant to be in the sitting position.

And so even though we are sitting upright there is still the organs are being compromised by being that position and so they can, we can see a decline in function over time. Especially if the effects of gravity are leading to a more rounded forward orthotic type posture, there is compression of those organs and so we want to try to use the seating system to get you into the best position to keep those organs functioning properly and same heart, lungs, digestion, bowel and bladder function can all be dramatically affected by how you are positioned in your chair. Next slide, thank you. Some of the potential barriers for obtaining right piece of equipment. If you are unable to attend a seating clinic, for example, I talked a little bit about seating clinic when I started talking, but that may not be realistic for everyone and I'm going to talk about solving each of these barriers, as I go through them. There is significant strict deadlines, for power wheelchair there is multiple steps that must occur under the rules of Medicare.

And some of you out there may be saying well I don't have Medicare, so that doesn't affect me. Unfortunately that is not true. Many of the private insurers follow, end up following Medicare guidelines so a lot of them have started putting in these same restrictions. So as I talk, when I say Medicare, don't kind of tune out on that, because it effects everyone for power chair, you have to have a face-to-face appointment with your physician, you need to go see your doctor and they need to talk to you, they need to assess your need for a power wheelchair and most important to know, and this is something for all of you who need power wheelchairs to listen closely, mobility exam must be the, it must be the primary reason for that appointment. So that mobility examination must be listed as the primary reason that you are seeing the physician. , if you see and pow in a small paragraph, that note is

not going to count towards your wheelchair this visit with a physician should have detailed account of functional abilities and any limitations on a typical day. This is important to note that especially for those of you who may be, if any of you out there are ambulatory part of the time, how the physician documents that could really affect your ability to maintain a wheelchair. They want as much objective, test and measures of strength and function, they want that information in physician note as not just in specialty avail by the therapist. For power wheelchair we need our face-to-face appointment and also need the specialty exam. That's the evaluation I talked about a few slides ago, very thorough eval by the therapist. Usually a physical therapist or Occupational Therapist that's going to be required to perform that evaluation.

And for Medicare, another big thing you'll see on this slide is the in-the-home restriction. So when your physician and when therapist are seeing you, the primary concern is, excuse me, sorry, the primary concern is how your mobility is being affected in your home. So you just want to be aware that yes maybe you can't access your community but unfortunately in many places that's not a not a concern for Madame can I remember at this time, if you can use a manual chair in the home and it is efficient, you will not qualify for a power chair outside of the home, for example. Seating clinic visit, limitation comes out of this under therapy cap, competitive bidding has created some issues for us, it is limiting access to equipment.

And then there may, you may actually get approved for equipment but can still be denied by insurer at the time of delivery. Go ahead and switch.

And then for you guys, for handling the barriers if you don't have access to a seating clinic that's okay, just make sure PT or OT is involved in your eval. Sometimes, sometimes I heard of loopholes where a therapist wasn't actually involved, I don't know how that happens, but really advocate for yourself and ensure there is a therapist involved. Understanding requirements and being prepared to visit when visiting physician, so know all the things you need to know about, that you would want them to know, medical history and detail report of your home and other environments, limitations and function or access and limitations of current equipment. Then research products ahead of time, have an idea of what you might want when you get there, maintain a relationship with equipment supplier. You want to be able to content them for maintenance needs, follow-up on orders and then get involved. So advocacy and Jen is going to talk more about this. But really getting out there and getting involved in the process and then also advocating for yourself on personal basis, with insurance company, with your practitioners and then one more slide here, then on our end some of the issues for your seating team, we're trying our best to make sure we are doing equipment trials and being thorough with outcome measures so we have a lot of evidence for why you need the equipment. We're providing more visits, longer slots, longer and then patients, not able to see you beyond cap visit so it is something to consider if you are under therapy cap that you may not have enough visits to get a seating appointment.

And then suppliers are being more stringent in review processes and kicking back of paperwork overall process is taking a little bit longer. If it is taking you a while to get wheelchair, I know that is frustrating, understand that's because we are trying to make sure process is being followed as it should, limitations and product choices. So you may find that the Chair you had now um and you are trying to get next chair and not qualifying for the same things and though I understand that's frustrating that's somewhat out of our control because it is what the limitations are being put on, placed on us. Now -- time for another poll, Angel?

>> The next poll we are going to ask everyone is do you think the process of getting your chair was simple? And again you can say yes or no. Erin went through the process of it being fairly complicated I would say, complex so please just take a moment to say yes or no to that question.

>> Bill: And we'll have results in just a moment. And it is pretty dramatic. The results to the question do you think the process of getting your chair was simple, 5% agree, 95% disagree with the process being simple.

>> Okay. Thank you Erin. Yeah -- yeah absolutely. Let's move on to, I'm sorry Erin, go ahead.

>>Erin: That's okay, I was going to say take it away Jen.

>>Jennifer: Actually Tangita is next.

>>Tangita: Okay. Thank you. Thank you very much. I really appreciate being here today as they said my name is Tangita Daramola and I work are to the federal agency that administers Medicare, Medicare has been mentioned several times already in our presentations and I'm really happy that I'm working closely with these ladies to make sure that our beneficiaries, Medicare Ben fishers, as mentioned earlier even before it has access to the services and products they are entitled to under the program. As I said I work for the Department of Health and Human Services and one of the things that was established when this bidding program was established, was the role of the Competitive Acquisition Ombudsman and I think Congress in infinite wisdom understood it was important to put in a role that was there to listen to and to respond to inquiries and complaints from not only Ben fishes and individuals, caregivers, et cetera, but also from suppliers regarding the competitive bidding program. As was mentioned earlier, competitive bidding, what do we mean when we talk about competitive bidding, it is a payment mechanism for durable medical equipment that is actually a part of Part B benefits for Medicare.

And this new way of paying for durable medical equipment includes various competitions around the country as was mentioned earlier, and those competitions help to identify those suppliers who are best able to provide the product in a safe, secure and cross-competitive environment.

And the role I play in the program is respond to inquiries and complaints and really look for systemic issues that may be impacting beneficiary access as we have been hearing a little bit about process it takes to get durable medical equipment as well as some limitations that folks feel they may have now that the program is in place. Hearing from our consumers in the beneficiaries is the best way of making sure that we respond to these complaints about the program. So next slide. We monitor access, we can go to the next slide. Okay there we are, methods for monitoring. We monitor access for beneficiaries having durable medical equipment here at the Department of Health and Human Services in a number of different ways. I already mentioned the inquiry and complaint process, which is relatively comprehensive in terms of being beginning to end triaging the incoming inquiry or complaint whether we got it in a letter, whether we got it in an e-mail or whether we got the information at a meeting, it is very important for us to take those inquiries and complaints and be able to categorize them and understand what types of issues are coming into us. So we have a very extensive process that includes responding, but also analyzing the data behind what are the types of questions that we're receiving. We always, we also work to establish relationships and engage partners and that is how I have come to know Erin as well as Alex is our partnering activities, we get together and sort of talk about our various issues and I try to emphasize the importance of when issues of problems, barriers are identified, there

are mechanisms that beneficiaries can use to improve their access to services that they require. Also in addition to the inquiry process as well as engagement with our partners and advocates, we also have a mechanism where we look at, we do claims analysis to make sure and identify the types of claims that are rejections and claims or particular groupings of beneficiaries who are having the same access they may have had in the past. So we collect and evaluate the health system data in order to determine and understand any effects of the changes in the program, in terms of the payment to the outcome and access to beneficiaries. So the next slide. As I mentioned, providing access and assistance to beneficiaries is very key and critical. The way in which all of us can be involved, that means those who are using the product, caregivers, providers and suppliers, is to know and understand that you do have rights, beneficiaries have rights and protections. On the right-hand side of this slide is actually a fact sheet available through Medicare on supplier quality standards. So all suppliers are required to meet certain requirements in order to be a supplier that provides, that provides products to our beneficiaries.

And these are considered beneficiary protection. So all beneficiaries have rights and protections. Required to be accredited and meet quality standards, it includes a number of related to respiratory or power mobility device or other durable medical equipment, very specific to those. Of these important protections and safeguards they will continue to be enforced by independent accreditation agencies, organizations under the program. This is really key and critical. Next slide, just a continuation, when we look at what those rights and protections are, we know they are protected under the law and have a right to expect the product that you receive are high quality and meet manufacturers standards. As Erin was just talking about there is a number of things that go into the appropriate seating, et cetera. So it is really important to be able to know that you should be getting the right type of seating, if this is what your doctor required for you, but if the seating that you obtain from a supplier doesn't meet these, it is really important to be able to let someone know about that. Correct product with proper instructions on how to use it, I have heard complaints from folks that certain products were just mailed to them and there was no one that came out and demonstrated and instructed them on how to use it, that's a violation of our quality standards. In the language they understand, that's also important. By a knowledgeable professional, available to respond with care and replace.

So again these are written out for you in our quality standards. I'm going to give you a little bit more information on how to execute your, your protections under our programs. Obviously a beneficiary made file a complaint with their supplier, you also have 1-500 Medicare, some of you have who Medicare may be already aware of 1-500-medicare, we at least inside the Medicare program think that could be your best friend, that is the main way in which we know what types of assistance our Medicare beneficiaries need. If you do file a complaint with your supplier, the supplier within five-days must confirm with the beneficiary they did receive it and is investigating the complaint. So for example, if you had a problem with a cushion that you were provided and you call your supplier first, it is really important that you do that, so that you give them a chance to understand that there is a problem and that they have 14 days, they have to send the results and response and writing to the beneficiary. If you have no luck with that, you certainly are entitled to call 1-800-medicare and if the complaint can't be resolved by our standard customer service representatives that answer the phone all day long, every day, it will be referred to the appropriate office including my own office. As Erin was mentioning on her slides, talked about how to handle barriers, one important way to handle any barriers you might encounter is to know what your rights are and protections are that entitled to you and to be able to engage those protections. So the next slide is really talking about how to use 1-800-medicare

effectively. We do hear from time to time the beneficiaries may have difficulty in using 1-800-medicare, we know some of our seniors are not always able to follow the prompt to get to where they need to be, certainly we do think it is really important for care-givers as well as those who are aid medical beneficiaries and including providers and suppliers, know how to use 1-800 Medicare on behalf of those beneficiaries who may have some challenges. So their purpose is to assist and provide customer service. So they really work to resolve your problem for the first time when you call.

And they may ask probing questions on the information provided and some of the scripts available.

And as you can imagine, 1-800-medicare supports over 52 million Medicare beneficiaries and they receive over 26 million calls annually. They do respond in English, Spanish and for the hearing impaired. They're open 24 hours a day, 7 days a week and here I'm giving you a little clue on when to best call, Monday and Tuesday are the busiest days, between hours of 10 and 4 approximation m, those are the hours of busiest hours, if you do seek out so some of the challenges or problems, or if you just need information, Medicare, the CSR are available to point you to and share with you lots of Medicare publications which have more details and answers to questions if you are using durable medical equipment. Next slide please. When using 1-800 Medicare a caller can also ask for an agent at any time to talk to a customer service representative and this is really key and important. Been fiduciaries should expand on the issue or problem and I know that's not always easy um for some beneficiaries that may have cognitive problems or issues, but it is really important for the CSR to really understand there is maybe something wrong you haven't been able to fix. Or else maybe they may not even identify the issue as a problem that needs to be resolved beyond what they can do. In other words, it could be a situation where they just refer you on to another supplier, but if you really make it clear that you are complaining about the service or the supplies that you received from a particular supplier, then that will be sort of handled differently. The state health insurance assistance programs, that's spelled out on my last slide here, SHIP, additional resource for information about the competitive bidding program and about gaining access to services and supplies within your location, within your locality. The state health, state health insurance assistance proceed grams are located nationally in every state and often times in most communities you'll find a were group of people to assist and provide that one-on-one assistance. In other words if 1-800-medicare is not meeting your needs you can work with state health insurance program and work directly with someone right there in your community.

And next slide please, I would like to mention, this is really important, because a lot of people use medical equipment, many of them are, from hospitals, may be very ill, may be very sickly. I would like to make sure people know that others can file complaints on behalf of Medicare beneficiaries, that means providers, suppliers and caregivers may file complaints on behalf of beneficiaries. If they are not available when the complaint is filed, to confirm they are speaking on their behalf, that individual will need to have the beneficiaries full name, their date of birth, health insurance number and one piece of information, such as their Social Security number, their address, their phone number, effective date, whether he or she has part A or B.

>> This is great information Tangita, thank you so much, I'm actually, I'm mindful of the time and I do want to make sure Jen addresses her presentation --

>>Tangita: Share the resources are there, so that's all I have and my contact information. But thank you very much.

>> Thank you Tangita and everyone does have the handout attached so you can always go back to the slide yeah here are all the, here is the blog slide Tangita was on and all of the links here and the e-mail you can contact Tangita with any questions, thank you very much, I appreciate it, really helpful. Okay, great. I will move on now, I think we will be able to squeeze in some questions as well.

>>Jennifer: I will try to speed through things, I'm not a wheelchair specialist, even though I'm an Occupational Therapist and I learned kind of hard way how difficult it is to get the right wheelchair and it is what got me started doing the advocacy process, this is a pick it you are of me in inaccessible hotel room. Next slide. So my first chair was great, I was able to, it was a K5, light ultra lightweight but folding, so it worked um I was semi-mobile after first surgery, after I, I filed ultra-light, titanium, it was awesome, I could tell how much less work my body had, how much better it was for my body and then I had to go through the whole process and figured out what Erin talked about is that I didn't qualify for the same, even the same chair I had the first time, much less the more advanced chair because of documentation issues. Next slide. , so I received this chair, it was completely functional, completely functional, almost, in my home, except the fact that I didn't demand they come for a homey valuation and so actually the length was maybe two inches longer and I actually couldn't go in my bathroom.

And you know, these are things that you just learn kind of the hard way unless you know things ahead of time. I hope you can see by the pictures that my posture, sit kind of funny, then I want to seating and positioning clinic, this is the right care. It is the rigid titanium, it is the proper back support, being in that other chair that my scoliosis got much, much worse because I didn't have back support and now when I do excessive rolling around I no longer have the symptoms that I used to. Next slide. So what can you do? I hope that's what you are getting the most out of this Webinar is prepare yourself, you know, really get to know what you need to have ready to go to that wheelchair evaluation. Find out more about wheelchair equipment. Get your medical history together. Be prepared to kind of being manipulated by the therapist, what they need to know about bladder and bowel, know about pressure sores, even though we don't like talking about ending up getting those. It really helps them document, get us the right equipment. , my therapist tell me it is the only time you have a therapist bring worst case scenarios up. Usually we're trying to bring the best out of people. Another thing is to fight. If you get denied, you need to speak up for yourself. You need to, go through the process, from what I'm hearing, most people do get denied the first time and you have to go through, it can be for, completely irrelevant issues like signatures, but it's kind of up to us to be sticklers and really keep on our suppliers, therapists and doctors to work together. Again that's another reason for working with sitting in positions clinic, those people do work more closely together. Next slide. There is, on United Spinal Association ask us site, it is called the Mobility Map. Kind of still being in the process of being revamped but really good information still there. It really helps you go through what to expect and what you should know. Next slide. , I put together a PDF of kind of the most important, the meat of it and you can print it off and I'm hoping we can get place for it on the Web page. But it goes through a page, it goes through the self-assessment, all the different steps of getting it. Next slide. Then it has your checklist, things we don't normally think about, because we are wheelchair users, part of our daily life, we don't think about it anymore. What you want to do with your chair, what is important to you, what do you like about your chair, what you don't like about your chair, that's your specialty. The clinicians know the most about positioning, the suppliers know about equipment, you know how you function in that chair. Next slide. , who, what is it composed of. It gives you a place to put those information all in one place. Then kind of again more of the steps helps you write down the date, keep everything in one

place in regards to your wheelchair assessment, the prescription, the appointment, the communicating with your clinician and some other things and some other questions for you to really think about. Next slide. What else can you do? It is easy to get frustrated with this process, it is so complicated. You can generally join us, United Spinal Association Alliance and learn more about how to fight kind of for legislative policy changes. You can always fight the denial and appeal your, especially with seating and positioning clinics. They know the most out of how to make that successful. So that really is key. Then you can always call or write legislator at any time. They even have local offices where many times they have case workers that can help you out on a more local level. Next slide. Just wanted to finish up with never doubt that a small group of thoughtful, committed citizens can change the world. Indeed, it's the only thing that ever has.

>> That is great way to end your slides Jen, thank you so much and you did a great job going over a lot of important information for everybody and we do still have some time for questions, which is awesome. I want, I want you to be able to ask us questions. So here is some links, obviously going back to United Spinal website and spinal cord website and I finally activated by WebCam guys, there you go.

And then let me go to some of the other slides where you can see other ways, let me get back to some questions, have everyone e-mail address right there for folks to follow-up if necessary and we don't have a chance to get to your question now, we will after the Webinar. So Bill, take it away.

>> Bill: Thank you Alex and Tangita and Jennifer and Erin for a jam-packed information, we have a variety of questions, let's get to some of them. Any information on questions one could bring or should bring to the wheelchair evaluation, what should we bring to the wheelchair evaluation.

>> I would say that's a good question for Erin.

>> I would. Erin, tell us.

>>Erin: So questions, I think the big questions, the big questions you should be asking during wheelchair evaluation are mostly surrounding type of equipment you are going to get and what the procedures need to be. I think more so than having questions prepared um is having your information ready. So, you know, using what Jen just talked about, the Mobility Map and some of those other resources to put together thoughts about yourself, your environments, the type of what you like about your chair, what you don't like about your chair, and any limitations that you have. I think more so than having questions you really should have information ready to be presented and then, but questions wise, yeah anything that you would like to know about equipment that's available, if you can't get to a seating clinic, you really should be asking about the process, you know, if you are working with a vendor and a therapist separately or a physician separately, you know, asking about who is going to be responsible for what part and then following up after the appointment with those people to make sure they are all communicating and your paperwork is getting pushed through appropriately. Next, I think I know who this might be for, under Medicare. How often can I get my wheelchair upgraded, under Medicare, how often can I upgrade my wheelchair?

>>Tangita: This is Tangita --

>> Go ahead Tangita.

>>Tangita: They usually take this for the useful life of the chair and that's generally thought to be five years. Alex do you have something else?

>> No, that's exactly what I was going to say, for on this perspective it is sometimes difficult if you get the wrong chair to begin with, you have to wait for five years to get a different chair unless there is a change in its condition and you have to go through, you know, submitting medical documentation, et cetera. So yeah that's exactly what I was going to say. Thanks Tangita.

>> Bill: Tangita, I have a quick follow-up on that, I see Erin has something to contribute also, I'm partially on year 7 with private insurance on my titanium chair and I have no problems with it and I think I want to keep it, but for maybe there will be a possibility in the future, maybe this is insurance decision that the repairs are not cost effective. Anything to add on that Tangita followed by Erin?

>>Tangita: Having your chair repaired under Medicare?

>> Bill: Well I guess maybe you can help us with Medicare perspective on that, in my particular case it is a private insurer.

>>Tangita: Yeah Medicare policy on repair of your chair, generally speaking, if approximate you have a rental, all of your repairs should be included as part of that rental. When the Chair is transferred over to ownership and you own your chair you should be able to go to any supplier that is willing to do Medicare repairs on a wheelchair. The most important thing to keep in mind there is if you are going to a supplier to have a repair done and it is, supplier that provided your chair originally, that's where you might need to work very closely to provide some of the original documentation, although CMS has gone a long way in trying to make sure that it's not based on just base equipment and how it was paid for. There are a lot of technicalities in there, the main thing to remember is you can go to any supplier for a repair of beneficiary owned chair.

>> Longevity if it is about seven or eight years old, would happen to be still working fine, except for normal regular maintenance items, tires, castors, occasional, Erin has a point.

>>Erin: I can speak to that a little bit in being involved in multiple repairs and new chair, appointments where we were going forward, do we repair current chair or do we pursue a new chair and really um at this point it's, we need to prove that the current chair um does not meet your current medical needs. So to your point Bill, if your chair, even if it is five years old, six years old, seven years old, if it is still essentially meeting your needs and only minor repairs or maintenance that are necessary, then we would go through with updating the parts of the chair um versus replacing the entire chair. It is getting harder for us to transition someone to a new chair just because a chair is a certain number of years old. We actually have to prove that it needs to be replaced and I have, I can speak, I've had a chair that we were denied replacing a chair and it was actually decided that they would um repair the Chair and the quote for the repair was more expensive than what the replacement chair would of been. But they pursued doing the repairs instead. I don't know if this is an option, the seating and design and shape of the chair is so critical, sometimes it's not worth the risk of getting a mismeasured chair when you already have one dialed in.

>> Uh-huh, yeah.

>> Bill: Thank you, lots of questions, let's move on. What can I do to get my insurance company to cover a cost for seat evaluation on a new Bill wheelchair I will be getting. They denied it saying it was not medical necessity, my doctor agreed with me that I need to, needs to allow me to transfer on to the toilet and into bed using the seat elevation.

>>Erin: Yeah so I'm not sure the person who asked this question, I'm not sure what your insurer is but according to many insurance companies, non-covered item it is actually considered to be, to have a seat elevator. So what we are, many of my patients have pursued their seat elevator with via out-of-pocket, an alternative payer, fundraising, you can depending on the insurer, you may be able to go through the appeal process and you may be able to provide them with some additional information um but for many, many payers these days, a seat elevator is not seen as a medical necessity, we are trying to fight that because I know and everyone here knows importance of seat elevators, but right now there is a chance your insurance may just view it that way. Seeking alternative payment may be your best option.

>> Wanted to add quickly to that seat elevation issue, this is Alex, United Spinal is working on that. We meet with CNF multiple times about including coverage for seat elevation, let you know we are active on that issue. I quickly want to let you know Jennifer Wolff e-mail should be Jennifer, Jwolff@uspinal.org, that was an older e-mail we just changed recently, Jwolff@usspinal.org. Do we have time for a question?

>> Bill. We have if everyone has time to go for another five or six or search questions we have many questions. The next is received an unusable chair, to use myself. Through a seating clinic process, how do I have, how do or what do I have to do to get a new chair. Cannot use the Chair provided, insurance is a, this is my inserting insurance is barely paid for it, but what they received is unusable, what's the recourse?

>> I can take that one.

>>Erin: Yep it sounds like you went through seating clinic and, you know, as though Jen and I highly recommend seating clinics sometimes mistakes are made or what, what people thought would be the most effective tool wasn't realistic for your environment or your, it sounds as though the Chair is too heavy, too big. Once insurance has already paid for it, it becomes difficult. My best suggestion and what I've done, we have had a couple chairs that have had, that were just unusable and whether it was a chair that we recommended or we received a patient from another clinic or someone who didn't go through a clinic and their chair wasn't appropriate, we've had the people advocate thoroughly with their supplier um to try to get that piece of equipment replaced. It's not an easy process, but sometimes the suppliers are, and the local equipment reps, if you know the company that made the Chair um and there may be a way to get that piece of equipment exchanged out and also getting, following up with the clinic that provided it for you. I'm not sure if you reached out to them or not. But letting them know if not feasible for you to use that piece of equipment, it's not an easy thing to do but there are options when that happens and good clinics, good clinicians and good suppliers will help you through that and help you replace it:

>> If you will stay with us for a minute, segue to this related question. Do seating clinics allow for home assessment as well as individual needs. Do seating clinics allow for home assessments as well?

>>Erin: As far as, at my hospital um we, at this time, are not -- we do not receive reimbursement to visit someone at home. However, you can have, you can have a home therapist involved in a seating eval with a vendor or the vendors are actually required to come out and look at your home and do an assessment, take measurements and document that, so it may not be myself that goes out there, but the vendors that I work with, the ATPs, they will go and look at the person's home and check doorways and but that's also information that you can bring, you know the measurements of your, what Jen was saying, couldn't turn in your bathroom, if you know there are spaces, even with current chair, fitting or they are tight or and you have those measurements ready to go, that can also help during the appointment. If you know your current piece of equipment is working for you in all of your environments, it is what you need, it fits everywhere you feed it to go, you can advocate that during your appointment and we will do our best to match a new chair to the same specifications so that it will still fit.

>> Erin stay with us some more, we have another. This is a quick one, how long does a typical equipment trial last?

>>Erin: Oh um I don't know that there is such thing as a typical equipment trial, um but we will um within, well working within the time period that my clinic allows, that can be anywhere from our seating appointments are up to 90 minutes long and then I also gone as far as having my equipment suppliers or my local reps provide equipment for somebody to trial for a prolonged period. So bringing the equipment out to the person's home to try in their home environment to see if it will actually fit. Now that being said, a good thing to remember, when we're using trial equipment we're actually all demo equipment, so remember this process, we're trying to provide a customized piece of equipment for you. So the demo equipment therefore is going to kind of be, it is a one size fits none type scenario. So we're doing the best that we can um because if, if we could get a piece of equipment that fit you exactly, then that would eliminate the whole idea of the equipment being customized for you down the road. So when we use trial equipment it may not fit you exactly, the idea is to look at the equipment to see how we can change it to make it fit you better for power chairs we can at least get you to try how they drive, to see how they turn, the base itself you can, you know, use that in your home and make sure that you can turn around and get in and out of rooms. Same thing with manual chairs, you know, we can at least let you see how the Chair folds, how the Chair, you know, what the design is and again how that moves and then with cushions, back rests and other parts of a seating system we can have you actually sit on those and try them with cushions and back rests. Remember we can only have you sit on them for a short period of time during the clinic, but what happens once we get you on the cushion and you have to use it all day, that can make it feel very different. So a trial is a best of a worst type situation, but it gives us, there is trials work well for really ruling out things that absolutely will not work and then we can start stepping back to things that seem to be okay.

>> Bill: Thank you for that Erin, we're going to do one more question, I know we have gone 15 minutes late, we could go another hour looking at the questions. Please remember you can direct the questions to panelists e-mail addresses are on the screen, the change made to Jennwolff, also this entire presentation will be archived in approximately one week on spinal cord.org. The last question though, we have one directed to Tangita, to you. Can you please clarify the right to the correct product. The right to get the correct product. Medicare indicates certain products can only be qualified for with a particular diagnosis and specific clinical criteria. Would you be able to address that?

>>Tangita: Um that is getting into some of the thick policy areas, which I would love to be able to respond to you or help you get an answer to that. My e-mail address is listed here, if you want to send me that question I'll make sure we can work to get an answer to you on that.

>> Bill: Perfect Tangita, thank you. That's going to be about as much time we have today, on behalf of United Spinal Association I would like to thank the panel, Alex Bennewith, Erin Michael, Tangita and Jennifer Wolff so much for sharing personal experience and professional model on the presentation finding the right wheelchair that works for you.

Our next Webinar will be your pathway to employment, benefits and incentives for working with a spinal cord injury on Wednesday, April 13th, from 2 to 3 pm eastern time. To sign up for and receive our Webinar newsletter and Advocacy Alliance, visit us at spinalcord.org or visit our publication site www.newmobility.com for coverage of everything active wheelchair users need to know. Thank you panelists.

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