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Event: Getting the Right Mobility Equipment and Services

Client: United Spinal Association

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(On stand-by)

>> Hello. Welcome to Getting the Right Mobility Equipment and Services for People with Disabilities. Thank you for joining us. We will be starting momentarily. Thank you.

>> Welcome to Getting the Right Mobility Equipment and Services for People with Disabilities. Today's webinar is the second installment in the 2013 Independence Through Advocacy four-part webinar series. This webinar will cover rules under Medicare that may currently impact access to wheelchairs and other assistive technology, therapies and prescription drugs. Tips will also be provided in how to be your own best advocate.

Today's featured speaker is Alexandra Bennewith, vice president government regulations at United Spinal Association. Alex advocates for regulations regarding disability and health policy at both the federal and state level to improve the lives of people with disabilities. She works closely with a group of stakeholders in durable medical equipment, supplies, prescription health, public health and disabilities. She has over 16 years of public affairs experience and worked with the patients and consumers at the Cystic Fibrosis Foundation and the Spina Bifida Association of America.

>> Thank you, Carol. That was Carol Tyson with the United Spinal Association and I will now start the webinar.

Let's see. Let me just make sure you can see my screen. Great. Well, here we are, March 28th. Those photos right there are from our last year's Roll On Capitol Hill event, and we had our first conference last year in June and so we're going to be having another one coming up in a few months and so as you see Senator Harkin, you might already know him, he's the democratic senator out of Iowa, and he's a huge champion of our association in the disability community.

Before we get started I just wanted to thank our sponsors for this webinar. Allergan and Permobil. Thank you. And I wanted to explain for those of you who don't know who United Spinal is, we do have a host of programs and services available to our members. As you can see we have the New Mobility Magazine, we have a program for children's sports, Kids Sports Spectacular, and the NSCIA is our chapter division and we have roughly 29 chapters around the country and around 200 support groups around the country for people with spinal cord injuries and disorders. UsersFirst is our grassroots division. We have VetsFirst as well that services our veterans and disabled veterans and a host of other programs.

Again I just mentioned Roll On Capitol Hill so I'll do that again. This year it's June 16th through the 19th. As I said, it's the public policy department working with our chapter and membership division as well as our grassroots division and we all come together here in DC and we do a lot of -- a lot of education sessions for folks that come and we have a lot of good speakers come and we do a lot of Hill visits as well and the fun awards night as well for members of Congress and for disability advocates so it's a good time. And you can find out more about the event at

that link there and I will show the slide again later in the webinar.

There's this webinar of course, and as Carol mentioned earlier, this is the second in a series of webinars related to policy issues. We had one on the Affordable Care Act back in January. And here are some upcoming webinars on Medicaid, Advocacy 101, to prep our attendees for Roll On Capitol Hill, which I will be doing with a new bank of users first, and of course the ADA anniversary, the 23rd anniversary. It was put into place in 1990 and we're going to have a webinar, James Weisman, our executive VP is going to be doing that. For all webinars you can find them archived here at this website address, www.spinalcord.org/webinar-archive/ and I'll have the folks that are helping me with the logistics send that link to everyone on the webinar right now.

Just a little bit more housekeeping before we get started. You can send in your questions at the question box on the right side of your screen and we will be answering them throughout the webinar, typing responses to you. At the end we'll have some time for questions, and we will answer some of them. If we don't get to all of them of course we'll

follow up with you to be sure that we're responsive to your questions. So there's my contact info, and I will keep moving.

Okay. So this is really about Medicare, about getting the right mobility equipment, services and therapy. But I wanted to just step back a little bit, for a few minutes, to tell you what's been going on in DC lately and it seems to be even crazier than it has been usually. The cycle of deadlines constantly seem to be coming up over and over again with short deadlines of funding that's terminating, that we have to continue to fund, the government funding, for example. You know, budgets that haven't been passed in four years on the senate side finally they were able to agree to a resolution, which isn't really law but it's kind of a blueprint of what they want to pass. And that happened just last week, both the Republican and Democrat budget. The present budget will be coming out in April which is much later than usual. Usually it comes out in early February. So everything is kind of out of whack as far as the usual process of congressional rules and procedures.

Many of you may have heard about the sequester and the government funding continuation that has initially

supposed to go into effect in January, various cuts to various programs including health care and defense spending, but that was extended for a couple of months and then finally did go into effect March 1st. And there will be some effects to Medicare on that. There will be a 2% cut to payments to physicians -- that physicians get that will actually be affected in April, and then government funding, they continued that through September. You know, all these short patches. It makes it very difficult to try to lobby on anything and we have to continually keep our voices, you know -- make sure they hear from us all the time on our issues. That's really the point of all of this is to make sure they hear from us on a continual basis about what programs are being affected.

But that ceiling limit, that's another issue obviously that both republicans and Democrats debate on continually, and there's another limit that it will reach 16 trillion in July/August of this year so they will have to meet again about whether they can extend it and how much money they would need to borrow to extend.

Physician payment cuts under Medicare, this is an issue that went into effect a long time ago, 1997, where they

wanted to cut payments to physicians and every year there's been fixes to delay the cuts so ways to pay for delaying putting the cuts in place and that's been going on every year since 1997. It's really an inefficient way to do, you know, payment mechanisms for Medicare so they finally are looking at ways to permanently fix the program, so that is happening as we speak. I mean, that was a report that came out just this month where they're finally looking at fixing it permanently so you don't have to have the threat of physicians not wanting to go to service Medicare patients because their cuts are constantly over their head.

Health reform, Affordable Care Act now is three years old. There are a lot of good provisions obviously that we like about it, including the preexisting condition denial being terminated, insurance coverage for people up to the age of 26 which is another good thing, a lot of wellness programs that have been implemented and obviously Medicaid expansion, so a lot of good things with the Affordable Care Act. I just wanted to list those as that's the general framework here dealing with. I'm not going to go into detail on health reform but I'll keep moving now.

So what does all that mean for us? What it means is there's

constantly issues going on. You know, they're constantly talking about Medicare and where they can get money from to pay for something or cut something so we really do need to continue to talk to our congressional offices to tell them your stories, tell them how you're being impacted or how you're not getting the equipment you need or the therapy you need or, you know, prescription drugs. And that's really -- it's as easy as that, just letting them know who you are and what your concerns are.

So let me just go into some numbers so you can get a better sense of how much spending there is on Medicare and really how much of the -- how much it really takes up of the federal government spending. You can see Social Security, Medicare and Medicaid is at 41% and everything else including defense, including other entitlement programs make up the rest of the pie so it's really a really important part of federal spending and obviously very often, you know, Medicare is exempt and Medicaid payments are exempt from something but they always look to these programs to cut where they can, so we have to keep them honest and keep our -- make sure our voices are heard.

To give you an idea about the characteristics of the

Medicare population, you can see the under 65 line there, four up from the bottom, 17%. That's about 8 million people on Medicare. So it gives you a sense of some of the other categories there.

And here is, you know, some of the things that I'll be talking about, the prescription drugs, in-patient services. I mean, look at the way Medicare is divided with all the different payment services.

Okay, let's go to the first issue here is complex rehab technology. Now, I know that's not the easiest term to use but what that refers to is really your wheelchairs that are highly powered or highly individually configured that as you can see with the picture up on the pop left there, it moves back, it can tilt, it will have, you know, head movements and hand tools that will help you with hand movement. So highly configured devices that really need a specific group of people with primary diagnoses that affect neuromuscular disease or injury or trauma so people with spinal cord injury, people with muscular dystrophy, multiple sclerosis as well as mobility limitations. An evaluation is needed to really look at what people need, what type of equipment they really do need. But that's

what CRT is under Medicare.

And united spinal has been working with various groups including N Cart, the National Association for Assistive Technology and various other consumer groups such as Brain Injury Association of America, Easter Seals and a whole host of groups working on really putting this into place because currently Medicare doesn't have this comprehensive benefit. I mean, I know they do -- you know, obviously there are some codes that cover some of this equipment but really not a comprehensive benefit where individuals are evaluated by a team approach of professionals that are licensed in some complex rehab technologies along with the consumer and the specialist to really evaluate what they need. So we're advocating that Medicare puts this into place. They've done this for other benefits for other -- the term is called orthotics and prosthetics, so limb devices that people need that was done we CMS in 2008 where they carved out benefits for artificial limbs, and we're saying we need that for complex rehab technology too to make sure people get what they need.

With this new bill that we've advocated, we finally did get introduced last year and we got it pre-introduced this year

as well and I'll give you the number for that but it's -- you know, CRT is slightly different than standard durable medical equipment. It serves a highly specialized small population, as I mentioned, people with mobility limitations that have significant disabilities, and it has to have physical evaluation with a credentialed specialist and all these companies that provide this service have to be accredited and have to be able to repair the equipment that they provide. That's the criteria for this new bill that we've been pushing recently.

So the message for this is ask your member of Congress because currently it's in the house, the House of Representatives, to cosponsor HR 942 that would create a separate benefit category for complex rehab technology. And we are working on a senate companion bill is what they call it, as well, but right now it's in the house and Congressman Crowley out of New York and Congress Jim Sensenbrenner Republican from Wisconsin, have both introduced this bill earlier this month and we have an action alert on our website, and I'll show you how to access that later on in the webinar that you can just hit send to your representative and get cosponsors on this bill. It's really important that we get this implemented.

Okay. Let me quickly shift to another issue. Many of you might have already heard about this bill, competitive acquisition program. What it is is it's really a program that suppliers have to bid to CMS, CMS is the Centers for Medicare or Medicaid Services, and then CMS decides, they set a median price, a mid price, and then they award contracts to suppliers and whatever is below that median price they set and those providers are awarded contracts to furnish Medicare beneficiaries with certain products. And there's a range of products that are included, that are included in this bidding program. They call it a competitive bidding program but it really isn't competitive because CMS sets the median price, it's not done independently, and it limits the number of suppliers that can provide service to consumers.

And if you happen to live in an area that's a bidding area, you really are limited regarding the number of providers and also the choice of products that you have access to. So we definitely oppose the current bidding program. We understand that Medicare does need to look at ways to save money, and that's always an issue here in DC, but we don't want it affecting access for our members and consumers that

need the equipment and services. So we support fixing the program. And I will show you some more issues around that. But, you know, our big concern is with coming up this July, this program that's currently only in ten areas -- well, nine areas actually. It started with ten in '08 but when they rebid and it left 2011 it went down to nine. It's going to expand to 90 additional cities this summer and that's a lot of cities so we're worried that a lot of consumers are going to be impacted and we just want to make sure that CMS has this program implemented properly and perhaps even delay it for a little bit before they put it in place for such a large area.

These are the areas that it's impacting now so you can see the cities. I'm happy to send this, you know, this information around separately and you all can access the archived webinar later on our website. And these are all the product categories that are impacted. So obviously for our group, you know, with the wheelchairs, diabetic supplies, hospital beds, support surfaces. I mean, there are a lot of issues. Some people need more than one product. And unfortunately with this bidding program, suppliers that are awarded contracts, you know, instead of having to rely on one supplier that you may have used to

be doing, you now may have to possibly go to multiple suppliers to get the equipment, different products that you used to use and it just makes it a lot more difficult for you and it makes it difficult for the discharge planners at the hospital to be able to match you with the right products if you are in hospital and you do need to go back home and enter your community.

So for round two, which I had mentioned that will start in July, you can see all the areas that it's going to impact, in the west, in the Midwest, in the south. And I know I'm going through quickly here but you can see just how many places it's impacting. Again, I'm happy to send that around separately.

Similar products that are included for round two, NPWT, that's negative pressure wound therapy, is a new product category for round two. And complex rehab technology actually is not included here. And that's part of our bill too. We want it to be permanently excluded. Our CRT bill, HR 942, to be permanently excluded from this bidding program. So that's another good reason why we should all get behind that bill and get it passed.

So I may have -- I mentioned some of the -- some of the impacts but I'll just go over that again. It's difficult to find a local equipment or service provider. You may get delays in wheelchair repair, you know, as I had mentioned, longer than necessary hospital stays because it is difficult to match patients to the right equipment. Fewer choices. And sometimes Medicare is confusing in what information they can provide on their website. Sometimes it takes awhile for them to update their website and, you know, which suppliers are in which area and that can obviously not be a good thing for you when you need to get the equipment and services that you need right away.

So ways to fix the program. We don't want suppliers to be able to just say no to CMS and not worry about having to provide service. Is on we want the winning suppliers to have a contract with CMS to say, you know, they can't walk away. They get it if they're a winning supplier, they need to be bound to their bid meaning they have to provide service to you because that's not an efficient system. It's not good for consumers.

And then we wrote about this earlier this year, the payment rates for products for suppliers is really cut back 45% from

before, up to 75% for diabetes products which is a huge cut. So there's no way that that cannot impact quality. So that's a huge problem.

And we just really want to know how CMS is calculating what suppliers are qualified, what, you know, what the patient demand is, consumer demand is in each area. And unfortunately they're not transparent with that information.

So the way we want to fix it is to -- we support legislation to fix the program. We had a bill last year. There's going to be a new bill that will be coming out any day now, and we will definitely send a note to our action alert list, advocacy list as soon as that comes out but it's really smaller areas that will be impacted. You saw all of the cities that will be impacted too. We want it more or less at a county level instead of at a state level because that's really a broad area especially if you're looking at a state like New York or something like that. And obviously demographics, New York is highly populated. We just need to cut down the areas, cut down the number of products that are impacted because again that's another issue for our members. So we'll send more information on that.

Let me move on to outpatient rehab payments. So this is another issue kind of similar to the doc fix problem, the physician payment cut issue that I mentioned. It was also in 1997 when they decided to put in an annual exceptions process every year. Well, we have to because the payment methodology just wasn't working, where you have to request an exceptions for needed therapy services. Luckily that was put in place, but the problem is you have to request that exception, you know, on a yearly basis. So every year we ask for an extension of the cap and, you know, every year the cap, the limit on payments for therapy services goes up a little bit but not, not anywhere near the amount that is needed for people perhaps that have just sustained a spinal cord injury that really need therapy services. There is an exceptions process in place which is good. The current exceptions process will end December 2013. We thank all of the advocates and people that sent in their stories about this when we were looking to extend it the last time so thank you. And again, you know, they are looking at a permanent fix to this every year exceptions request which hopefully will help with giving you continued service and just not having choppy service which is not helpful.

So again, we do have specific legislation on that issue and it's called the Medicare access to rehabilitation services act. It's the same bill that gets reintroduced on a yearly basis with the same folks most of the time it's the same people that lead the bill, as you can see. There's already some sponsors on it and it just got introduced last month so making pretty good progress.

And we want to -- we just want to, you know, make sure that Medicare folks are not being denied access so this is one way to fix it but we also are wanting to make a permanent -- a permanent fix to the program so you don't have to do this every year thing. So we are working on that with the committees of jurisdiction that cover Medicare.

Okay, let me move on. So that bill, the message for that is to cosponsor HR 713. That's the house bill, and S 367 which is the senate bill, to eliminate Medicare's arbitrary and unfair out patient rehab therapy payment caps.

Well, the other things they'll been mulling around DC, there was a report that came out not too long ago from what they call med pat which is the payment commission that looks

at Medicare, and they came out with a proposal to cut payment even more for people that have multiple procedures at one time so like a second or third service in the hospital they want to cut with initially a 25% payment reduction, they now want to go up to a 50% payment reduction on, you know, those providers that give you the care, the services in the hospital, and we think that's way too high. It really -- I know they're looking at bundled payments but they're looking at this across the health reform delivery system, the delivery system throughout. But 50% cut in Medicare, what they call multiple procedure payments, so when you're doing -- when you have, you know, two or three services at one time, that's way too high. So we're also pushing back on that issue as well. So there's plenty it do here in DC.

Let me move onto the next issue, prescription drugs. Let me just describe to specialty tier drugs. Specialty tier drugs are drugs that are expensive, high cost drugs. They're drugs that, you know, are thousands of dollars a month. And, you know, an example, as you can see there is Copaxone which is the treatment for multiple sclerosis which I know many of our members have multiple sclerosis. And there have been some changes -- the good thing with the

Affordable Care Act is there have been some changes as far as covering, you know, limiting the doughnut hole and getting rid of it over time, which is great. But, you know, this is what the general look of prescription plans look like, coinsurance for covered drugs, cost sharing, so there's generic preferred and specialty tier, it's high cost drugs. And then those drugs that cost more than \$600 a month are known as specialty tier drugs. So this is from 2009. I didn't -- I couldn't find more updated data than this. There's a lot of changes now with the Affordable Care Act so once that kind of sets in place a little bit more, we'll be able to get some more updated data but currently, you know, almost 90% of the plans nationwide use specialty tiers. So let me explain what they're doing on this front.

So Congressman Hank Johnson introduced a bill last year called the Medicare -- the fairness for Medicare Part D Beneficiaries Act. And we're looking at him reintroducing that again this year. So we're also looking at other, other issues within Medicare to help improve the benefit. As you mentioned before they're always looking for ways to cut spending, to cut savings in quote. There are several other ways we want to make sure that you're getting the

coverage you need so in addition to all the changes with the Affordable Care Act and making sure that the protected drug classes are covered under Medicare under the state plan, protected classes are those like antipsychotic, you know, immunosuppressants for transplant surgery, things like that, there are protected classes that we say must be covered. There must be a robust formulary in place.

Utilization of management techniques so things that are called step therapy or, you know, when you're testing or being put on a particular drug, we want to make sure that they're tufting that appropriately and not giving you the wrong drugs inappropriately.

Okay, so specialty tier drugs, what's the message? The message is we support an implementation of an appeals process under Medicare Part D for individuals who are dependent on specialty tier drugs. So that means, you know, you can request to place your drug in a specialty tier and that insurance companies cannot block that request. They cannot say well, for this plan we don't offer that. They're not allowed to say that in legislation that we supported last year along the same lines and we're looking to do the same thing this year. So again, we'll update our team advocacy list when the new legislation is introduced,

and that will be in the coming weeks and months.

So here's a recap of all the messages that I just went over, to just to remind you. Cosponsor HR 942, the separate benefit bill, support legislation to fix the current bidding program, and that's going to be out any day now. Urge your representative and senators to cosponsor HR 713 or S 367. So that's a house and senate bill to eliminate those therapy payment caps.

And then part D issue as well, support implementation of an appeals process for people that need specialty tier drugs.

So I wonder if any of you are a member of team advocacy. I wonder if you have visited our advocacy actions center. We do have a lot of good updates on our action center. How to get more involved in united spinal and make a difference. You can become a member of the United Spinal Association. You can join our team advocacy team and get updates. Can you go to the advocacy action center and you will see national and state activities. You can go to our website, unitedspinal.org and click on the advocacy center, action center button right on the homepage, and it will give you

all of that information. Chapter and support group you can join at spinalcord.org. If you want to get really much more involved in policy, you can become a policy adviser at your chapter or support group at spinalcord.org. And you can also be a grassroots advocate, really work in the state, on state-specific issues. And if that you can go to usersfirst.org.

There are so many more ways to get involved. You can attend a town hall hearing in your state. Again, that's senator Harkin, chair of the senate help committee, and they work on a lot of issues that we are interested in obviously, health and employment issues, education issues of course.

So find your senator at www.senate.gov and your representative at www.house.gov and you can also call the main switchboard to find your house rep or your senator. You can e-mail them, you can call them and you can visit them here in DC or visit them in your home state. Every senator and rep, repetitive has district offices that you can visit them there.

Again, here's our Roll On Capitol Hill website link and date. And as you can see, public policy department and the

United Spinal and users first will work together in putting that on, and you could find more information on that at that link.

So we do have a little bit of time for questions, and I do see some of these questions here. Let's see. Oh, yes. Let me know back to slide ten. Let's see if I can do that. One person asked about the ADL limitations on one of the graphs that I showed earlier. ADL just means activities of daily living, so that's two or more activities of daily living that you need -- that you need to do on a daily basis to get around with what your mobility limitations are.

The name and number of the complex rehab technology bill, that was another question, HR 942, is called the Insuring Access to Quality Complex Rehabilitation Technology Act. So it's kind of a mouthful, but that's what it is. I can repeat it. It's Ensuring Access to Quality Complex Rehabilitation Technology Act of 2013.

So the legislation that I -- another question about congressman Johnson's legislation is that it does look at Medicare. It really focuses on Medicare. But I know there are other bills that look at the same issues within

private insurance, and I'm happy to send that information along separately. There have been some separate bills and some separate activity on that.

Let's see if there are any other questions that are coming up. Let's see. I had a good question about motions therapy, and that actually doesn't fit under the bidding program. The bidding program that I talked about in the beginning really focuses on equipment such as wheelchairs, enteral nutrients, oxygen equipment, some assistive technology. So I'm happy to look into programs and services for motion therapy specifically that that person asked about but it's not specifically under the competitive bidding program.

Let's see if there are any questions, any other questions. Just to let you know, you can go to the archive link at spinalcord.org for the webinar archive. And I think that's it. I don't see any other questions at this time so I wanted to thank you all for dialing in. Please do -- if you have any other questions, you can always e-mail me at aBennewith@unitedspinal.org. Or my number is (202)556-2076, extension 7102. Thanks so much. Have a great day, everyone.

>> The organizer has ended the session and this call will be disconnected. Good-bye.

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