

March 16, 2016.

United Spinal

"Solutions for Bladder and Bowel Management"

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>> Male Speaker: Thank you for joining us today for the United Spinal association webinar. "Solutions for Bladder and Bowel Management" with presenters Jennifer French, and Doctor Kimberly Anderson-Erisman. My name is Bill Fretag, and I will be your moderator. All of our webinars will be archived on our website at

www.unitedspinal.org.

Please use the questions window of the control panel on your screen to submit your questions for the panelists and we'll do our best to get to them today. For any questions remaining unanswered, please pose those questions directly to the presenters whose contact info will be displayed on the last slide. Please note the instructions for use of closed captioning, should you need it, for the webinar, appear in the chat panel of.

Jennifer French, MBA, became quadriplegic from a C7 incomplete spinal cord injury in 1978. She is an active user of the standard transfer system provided by the Cleveland FES center. The first woman to receive such assistance. The cofounder and executive director of the 501C3 nonprofit organization, Neurotech Network to focus, and advocate for access to neurotechnology. French is also the associate publisher, senior editor of "North Tech Reports." From the neurotechnology industry. She is a silver medalist from the 2012 Paralympic games and 2012 Rolex yachtswoman of the year. The first woman with a disability to receive this distinction. The cofounder and development officer of the warrior sailing program. A Mary education program for wounded ill, service members through the MSMMA, sailing organization.

Doctor Kimberly Anderson-Erisman is the director of the Miami Program to cure paralysis at the University of Miami's Miller school of medicine. Her research is focused on translational investigations and bridging the gap between science and the public community living with spinal cord injury, SCI. Her training

spans the spectrum of SCI research from cellular and molecular studies to whole animal and behavioral studies to clinical research. She has conducted a multi-centered clinical study evaluating the reliability and the validity of the SCI independence measure in United States healthcare setting. Several studies have obtained those living with spinal cord injury on various aspects of research, including functional priorities, acceptable benefits and risks, preferences for neuro prosthetics and exercise participation.

Her current projects focus on aging related changes in bladder health after SCI. Determining the amount of exercise and loco training required for chronic SCI, and identifying the facilitators and barriers for clinical trial participation from the SCI consumer perspective.

In addition to pursuing her own research regarding chronic injury, she's part of a leadership team running the Schwann cell transplantation clinical trials at the University of Miami and collaborating with Doctor Levy to lead their participation in a industry-sponsored stem cell trial.

And now, I'd like to hand it off to Jennifer French and Doctor Kimberly Anderson-Erisman for their presentations. Jennifer?

>> Jennifer: Thanks for that great introduction, Bill. Thank you all for attending the webinar today. The topic at hand is going to be bladder management and we understand there's quite some interest out there. So hopefully we'll provide you with some great information today. As Bill had mentioned earlier, we wanted to reinforce to you, that during

the webinar, if you have a question, you will see the question box. You are more than welcome to type in a question, and we'll make sure that we have time at the end to address those questions. If your question doesn't get addressed we'll have our contact information at the end of the webinar and allow you to contact us and hopefully we can address your question later on.

I also wanted to point out to you, on the screen you can see that there's a handout. During this webinar, we're going to refer to a lot of resources and some links to different websites. Those are all available on the handout in the PDF handout. Please don't feel you need to write it all down, we have that available for you in a PDF form in the handout section. Let's get to the good stuff.

Introducing our two organizations. Kim, would you like to introduce the Miami project?

>> Kimberly: Yes. You have just briefly, the Miami project is a research center within the University of Miami in Florida. Our goal is to find more effective treatments and ultimately a cure or combination of cures for paralysis and all of its assets resulting from spinal cord injury.

>> Jennifer: Great, thanks, Kim. Neuro technical, we focus on education of and advocacy to assess neurotechnology device therapies and treatments for people living with impairments their caregivers and med catholic professionals.

We provide a lot of resources on our website and to be able to access

those and learn about the technologies that are coming in on the pipeline. Medical professionals.

We have to read this because our lawyers require us to. The information presented in this webinar is not meant to replace the advice for a medical professional. You should consult a healthcare professional familiar with the specific case concern and condition.

Neurotech Network and its representatives do not endorse, rate, sell, distribute, prescribe, admire or recommend any products, we highly suggest for you to take information to a trained professional. Whew, let's cover what we'll cover.

The urinary tract anatomy to get a baseline before we get into anything further managing the bladder. We'll talk about the complications that come from poor bladder management, and those living with SCI, and disorders. And catheterization, and voiding technique and pharmaceuticals and medical devices. We'll then cover some of the investigational and clinical trial options for you to learn more about those.

Items and treatments that are coming down the pipeline, and finally, we'll give you resources to learn some more. At this point, I would like to hand it over to Kim to be able to go into the introduction of the urinary tract anatomy.

>> Kimberly: Thank you. We'll start out talking about the bladder in general and in relation to spinal cord injury. What the first slide is showing, and everybody in the audience with a spinal cord injury, or

spinal cord related disorder, knows that the bladder is very important when you have an injury. This is information from a survey that I published in 2004. It was information obtained directly from a large population of people living with spinal cord injury. And they were asked to rank different physical functions in what would be the order of most importance to them. To regain. You can see that the autonomic functions, the sexual function, 2 and bowel are rated very highly to people with spinal cord injury. The bladder, and bowel, are rated while. We'll go into the bladder function and in May we'll have a webinar on bowel function.

Just about everybody with a spinal cord injury, no matter the level or severe or mild it is will have some problems with bladder. And the importance of that to people living with spinal cord injury is not just based on my study. There's been a number of studies over the last 12 to 15 years that have consistently shown that bladder, ball, and autonomic function is very, very important to people with spinal cord injury.

So what is the bladder? What is it made of? [indiscernible] or are there other organs with it. What kind of voiding dysfunction occur after spinal damage. And what are the different classifications of bladder management methods that are out there for individuals.

First, let's talk about the urinary tract system. This is showing your kidney. You have two of them. And you have a tube, basically, called ureter. It connected the kidney to the bladder. The ureter.

You have two of those. And that's considered to be the upper urinary tract. The kidney and the ureter. And then you also have the bladder itself as well as an internal sphincter, which is a muscle. And you have the urethra which is where if you are cathing, that's where the catheter goes. If you are voiding, the urine goes out there. And there's an external sphincter there. The bladder, the two sphincters and the urethra are considered the lower urinary tract. You want to maximize, after spinal cord injury, in relation to the bladder functions is everything that you can do to lower urinary tract that prevents damage to the upper urinary tract. And as we go along, you'll see how it works together

Paragraph the whole thing is involved from the kidney to the external sphincter. How do you normally control the bladder? The brain and spinal cord are very much important in controlling the bladder in a regular, healthy individual. So the brain and spinal cord are connected. They make up the central nervous system. Down here in the lower part of the spinal cord are nerve signals that actually go out to the bladder. They go to the internal sphincter and then there are signals that go to the external sphincter. When you have a spinal cord injury, these, the control of these signals gets altered. That's why you have bladder dysfunction.

Now there's two different types of bladders that you may have heard of. Some of them are hyper active bladders and some are what they call flaccid bladders or leaky bladders. The general difference in

whether or not your bladder is like that is most likely related to whether your injury was down here at the lower end of the spinal cord. So if your injury is down here in the lower part, it damages and kills the cells that provide the input into the bladder, then you basically have a fully paralyzed bladder and it's considered to be flaccid. An example, it doesn't have spasms like a hyper bladder does. If your injury is anywhere above, at the top level, you have damage, but the cells down here are intact but not receiving any information, you can get hyper active bladder. We'll talk about that in a little bit more detail in a minute.

When it comes to void dysfunctions after spinal cord injury, one of the big things that can happen is hypertrophy of the bladder wall. Basically what it means is a thickening of the bladder wall. That comes from when you have a hyper active bladder. Just like I said in the slide prior to this, if your injury is anywhere in the upper portion of your mid to upper portion of your cord, you still have all of those neurons that control your bladder, then just like the way that we can get hyper active muscles in our legs and in our trunks below the injury, the spasms that happen there, our bladder can have hyper active input. The bladder wall can start having spasms. If you have that for a prolonged period of time you can get thickening of the bladder wall. That's an example here at C. And this is non-injured at B. And the C is the bladder that had spinal cord injury for a specific period of time. You can measure the thickness of the wall and you

can see it's much thicker than it is here. That's because there's repetitive spasms of the bladder over time.

So one of the things that can happen with hypertrophy and hyper active bladder is that the bladder starts spasming all the time. And those spasms cause contractions where it's trying to empty the urine.

So you may get contractions before the bladder is completely full.

Normally, what happens the bladder fills into its got a signal that it's ready to empty. When that signal comes, the external sphincter opens and then the urine just squeezes out. Normally, there's not -- it's either filling or emptying. Filling or emptying. There's normally not repetitive spontaneous movement of the bladder wall related to [indiscernible]. When you have this continually, you have a thickening of the wall, you get the bladder contracting multiple times and you can get leaky urine. Even if you have a hyper active sphincter. You can get leaker urine.

You have damage to the lower part of your spinal cord, and this sphincter is no longer getting any kind of input, then it would be constantly leaky. It's a little bit different than if you have the hyper active bladder and the spasms frequently happening, you may get small drips of urine every now and then that are causing incontinence or it may never -- or you may never have a leak. You may have the sphincter being tight all the time.

What that is called is on our next slide. It's actually called dyssynergia. This happens when you have the bladder constantly

contracting from the hyper active input. You have this sphincter constantly closed because it's not getting any regulation from the spinal cord or the brain that the cells are still there. The injury is above the lower part of the spinal cord. So the sphincter will constantly be closed. The dyssynergia is the sphincter constantly being closed. It's underactive, not getting used or controlled. Then you have the overactivity of the bladder. The dyssynergia moving in non-rhythm, basically.

This can be a difficult problem because if you have constantly filling of the bladder and for whatever reason you are not able to void, and you have the constant contraction of the sphincter, your bladder can continue filling and filling and filling. You can actually get reflux up the ureter up to. And you can get increase in infection. And the increased pressure can cause damage to the kidney as well. We want to avoid that. And the full bladder can also autonomic dysplexa which we will go into a couple of slides.

What are some complications from poor bladder management? I just described some of the kidney injury problems that can happen. But one of the biggest ones that many people obviously know is that you can get bladder infections or urinary tract infections which are typically in the bladder. They can be in other parts of urinary system as well. You have symptoms and repetitive have to take antibiotics that can create other problems down the road where your body doesn't necessarily respond to the antibiotics.

If you have a very good bladder management program for you, and it's working for you that will help you reduce the probability of having infections. I also mentioned it's important that any pressure or urine go backwards up into the kidney so you don't get damage.

Urinary tract damage, you can get lower urinary tract damage from doing intermittent catheterization. And autonomic dysreflexia, we'll go over. But more importantly, if you lose control of the bladder, you can lose independence. And it's a bad mess. Many of us have gone there and we don't want to go there again.

We'll talk about dysreflexia and then into management. Talking about the autonomic nervous system which controls pretty much all of the automated functions in your body. You can also call it dysreflexia hyper because it's basically an overload in your system.

The autonomic nervous system involves the sympathetic nervous system. This is what we call our fight-or-flight response. You get a sudden onset of adrenaline and it helps you automatically flee.

Quote, end quote. Basically, it's a big warning sign. And then you have the parasympathetic nervous system. We like to call the parasympathetic the rest or digest nervous system. It's taking care of counterbalancing the sympathetic nervous system. So your body is pretty even most of the time.

What happens after spinal cord injury is you lose the regulation of the autonomic nervous system. So just to point out, sympathetic, which will be related to what I tell you autonomic dysreflexia causes blood

vessels to contracts which increases your -- actually this should be blood pressure, not heart rate. Sorry. And for the parasympathetic nervous system, that's a current balance causing your blood vessels to relax and have a decrease in heart rate.

Let's get to the dysreflexia and spinal cord injury. We have a picture here of a person that has a brain and a spinal cord coming down here. Imagine that you have an injury here. Now it's very important that for everyone to know that autonomic dysreflexia is really most common in people that have injury at thoracic level 6 or higher. The reason for that is because all of the output from your sympathetic nervous system is pretty much below [indiscernible]. When the injury is above [indiscernible] 6, you have zero control of the sympathetic nervous system. So what happens is your body senses a noxious, stimulus, or painful stimulus below the level of injury. You see, for example, if you have a full bladder, or stool, bowel, or fecal impaction, or skin breakdown, these are the most common symptoms or triggers for dysreflexia.

Your body has an automatic warning system to tell you that something is wrong. And what happens is that signal comes to the spinal cord. But because of the injury, it can't reach the brain. But it can still trigger the sympathetic nervous system, which I told you was related to constricting your blood vessels. And this causes an increase in your blood pressure. And what also happens is above your injury you still have normal control down to your heart that tries to

counterbalance the blood pressure. This is the parasympathetic nervous system. What the brain does, to the whole body rise in blood pressure, it tries to compensate.

It sends a signal from above your injuries to the vagal nerve which goes to your heart, and that's to try to slow down your heart rate.

It's trying to counterbalance the increase in blood pressure. So the problem is that the decreased heart rate is supposed to trigger a signal down your spinal cord to reduce the sympathetic activity which then would reduce the vasoconstriction, which would stop raising blood pressure, but it can't get down past the injury site. So you end up having continued vasoconstriction below your level of injury.

You end up in this vicious cycle of continually having an increase in your blood pressure. Your body is trying to respond. It's lowering your heart rate but it's not getting any [indiscernible] on the blood pressure. If this happens long enough, and the blood pressure increases high enough, it can cause you to have a stroke or bleed in the brain or ultimately die.

So we can learn what our triggers are. But if we don't stop it from happening, it can be extremely life threatening. So how do we treat autonomic dysreflexia? For providers and nurses with spinal cord injury to know. Prevention or the elimination of the cause is the most important way to treat. AD. You want to remain sitting. It helps prevent the inter-cranial pressure, that's what ICP stands for, and that helps reduce the blood pressure in your brain. Very important that

you want to find whatever is at stimulus. If it's your bladder, you need to empty your bladder. Or if it's your bladders, you need to dis-impact your bowel. And if it's your skin, you need to address that. If you can't eliminate and it doesn't go away, you need to seek emergency treatment so they can give you [indiscernible] while they're investigating. And you want to monitor the blood pressure. At the emergency room or some people will even, if they have repeated episodes of dysreflexia they can carry nitro pin. The blood pressure goes down, and you can immediately reduce, or take the nitro paste off so it stops working. You want to very much make sure once you get rid of the stimulus, get the medication that the blood pressure doesn't drop too low in the opposite direction.

Okay. So now I mentioned the four. We'll get into a couple of bladder management options and Jen will go into the device options. You preserve your upper tract. And minimize lower tract complications and you want to [indiscernible] management schemes that fit your lifestyle.

There are several different options. Obviously, the most common option that mean people use is with intermittent catheterization. That's where every four to six hours or so you put a catheter through the urethra so it goes into the bladder. You empty the urine and it take it back out. There are many, many different times of catheters out there. It's a matter of your preference and what works best for your body.

There's also a CREDE, Valsalva maneuver, pressure to cause the bladder to empty. And indwelling catheterization through a Foley inserted through the urethra into the bladder. It stays there. And the urine goes into a bag. Or a super [indiscernible] catheter which is surgically inserted from the lower abdomen area straight into the bladder. It stays there. Goes into the bladder. Operating on the same principle as regular Foley catheter. You have a tube coming out that empties into the collection bag.

You also for men can do external or condom capping. Basically, an external condom catheter that goes over the penis and then the bladder can spontaneously empty on its own into a collection bag.

There's also medications that can work in addition to common ones that reduce bladder spasticity. Many people may be familiar with Ditropan, or oxybutynin. Working on the spontaneous spasticity of the bladder. Here these other medications, alpha blockers are trying to reduce the actual resistances in the urethra to reduce the pressure. And some people have very severe spasticity in the bladder and they have Botox injections.

You can also do reflection voiding, which the little cat is demonstrating here. Basically, when the bladder is full you have, if you don't have the dyssynergia it can reflectively -- and used with the Valsalva. And there are interventions that you can see here below the picture.

These they have different pros and cons. All different options have pros and cons. You definitely want to know how is the core of your

lives affected by the bladder management and the different surgical options before you [indiscernible]. I will leave it here and hand it over to Jen where the one strategy that is under developed that is in relationship to catheters is called a spinal singularity. This is the connected cap. Not available on the market yet. The connected cath. It would be basically a semi permanent catheter that goes into the bladder. But it has a pressure sensor that can test the pressure within the bladder and trigger release when the appropriate pressure is reached. Okay, Jen, I will hand it back over to you.

>> Jennifer: Great, thanks, Kim. Can everybody hear me okay?

Great. We'll go into some of devices as well that Kim led us into one device that's being investigated. When we go into some of the other medical devices, first we'll address the once currently on the market and new ones being developed.

The first one he would like to introduce to you is what is called the fine tech brindly or also the VO Care system. It's implanted, fully implanted with external controller. Both FDA and CE Mark approved in Europe. Basically, what this device is, it uses an implanted electrode with an external controller. That when this external controller, when the person presses the button to activate the stimulation, the stimulation goes through the antenna to the electrodes, the electrodes stimulate the gladder to contract and therefore empty the bladder.

It's been around for quite some time. It requires surgery. And a

dorsal [indiscernible] which is a snipping of the spinal cord. It offers three different options for one but the phenomenon controlling bladder, one for controlling bowels and one for controlling an erection. It's an on demand function. Something that's fully implanted. And the user person controlling the device, can decide when they want to activate and when they want to turn the stimulation off. It's FDA, CE Mark approved. It's available in Europe by fine technical medical. It's called VO care here in the U.S. It's not a distribute -- there's not a distributor here in the U.S. even though it's approved. You can find more at the Fine tech care website.

And the sacral nerve stimulator. It's a simple implantation that stimulates the sacral nerve which is at the bottom of the spinal cord. This is commercially available for overactive bladder management. It also can be implanted for fecal incontinence. We have a picture to give you an idea of what it is. An implanted lead or electrode, if you will, to the sacral nerve. A connecting and the control device as well. Typically, before someone goes into a surgery to get the device, you go through what is called a trial implantation. They'll do a quick implantation that is not the permanent electrode lead to see if you are a good respondent for that device and if it works specifically for you. If it does, you can proceed to a permanent implantation. If it doesn't, you can seek other options before you go through the full implantation and surgery. This device has been available under the brand nymph inter-STIM. Brand name inter-STIM. We have a link here to be able

to talk to other ambassadors and find a physician near you. The device has had a new entrant into the market, sacral, nerve stimulation. Offered from Axonics and here's the link to learn a little bit more about the option as well. Again, it's a device that's FDA approved. And it's, again, an implantation device, so it requires a surgery.

Another potential bladder management tool from a medical standpoint is the tibial nerve stimulator. The way this works is that there's a small electrode lead, if you will, that is placed or inserted right around your ankle. Then there's that electrode is connected to a battery powered stimulator shown right here. Typically, a 30 minute treatment. Providing mild stimulation through the lead going up your leg to the tibial nerve to be able to exercise the bladder wall or the pelvis muscles.

Some this device has been around for quite some time. A noninvasive device. And the most of them that were on the market today are considered external devices. Again, it's a small needing that goes in through the skin. The urgent PC, it's been around for quite some time. It's kind of the market leader, if you will. You can read about it, and link to it here at this link.

Nuviant is another company. They're a new company that came on the market. They're testing an implanted wireless lead instead of having a wired lead, if you will, with an external controller.

Medtronic entered into the market with a device called NURO. FDA

cleared in 2013 for the treatment of overactive bladder and the symptoms of urinary urgency, frequency, and as well as urge incontinence.

Estimate guard is another new company -- STIM guard is another new company. Testing a wireless lead stimulation for tibial nerve stimulation. Right now it's being tested over in Europe for CE Mark. And finally, Blue Wind medical out of Israel. They are working right now for an implanted wireless tibial nerve stimulation system. Currently, they're working in trials in Europe right now to gain CE Mark. Those are kind of the different devices that are available for when a treatment is called tibial nerve stimulation.

For those of you with the lower level injuries, there's also one called the pelvic floor stimulator. It's barned for quite some time. It's been used in the past typically for women after they give birth to restrengthen the pelvic floor wall. There's quite a few different companies. I won't go into all of them specifically, but really it provides stimulation to that pelvic floor muscle to improve the opening and the closing of the urethra. These are typically probes that are inserted and providing a mild stimulation treatment for a periodic period of time. However, those parameters are set by the clinician. It's basically a therapy tool or a tool just to use to restrengthen the muscles within the bladder wall.

There's a lot of different devices under investigation right now. We just wanted to kind of go over some of those briefly. One is called the

epidural stimulator. Epidural stimulation has received quite a bit of press. There's been a variety of articles and reports investigating epidural stimulation as it relates to bladder restoration. Most recently, there's been a published study looking at bladder voiding using epidural stimulation. Again, these published studies are in the preclinical stages and there are some anecdotal responses for some of the epidural stimulation, clinical trials going on been but, again those are case studies and not necessarily scientific studies. Again, it's in the preclinical stage but it does have some very promising possibilities for the future.

The other investigational pathway, if you will, is the urethral stimulation. This is a picture that Kim introduced earlier on in the webinar talking about the urethra. What they're looking at is being able to use electronic Rhodes and stimulation -- electrodes and stimulation for the urethra here. And a couple of case studies have been published using human in human studies with subjects that have what is called an Asia A, meaning fully left spinal cord injury, and they're able to determine that the stimulation provides, and provokes a stimulation for emptying the bladder. It's promising but in early clinical stages for humans. And, again, there needs to be more studies and it's still in the investigational stage.

Similar to the urethra stimulation is the sphincter sensory stimulation. Kim described what the sphincter is. Using sensory electrodes to sense when the bladder is full and using stimulation to open and close

the sphincter. Again, this is in preclinical stages. It's not in humans as of yet, but, again, the animal models are showing promising pathways for this type of stimulation as a device. Dermatome stimulation is another path. You think of dermatome, they're nerve fibers originating from a single dorsal root nerve. The thought is to be able to use patterned stimulation to the dermatomes to be able to reduce the urethral reflexes that happen with people with chronic spinal cord injury. The thought is that this stimulation, if we can come up with the right patterns, would be able to suppress that type of reflects or that type of spasm, if you will, that will occur to try to empty the bladder.

Pudendal nerve block stimulation. It's been in clinical trials for some time, and showing great promise. Here are pictures where the pudendal nerve actually is. They are looking at blocking nerves. Instead of the nerve constantly sending stimulation to the bladder to be able to contract it and leak, if you will, is to be able to block the nerve to relax the bladder. In the same sense that Kim mentioned some of the pharmaceuticals, the alpha blockers used to relax the musculing, what they are looking at for the pudendal in a similar way using the medications to relax the bladder. Again, that's a very promising stimulation for both the bladder and the sphincter that we're finding in terms of investigation.

And finally, another investigation device, this is actually a corporate sponsored device called femme pulse. It's a femme pulse. It's a

simple device implanted specifically for females with overactive bladder. Using small electrodes to be able to stimulate the opening and closing of the bladder. Again, that's still in very early human stages but shows promise for overactive bladder.

There's one other device that I want to spend time with. A new promising one. A lot of the devices have been talking about implanting, inserting, or being in a clinic, but this one is in human clinical trials but I think it's really interesting. It's using combined efferent and afferent electrical stimulation. Basically, it's providing stimulation for the dorsal penile nerve or females for the dorsal clitoral nerve. What it is basically a surface stimulation to be able to have the bladder inhibit to be able to obtain the lower stimulation amplitudes that are typically used in order to control the bladder and those sensations.

So right now it's in clinical trials with 20 participants. And the results have not been published yet, but we're expecting to see some results presented here in the spring at the American spinal injury association meeting. We hope to see some results from this study as well.

Again, this is a surface stimulation device used for stimulation to be able to control the bladder and the reflexes that happen with the bladder. I think this is really an exciting one that's not necessarily an implanted device but an external device.

So we've gone over a lot of those, what's available, what are some of the devices available, and what is being under investigation, and we

want to give you some resources as we close out this webinar, and for you to learn more. We left you with talking about a lot of these investigational devices and the best place to find out about those in human clinical trials is going to www.clinicaltrials.gov. Searching, and put and in all caps and whatever nerve stimulation you are interested in. We were talking about the pudendal, for instance, or nerve stimulation, you can find those studies that may be right for you. We mentioned the devices through the Cleveland FES Center. In terms of spinal cord injury. And NeuroTech Network provides two fact sheets for free. The first one is the bladder management fact sheet. You can find it through the link. You will find different devices that we discussed today and more in terms of fecal incontinence as well. We also offer a fact sheet which was specifically for spinal cord injury. We created this in conjunction with the United Spinal Association to be able to learn more about the neuro technology devices specifically for spinal cord injury. So as we mentioned earlier today, that we originally talked about this webinar being for both bladder and bowel. We're starting to round out the hour and not even touched on bowel yet. We're going to offer a webinar specifically for bowel management on May 5, 2016. We wanted to give you an outline of what to expect for that webinar. We'll talk about how the bowel works. What happens to the bowel system after a spinal cord injury? We'll talk about some of the nutrition options and the importance of nutrition for controlling your

bowel, and the medications and complications and we'll round it out with resource and you can learn more about managing your bowel system. I think that rounds us out. We wanted to give you this slide for both of our contact information. We would like to open it up for questions. If we don't address your questions, both of our e-mail addresses are there, and you are more than welcome to e-mail us. Bill, we would like to hand it back over to you so if there are questions we can answer.

>> Bill: Thank you, Jennifer, and Kim, for that presentation. A lot of ground covered, obviously, and we do have some questions. So let's get to those.

This is a "did you know." Did you know the national association for confidence, NAFC is a great resource for consumers and caregivers to find out the latest information about bowel and bladder management. Would you like to comment on that?

>> Jennifer: Yes, actually whoever put in that comment, that "did you know" thank you for mentioning that. We do have a link to the National Association for Continential on the bladder management fact page, NeuroTech Network, and you Google, but thank you for whoever mentioned that. That's a fantastic resource for people

>> Bill: Thank you for that. Go ahead, Kim.

>> Kimberly: Another good resource is the Paralyzed Veterans Association website. They have many different consumer -- actually a consumer packet basically. They have one for bowel and bladder.

And that's on their website. PVA.org

>> Bill: Very good. Let's move along. And a question from a person. I think it would probably be helpful to try to address both the female and male versions of this answer, for this problem, if they differ. The question is, I am P10 complete paraplegic who does intermittent catheterization. I will be traveling abroad, Germany, for the first time this summer, and looking for suggestions for cathing during the flight or before or how do you handle the long distance flight situation?

>> Jennifer: Kim, do you want to address that? Both of us have traveled overseas.

>> Kimberly: We can both do it. We both cath different ways.

>> Jennifer: That's true.

>> Kimberly: If you want to start out.

>> Jennifer: Sure. One of the things I would look into is what type of airplane you fly on. Some of the airplanes, A380 and the bowing triple 7, and the Boeing 787 has the option as well. The bathrooms open up to make them wheelchair accessible and have an aisle chair on board. Look into what airplane you will fly in overseas. If you are on one of the airplanes, you can get in an option to actually use a restroom. Believe me, it was a great surprise to me when I first blue on the Boeing 777 to use the bathroom on the airplane. A
What I do when they don't have a wheelchair accessible restroom, when on the long flight, I put in a temporary Foley catheter. And a

bag. And that's what I use while I am on that long flight. So that's an option. You can work with your urologist to be able to supply that information for you and be educated by a nurse on how to do that yourself to be able to manage your bladder while on those long flights. Kim?

>> Kimberly: Yeah. And I think what -- actually what I will recommend is what Jen just recommended. And that is to be safe I would have access to an indwelling catheter that you could have during the flight and have a collection bag. You may hear in conversations with different people, and I certainly have done it myself before I figured these things out, but that people will often dehydrate themselves or not drink when on flights so that they don't have to go to the bathroom frequently. If you are going to be on a long flight, you definitely don't want to do that. You don't want to end up risking some kind of infection once you get to where you are going. Having an indwelling catheter option is good to be on the safe side

>> Bill: Jen, a question on the 777. I should know this, but I have forgotten. Is that the one dubbed the Dreamliner?

>> Jennifer: That's the 787

>> Bill: To come. The quad cabins and the quad restrooms that are convertible into an accessible restroom when needed.

>> Jennifer: Mm hmm

>> Bill: Thank you. The next question. How can we identify our AD triggers, autonomic dysreflexia triggers?

>> Kimberly: Okay. One thing I did not include on the slide were some of the very common symptoms that people have.

One really big symptom is that you could get a very strong pounding headache if you start to get chilled that you are not sweating. If you have an increase in your spasticity or if you start to get goose bumps above your level of injury. Those are -- or sweating above your level of injury or your face starts to get red, flushing above your level of injury. Or nasal congestion is another one that happens above the level of injury. Those are all different types of symptoms you can have. Different people have different triggers that will [indiscernible] that will come on more predominantly. That's what you need to start identifying. If those start to come on, and there's nothing, you know, that you know has happened to you, you should start looking at what is a trigger of dysreflexia.

>> Jennifer: Exactly. If I could just step in here real quick. Bill, you can help us with this.

I believe that United Spinal still offers this as a little wallet card explaining what the symptoms of AD and what to do. Sometimes some emergency professionals might not be familiar with autonomic dysreflexia. Do you still offer that reflects?

>> Bill: We do. Thank you very much for flagging that. We have written a first person version of an AD card that covers all the bases. It's written very authoritatively. One of the hospital member partners has contributed the medical device segment and takes credit for that

as a medical provider. It identifies to its medical personnel or to emergency medical personnel, I have a spinal -- I am experiencing autonomic dysreflexia. I have an injury above this level. You need to do A, B, C, D. There's a course. We have those available. Anyone wanting to write or call, we would be happy to provide those cards to you.

We have a trifecta, if will you, of questions of it's ever popular UTI question. Specifically frequency of recurring UTIs and how best to approach that. Three question, pretty much addressing the same issue from different perspectives. Any vice in general about recurring -- any advice in general about recurring UTIs not responding to treatment?

>> Kimberly: I guess one of the biggest things I hear from urologists on whether or not the UTI is showing symptom, clinical symptoms. And that's where they do want to treat. Because most bladders have a certain degree of bacterial colonization in them. If you are not showing actual symptoms of a UTI, they typically don't treat it. It's up to the discretion of the clinician. Common things you want to start to investigate, if you have recurring UTIs, what is your bladder management system and is it -- if it's intermittent cathing, are you doing everything in a clean way all the time. If it is indwelling catheter, are you leaving it in too long when I change it? Is it not done in a clean manner, those kinds of questions can you look for? Many people la drink cranberry juice or take cranberry pills even

though there's not technical evidence that it helps to reduce the urinary tract infections many take that and find it beneficial to them.

And also remaining hydrated

>> Bill: Thank you for that, Kim.

>> Jennifer: From a UTI perspective, Kim can comment too.

Managing the bladder, our bodies change over time. For those of you with chronic spinal cord injury for quite some time. Five to seven years that work well for you that might change over time. Therefore you have to look in terms of what are the new interventions different pharmaceuticals, maybe different ways of cathing as your body changes as you age. I believe you have done some studies on this.

Is this right, Kim?

>> Kimberly: I have done studies on myself because that happened to me a couple years ago. After 20 years of great bladder management and everything under control and nothing going wrong, all of a sudden things started to change. And I ended up switching to drinking cranberry juice. And the pills I had been taking forever. I was not thinking that it was going to make a difference, in fact it did for some reason. When you have had a system that's been working great, it can change the spinal cord injury spontaneously pen you work by process of elimination. And then a little bit of experimentation with the guidance of your physicians to see how it will alter your seem.

>> I think that goes back to the question of UTI as well. You may be have been using a method for quite some time that worked well but

you are getting a lot of recurring UTIs. You may be looking back at how your body has changed over time. A lot of it is a bit of investigation work between you and your urologist. And make sure you have an urologist that's willing to talk to you with the types of options you could have. And bringing something like this webinar that we brought to you with the resources can help drive that conversation as well.

>> Bill: Thank you for that. We have many, many questions pouring in. We won't, unfortunately, be able to get to all of them. We want to let the audience know that any questions remaining unanswered you can pose directly to the panelists. You might want to take a moment to jot down their contact information on the slide that's on screen right now. We want to hit on a couple of the questions. I am going to pick around here a little bit with our remaining few minutes as to some that might require some guidance. From this particular individual who identifies as having an injury level of P5 thoracic level No. 5 complete. Why would my capacity of my bladder suddenly go from 500CC to 300CC?

>> Kimberly: I can -- I can start. Typically, that happens with time post injury as the bladder is hyper active and the wall starts to thicken. The capacity of the bladder to expand and hold as much as it used to starts to restrict. So that, you know, with time the bladder will be able -- it's able to hold less volume. It's not as elastic, if you want to think about it that way

>> Bill: Got it. Somewhat related but different problem, I would imagine. While swimming, I notice that my bladder fills after about 40 minutes. My UCI level is thoracic level No. 12. Lumbar 1. Is this typical?

>> Kimberly: Jen, would you like to try --

[Overlapping Speakers]

>> Jennifer: Jen that happens to me too. And this is more of an experience from a person with a spinal cord injury that swims rather than a scientific answer. A couple of things are at play here. One is that typically we have swelling in our feet. That starts to drain. Part of that draining is through the bladder. Therefore your bladder will fill up. Because you are in a different fluid environment, that could be the case. It also could be the case that there's just some liquid that's going up into the flaccid urethra into the bladder and being able to leak it out. So there's a couple of different experiences. But that's a common experience, and I experience the same thing when I swim. I am sure, Bill, you want to touch on that as well, because you swim

>> Bill: Ditto. I don't know if it's pressure or what. But it is a thing. For whatever reason it's pretty typical. So I have another question from someone identifying as T2 Para thoracic two. A Foley catheter for the last year. After an upcoming flap surgery will there be problems going back to intermittent catheterization?

>> Kimberly: No. There shouldn't be an issue going back and forth from regular intermittent catheterization to Foley catheter and back.

Unless there were some sort of damage to the urethra. Jen, do you have any input?

>> Jennifer: No, I think you answered that correctly. You might see as you go between those is to get your bladder back on schedule and get you back on your regular schedule from being from a Foley, from being, I assume that you were probably in the hospital or in some type of acute care where you had a Foley going back to intermittent. You might see a bit of a change when you immediately do it, but just a matter of getting yourself back on your schedule

>> Bill: Great. We've pretty much exhausting our time. Thank you to the audience for your great questions. There are more here to be answered. So please don't hesitate to address them directly to Jennifer French, and Dr. Kimberly Anderson-Erisman. To help you in the right direction. On behalf of United Spinal association I would like to thank Jennifer French of NeuroTech Network, and Dr. Kimberly Anderson-Erisman of the Miami project so much for sharing their personal experience and professional knowledge with us today on "Solutions for Bladder and Bowel Management." Thank you, Jennifer, and Kim.

>> Kimberly: Thank you.

>> Jennifer: And thank you all for attending

>> Bill: A programming note. We got a report from an attendee that the handout, the links were not hot links. So we will do our best to ensure that the archiving version at www.unitedspinal.org will be a

version with hot links. Solutions for bowel management will be presented by Jennifer French and Dr. Kimberly Anderson-Erisman on May 5. Look for that registration announcement.

The next presentation will be "How to Get the Right Wheelchair That Works for You" with a team of distinguished panelists.

Including Alex Benylwith from our Policy Department. Sign up to receive our webinar.

This will end today's presentation. Thank you all for your attention.

[Webinar complete]

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