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>> Good afternoon. Thanks for joining us for the Webinar, rehab is over, now what. I am Bil Fertig, manager of the NIA resource center and I will be your moderator for study's presentation. Today's Webinar is one of several spinal cord injury association will be hosting and all of our Webinars will be archived on [WWW.spinalcord.org](http://WWW.spinalcord.org). Today, our presenter is Ms. Jennifer French, NBAA and panelist Kim Anderson-Erisman.

Jennifer French became a paraplegic in a completely spinal cord injury in 1998. She is an active user of the functioner FES, implantable stand and transfer system, which she first received in 1999. She also represented team USA at the 2012 Paralympic games.

As a user of neurotechnology, who has reaped its benefits she is cofounder and Executive Director of the nonprofit organization known as Neurotech Network. She currently serves on the advisory boards for the FES for cerebral palsy project at Stanford, the Browne University institute for brain science, and advanced platform technology center in Cleveland, Ohio.

Dr. Kim Anderson-Erisman is a research associate Professor and director of education for the ma'am project -- paralysis at the University of Miami Miller school of medicine. Her research has focused on transitional investigations and bridging the gap between basic science, clinical science, and the public community, living with spinal --

>> So I think we lost Bil there for a second, but I want -- this is Gen French and I would like to start our Webinar and complete the introduction of Dr. Kim Anderson-Erisman. It is a pleasure to have her here with us today. She is the director of education at the University of Miami and the Miami project to cure paralysis. She has been spearheading a lot of the

translation of the science that's going on at the Miami project and she has a world of experience of not only what's going on in spinal cord injury research, but also reaching out to those living with spinal cord injury and really helping to translate what's been going on in spinal cord injury rehab, in the world of care, as people living with spinal cord injury long-term, but also what's going on in the research world as well. Thank you, Kim, for joining us. It's great to have her here today.

As we go on through our presentation today, you're going to see, in your Webinar, if this is one of the first ones you've joined us, you'll see a little question box that's over on your screen. If you have any questions during the Webinar, please type it in there. And we'll be able to address your questions. We will have a question and answer period at the end. If we don't get to your questions at the end, we will have those e-mailed to us, and we will be happy to respond to them afterwards in the event that we don't have enough time to address yours. So we want to make sure all of those questions are answered, and we address any issues that we might have within our audiences, and what you guys might be thinking out there as well.

Also, as we're going through this presentation, if you, as the audience, have any questions or have any suggestions, in terms of what you might like to see in Webinars going forward, and into the future, please feel free to add that to the question box as well and we can take those into consideration. I know that united spinal and the national spinal cord injury association looks at that in terms of their planning of what to offer you all and your audience here in the future.

So as we go through this presentation, we wanted to introduce you to both of our organizations. Kim, would you like to introduce the Miami project?

>> Kim: Yes. The Miami project is a research center. It is based within the University of Miami, down in Florida. And the Miami project is dedicated to finding more effective treatment and ultimately cures for paralysis resulting from spinal cord injury. And we have many different faculty here looking at all of the different issues with spinal cord injury, from different basic science on how to repair damage, as well as clinical studies of the more long-term issues that people experience.

>> Jennifer: Thanks, Kim. And we will introduce you to Neurotech

Network, we're a nonprofit organization and we focus on education of and access to neurotechnology devices, therapies and treatments for people with impairments. Their caregivers and the medical professionals who care for them. So we have a lot of free resources that are available on our website and we do a lot in terms of not only education of consumers and people living in those environments and caregivers but medical professionals as well. That gives you a quick introduction to our two organizations, before we go into really what happens with rehab.

So our legal people make us go ahead and go through this disclaimer so we're going to get through it really fast. So the information that's presented in this session is not meant to replace the advice of the medical professional. You should consult a healthcare professional familiar with your specific case, concerns, and conditions. We highly suggest you take this information to a trained medical professional familiar with your case to discuss options that are best for you. We got through that.

Now that we're through our disclaimer let's get into the good stuff. What we're going to talk about today -- and the session is titled rehab is over, now what -- is that we want to go over what is the importance and the need for rehab, post-rehab programs. So we'll review that briefly. We'll go into what different types of programs there are available out there, and what questions to ask before you want to get involved, any type of post-rehab program, and finally we're going to give you some resources at the end, to be able to find those types of post-rehab programs in your area or closer to you.

So why are post-rehab programs important? So we know that inpatient and outpatient stays have gotten shorter and shorter over a period of time. But the other side of the coin is that we've also learned that the human body only heals so fast and we learned that -- actually the healing process takes quite a bit of time. So what kind of filled this gap, if you will, between these shorter stays and us learning that the body does have this longer healing process, is what's called these post-rehab programs. So once the intense rehab programs are overwith, these post-rehab programs are starting to fill that space.

So why is exercise important to people with paralysis. Well there's lots of reasons actually. There's high incidence of obesity amongst people with paralysis. CDC has reported that people with disabilities are 58% higher incidence of obesity compared to the able body people. That is a big

concern for people with paralysis. There's incidents of cardiovascular disease, diabetes, low metabolic rates, pulmonary disorders, including respiratory disorders, osteoporosis, pressure source. We can go on but that hits some of the big bailiwicks.

The take-away is two things. One, exercise has the same impact on people with paralysis as it does with able-bodied people. So you really need to look at how important you need to fit exercise into your daily lives. And, also, that you can't maintain any gains that you've made with exercise if you stop. So if you want to hit a goal of let's say losing 10 pounds and you start exercising, and you lose those 10 pounds, as soon as you stop you're not going to be able to maintain those gains. So it's very important to fit exercise into your lifestyle and that is an evolution process as well.

So one of the things that we kind of also want to help define is that we talk about exercise, but exercise for rehabilitation and exercise for fitness are two very different things. And I think it's really helpful for you all to understand the differences between those. So when we talk about rehabilitation, rehabilitation is the treatment or treatments designed to facilitate the process of recovery from an injury, illness or disease, as to a normal -- as to normal a condition as possible. So rehab, or exercise within rehabilitation, focuses on these four things. It focuses on restoration and recovery, focuses on compensation, for instance a paralysis or for involuntary movement, muscles, if you will, it focuses on limitations and adjustments, and it also focuses on gaining independence. So that's the focus of rehabilitation. And when you have exercise and rehabilitation.

To the contrary, fitness is physical activity that's planned, structured and repetitive for the purpose of conditioning any part of the body. So it's really more for conditioning. And the focus of conditioning is to improve health conditions, to maintain or improve fitness or wellness and prevention and performance. For instance, if you're stale fit to perform better while performing wheelchair basketball, or fitness so that you can perform transfers more smoothly. So, for instance, rehabilitation will get you to the exercise to help you with transfers, whereas fitness helps maintain that level. So that's really the difference that we see between rehabilitation and fitness.

One last point we'd like to make on this slide is that the definition of

wellness. So we hear a lot about fitness and wellness, health and wellness. We see that a lot in the vocabulary today. Wellness is an active process of becoming aware of and choices toward a more successful existence. When we talk about staying healthy, wellness falls into that large bailiwick, if you will. So when we're looking at different types of options for exercise, there's lots of different types of options that you have. There's low tech and high tech.

So we have, for the low tech side, there's things like Therabands, weights, yoga, dance, ropes, aquatics, adaptive equipment in terms of using for staying fit. That's the low tech side. We're also starting to see high tech sides of exercise, items like video gaming, and using video gaming, like boxing, or bowling, in your video games, for exercise, virtual reality, robotic or repetitive motion systems, exoskeletons, we've seen a lot about that in the media. NMES neuromuscular stimulation and biofeedback and FES, electrical stimulation.

That's an introduction as to why it is important to consider exercise and post-rehab programs, and also some of the options that you have when you're looking at formulating an exercise program. So here, I'd like to hand it over to Kim.

>> Kim: Some of the research that I have done in the past has been querying people with spinal cord injuries that what is important to them, and what they experience so that we can give that information to researchers, so they can be better informed, and design their studies better.

So one of the things that I asked, in a big survey, was what is the importance and access of exercise, to people with spinal cord injuries. So I asked individuals -- that exercise was their function. We are having a little bit of -- difficulty here with advancing the slide. Jen, can you give me keyboard access. If you look on the left-hand side of the screen you can see an overwhelming majority of people with spinal cord injuries feel that exercise is important to their recovery. However, if we asked individuals about whether or not they currently have access to exercise, we see that about 56% do have exercise -- [Audio Skipping] -- however only 12% of those individuals have access to somebody that can guide them or -- [Audio Skipping] -- therapist -- [Audio Skipping] -- regimen to make sure they're really getting -- [Audio Skipping] -- that exercise is important. However the majority of people do not have access -- [Audio

Skipping] -- to oversee -- so we went to another study -- [Audio Skipping] -- injury, what they felt were prevalent -- or what were their barriers to participating. So we know everyone -- or most people like exercise and feel it's important, but not everybody engages in exercise because there is a lot of things going on in life. What we identify from our survey was some of the most prevalent barriers expressed by individuals with spinal cord injury. So the number one most prevalent barrier that people -- was actually the lack of energy to engage in exercise.

The second barrier that people stated was the lack of motivation. The third barrier was lack of time. We know that it takes extra time to do everything with spinal cord injury so there's only a certain amount in the day and we have a lot to do.

Another barrier was not knowing where to exercise. This is really important. And, finally, the cost of the program. So we're going to address these last two issues here later on in the presentation.

We went on to ask a few more things and we wanted to know, okay, we just identified what are the five most common barriers that people state, with spinal cord injury. However, what are the most impactful barriers.

Now, when I say impactful, I mean in really having a strong influence on whether or not someone will engage in exercise activity. So the most impactful barrier was somebody thought that exercise could actually make your condition worse. Now this is not necessarily true in all cases. So we do have to know the type and extent of exercise to do. So that's where having some guidance can be important.

Some people felt that when they said they were too lazy to exercise, that was actually a really big -- had a really big influence on whether or not somebody was motivated to exercise. Another impactful barrier was the feeling that exercise is too difficult. Not knowing how to exercise really had an impact on whether or not people engaged in exercise. And lack of interest, which is relevant to the majority of the population with or without spinal cord injury as well.

So when we analyzed our data, we didn't see any really big striking differences in age, education, employment, injury level, completeness, or independence, in our survey participants, and whether or not they

exercised or did not exercise. There was a slight tendency for people in the lower income spectrum to not be exercising as much. However, that was not the predictive component.

Some of the important points that I want people to take home with, which is also what we are stressing to researchers and clinicians as well, more than half of the people in the survey reported that their physician had advised them to exercise, however less than 25% of those people actually received specific instructions from their doctor, regarding the kind of exercise that they should engage in, and how often. And this is really, really important. Because we need to make sure that the doctors are actually engaged and armed with information to give to their patients on how to do exercise.

Another important point that we discovered was that not having exercise equipment at home reduced the odds of being exerciser pretty significantly. So you could actually get some exercise equipment that you can use at your house. It's a little bit easier to engage in more often.

Finally, the lack of transportation did not necessarily decrease the odds of being an exerciser, but not knowing where an accessible facility was really important. And this is important because lots of researchers say, oh, well not having transportation is the biggest barrier to people to engage in exercise. Well that's not necessarily the case, is not knowing where to exercise and not knowing how to exercise. Hopefully we will be able to answer some of these questions for you guys today.

So, conclusions about this research portion, our results suggest that the prevalence of a barrier may not necessarily be indicative of whether or not that barrier is associated with somebody's exercise status. Highly prevalent barriers may not necessarily decrease the odds of being an exerciser while very uncommon barriers may strongly decrease the odds of being an exerciser.

One of the things we think is perhaps having multiple barriers is where people reach a tipping point of not being able to engage in exercise or not choosing to engage in exercise. And what we need to do is reduce the number of barriers.

Also, our results do suggest that internal barriers, followed by resource barriers, are the most strongly related to exercise participation. I'm going

to hand this back over to Jen.

>> Jennifer: Thanks, Kim. Leading off of some of the research results that Kim conveyed to you, we're hoping that this section of the Webinar will help answer some of those questions, particularly for people not knowing where to go for accessible fitness equipment. So there are really kind of -- when we talk about post-rehab programs, there's really three types of programs that are out there. There's the clinical programs, there's stand-alone programs, and then public access and private gym programs. We're going to review each of those with you today.

As we go through this, I just want to make you aware -- I failed to mention this, this will be available as a PDF file. So if you're trying to take notes, you will be able to get this electronically as well. We will go over this in your PDF.

Let's talk about clinical programs. Clinical programs typically are in rehabilitation facilities. A lot of rehabilitation facilities are finding they know that these rehab stays of inpatient, outpatient stays are getting shorter so they're providing post-rehab programs. When you go to a rehab facility you might ask if they have any post-rehab programs. What's unique about the clinical programs that they give access to, number one, they give you access to trained rehabilitation therapists. Typically, when it's in a clinical program you will have access to physical therapists, occupational therapists, nutritionists, those trained in the programs. They will have other trainers along with that, but you will have access to at least one trained therapist to give you guidance as you're looking at forming your own post-rehab program.

It also gives you access to a lot of rehabilitation equipment that you normally wouldn't be able to get in other different types of programs, and also be able to get at home. For instance, a lot of these programs offer FES cycling programs, although it's available at home today, you can also get access to it, if you can't afford to buy one at home you may be able to get access to it through Wendy's program. Motion robotics may give you access to that. Understanding the goal of clinical programs for post-rehab is very goal-oriented. Where those set kind of expectations of what you expect in the process, and to be able to customize an exercise plan for you. That's typical in these types of programs.

Also you want to look into the financial commitment. A lot of these



programs typically are not covered under insurance but they offer payment programs, almost like a gym membership is, if you will. So that you want to look into, when looking into a program. That's a typical structure of that program.

This is a pictorial view of what they give you access to. We mentioned FES cycling, electrical stimulation. The picture on the left, right below that is a repetitive machine. It will give you access to possibly some seating clinics to body weight support systems, to zero G systems, to FES elliptical, which is what you'll see at the bottom near the middle of the screen, also aquatic therapy for -- and also for neuromuscular stimulation as well. It also gives you access to different types of fitness program and that goes along with it as well. As I mentioned you might have access to a nutritionist.

Here are some examples of those types of clinical programs that are available around the country. All of these web links will be available in the PDF as well but this is some of those examples. For instance, beyond therapy offered through the Shepperd center in Atlanta, the Brooks program in Jacksonville, Florida, the recovery network, through the Christopher Reeve foundation, the hospital in Colorado as well as precision rehabilitation in Long Beach, and the share program through the courage program in Minneapolis. That gives you examples of those types of programs. Kim will talk about stand-alone programs.

>> Kim: So the next type of program is a stand-alone program. These are very much like the clinical programs that Jen was just talking about. However, these are not affiliated with a rehabilitation facility. They are typically specialized facilities. And you may have -- you will have access to personal trainers, and exercise physiologists, rather than rehabilitation therapists. And the personal trainers and exercise physiologists are actually really good at maintaining fitness is what your goal is. They're trained in how to develop programs for maintaining -- establishing fitness, maintaining fitness, and helping you stay healthy.

These programs are -- you do have access to specialized equipment, and I'll show you some pictures of those in our next slide. The stand-alone programs are goal-oriented. And that's really important. So the personal trainers and exercise physiologists can help you establish your goals, help you set realistic expectations and time frames, and help you create an exercise plan that is important to you.

These programs will typically have membership fees, or they will have an up-front payment, or a certain type of degree of services. And some of the equipment that you can access through these stand-alone programs, also include the FES cycling system, or the arm ergometry. You can also do some of the step training, with the body weight support system. Sorry about that. And, also, you can do aquatics, and then you can also do circuit training with upper extremity equipment.

So some locations, where these stand-alone programs are, include core, in North Ridge, and journey forward in Canton, as well as Neuroexcel up in North Palm Beach, and next step fitness, in California. Project walk, Sci Fit is another one, the recovery project and walk the line. These are all locations that you can go to their own specialized facility, you have access to some guidance, and you can use many types of equipment.

>> The final type of program that we're going to review today is the public access or private gym programs. So for the locations, they're typically in a gym, for instance maybe a YMCA in your area has an accessible program, wellness centers that are community wellness centers, will have programs as well as some parks and recreation programs, depending on what type of city that you live in, where you might have access to this.

The difference with the public access or the private gym programs is that you don't have -- you either have limited, or you have no supervision. So the two previous programs we showed you, either you have access to a trained professional, a trained therapist, or an exercise physiologist, or possibly a trainer. In the public access and private gym programs, there might be personal trainers, but you can't rely on that. So that's definitely something you want to look into if you're looking at joining a private gym or getting some private access, to see if there is, because it's not always reliable.

You will have access to fitness equipment. We'll review what types of fitness equipment that you can find in both public access and private gyms. They are not always consistent. That's one thing you need to consider when you're looking at a public access or private gym program.

There is, also, no structure or limit structure in these programs, meaning that the two previous programs were very goal-oriented, you had

somebody to help you pull together an exercise plan for you that's familiar with working with people with disabilities. In public access and private gym programs, you might not get that structure and you might not get that monitoring of a trained professional. With the exception, if you want to hire a trained professional privately. But that's a different scenario. But we're talking about public access here. So be aware of that.

You know, the benefit of these private gyms is they can be very affordable. They can have very low cost fees or be free altogether. So that's something to consider if somebody has some -- if your financial issues, when you've looking into different types of programs.

So what type of equipment can you find when you look at a public access or even a private gym. And, again, a private gym could be free. It could be something that you set up in your own backyard, or in your own home. So when we first started and going over the importance of exercise, we were talking about Theraband and some of these low tech option that you can have at home. These are things that you can set up in your own home. But, for instance, YMCAs or gyms can also offer different types of weight equipment, or ergometry that you can use to help get some cardiovascular. Also we're starting to find that parks and rec programs are starting to put what's called fitness zones into their parks. Over on the right-hand side of the screen you will see some of that outdoor fitness equipment. Those are free access. And to be able to find those, again you'll want to check with your park and rec department. But those are starting to pop up around the country as well. As well as you might find some health and wellness programs in your area.

So when we look at wanting to join a program, whether it's clinical or it's a stand-alone or it's a public access or a private gym program, there's some very specific questions you should ask before you want to join these programs. And this will help clarify, for you, if that post-rehab program is what you're looking for, and it's what you need, or what your goal is focused on rehabilitation, or it's focused on fitness.

Let's go over those. First you want to know what should you expect from the typical program. Make sure you visit them, make sure you talk to somebody that's very familiar with that program, and find out what your expectations will be. If you go ahead and join this program, particularly if your making a financial commitment for the program.

Ask if this is a rehabilitation program, or a fitness program. This is very key. Remember, we reviewed that earlier in the presentation. And difference between rehabilitation and fitness. And that's going to help you to decide, A, again, whether it's good for a program that you're looking for, but also to help you formulate the goals, when you join that type of program.

Also, you want to know if you'll have a trained professional monitoring your program. And if they say yes, of course we have trained professionals, ask what their qualifications are. So that way, you'll know if you're going to be working with a nutritionist, or you're going to be working with a personal trainer, or are you going to be working with a physical therapist. You want to be able to know the qualifications of the person you will be working with directly that's going to help you pull together an exercise plan for you.

What type of equipment will you have access to? We gave you an overview of each of the programs but again not every program is homogeneous, meaning not every program is the same. For one clinical program you might have access to one set of equipment, and a different clinical program you may have access to a whole other set of equipment. So you really want to know, for the specific program you're looking to join, what type of equipment do they have and what type of equipment will you have access to.

Another key related question to this is, if they do have that type of equipment, is there an additional access fee for you to be able to use that type of equipment. That's another key question to ask.

You want to know the length of the program. Are the programs very specific, meaning they only last three months or six months, or are they ongoing, something where you will join that program as long as -- you may your monthly fee or your monthly membership fee. Also ask, as a related question, is not only the length of the program but let's say you review your exercise program when you first start off with a personal trainer, how often will you review that program with a personal trainer to see how you're progressing and you might have to adapt your exercise plan as you progress. So that's a key thing to ask as well.

Finally, the big dollar question is you want to know how much it's going to cost you. What type of payment structure do they have, and how much

will it cost to join the program, and particularly as it relates to the length of the program. So those are some really key questions to ask, if you're going to join a post-rehab program.

So, finally, where do you find these? We reviewed a lot of these programs. And where do you go to get access to them, or find other ones out there. We only highlighted a few of them in this presentation. But we want to be able to give you the resources as well. Spinal cord central has a -- their resource center, and they have a listing of a lot of these post-rehab programs, as well as links to their websites and contact information. That's a great resource for you to look for when you want to search for a post-rehab program. The national center on health and physical activity for disability, their website is here as well. And that will also give you access to different types of fitness programs that are available around the country. And they also have a lot of resources on there, if you're looking to create your own exercise plan at home, what you can do, and what type of exercises you can have. So that's another great resource, not only if you're looking for a program that you can go to, but also building your own program at home.

Finally, we mentioned earlier there's community wellness centers and YMCAs. A lot of them have access, and wheelchair access, according to the ADA, because the ADA does have some guidelines in terms of public access fitness equipment, and how to have access to that equipment. So those, you want to look into. Therapeutic recreation programs, so that also goes alongside with park and recreation departments. So within your own city, within your own community, there's park and recreation programs. And you'll want to look into them to see if they have specifically a therapeutic recreation program to allow you to get into recreation sports and fitness within the park systems. But also, again, we mentioned some fitness zones that are popping up around the country that are free access and many of them are accessible for those with mobility impairments.

So those are kind of an overview of where you can go to find some of the resources that you can use to start your own post-rehabilitation program. And, Kim, would you like to explain this program too.

>> Kim: Yeah. We'll like to leave you with one last resource. We have resource page that we have created on the Miami project. You can go to the website up here, [WWW.themiamiproject.org/stayinghealthy](http://WWW.themiamiproject.org/stayinghealthy). We have

collected many different resources. As we get more we keep adding them to this page so that people can get some information about, for example, how to stretch, what are the different ways that you can stretch your muscles, so that you can maintain your range of motion. We have many different resources for exercise, and what you can do at home, versus what you can do at different organizations. Another really important area that we didn't really talk on today is diet and nutrition. This is becoming really important for all of us living with spinal cord injuries. To really help us, one, maintain a health inside, and also help us lose weight and prevent additional weight gain as we keep going through our time with spinal cord injury. So it's really hard to try to change your diet, and improve your nutrition. So there are some tips here on the website. All you have to do is click on the button down here.

Finally, we have a lot of different resources throughout the country for sports and leisure activities and how you can be engaged in exercise, and activity, and not necessarily be doing just weights.

Finally, we also have a small video library that we are creating. And we will keep adding to that, as we get more videos for people to view on line. So we would like to -- we would like to leave it open for questions now.

>> Bil: Thank you, Ms. French and Dr. Anderson-Erisman. We have a couple of questions. First, are you aware of civil action requiring Medicare to reimburse physical rehab without an improvement standard? Any persons with MS require maintain PT to prevent worsening of condition. Anything you could add to that?

>> Kim: Jen, do you want to try to answer that?

>> Jennifer: Actually I'm not aware of the civil action that's going on in terms of Medicare and reimbursement for ongoing. I hate to speak on something that I'm not familiar with, and I would really have to direct people towards the Medicare and CMS website. We all understand that our healthcare system is changing, and changing rapidly. So I don't think I could really answer that question, without doing a little background research, before I do. But I would be happy to get the person's contact information and be able to look into it a bit more.

>> Bil: Certainly. You will be provided with the contact information and I will leave that question unanswered so you can get to it after you do

some research on it.

Next question, how many people took place in the -- how many people participated, I'm sure the question was, in the survey that you referred to early in the presentation, or survey on the exercise?

>> So the first survey that I mentioned, that was asking people whether or not they felt it was important to exercise was almost 700 people with spinal cord injury. And then the other survey I was discussing that was talking about barriers to exercise had over 200 people with spinal cord injuries in it.

>> Bil: Thank you. Scrolling down to the next flagged questions. We have a comment, really. Maybe you can comment on this comment. And that is that it's very hard to get accepted for trials, when you are 35 years post, in other words post-injury.

>> Okay. I can comment on that. Yes, it is, right now, very difficult to be accepted into trials, when -- probably for anyone that is 20-plus years post injury, including myself. And the reason for that is because we're seeing many phase one clinical trials right now, looking at the safety of new interventions or drugs, or devices. And so the criteria is typically very conservative or very strict for those early phase one trials because they're really wanting to look at safety.

As we learn more from clinical trials, and we go into phase two trials, we learn more about what we can do safely, and how open and unrestricted we can get, the more we will be seeing the inclusion criteria open up. And there are opportunities coming up in the future for people with spinal cord injuries to give their input to clinical researchers as they design clinical trials. And I think it's very important for us to make sure that researchers don't just exclude people because that's the perfect scientific model. They need to know that those of us that have been living with spinal cord injuries may have some complications that are not necessarily the easiest to deal with, but we should be able to be included in trials as well.

But another thing, important of maintaining health, as you -- health as you age with spinal cord injury, is so that you can rule out some of the other diseases that could develop, like diabetes, that might -- [Audio Skipping].

>> Bil: Thank you, Kim, for your considered response. The next question that I have for the both of you is, is there any evidence that these stand-alone programs are not -- with the timing of the question, I believe they're speaking about the stand-alone models across the country that you were highlighting some of them. Any evidence these stand-alone programs have improved outcomes or add value, evidence-based?

>> Jennifer: Kim, do you want to address that?

>> Kim: Okay. I can make a comment and then maybe you can comment as well. From what I know about the stand-alone program, there have been some efforts, by some of them, to select research data or clinical data, actually, to demonstrate improvements. One of the issues, I guess, of showing improvements in outcome is that they're individualized for what your goals are because you're paying for the services. So many people get many types of services so it's difficult to say that this service has this outcome.

Jen, do you want to add to that?

>> Jennifer: Yeah. Kim touched on the key thing, they're customized so it's very difficult to get evidence on it. There have been efforts to be able to collect the data, and there has been a few, not a lot, but a few published papers on post rehab programs, but they're more anecdotal data than so much survey data, like what Kim presented today. So I think that body of knowledge is still growing, and we're still learning from it. So part of looking into papers that have been published on Pub Med, shows whether or not there's specific outcomes for specific conditions, that's more qualitative and more case-represented than it is data-oriented. So I think that body of knowledge still needs to grow at this point. And unfortunately the evidence that the actual, quote unquote, clinical evidence isn't quite there yet.

>> Bil: Thank you both for that.

The next question, do you have professional resources that you offer to clients, or recommend professionals who are certified?

>> Jennifer: I think when you're looking into --

>> Kim: Go ahead.



>> Jennifer: I think that question leads into what type of program that you're looking into. So when you're looking into the quality of the people, part of what we showed in the different types of programs is what you have access to, and the qualifications of those people. There's no real, quote unquote, certification for post-rehab trainers, if you will. There are certifications for physical therapist, for occupational therapists, and also for personal trainers. And also for what's called physical therapy assistant. So when we're talking about certifications, that's what I would look into, is what their professional certification is, in each one of those disciplines. Of course I shouldn't leave out the exercise physiologist because each of those have certifications in each one of their disciplines. Kim, would you like to comment further?

>> Kim: No. I think you covered that well.

>> Jennifer: Okay.

>> Bil: Okay. The next question we have is, can an exercise program cause syringomyelia or make it worse?

>> Kim: I'll take a stab at that. An exercise program won't necessarily cause syringomyelia. That you get a growing cyst because of imbalances in the fluid pressure. However, if you are in an exercise program, and you're straining a lot, which you shouldn't be doing, that could aggravate the cyst. So if you do have syringomyelia, definitely talk with your physician before you start an exercise program, let him or her know the degree of exercise activity you're going to be doing, and then don't overly exert yourself. And stay in contact with your physician, to make sure that you monitor your syringomyelia.

>> Bil: Thank you, doctor.

The next question, can you comment on improved breathing and exercise programs please.

>> Jennifer: I'll talk about that one a little bit. I'm assuming that this person's -- I'll touch on the question actually two ways because I don't want to assume whoever asked the question what condition they might be in. For those with higher level injuries that have compromised breathing there is exercises under a physician to be able to exercise those lungs and

keep your lungs healthy. So those, for people with very higher level injuries, to help improve their lung capacity, really should look at breathing exercises under the advisement of a -- specific advisement of a physician and possibly a respiratory therapist because your lungs are just as much as an organ that you need to exercise as much as any other muscle. So I'll leave it there. But, again, that also applies for those that are -- maybe they don't have -- their lungs aren't compromised, but they still are looking at improving their lung capacity, for those that are living with paralysis or with impaired movement, if you will.

So lung capacity, even for those that might have healthy lungs, but are using wheelchairs, we don't always use our lung capacity as best we can. So focusing on breathing while you're exercising is very important. A component of your exercise plan should be cardiovascular. So that's why we have such a high incidence of cardiovascular disease and pulmonary disorders for those with mobility impairments because we don't always get that cardio that an able bodied person can do. So you want to put an component into your exercise plan where you're breathing heavy, where you're actually getting into the -- a higher heart rate. Now, again, that needs to be under the advisement of a physician if you have other ancillary conditions but again that's kind of a different exercise than those that have pulmonary disorders with the higher level injuries. Kim, would you like to add to that?

>> Kim: No. I think you covered that very well.

>> Jennifer: Okay.

>> Bil: Thank you. Another question, can you explain the role of occupational therapist, when rehab is over. And they -- this person makes an exception for FES. I'm not sure if that's appropriate, or if you'd like to comment on the role of an occupational therapist after the traditional rehab is complete. And how that relates to FES.

>> Jennifer: Sure. I'd like to comment, and I'm sure Kim can add to this as well. As a person living with a C6-C7 spinal cord injury, I have gone to revisit my occupational therapist quite a bit. Just to be able to work with upper extremity and to help with hand function, and hand exercises. We don't always focus on when we're working with personal trainers or with physical therapists. So the importance of an occupational therapist, just from an exercise standpoint, can help give you some of that

range of motion in your upper extremities or be able to help you in terms of technique to be able to help you with some of those activities of daily living.

Now how it relates to FES there are electrical stimulation devices specifically designed for upper extremity, and exercising upper extremity. Some of them use, for instance, external stimulation or those little electrical pads that you put on those muscles to exercise those muscles to help you regain some function. If it can be improved from a voluntary standpoint. There's also devices out there that can use sensing electrodes to help improve some of that voluntary movement as well. Again, in your upper extremities. When it's focused on your upper extremities that's where your occupational therapist can really help improve those functions.

Kim.

>> Bil: Thank you. The next question -- I'm sorry, Dr. Anderson.

>> Kim: I just would comment that occupational therapists are really, really, really good at helping you improve and create adaptations for doing all of your activities of daily living. So even for example, if you wanted to change your diet and start cooking a different way, but can't figure out how to do it because of impairments or restriction that you have, you can always go to occupational therapist and really work with them to try to get some ideas in addition to the traditional upper extremity and hand rehabilitation that they know, that Jen explained.

>> Bil: Thank you. The next entry we had was more of a comment than question. It's on our -- one of our most recent questions. The comment is probably from -- the OT professional can also help with lifestyle redesign to help clients integrate physical activities and exercise in the daily routine. Can you agree or disagree, comment on that.

>> Kim: I agree.

>> Jennifer: I agree 100%. I'm glad somebody in the audience made this observation, is that one of the most common questions is how our lives are so busy already, how in the world do I fit an exercise plan into it. I mean we know that both Kim and I know, as living with people with paralysis is getting dressed every morning, getting your morning routine takes a lot longer than an able-bodied person. Figure out how to fit

exercise into your daily plan and how to motivate yourself to do that, an OT can definitely help you do that.

>> Bil: Great comment.

>> Kim: Agreed.

>> Bil: Next question, why do you think -- this is interesting. Why do you think people are afraid that exercise will make them worse? Jen or Kim?

>> Kim: I think sometimes that a lot of people don't get a lot of education when they're first injured, and they're interacting with their physicians, particularly. They don't know if they can go ahead and go out and do things, that are -- that they might consider kind of rough. And it's really important for clinicians to educate people that, yes, you can be active, and it's important for your health. I think it comes down to education.

>> Jennifer: And I do have to agree with Kim. You know, this is, again, an observational rather than an evidence-based response. But I think a lot of it stems from when we're in rehab, at least this is the way it was when I was in rehab but I'm sure for a lot of others I've spoken to, you're so focused on the rehabilitation process and trying to get your life back together, as we don't think of what we need to do to keep ourselves in health long-term. We go down the slippery slope of not putting it in your lifestyle before the onset of injury or disease. So I think a part of it -- a lot is education. That's why we do these types of Webinars, if you will.

>> Bil: Thank you, Jen. This comment, followed by a question by the same viewer. C5 injury prevents heart rate increase. So how could he/she, get cardio work out. Could you comment.

>> Kim: I could make a comment on that from my own personal experience. I'm C5 spinal cord injury as well, complete. And I had a Vida Glide at home. I will do that to try -- one, I do it for cardiovascular work out and I try to get my heart rate up. And I have somebody test it when I'm done, and see if it actually goes up. Sometimes it does, sometimes it doesn't. But having that activity, even if your heart rate does not go up because of the autonomic changes of your spinal cord injury you're still getting a good cardiovascular workout if you're pushing

yourself to a moderate level.

>> Jennifer: Exactly. And another possible resource for the -- whether you have access to it at home or in a clinic is to be able to incorporate electrical stimulation to give you more of the cardio that goes along with it, for instance ergonometry, or using electrical stimulation to help you with that improvement. There's also some movements you might be able to do, that I've seen some resource videos on line for higher level injuries to be able to get some cardiovascular as well.

>> Bil: Thank you very much. We've had a variety of questions come in. And these will be sent on to the panelist and presenter for answer at a later time. But we are out of time at this time. So on behalf of the National Spinal Cord Injury Association, I'd like to thank Ms. Jen French of Neurotech Network and Dr. Kim Anderson-Erisman for sharing their experience and knowledge on opportunities following acute spinal cord injury rehabilitation. We're sorry we experienced some technical difficulties during the introduction phase for Dr. Anderson. Sorry about that.

Our next Webinar will be getting the right healthcare. On Thursday, January 30th, at 2:00 PM. The speaker will be Carl B. Cooper, with the American association on health and education. To get our newsletter visit us at [WWW.spinalcord.org](http://WWW.spinalcord.org) and visit us to see what we're all about. Thank you, Jen and Kim. This concludes our presentation for today. The archived version will be available within approximately one week. Thank you.

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>> Jennifer: Thank you, it was a pleasure.

>> Kim: Thank you.

>> Jennifer: The PDF versions will be available on [spinalcord.org](http://spinalcord.org). Thank you for attending and thank you for this opportunity.

>> Kim: Thank you.

>> Bil: Thanks.