

[Please stand by for real-time captions.]

Welcome again. We're going to pause for a moment before get started to get our recording going. My name is Nanette Relave and I managed the National Information and Referral Support Center which is administered by the National Association of states United for Aging and Disabilities. I would like to welcome all of our participants to our March webinar. We often get questions about the slides and the audio recording so I just want to let everyone know at the start that the slides the audio and a transcript from today's webinar will be posted to the website in the next several days. Please visit the I&R Center webpage. You will be able to find the archive there. Also, if you look in the chat box and scroll up just a little, my colleague has put a direct link to that page. You can find it right there.

I am going to go over a couple of housekeeping items before we get started. All listeners are on mute to help reduce background noise during today's webinar. But we welcome your questions and comments through the Q&A function which is available to you on your screen. -- On the right-hand side. Please feel free to submit your questions at any time during today's presentation. And we will address your questions following today's presentation -- following the slides.

We also have a real-time captioning for today's webinar. On your screens again on the right-hand side towards the bottom, you should see a media viewer panel on the bottom right. This is where the captioning will appear. You can minimize this panel or have it open. It will not interrupt the slide presentation. In order to start the captioning, you may need to enter your name and organization and then click submit in order to be able to view the captioning in the media viewer.

I am very pleased for us to have an opportunity today to learn about the National Limb Loss Resource Center which is operated by the Amputee Coalition. As a specialized information and referral program, this Center can be a resource for any I&R program and the people that you serve. Limb loss affects people of all ages and can result from a variety of conditions and life events. With that I'm going to turn over to our presenter George Gondo who is director of research and grants at the Amputee Coalition and joined us at the AIRS conference last year gave such an awesome presentation we are pleased to have him back. And talking to the aging and disability I&R network again and with that George I am going to go ahead and turn it over to you. Please let us know if you have any difficulty with the slides.

Thank you so much for that introduction and I want to thank you in the national I&R support Center for allowing us to present this webinar today and as Nanette mentioned in her wonderful introduction, our National Limb Loss Resource Center is -- to serve as a vital resource for anyone working in aging and disability to help meet your clients with limb loss and help meet their needs. I want to begin our presentation today and talk a little bit about the background of our organization and talk about the limb loss community. What the needs of the limb loss community are and talk specifically about many of the programs and services that are available through our national limb loss resource center.

Our Resource Center is supported through a cooperative agreement through the Administration for Community Living so any of the views being expressed in the presentation today do not reflect ACL policy and are strictly our -- are our own. The Amputee Coalition was formed with a mission to reach out to and empower those affected by limb loss to achieve their full potential through education support and advocacy and to promote limb loss prevention. Within this mission statement I want to explain just two things. Will use the term affected by limb loss we are talking about the broader limb loss community. These are individuals who have lost limbs or born with a congenital limb difference in this includes family members who are affected by the individual losing their limb are being born with a

congenital difference and also the individuals who serve, provide services for those with limb loss or limb difference and healthcare providers who provide care to them.

We look at the limb loss community from a very global perspective. When we talk about limb loss prevention we are talking about prevention in 2 ways. One is the prevention of the primary amputation which as I get into the slides we will talk more about that. But also talking about preventing a lot of the common secondary conditions that often occur to someone who loses a limb. We're looking at prevention on both sides of the equation.

Our organization is the leading donor supported national nonprofit organization serving the limb loss community but there are a lot of other smaller nonprofits that serve people with limb loss on a more specialized or local or regional level but there is nothing quite to the scale of the amputee coalition and we work with all of those organizations as well. We recently celebrated our 30th anniversary. We started out very humble beginnings just from a group of the support group leaders who banded together and wanted to create an organization that met the needs of consumers with limb loss or individuals with limb loss. We have two offices one in Manassas, VA and another here in Knoxville Tennessee where I am at. We have about 19 members of staff and we have a really large organizational reach. As a national organization we are engaged with more than 270 limb loss support groups around the country. We have a certified peer Visitor program that I will talk about during my presentation that has over 750 active certified peer Visitors. We partner with hospitals and rehabilitation facilities to ensure that their patients to lose limbs are visited by trained and certified peer Visitors and also have a partnership with the Department of Veterans Affairs and the Department of Defense to ensure that our veterans and active-duty service members lose limbs also received support from another person with limb loss. We have a very active database of people who we regularly engage with the contains over 65,000 individuals. We have a very robust social media presence. Our Facebook community has over 115,000 members so it is a great way of communicating information and a great resource to point people to and then our website which is just filled with a lot of resources is regularly visited. We get over 800,000 individual and unique website visitors each year. That continues to grow.

Currently there is estimated to be 2.1 million individuals living with limb loss and as Nanette Relave said in her introduction, limb loss can happen to just about anyone at anytime and at any age. As you see in the chart below, the distribution of those who are living with limb loss is fairly well distributed across all age ranges. And you can see in the pictures that it can happen to young individuals, older folks, in their retirement age or individuals who are just sort of getting out and getting into their professional careers.

When we talk about amputation we are talking about specifically levels of the amputation. Among those living with limb loss with the larger prevalence of lower limb amputation compared to upper limb amputation. As you see from the pictures on the slide, a lot of individuals and is fairly common to encounter someone who has lost multiple limbs. They may have lost both limbs below the knee or above the knee and in their lower extremities or they may have an upper extremity and a lower limb amputations and in the case of the young woman who is wearing the Julia Child t-shirt, she is missing all four limbs. -- 4 limbs. There is not just one level of amputation, there is a lot in people who have amputation may have multiple amputations.

The causes of amputation as Nanette Relave mentioned and as I mentioned at the beginning, largely are due to disease so roughly 80 or 90% of the amputations that are performed each year in the United States are from applications related to vascular disease or diabetes, trauma represents a very small number of the actual amputation procedures that are performed but what we find is that individuals

who lose limbs from a vascular disease or diabetes have a relatively high mortality rate so among the prevalence of amputation or the prevalence of those living with limb loss, we see a larger number of those individuals lost limbs from trauma or cancer. When I first started working at the coalition, 10 years ago sort of at the height of a lot of our complex in Iraq and Afghanistan, -- complex. When people thought of amputation it made -- immediately which were active-duty personnel losing limbs and those conflicts. Although they have gotten a lot of media attention and rightfully so there has only been around 1600 or so amputations from those conflicts and the US Department of Defense recently announced that 2016 with a milestone -- the first year since the beginning of those conflicts that a service member did not experience any amputations due to combat. We're seeing a significant reduction in the number of amputations that occur from those events.

When someone loses a limb, the process of adapting to limb loss is one that can take a number of different turns and twists and it can take an extended period of time. Typically, adapting to limb loss will require a variety of assistive technologies. One that we most commonly think about are prosthetic devices, but an individual may use multiple prosthetic devices. As you see in the picture, of the hands of the feet. These are different terminal devices that an individual with upper limb amputation may use. There is a couple of task specific or activity specific devices. There is a device for playing baseball or a ball sport and there are -- use the a lot of pediatric devices in that picture for small children who were born or lost and upper limb as a small child. Individuals may also use prosthetic devices in conjunction with a variety of durable medical equipment. There may be a prosthetic user but that may also use a wheelchair or they may use a walker. They may use a power wheelchair in some instances although that is not very common. They may use forearm crutches. Some individuals do not use prosthetic devices at all. For some amputation levels, to truly does that are more a proximal to the trunk of the body so someone who has a Hemipelvectomy or Hip Disarticulation or shoulder design petition -- this articulation that wearing a prosthesis may be uncomfortable and find it improves their function or ability to not wear prostheses. Most individuals who lose limbs will require some home or vehicle modifications in order to return to their communities. Among those who lose limbs, we see a range of functional abilities. Contrary to what is often depicted in popular culture or mass media, not everyone who loses a limb goes on to climb Mount Kilimanjaro or run a marathon or goes on dancing with the stars. Most people lose a limb are just your normal average person. They go back to the lives they led prior to their amputation. Most of them were not runners beforehand and they are probably not going to run a 5K or marathon after losing their limb. They make a back to golfing, they may have back to playing basketball or doing any number of activities that they enjoyed prior to the loss of their limb.

One thing that living with limb loss requires is often management of other comorbidities. So as we saw one of the earlier slides about the incidence of amputation related to disease, see a lot of individuals who live with limb loss they also have to manage diabetes heart disease or cardiovascular disease. Depression is fairly prevalent among those who lose limbs as well as for someone who has had a traumatic accident that resulted in their amputation. They may be experiencing a traumatic brain injury or some effects of a traumatic brain injury and posttraumatic stress disorder as well. These are all convocations that individuals who lose limbs have to be -- have to manage and these are also things that we as service providers who served them have to be aware of both an understanding their information needs and understanding how best to meet those needs.

One thing that is really interesting is that most people lose a limb really have no information about what amputation means no source of information related to prosthetics or assisted devices -- assistive devices and find themselves at an information deficit. Which can in many instances exacerbate a lot of anxiety and a lot of concerns that people may have about their ability to go on and live their life as they want to.

This is something where we as an organization step in and try and meet those information needs of people who lose limbs. Some studies that have been conducted on individuals that have lost a limb and was copied perioperative stage. This is the period right before or immediately after they are invitation of a limb, have identified that there are certain topics -- certain questions and concerns the individuals who lose limbs are particularly seeking information about. There is also these studies also show that how the information is delivered both in terms of the method, the content of the information and a lot of other factors need to be considered in order to meet the needs of information needs of someone who loses a limb. In the approach that is used to deliver it is also something that must be considered.

When we think of the information topics here is a list of some of the common topics that individuals are most concerned about after their amputation. They are particularly concerned about managing the surgical wound. If anyone on the webinar has ever looked through medical journals and looked at the surgical images of an amputation surgery, they are fairly graphic. It will something when I first started working at the coalition I had to warn people that when they would see -- doing research on a particular topic that they may want to do that -- considered what time which is when they are doing that because the images can be quite graphic. They also -- individuals are thinking about how to manage pain, what the pain will be like. Especially after their amputation surgery that are likely to be in a significant amount of pain. One think they may have heard of and be concerned about is what is called phantom limb sensation or pain. This is the experience of feeling as if the amputated limb is still a part of the body even though the surgery has been completed. Most individuals have no real understanding of what to expect during the rehab process or even really -- and this is important especially as individuals need to advocate for themselves in order to get access to the health services that really can maximize their post amputation outcome. Individuals also are thinking about aesthetics or different sites -- different assistive technologies. One of the big concerns that individuals have is whether they will be able to walk or run again. They may have seen a media story about 3-D prosthetics or they may have seen a story on the local news or national news about research on some of the more advanced technologies that are out there but they may not be really familiar with the actual prosthetic and assistive technologies that are available to them commercially. Even more importantly may not be aware of what the most appropriate technologies might be for them given the type of lifestyle that they wish to lead.

Obviously, as with the most issues related to someone's health care or their health and well-being and having incurred a significant amount of medical expenses, people are very concerned about their financial situation and whether they will be able to return to work. Whether they will be able to afford a prosthetic device. They are also looking for support. One of the things that we commonly hear and most people don't know of anyone else who has lost a limb prior to their amputation. So they do not have a peer group in which to imagine themselves belonging to and that can really create a lot of feelings of isolation and amplify anxieties and concerns that they may have.

Of course, going back to the rehabilitation process, helping them to understand that the recovery process from an incident like the amputation of the limb is not a linear process but is one that is more like a roller coaster where individuals can make progress at certain points in time but then they may experiencing setbacks and have to revisit some earlier feelings that can be quite frustrating at times.

We are looking at how to deliver this information to individuals we have to consider is like a person's age. Again because of the comorbidities that are often experienced by someone who loses a limb, they may have a hearing or vision impairment. If they are older or younger we may want to think about delivering the information a little differently. At the coalition we put a lot of things in print whereas the

younger generation tend to like small video clips or things that are a little more interactive and that are not as friendly to someone who is maybe and therefore -- more advanced in their years.

We also have to consider whether an individual is experiencing a significant amount of pain or whether they are on medication but the of those can impair their ability to absorb information. This really means that the information may need to be repeated multiple times in order for them to really absorb it and it can also be helpful in these situations to give them the information in print so they can look at it and refer to it at a later stage when they might be -- a better position to absorb information.

A person's emotions obviously can change how they perceive the information that is being delivered to them are being given to them. If they are afraid or experiencing a lot of anxiety, we don't want to tighten those fears or further amplify their anxieties but to reduce them by providing them this information people want to make sure that the information is presented in a way that doesn't exacerbate those feelings.

In the hospital setting at least, the environment sometimes is not conducive to delivering a whole lot of information at a particular point in time. There is a lot of distractions, you have the healthcare team coming in and out, other persons, you have a lot of family members around. Everyone is trying to be friendly and supportive but that can be a distraction.

One of the things that we find in the limb loss community in particular is the overall the individuals who lose limbs, the level of education is sometimes a little lower than the general public so we really try to avoid technical terms when we are creating information and when we are trying to deliver the information to them.

When you think about providing the information, the timing is important. Whether it is right before the amputation surgery or after, you want to give different levels of information. Think of the mode, whether it is a verbal written or through video and one thing we find to be very important is to really consider the amount of education or information that someone is given. We don't want to give them too much information because we hear that that can be very overwhelming and really exacerbate or increase feelings of being overwhelmed or anxiety of the situation they find themselves in. At the same time we don't want to provide too little information because it can also make them -- make individuals feel more frightened and afraid.

With all of that background and understanding the information needs and how to best meet those needs, they national limb loss resource Center has created a fairly wide array of programs and services to serve the limb loss community. We have our traditional information and referral center which disseminates and creates patient education materials in a variety of formats. We have our peer support network which connects individuals who lose limbs with others whether they are trained as peer Visitors or if they are a limb loss support group. In conjunction with partnerships with researchers at Johns Hopkins, we created self-management programs to help individuals who lose limbs develop the coping mechanisms that really going to help them adapt to losing a limb and we also conduct educational events and put on a youth camp to help individuals who lose limbs become more independent and a transition into adulthood. Will take a little time to talk about these programs. And give you a little bit of a review of each one.

As Nanette Relave said in the wonderful introduction to the presentation, our information and referral center is a very specialized I&R center. We have a wide variety of information of materials about limb

loss whether it is living with limb loss, being active with an amputation prosthetic options, rehabilitation options. We have a tremendous amount of educational resources and patient education materials available through our I&R center. These are available for free. Anyone anytime can call us or email us and certainly for anyone on this call a service provider's we can provide this information for your clients free of charge or if you want to just point your clients with limb loss in our direction we are happy to provide those services and those materials to them as well.

Some of the resources that we send out a very customized information packets. These are things that are very specific to someone's needs. If someone contacts us and they are having some issues related to residual limb whether it is skin breakdown or sores, we would send them some information around wound care. We get a lot of people that contact us about options for managing phantom limb pain so we have a lot of information around pain management and this is something where you as local service providers -- as you are engaging with someone with limb loss can refer them to us. If someone comes to your agency and they have an amputation and you notice that maybe they are experiencing some other issue related to their limb loss, this would be a great opportunity to refer them to us.

On the other hand, get a lot of people who are looking for local resources. One of our most popular requests is for home modification programs. These may be someone who is recently lost a limb or are still in the hospital and the family -- a family member contacts us and they need a ramp built, the individual can return to their home. -- Wrap built our referral staff will work for our clients to your agency. We send out a lot of referrals to local centers for independent living, area offices on aging and ADRC. A lot of the folks who are on this call, you may be getting clients from us because you know what is available in your community rather -- better than we do because of our specialized focus on limb loss can provide a lot of information specific to living with an amputation.

Our materials over the last three years -- we have really implemented a some quality improvement measures and you see here they really have paid off. People who receive our materials are very happy and satisfied with the materials that they receive. They find that the information in those materials is very useful which is something that we in particular are very proud of and I really have to commend my staff who are all on this call or all on this webinar. I want to commend them for their hard work and dedication to making sure that our materials are current, the links that we send out or the referrals that we send out contains good information and that would really do our best to make sure that we are meeting the needs of people that call is whether it takes a five-minute conversation or whether it takes a two hour long conversation to make sure that those needs are assessed and the needs are met.

What are the things that we provide is a lot of patient education material. We develop and publish and disseminate a lot of publications. These may be in the form of magazines, brochures or booklets. We also host regular webinars. Right now we're doing a monthly webinar series -- you can find out more information on our website and then also on our website we have a number of video resources that are available whether we have three different video series -- one on basic education, we have some physical therapists talking about physical therapy exercises that people can do to improve their balance and gait. We also have some videos that give people an introduction to the rehabilitation process, what to expect during their rehabilitation how to best work with their rehabilitation team. We also have a video series talking about how to re-integrate back into the community after an amputation.

Again, these are some of our publications -- InMotion is our bimonthly magazine that covers a variety of topics related to living with limb loss and living well with limb loss . Is completely free anyone can receive it. You just need to provide us with their mailing address and we are happy to send it to them.

First Step which is available in Spanish is our guide to adapting to limb loss. This covers sort of the first two years after an amputation. It is fairly comprehensive -- amputation and is fairly comprehensive. It is probably looking at the process of adapting and recovering from an amputation and not some of the more specific -- it doesn't drill too deep into the specifics.

One of the things that we have seen over the last four or five years is that insurance companies, Medicare, Medicaid and also private insurance companies are increasingly denying coverage or denying claims for prosthetic and assistive technologies. In response to this growing need we have created our insurance coverage and reimbursement guide which helps individuals understand their insurance policy especially as it relates to prosthetic coverage, durable medical equipment coverage and other types of rehabilitative technologies. It also can help them understand how to appeal potential denials and be better advocates for themselves in this part of their health care. Obviously, given the current state of health care reform we are looking at revising this publication, that will be waiting to see what happens at the federal level with healthcare and moving forward.

Also have a couple of brochures series. One is what we call our First Step series. It takes some of the information in First Step and breaks it down to brochure form. It specializes on topics like physical therapy or wound management. Or an individual may not need the full first step publication that they may need specific information related to wound care or preventing secondary conditions. That is a nice publication on those types of topics. And we have a nice brochure series on pain management. These are probably about anything related to pain, pain management especially phantom limb pain and residual limb pain.

Our publications are nonbiased so we do not advocate for a particular manufacturer or particular service provider. They are evidenced-based. They are patient centered and they are created by an advisory committee that includes clinicians and consumers. This is a very holistic approach, very organic and we make sure that it is clinically relevant but also very relevant to the actual experiences of individuals who lose limbs. The best thing about it is if you call us or contact us we are happy to send those to you for free. Again this is some data about our publications and the satisfaction and usefulness of them. Again, as we have implemented our quality improvement initiatives we see satisfaction with InMotion improving, the usefulness of the information in the magazine increasing over the last three or four years as well as with First Step. We just put out a new issue edition of first step this year that builds upon the feedback that we have gotten about this publication.

A couple of new things that we have in our patient education material arsenal is what we call our your New Journey folder. This is an evidence-based publication that focuses on what new amputees need and -- in the perioperative period of their recovery. This is right before their amputation surgery or right after. It provides information on all the topics that we talked about earlier but it doesn't really overwhelm them. It gives them just enough information to alleviate their fears and concerns, it refers them back to our organization or other places that they can find additional information on those topics but it doesn't really overwhelm them with too much information. This publication is available in Spanish so that is something that we have been able to do and the individuals who lose limbs that are Spanish-speaking a very happy to have this to educate their patients.

We combine this with some other materials which we call our Your New Journey Packet. They get the folder, a copy of InMotion and some copies of our brochures that individuals find to be most helpful so this is what we call our secrets of success brochure. This is one that individuals who have lost limbs talk about what they have found to be key to their recovery process. And it offers individual's tips on what

they might think about during their own recovery as well as some brochures that focus around pain -- phantom limb pain since that tends to be a prominent topic.

We're putting out some new patient education booklets. These are completely redesigned -- last year. They are available for specific amputation levels. What now we have it for below knee, above knee and one for caregivers and we're developing additional booklets for the Hemipelvectomy or Hip Disarticulation amputation level as well as the needs of children who lose limbs.

Our Certified Peer Visitor Program. This program -- we have been doing it for a long time since 1993. And we have a very extensive matching process. We ask individuals whether -- with the preferences are for what they want from their peer visit. Or if they want to talk to someone who is the same age, same sort of life situation as themselves, individuals can contact us to request a peer visit through an online form or by telephone. And our certified peer visitors operate under a very strict code of ethics. The information that they provide is not biased, they're not affiliated with any particular service providers or prosthetic manufacturers and they are really there to just answer the person -- person's questions from the perspective of someone who has been through that same situation.

Peer support is particularly important to the limb loss community. Again most people prior to their amputation do not know of another amputee. One of the central tenets of our organization is to ensure that no amputee is alone. We really want to connect someone loses a limb to the larger limb loss community. Amputation is also a very personal experience. It involves your body which is obviously a very personal thing and a lot of the most common post amputation issues can really be appropriately addressed by talking with another person who has lost a limb. These are things like body image, sexuality and relationships, returning to work and getting back into their community.

Want to highlight the link on the slide. We have a great video from one of our certified peer Visitors -- peer visitors in Houston who talks about how peer support played an important role in his recovery and why he has gone on to become a certified peer visitor and what certified peer visitors -- the role but they play. I encourage you all to click on that link as this presentation is available online on the NASUAD website and view that video.

This is the slide with some of our hospital and rehab partners that we partnered to implement our peer support program to all of their patients you will notice these are some of the larger names in rehabilitation. We're very excited to partner with them.

Another program we developed is our promoting amputee life skills program (PALS). This is a self-management program developed in partnership with Johns Hopkins school of medicine. We have conducted a study of the program truly demonstrate its impact in the whole purpose is to really help individuals develop the skills that they need to manage the day-to-day obstacles of living with the limb loss to improve their outcomes and quality of life. It is in 8 lesson program. It is available either online or in person. We're actually just finishing up an element of the online program now. And again, it helps individuals learn problem-solving skills, that they would need to really be successful after their amputation it helps them learn relaxation techniques to lessen the bothersome this of their pain and helps them set appropriate goals and communicate with our healthcare team.

This is just some of the outcomes that we have seen from Promoting Amputee Life Skills (PALS) -- improved self efficacy and social support while reducing catastrophizing and it reduces pain and depression while increasing positive mood and in the long-term we see that it improves their activity,

participation and quality of life. It is a really great program. This is the link to the online program that we are launching this year. Right now you can look at the site but you cannot really access the program itself until later this year as we are wrapping up a study to ensure that the online program is as effective as the in-person program but will be opening it up to the public later this year. Please check back for when that is announced.

This is what it looks like. Right now there is a video that talks about information about the program and once it goes live you will be able to sign up for classes when they are held.

As I said, we put on a lot of educational events. Every year we put on a national conference which is the premier event for the limb loss community. We have over 1000 attendees from all over the country, 80% of our attendees are someone with an amputation or their family members so it is very consumer focus. This year we will be in Louisville Kentucky August 3 through the fifth. If you are in the area, I encourage you to check it out. If you are in the area and you're interested in exhibiting or having a table, contact me afterwards. We are working with the Center for accessible living in Louisville to make sure that they have a presence and make sure that people are aware of their center and what they do and we're happy to do the same for you and your organization.

We do in addition to the national conference we do one day events around the country that we call our limb loss education day events. We put some education programming together and we always like to incorporate of local adaptive sports and recreation program and these events have a local focus. You can see on the slide where we are going to be in 2017. If you are in one of those areas I encourage you to reach out to me and see about how to incorporate your center or your agency in the event if someone has a particular presentation they want to do or if you just want to exhibit and increase awareness about the services you provide we're happy to do that as well.

Finally I want to wrap it up and talk about our youth camp. Our Paddy Rossbach Youth Camp is a traditional summer camp ages 10 to 17 and we have a leadership camp for older campers between the ages of 17 and 19. Last year we had about 150 campers who attended and it is a very unique camp in that all the kids, all the councilors, are all someone with limb loss or limb difference. Is a place where kids can come and just be a kid. Is completely free. Cover all of the costs of attending the camp. The airline ticket, any of the travel costs associated. It is a tremendous event. And just like our peer support program this is a really important component of our organization to ensure that we that no amputee feels alone. Most children who come to camp have never met another child with limb loss prior to coming to our youth camp and let alone have met and another -- another child the same amputation level or same limb loss experience or limb difference experience. It is important in helping them normalizing their experience. The camp is a great opportunity for them to build confidence and independence. We have children who have come to the camp that learn how to shower by themselves for the first time our learn how to feed themselves for the first time by working with other individuals with a similar amputation or difference level. It plays an important role in helping them transition to the next stage in their lives as they think about going on to college, moving out of the house, and thinking about their professional careers. Our counselors professionally run a wide gamut. Some of them are college students, some are professionals, they may be engineers, in the healthcare industry, or may just be teachers. It is a wonderful opportunity for them to see that someone who loses a limb can go on and have a professional career.

Again, I encourage you -- we have a great video on our website about the youth camp. It is much more entertaining than listening to me talk about it. Is a great video of the kids talking about their experience at the camp and what it means to them. I really encourage you to visit that link on the screen.

That is what I have for our presentation and now I would like to just open it up for any questions that you may have.

Great. Thank you George. That was fantastic and I also want to second the camp video. That one I was able to see and it is amazing. I encourage our participants to go and view that and the other video. Again if you have questions, please use the Q&A function available to you on the right-hand side to submit your questions. Our first question just asks for your I&R services. Are those times Eastern time? Is that when your call specialists are available?

Yes that is correct. It is Eastern time.

And I'll follow up and ask what about after hours? Are callers able to leave a message or is there a voice response system?

If someone calls after hours, then they can leave a voicemail and our staff will get back to them the next day.

Okay great. I have so many questions as I was listening so I will get started but also invite our listeners to submit their questions as well. When you were talking about your Promoting Amputee Life Skills (PALS) evidence-based program, probably a number of the agencies on the webinar are also very much encouraged to implement evidence-based programming within their network agencies. I'm just wondering as you continue to implement this program do you envision having any training (train-the-trainer) where another agency might be able to provide the program or is that not something you are thinking about.

We do offer trying to trainer programming for the in person Promoting Amputee Life Skills (PALS) classes and would offer those through our hospital partners. The way that the online program will be disseminated won't -- is it likely to require a train to trainer program. Although if one is needed then that is certainly something we do want to do. I do want to encourage anyone that is on this call or webinar -- if they are interested in the Promoting Amputee Life Skills (PALS) program to reach out and get in contact with me so that I can notify them when it is live and when we are opening courses so that they can make their clients aware of it.

Wonderful. Thank you. Many different types of I&R from aging and disability to 211 and comprehensive programs are serving veterans and so I have a colleague who asks if you have any specific resources geared towards veterans experiencing limb loss or partner with the VA on any of your programs or any other veterans organizations?

We have a really great partnership with the VA. We work with the VA -- operates the amputation system of care which is a very comprehensive amputation and limb loss rehabilitation program through some of their [Indiscernible] in regional centers. Work with them to make sure that they have trained and certified peer visitors. We also provide all of our patient education materials through the VA through a contract. We provide them with technical assistance, we regularly are talking with the VA and the Department of Defense on how can collaborate. In fact I was on a call with some of the leadership for the extremity trauma center of excellence just earlier today. We work a lot with the VA because they do have even though amputation from combat injuries isn't as high or prevalent anymore, the VA still does see quite a number of veterans who lose limbs from diabetes or vascular disease so we want to make sure that those veterans are appropriately served.

Great. Thank you. We have another question come in from one of our participants asking if your organization ever offers direct financial assistance to individuals and I which is follow up because financial assistance is a frequent need among I&R callers. What type of referrals do you make to folks around financial assistance?

So, we do have some financial assistance but it is mostly for scholarships to attend our national conference or financial assistance by someone being able to attend our youth camp. We mostly meet those needs by referring them to other foundations that do provide that service so there are a couple of foundations that partner with manufacturers or they may partner with service providers or prosthetic service providers to provide either free or low-cost prosthetic services for someone with limb loss. We do have a fact sheet on those agencies that we send out.

Thank you. That sounds like something that would be very helpful. We have another question coming in about whether you partner as well with the diabetes and heart associations?

We do partner -- with the American Diabetes Association. Not so much with the heart association but we do work regularly with the Society for vascular nurses and we're building partnerships with one to care centers because that is where we see a lot of individuals who progress to an amputation from diabetes. We see that that is a very critical area for reaching them and possibly preventing that amputation. List of our partnerships really focus right now on the -- what happens after an amputation so we partner a lot with physical medicine and rehabilitation doctors, physical therapists and Prost is -- [Indiscernible]

I will jump in while waiting to see if any other participants have any other questions. We discussed pain and pain management frequently, at the same time I think there is also a lot of focus around effective and appropriate use of opioids. I'm wondering if issues of opioid use or substance use if this is something you are seeing more of for if you have developed any products and tools to really address this. For a number of communities in our country it has become a real crisis.

Yes. It is something that one of the approaches we take to pain management is a more holistic approach that really focuses on the mind and body connection. We do make people aware of pharmacological interventions for pain management or pain reduction. But we also emphasize that these -- typically these are not really great long-term solutions. And especially for individuals who are experiencing phantom limb pain. These pharmaceutical options typically are not as effective as some of the other mind body approaches things like mirror therapy. We have a great webinar on our website about mirror therapy a lot of promise helping individuals manage their phantom limb pain. We do offer that but we emphasized that, pharmaceutical is not the best long-term solution.

As we are wrapping up I will as one last question. As a provider of specialized I&R you probably see many -- trends and questions and when you hear from inquirers and I'm wondering if there is any particular issues you may see from callers who are older adults who are experiencing limb loss later in life as we may have a number of agencies from the aging network participating today.

Some of the big questions there are around continuing to live independently, and returning to home. We have a lot of -- for some reason we get a lot of calls from the New York and New Jersey area and we get a lot of callers to our -- they are older adults. They live in possibly a rent-controlled apartment that may be a two or three flight walk up which is common in those areas. They are in the process of being discharged home the thought of how are they going to get back to the house is a big question. A lot of the same topics that I'm sure that these -- your agencies are experiencing around living independently and living in the community -- those are the types of questions we see a lot.

Thank you. I have many more questions but we have reached the top of the hour. I know your contact information is on the last and final slide of the presentation. For anyone who wants to follow up with you again -- you have provided such good information. You may be hearing from some folks who want some of your resources for their own agencies or just maybe have some more questions about how to connect with I&R. I really want to thank you for joining us again. We really appreciate this. It has been a great presentation with lots and lots of helpful resources. Want to thank all of our participants as well and also our captioner for doing such a nice job for us today. Again, all of the materials, the slides, the audio and the transcript will be available on our website in the next several days. Again, I just want to thank everyone for a great webinar this afternoon.

Thank you Nanette Relave for having us present. We really appreciate and look forward to anyone that contacts us in seeing how we can help them meet the needs of their clients.

Sounds good. Thank you.

Thank you.

[event concluded]

I&R Center webinar

March 22, 2017

The Amputee Coalition's National Limb Loss Resource Center: A Critical Tool to Help You Meet the Needs of Your Clients with Limb Loss