

Acquire In-Depth Knowledge on a New SCI Personal Caregiver Course – Transcript

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JEAN ZANCA:
00:05

[music] Good afternoon, everybody, and welcome, and thank you for being here. My name is Jeanne Zanca. I'm very happy to be here representing a team of people who have contributed to this free online course that we've designed to try to help improve the quality of personal care assistance services that people with spinal cord injury receive. I'll just say a couple of things quickly, and then Trevor will give you a little bit more background on what helped inspire this course. First of all, we always have to thank our sponsors who helped make everything happen. So the bulk of this work was funded through a field-initiated development project grant funded by NIDILRR, the National Institute on Disability, Independent Living, and Rehabilitation Research, and then we were fortunate to receive funding from the Paralyzed Veterans of America Education Foundation to create an additional set of content for this course that we'll talk about a little bit later. And I'm very happy today to be joined by my colleagues, Trevor Dyson-Hudson and Denise Fyffe, but we are a few of a larger team that contributed to this project, including Juan Segovia, who is now off in the professional world having completed his social work training - so we're sending him our good thoughts - and our colleague John Morris at Shepherd Center with whom we collaborated on this project. We also had the advice of a steering committee full of a number of people with lived and professional experience that Denise will talk about a little bit later and also a production team called Remark Creative, which is the professional video production company that worked with us on this course and were real partners in helping us to create something that we are very proud of today. So with that, I will switch and invite Trevor to tell you a little bit more about the background behind the course.

TREVOR DYSON-
HUDSON: 01:38

You all know how important personal care assistance can be to people with disabilities. I think back to about 30 years ago when I was injured. And I'm quadriplegic, or tetraplegic as they say now, and I can't use my hands. And so so many things that I could do on my own, I needed assistance. And it drove me crazy that I needed that assistance, but I needed to work with someone. And with that person helping me, they gave me just so much more independence that-- I mean, that's why I'm where I am now. Unfortunately, most personal care assistants have little knowledge of spinal cord injury. It's such a small population relative to the larger disability population, so when they're coming in to meet a client, it's often the first time they've ever met somebody with a spinal cord injury. So what we wanted to do was create an intro

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course, basically just telling individuals about spinal cord injury itself so that they could have a better understanding of the type of injury and that impact it may have on the individual, that basically would lay the foundation for then an individualized training that the individual with spinal cord injury would then guide them through. As I said, wanted to give personal care assistants a better idea before they walked through that door, an intro course. This way, they could ask good questions during their hands-on training, and it would also give them a better understanding of why their care tasks are needed-- why certain things are needed, may increase motivation because they realize the impact that they have on this individual's life and their role, and it would promote mutual respect.

DYSON-HUDSON:
03:45

What we didn't want to do was reinvent the wheel. There's a lot of great training programs out there for different things, so we weren't going to get that detailed. We didn't want to get too technical. Again, this is just intro. We didn't want to overwhelm people. Each individual has their own unique needs, so the hands-on training is often with the individual themselves guiding their personal care assistant. So we didn't want to replace that. So we didn't want to get too specific. Our potential users run the whole gamut. Could be home healthcare organizations that are training PCAs - so before they send somebody into the home, they can share this resource with them - people with spinal cord injury or family members if they're trying to learn about it themselves; newly injured or family members or friends, as well as sharing this resource with people they're hiring, because not all PCAs come through a home care agency; rehabilitation programs - this is a resource for you guys to share with others and to share with your clients and share with new people joining you - and then individual personal care assistants who may be seeking more knowledge. They have a client. They know very little about the injury. This is a potential resource for them.

ANNOUNCER:
05:11

Dr. Dyson-Hudson turns the mic over to Dr. Denise Fyffe.

DENISE FYFFE:
05:14

We're going to talk a little bit about our community partner collaborations. So wanted to make sure that our educational program was informed by the voices of key stakeholders who would be involved in the care of individuals living with spinal cord injury and could benefit from this educational program. Our key partners included people who are living with spinal cord injury, their family members, as well as experienced personal care assistants. And here we're talking about personal care assistants who had worked with individuals living with spinal cord injury, home healthcare agency leaders, as well as rehab

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professionals. And let's talk a little bit about how we integrated them into the team to work with the research team. It was a few different ways, thankfully. So they contributed via a steering committee as well as - we collected some data because we want to do some research, right? - via focus groups and interviews. Once we understood what the content was that we wanted to address in the educational program, we worked in workgroups to really try to figure out how we would streamline it and target the content of the educational material, as well as pilot testers. And I'll get to that in just a second.

FYFFE: 06:29

So let's talk about each of these types of contributions that our key stakeholders-- how they worked with us. In terms of the steering committees, our steering committee helped to advise the content of the question guide. So before we even went in to conduct our focus groups and our interviews, we talked to our steering committee members about important questions that we needed to ask. They helped to inform that content based on their experience and things that they were curious about as well. So they gave input in that way as well as before we even went out to pilot-test the content and the materials that we developed through the different phases of the educational materials being developed. They helped us decide revisions along the way. So when you're developing educational materials, you develop it based on the feedback that has been suggested. And then it's like, "Is what we created-- does it make sense?" Right? So we took it back to our steering committee. They suggested revisions in terms of ways we could revise things to make it tighter. In addition, they also helped to inform the worksheet and the guides and the resources in terms of dissemination pieces. They were also very helpful in terms of taking a look to give us a critical eye outside of, again, the research team, to talk about what was informative to them, as well as helping to share the course with the community. So our steering committee were working in the SCI community and working with their agencies and could really help to share some of the information and the fact that the educational program is actually now available, too, with the SCI community. And our steering committee members were also compensated for their time.

FYFFE: 08:08

We also recruited people living with spinal cord injury and other partners to participate in focus groups and interviews and, again, to make sure that the content of the educational materials was informed by our key constituents and people who would be actually using the materials. We conducted 10 interviews and 7 focus groups, and from that, we identified different themes and content topics that were important that we wanted to include. The focus groups and the

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interview really helped to outline the modules and the topics that we were going to be talking about and helping to educate our PCAs and family members. So gathered the information, right? Then we needed to make sense of, "Well, and how do we incorporate all this information into educational modules?" whether it was the script that was being used or the educational supplemental guides that we're going to be using. We put together workgroups, anywhere from three to four members. And again, this included three people living with spinal cord injury, three personal care assistants, two clinicians, and two home healthcare agency leaders. We met regularly, at least twice a month, with our workgroups. We actually broke out-- because it's a big group of individuals, we decided that maybe we should separate and address different themes that were generated from the focus groups and the interviews based on interest, also just overall experience.

FYFFE: 09:37

So our workgroups worked on three different themes. First you see there is What is SCI. The second group worked on theme number two, Addressing Secondary Complications. And the third workgroup worked on theme number three, Misconceptions and Non-physical Effects of Spinal Cord Injury. So again, we met regularly to take a look at the content of the educational materials and what we wanted to say and what we would glean from the material that was important. So they helped us to prioritize the content and tweak it so it could also make sense in terms of how we were going to be delivering the material, making sure that we were sensitive to the educational needs of our PCAs, potentially, and really just being very mindful about how we're conveying the material to folks who are observing and look at the modules online.

FYFFE: 10:29

And from there, once the educational modules were developed and uploaded to klearn, we needed to go through pilot testing, because you want to make sure if you're developing educational materials that, again, it makes sense to the target audience, right? So we pilot-tested with two different groups. The first one were 15 personal care assistants with little experience assisting clients with spinal cord injury. And that's important because you want to see, "There was the learning curve," right? So, "What did they learn over time in terms of going through all the modules that we developed? And did it make sense to PCAs who are new to SCI?" But then we also had a second group. We had a small group of PCAs who actually had experience working with clients with SCI to also get their input about the content as well. And that was really important too because we wanted to make sure that, again, we weren't missing anything and that the content was consistent with some of their experiences as well.

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FYFFE: 11:27

So in addition to having them run through all of the modules, we also gathered information via questionnaires about their experience with the materials, "Did it make sense? Did it not make sense? And if it did or did not, what did they find informative or what could we change?" Right? A part of pilot testing is really trying to make sense of, "What do we need to change? What do we need to tweak?" again, so that we're making sure that we're sharing most informative content that makes sense to individuals and it'll be useful to them while they're working with their clients in their homes. We also had interviews with both groups, either PCAs who had little experience with clients with SCI as well as PCAs who did have experience, again, to learn about their experience while going through the modules, so, "Was the content blurry? Did we talk about bowel and bladder care a little too fast in terms of the rhythm or the cadence of the speakers?" and things like that. So it was really helping us refine and tweak it, again, so it made sense and ran smoothly. In addition, we had our steering committee help to guide feedback from both of those groups, revise the guides that accompanied the online content as well. From there, I'm going to turn it over to Jeanne who's going to tell you more about the course content.

ZANCA: 12:49

Oh, I get the fun part, sort of, to talk about what the product of all that hard work that Trevor and Denise was talking about led us. So I want to present to you an overview of the course modules and the different components of the course, and then in a few minutes, we'll actually play about a four-minute segment of the course so you get a sample of what that looks like. So first, there are eight modules in the course. They range from number 1, which is You Make A Difference, which was intended to really help personal care assistants who are looking at this course feel valued and recognized for the contributions they make to the lives of people with disabilities, specifically SCI, that they serve -- at the very end, we have a Special Topics set of modules that talks in depth about some additional topics our advisors felt needed more depth, and we'll talk about those in a little bit. And then kind of in the middle, we have What is Spinal Cord Injury, Physical Functions Affected by Spinal Cord Injury, Personal and Social Challenges, Common Misunderstandings, Complications. And then these were followed by an Applying What You've Learned, which is sort of a capstone to the course. So in the next few slides, I'll talk to you about the things that you see in red there, 2 through 6 and 8. Those are the modules I'll talk about in the most depth today.

ANNOUNCER:
13:58

Please refer to pages 18 through 25 of the presentation slides.

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ZANCA: 14:02

After our introduction, our second module is What is Spinal Cord Injury, and it includes the kinds of things you might expect to see: a definition of the spinal cord injury and what a spinal cord injury is, different causes of spinal cord injury, the characteristics of people with SCI, including that they can be someone who's in the prime of life and have this hit them all of a sudden. That's not uncommon, as we know. We talk a bit about paraplegia versus tetraplegia and what level and completeness means so, if they hear those terms, they have a basic understanding of their implications for somebody's functioning, and how everyone with spinal cord injury is different. And you hear that multiple times throughout the course because we wanted to encourage people to be flexible and to think about the individual needs of the person they are assisting as they go through their day. The next module talks about physical functions affected by spinal cord injury, and these include the things that one can see, like a lack of movement, but also lots of things you can't see, like not being able to feel or having your breathing affected or reflexes and spasms, a loss of temperature, blood pressure, and bowel and bladder control. Some of these are things that people would not even think about if you didn't really know much about a spinal cord injury. You just focus on the wheelchair and the not walking part, but there's a lot more to it. So this module tries to give people that bigger picture sense of what a spinal cord injury affects in somebody's physical functioning.

ZANCA: 15:21

And then we wanted to spend some time talking about personal and social challenges created by spinal cord injury. And one of the major observations we made in those focus groups and interviews that Denise was presenting before was that a lot of the sources of stress and difficulty really didn't have to do with the physical aspects of caregiving but had to do with misunderstandings between the person who's providing assistance and the client, and maybe people not being sensitive to the dynamics of what it's like to live with spinal cord injury. Because remember that many home healthcare aides or personal assistants have experience with people who may have memory impairments or may be less cognitively able to participate in decision-making and interactions than is typically the case for most people with spinal cord injury. So the dynamics are very different. They're working with someone who's completely cognitively able to participate but needs physical assistance, and that's different than if you are assisting someone who has less of that cognitive capability. So in here, we talk about things like loss of control, feeling vulnerable because you're dependent on somebody else for the most basic of tasks, loss of privacy, keeping in mind that a lot of what someone needs help with, especially when it comes to bowel and bladder, are pretty intimate

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things. Talking about sadness and lack of confidence, including depression but not necessarily with a focus on that because that's not necessarily an issue for every person with spinal cord injury. But it's quite common for people to have high periods and low periods and go through difficult times. We also talk about social isolation and a little bit of how personal care assistants can help with that and financial stress as well.

ZANCA: 16:50

Then we have a module about common misunderstandings. And the content of this module overlaps a bit with some of the previous ones, but it helps to reinforce concepts that we thought were particularly important. So there's three categories of myths that we presented and facts associated with them. We talked about myths and facts related to physical effects of spinal cord injury, thoughts and feelings that people with spinal cord injury express, and their preferences for help. So to give a couple of examples, one of the myths we might present is that all people with spinal cord injury are the same. You have an SCI, we know what that looks like. But the truth is, no people with SCI are the same even if they do have the same level or completeness of injury because there's lots of factors that affect their life and how they operate within it. Also, a common myth is that SCI affects both moving and thinking ability. Now, here I will give a nod to my colleagues in the TBI lab who are doing excellent work on how SCI can affect cognition, but the key issue here is decision-making. For the majority of people with spinal cord injury, they can think and make decisions just like other people that someone might interact with in everyday life, and it's important for their assistant to understand that and to be respectful of that. Another myth is, "If it looks like your client is struggling, you should help," but there are some situations in which a person with spinal cord injury might not want help. Maybe it's something they feel more comfortable doing on their own or they're trying to learn. There's lots of reasons. So ask. Don't just jump in. And another example of a myth is, "People with spinal cord injury who cannot walk must be unhappy." And we had lots of people in focus groups tell us that they had people saying how sorry they felt for them and things of that nature, but they wanted to emphasize that, "I can have a pretty good life, and I can be pretty happy even though I have this challenge that seems pretty difficult." Keep that in mind.

ZANCA: 18:27

And then our final module, which actually is split into two sections, is Complications of Spinal Cord Injury, because clearly this is a huge issue for people with SCI that has a lot of effects on their health and their quality of life, and what personal care assistants do plays a really direct role in whether or not someone will have these complications. So we talk about skin issues, autonomic dysreflexia, blood pressure, both high

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blood pressure and low blood pressure, infections, pain, blood clots, problems with joints, muscles, or bones, and mental health challenges as well. And then I had mentioned that we have these special topic modules that we wanted to include. And the reason we split out this content into special topics is that we wanted to make sure the course was not going to be cumbersome in its length. So the main part of the course, those modules 1 through 7, take about 2 hours in total to do. That includes watching the content and then taking quizzes and assessments associated with those modules. And then this set of special topics is about another 45 minutes at the end, and they dive deeper into particular things that our advisors thought were really important but that doing a deeper dive on in the main part of the course might derail the content. So they wanted to see some additional content at the end. Those four topics are: Building Positive Working Relationships, Equipment and Spinal Cord Injury, Tips for Safe Transfers, and Managing Blood Pressure.

ZANCA: 19:45

So for Building Positive Working Relationships, the content includes things like establishing expectations upfront for what falls within the scope of someone's job as your assistant and what doesn't, defining those responsibilities, identifying who is directing care - and this can be particularly challenging with someone who lives with their family, perhaps, and they have other people in the household who might potentially be talking to the home healthcare assistant about what's needed - being clear about who can give those instructions. We also wanted to encourage a professional relationship. There's a fine line between being friendly and being overly friendly, and we encourage people to err on the side of a little bit of a more business-like relationship than a friend-like relationship because it preserves the dignity of both parties. We also encourage assistants to speak up if they're not sure about something or they're feeling uncertain. Say it. Don't just let it hang there and cause resentment and problems later on. We also encourage them to check in regularly, "How are things going? How is today? How am I doing? Are there things you would like to be done better?" or on the side of the personal care assistant, if you're having challenges, maybe talking to your client about things that would make your life easier in helping them. And then identifying people who can help you as a PCA. So this might be family members who can give some additional advice. It might also be home healthcare assistants in your larger circle, at your agency perhaps, who have expertise to give, or it could be other people, perhaps the therapist that your client's working with. Maybe you can come with them to therapy and learn a little bit about how to transfer. So trying to connect them to other resources to help them learn.

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ZANCA: 21:14

Then we talked about Equipment and Spinal Cord Injury: how important it is for function and safety, how maintaining it is important, and the types and their general function. So we really don't get into the specifics of how to use a particular piece of equipment, but we just didn't want people to be surprised when they saw certain things in someone's home, especially because there are certain pieces of equipment that are more common for people with spinal cord injury than for others. So we wanted to orient them in general to what those things do and how they can be helpful and what their role is in using that equipment and, again, who to ask for more information so they always feel like they have a resource to go to. Next, we talk about Tips for Safe Transfers. And again, this is not a how-to of how to do a sliding board transfer or a Hoyer lift transfer, because everyone's going to be different in what they need, but we talk about a general range of techniques and the idea that not everyone with spinal cord injury needs a lot of physical help, but some people might - so there's a range - what to check before you move, regardless of what your style of transfer is going to be; a little bit about mechanical lifts, because those Hoyer lifts are very confusing for many people; the importance of assessing the individual client and what they need; and pausing if needed. So if you're in the middle of a transfer and something doesn't seem right, pause. Don't just keep plowing through because that could lead to a fall. So we encourage people to stop, communicate, rethink if they need to. And then finally, we talk about blood pressure, including what autonomic dysreflexia is, the signs of it, and how you respond to it, and also low blood pressure, which can be a big issue for lots of people with spinal cord injury, and lots of different ways that that can be managed. In addition to these video modules, we have a set of supplemental materials that provide a discussion guide that goes over different topics to discuss between a client and a personal care assistant to help establish those expectations and communicate. We have a list of web-based resources from lots of great organizations. As Trevor was saying, there are great things out there. They're not necessarily targeted to home healthcare aides, but they can have relevance for them, and so we connect them to those resources as well.

ZANCA: 23:08

So next, I'll talk a little bit about the course platform that we used. We used a service called Thinkific. That's the platform that our website, klearn, runs on. It's a commercially available course delivery platform, and there are many that have developed over time. But the thing that's really wonderful about these is they really make it easy to make a web-based course and to share it, because you don't have to have any programming expertise. You just make your videos. You make your

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documents. You can upload PDFs. You can upload MP3s. You can upload videos. And all the infrastructure is there. You don't need a programmer. You don't need a whole website designed from scratch. So it really makes things a lot easier for people who are developing courses, and it makes them more cost-effective to create because you don't need that technical expertise. Now, the courses that Thinkific and other platforms run are divided into sort of chapters, which are the big sections, which we have been calling modules, and then lessons that are nested within those. And there's lots of different content types that you can include, including slides with images and voiceover; videos, which you'll see a little bit later, of interviews; and assessments as well to help people test what they've learned. So what I'm going to do now is play you a lesson sample. So I'll just take a moment to locate that file. And this will be about a four-minute module. It's from our section on personal and social challenges created by spinal cord injury, talking about feelings of vulnerability.

ANNOUNCER 2:
24:34

People with spinal cord injury may also be concerned about risks to their health, such as getting an infection or breaking a bone during a transfer.

MALE 1: 24:43

My spinal cord injury happened when I was 16 years old. So at that age, having to adapt to someone coming in, dressing me, bathing me, and doing all those personal things-- adapting to that change was a little bit hard, and I would say, mostly, it was just embarrassing at first. But then after time, you get used to it, and eventually, it just becomes normal.

FEMALE 1: 25:05

It was very difficult to adjust to get help with personal tasks. First of all, no one's used to a stranger coming into their personal space, being undressed in front of this person, having to use the bathroom in front of or with this person. You don't have the benefit of getting to know somebody first. It's kind of like, "We hired you. Come on in. Get me naked and get me bathroomed and dressed. By the way, how was your day? Tell me about yourself." It's this really quick comfort that has to happen because you have no choice.

DYSON-HUDSON:
25:37

When I first started working with PCAs, it was really challenging. You don't realize what you can't do until you can't do it. In the beginning, I really hated the idea of working with a PCA. Before my injury, I was very independent, and the thought of asking for help from someone just really drove me crazy.

MALE 2: 25:58

Giving someone feedback or input, some people would say criticism-- I think the biggest thing that I had to figure out how to do and continue to do and be consistent at it was give constructive input even though I

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was, and still remain, very, very vulnerable. It's very difficult to say, "Hey, next time, would you do that a little bit better by doing X, Y, or Z?" when that same person has to turn right around and provide my care five minutes later or an hour later. And I don't want to lose someone that I've been with for weeks or months or years.

ANNOUNCER 2:
26:34

How do feelings of vulnerability affect the care you provide? Understand that your client is counting on you. If you are not there to help when needed, it can leave your client stuck in bed or at risk for health problems. Arrange for someone else to fill in for you if you cannot be at work. Early in your relationship with your client, express that it is okay and helpful for him or her to tell you when something does not feel right or if you are doing something that makes your client uncomfortable. This will help your client feel more comfortable communicating concerns. It is important to avoid reacting angrily if your client expresses a concern in a respectful way.

ZANCA: 27:14

To make our clients feel comfortable when we're doing the personal tasks, it's making sure they're covered and that if anybody would walk in the room, there's nothing exposed or that the door is shut or that the house is locked, basically. Well, when we're doing personal care, conversation is always part of it so that they know what we're doing. And then we'll watch the news and just talk general conversation so that it's not out of the normal-- that life is just kind of normal. We're doing our range of motion, and we're just doing it and having a conversation.

ZANCA: 27:51

They know what I'm there for, but they're still not comfortable. So talking to them, if they see you comfortable and not nervous, they slow down and they won't be nervous.

ZANCA: 28:01

Reliability is key to the relationship because the client is so dependent upon another individual for their activity of daily living. And if you're five minutes late, to them, that might seem like an hour because they're not sure if help is ever going to come. So it's very important to establish trust.

ZANCA: 28:26

You need to take your client's feeling into consideration, "What if that was me?" So for me personally, I never fully undress my client and leave them naked. I always cover them with a towel, and I will wash them section by section. And as I am going through the different sections, I would also tell that client what I'm going to do next so that they can be prepared mentally for me doing that.

ZANCA: 28:58

So you see how we had sort of a rhythm where we had people with spinal cord injury talking about their personal experiences, then we had a little bit of a didactic that kind of described some key concepts,

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and then experienced personal care assistants talking about how they apply those concepts in what they do directly. So one of the things I'm very proud of about this course is that every voice you hear is someone with some lived experience related to the situation. So even our voiceover artists are people with disabilities that our production company helped us connect with. So everybody you hear knows about this from real life, and I think that gives the course a credibility that it would not otherwise have. So we feel very fortunate to have had the opportunity to work with this team. Now that we hopefully have gotten you excited about this course, how do you access it? It's available on the web for free. There is no cost to access this course, which we hope will encourage its use. We are very happy to have your support in helping us share the course with people who might be interested. So this could include people you work with in the context of research, patients that you're seeing as part of your clinical rotations or your clinical work. And there's others in the community that we'd like to reach out to - and really, we're at the beginning of sort of a long process of dissemination - including places like independent living centers, SCI organizations, home healthcare agencies - I have a presentation with some folks from BAYADA next week - agency associations, accrediting bodies, and any other ideas you have for us. We're actually quite excited because FacingDisability.com, which if you don't know about it, is a wonderful educational resource for people with spinal cord injury, picked up this course and put a post about it in their weekly newsletter. So we're excited to see what bump that gets. And I give many thanks to our communications team for all their assistance in helping us create a press kit to help share this course, which I'm happy to share with anyone who is interested, for use in social media and print and other kinds of venues. Our team has made really helpful materials to help get the word out, and we're grateful for that. So I'll just close with another set of acknowledgments. Again, to our funders, NIDILRR and PVA. We also are thankful to United Spinal Association, which provided some of the still images that are used in the course, and to the National Center on Health, Physical Activity, and Disability, which provided some images and video as well. Thank you so much.

ANNOUNCER:
31:07

If you have any questions, feel free to email Dr. Zanca. Her email is listed in the program notes. Tuned into our podcast series lately? Join our listeners in 90 countries who enjoy learning about the work of Kessler Foundation. Be sure and subscribe to our SoundCloud channel, Kessler Foundation, for more research updates. Follow us on Facebook, Twitter, and Instagram. Listen to us on Apple Podcasts, Spotify, SoundCloud, or wherever you get your podcasts. This podcast was



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