

Speaker 1 ([00:13](#)):

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Kevin Gregory ([00:52](#)):

Hello, and welcome to another episode of the HD Insights Podcast. As always, I'm Kevin Gregory, Director of Education, Communications and Outreach at the Huntington Study Group, and your host as we talk with the special people doing extraordinary things in the field of Huntington's disease research. The topic for this episode is physical therapy for HD patients, and our guests are Dr. Lori Quinn, Associate Professor in the Motor Learning Program, Department of Biobehavioral Studies and Director of the Neurorehabilitation Research Lab at Teachers College, Columbia University, along with Dr. Nora Fritz, an Assistant Professor in the Physical Therapy Program, Department of Healthcare Sciences and Department of Neurology at Wayne State University School of Medicine.

Kevin Gregory ([01:38](#)):

We wanted to have Dr. Quinn and Dr. Fritz on the podcast for a couple of reasons. First, the topic of physical therapy for people with HD symptoms is a very important one but doesn't always get the attention or publicity that drug therapies tend to garner. And the other reason is because they led a research team that has been working for the past few years on developing clinical guidelines for the use of physical therapy with HD patients, with funding provided by the Huntington Study Group along with EHDN and the Griffin Foundation. Those guidelines have recently been accepted for publication by the journal *Neurology*, and we're excited to have them on the podcast to talk about it.

Kevin Gregory ([02:17](#)):

So now, without further delay, here's our interview with Dr. Lori Quinn and Dr. Nora Fritz. Well, Dr. Quinn and Dr. Fritz, thank you so much for joining us on this episode of the HD Insights Podcast. We're thrilled to have you today.

Dr. Lori Quinn ([02:35](#)):

Great. Thank you.

Dr. Nora Fritz ([02:35](#)):

Thank you.

Kevin Gregory ([02:36](#)):

And so I want to kind of dive right into it because I know you're at the annual physical therapy conference right now and I appreciate you taking time out of your busy conference schedule to chat with us. But we want to talk about the guidelines that your group has come up with for physical therapy for HD patients. So first of all, I guess I'll start with you, Dr. Quinn. What made you want to pursue this particular project?

Dr. Lori Quinn ([03:06](#)):

Yeah. Well, I have to say, something we've been thinking about for a really long time is how can we sort of get the word out about the potential benefits of physical therapy for people with Huntington's disease. Because it's a relatively rare disease, it's difficult to do sort of large scale clinical research projects in HD, but we have sort of over the past I think 10 to maybe 15 years, we made a lot of progress in getting a range of studies completed, both our groups and other groups internationally have done some really excellent work that have shown the benefits of exercising physical therapy.

Dr. Lori Quinn ([03:49](#)):

And so I guess a few years ago now, probably almost four years ago, we sort of looked at the literature and thought it might be time to try to develop clinical guidelines. And so we pulled together our group and we sort of scoured the literature and I think came up with sort of a really good approach to trying to document sort of an optimal, at least what the literature is demonstrating right now, about how we can use exercise and physical therapy to help people with HD.

Dr. Nora Fritz ([04:24](#)):

I think something that's also important to add is that Dr. Quinn and I are often approached by community therapists who are looking for tools and resources that they can use and apply with person's with Huntington's disease because they don't often see these patients, but when they do, they want to know what is the best way to treat these patients. So we've had the pleasure of working together for over 10 years and that started with a really early, early version of clinical recommendations that was published in 2009 through a partnership with the European Huntington's disease network Physiotherapy Working Group and over the course of the last 10 years, we've sort of been refining some treatment based classifications that help us classify individuals with HD often by their primary impairments, and then understand how we can go about treating them.

Dr. Nora Fritz ([05:16](#)):

And so this clinical practice guideline was a really exciting culmination of that work that we can apply these treatment based classifications and also apply the best [inaudible 00:05:28].

Kevin Gregory ([05:29](#)):

And so, Dr. Fritz, as far as this being the culmination of many more years kind of working together, how did you and Dr. Quinn first get paired up on this particular initiative?

Dr. Nora Fritz ([05:45](#)):

So, actually, I was a PhD student when we met for the first time and two of my PhD advisors, who are also authors on this guideline, we attended a European Huntington's disease network meeting and Lori was there and she was at the time living in Europe and leading the Physiotherapy Working Group and really had an amazing vision of how we could help clinicians to guide practice for people with HD. And so we met at that meeting and I think we've been working together consistently ever since.

Dr. Lori Quinn ([06:21](#)):

Yeah.

Kevin Gregory ([06:23](#)):

Wow. And what about the rest of the team? So I know, certainly, there are the two of you that we're speaking with today, but I know there are a number of other key contributors that you had on the working group that ultimately developed the guidelines. Who else played that key role for you?

Dr. Lori Quinn ([06:40](#)):

Yeah. So I'll just acknowledge the other authors. So Deb Kegelmeyer and Anne Kloos are both at Ohio State University. They were Nora's PhD advisors, and again, we've been working them for a number of years and they've been part of obviously both HSG and also had joined the Physiotherapy Working Group as part of EHDN. Ashwini Rao is at Columbia, so he's actually an occupational therapist, and I've worked closely with him for a long time. So he contributed to these. And Monica Busse, who I worked with at Cardiff University when I was living in Europe, and she and I were co-lead facilitators for the European Huntington's disease network Physiotherapy Working Group.

Dr. Lori Quinn ([07:23](#)):

I do also want to acknowledge that sort of behind this was a whole really group of other physical therapists and physiotherapists who supported us, red versions of this, contributed to the initial guidance document that Nora talked about we published in 2009. So there's a lot of physical therapists who are acknowledged, some of them by name in the document, but some in some of our other work who've really been very supportive of this work.

Kevin Gregory ([07:59](#)):

I want to talk about, yeah, I want to dive in a little bit more into the guidelines and the recommendations from your research. Specifically, some things that jumped out to me was you mentioned, there's mention a few times of a dance based video game that seems to have aided in some specific improvements for folks. What other ways have you seen advances in technology, kind of along those lines, where technology is really driving improvements in PT techniques for HD patients?

Dr. Lori Quinn ([08:35](#)):

Well, I think, so as far as an intervention goes, that's probably one of the few interventions that have really had a technology base to it in terms of utilizing that for the intervention. There's certainly things like virtual reality and augmented reality that are being used in a lot of other diagnoses, but we haven't seen that hold into HD very much. Where I would say that we're using technology a lot is in the use of wearable technology to evaluate patients, and this is something that I think has application not just for exercise and physical therapy trials and interventions but also for pharmacological. And there's a lot of trials going on right now that are using wearables.

Dr. Lori Quinn ([09:22](#)):

But we have been using wearables for a number of years, both to look at movement analysis, so parameters of gait analysis, and Dr. Rao has done quite a lot of that work. We're doing a lot of work right now on balance assessment and importantly looking at physical activities. So some of the studies we have ongoing right now are using physical activity monitors to quantify movement and quantify physical activity. So I wouldn't, yeah, I wouldn't say that right now, technology is at the forefront of the interventions, but certainly on the assessments.

Kevin Gregory ([09:58](#)):

Were there any results or outcomes during the course of this research that surprised you that you weren't necessarily expecting when you first went into it?

Dr. Nora Fritz ([10:08](#)):

I would say that we were a bit surprised to find almost no literature in the areas of secondary musculoskeletal and postural changes and end-stage care for persons with HD. Very little work has been done in that area and no randomized controlled trials of any sorts or no high level evidence. So this was a time where we really had to rely on the expertise of physiotherapists around the world and other healthcare providers for persons with HD. And as part of our process, we actually ended up surveying therapists and healthcare providers around the world. We had hundreds of people respond to the survey. It was really encouraging, providing information about the way that they manage secondary postural changes and end-stage care.

Dr. Nora Fritz ([11:05](#)):

And so just from the perspective of the collaborative nature of researchers in the field of HD, it was a really exciting way to kind of learn about those areas and to set future directions for how we can improve what's in the literature.

Dr. Lori Quinn ([11:24](#)):

Yeah. And the other thing that I would just add to that is the thing I found surprising was the lack of high level evidence for balance training. Balance is such a big problem with a lot of the patients that we see and we, one, don't have very good assessments for balance. And two, there's really just very few interventions that were solely focused on balance. There were exercise interventions that measured balance, but not so much really specifying interventions that could improve balance. And that's something that I really paid attention to and started to think about ways that we can design some trials looking at specifically balance and falls risk.

Dr. Nora Fritz ([12:08](#)):

And to springboard off of that, because of this, Dr. Quinn and I and a group of researchers have really sat down thinking about perhaps one of the reasons why it's been so challenging to look at balance and balance interventions is that we don't have a disease specific outcome tool looking at balance for HD. So together, we're partnering with several other institutions to study and develop and HD specific balance tool. That's one of the things we're working on right now.

Kevin Gregory ([12:39](#)):

Do you find it to be more of a challenge to get interest in studies around physical therapy? I know, obviously, the drug therapies get a lot of the media attention and the publicity. And so patients or even providers may not necessarily think physical therapy is a route that can drive a lot of improvement. Did you find that through the course of your research and investigations that there's kind of more of a prejudice towards other clinical trials, drug type clinical trials versus the interest in doing the physical therapy work?

Dr. Lori Quinn ([13:27](#)):

Yeah. So I've been doing clinical trials in HD, yeah, probably, yeah, for over 10 years. And, I mean, yes, most definitely, I think there is maybe a bias or prejudice towards pharmacological interventions. And I'm the first one to completely understand that. I think what we have tried to do when we have

designed clinical trials and when we're choosing sites for clinical trials, we have a relatively large study going on right now, we've tried to choose those sites that maybe aren't the ones that are being chosen for drug trials and that have the therapy support that would be able to conduct the research.

Dr. Lori Quinn ([14:15](#)):

But ultimately, I felt that while funding is certainly difficult for everyone and that's something that we've struggled with to try to get the proper funding to do the larger scale studies, we have found an incredible amount of support through HSG, through EHDN, through a lot of the neurologists that we talk to, people like Martha Nance, who are incredibly supportive of the work. So I think we get really empowered by that, and people are generally really supportive. And we're certainly understanding of the kind of bias towards pharmacological interventions.

Dr. Lori Quinn ([14:52](#)):

I think both Nora and I feel, and our group feels that we'd love to see physical therapy and exercise interventions really be pushed a little bit more to the forefront when we think about interventions because when you think about diseases like Parkinson's disease, it's a frontline intervention. The first thing that doctors tell patients with Parkinson's disease when they get diagnosed to do is to exercise. There's hundreds of trials in Parkinson's disease. And they know that drug plus exercise has almost this synergistic effect, and the exercise can sort of address the issues that the drugs [inaudible 00:15:31] Parkinson's disease can't.

Dr. Lori Quinn ([15:32](#)):

And we are feeling really strongly that even in Huntington's disease now and potentially in the future with new medications, that, that still will be the case, that there's a really important role for physical therapy.

Dr. Nora Fritz ([15:45](#)):

The other thing I would add. I think it was the director of the NIH had this really wonderful quote that if exercise was a pill, it would be the most widely prescribed pill in the world.

Dr. Lori Quinn ([15:56](#)):

Mm-hmm (affirmative).

Dr. Nora Fritz ([15:57](#)):

Everyone understands that exercise is beneficial and it is harder potentially than taking pharmacologic, but this synergistic effect I think is really important for us to educate patients and families about there are no side effects of exercise. It goes well with everything. And so we always want to educate people that this is something that they could take control of in a disease where they might feel like they don't have a lot of control, so they can control their exercise and take, and we feel that, that's really important to empower our patients. So that's one thing that we educate.

Kevin Gregory ([16:32](#)):

Well, I guess the other thing too is with a trial in terms of physical therapy, it wouldn't probably necessarily exclude you from pharmacological clinical trial, correct?

Dr. Lori Quinn ([16:47](#)):

No. So we have a study going on right now, PACE-HD, and we've had a couple of people who've entered into some of the ongoing clinical trials and they've had to drop out of our study. So the major issue on the part of the drug trials is that they don't want obviously anything else potentially interfering with that the patients are doing additionally, even if it's just doing some assessment. So on our end, we don't exclude people if they're in other clinical trials. We try to really have a very pragmatic approach. But it is a bit difficult and it's something we have to think carefully about if we're going to be continuing to do rehabilitation trials going forward with these large number of other trials.

Kevin Gregory ([17:33](#)):

Can you talk about the PACE-HD trial for a minute, the size and scope, how long it's been going on for and what the expected duration is for that?

Dr. Lori Quinn ([17:43](#)):

Sure, yeah. So the PACE-HD study was funded by the Gossweiler Foundation, which is a European, it's a Swiss based organization. The sponsor for the trial is Cardiff University, which I am affiliated with and worked at for a number of years. And Monica Busse and I are leading that study. It's a six-site study that's taking place over three countries, and we've enrolled 116 people with Huntington's disease. Half of the individuals who've come in are just doing a longitudinal evaluation, so they come in at two assessments, at baseline and one year later, and we're measuring a whole range of physical activity, physical fitness and mobility measures. So we're sort of almost looking at natural progression over a year.

Dr. Lori Quinn ([18:32](#)):

And then the other half are part of a randomized controlled trial where we're doing a one-year physical therapy exercise intervention. So half of the people get exercise and half of the people continue as usual. So we are about three months away from the final endpoint, which is the one-year followup for the trial. We're putting together the baseline results right now and we should have, by the end of this year, the kind of full study results available.

Kevin Gregory ([19:06](#)):

Excellent. I want to go back to something, and I apologize, I think Dr. Fritz, it may have been something that you mentioned, and I saw it being alluded to in the research on the guidelines is that you didn't see a lot happening with folks more in late stage or end-stage. And typically, in terms of physical therapy interventions, is it something that HD patients aren't getting until they're well into showing symptoms? Is it something that they should be looking at earlier stages? What did you find during the course of the project?

Dr. Nora Fritz ([19:51](#)):

So I can just start anecdotally and tell you that the majority of patients with HD do not receive their first or ever physical therapy evaluation until they begin showing over motor symptoms, particularly when they start falling. And we would advocate that people should be referred to physical therapy upon diagnosis so that we can establish a wellness program and really focus on and emphasize physical activity and wellness throughout the disease course and so that we can sort of prevent some or at least delay some of the respiratory issues and positioning issues and potentially, secondary changes in postural alignment in musculoskeletal conditions.

Dr. Nora Fritz ([20:42](#)):

So I would say yes, I think that, that is true, most patients do not receive physical therapy until later in their disease. I think Dr. Quinn would second that.

Dr. Lori Quinn ([20:52](#)):

Yeah. We did a survey of physical therapists back in 2008, and that was one of the sort of overriding themes was that patients were not being referred early enough, and that often, by the time that therapists would see patients, there were certainly things that could be done, but there was so much more that therapists felt could have been done, especially in the earlier stages. So we've been really pushing for earlier and earlier intervention. And we actually did a physical activity coaching study at Columbia, where I work, in individuals with pre-manifest and newly diagnosed, so newly sort of motor diagnosed patients.

Dr. Lori Quinn ([21:35](#)):

And that was really beneficial I think for people, and it's a model that we use at the clinic and something that we really want to try to push forward a little bit with these guidelines because some of the overwhelming evidence is in aerobic exercise, which is something that people can do from the minute that they're diagnosed, and certainly, in pre-manifest or prodromal is something that people can engage in. And it might potentially affect the course of the disease.

Kevin Gregory ([22:07](#)):

Did you find any evidence also, so there's certainly the aspect of physical therapists not having the background or the guidelines up to this point to refer people to physical therapy early on, is there resistance on the part of patients potentially, maybe around the stigma of having PT, maybe if you don't feel like you have the symptoms? Did you encounter any of that kind of evidence?

Dr. Lori Quinn ([22:39](#)):

I mean, I would say I didn't in the clinic setting that we worked in because we really just tried to use a wellness approach, sort of as Nora was mentioning. And we really just try to talk to individuals about there's so much benefit about exercise in general and almost using that as a coaching framework that it can be beneficial for everyone and, look, it might even have this additive effect of having, there's this concept of neuroprotective effect, that exercise might have a neuroprotective effect. And there's some evidence in other diseases that this is the case, and we don't really know that it's the case in HD, but kind of framing it in that way I think was helpful.

Dr. Lori Quinn ([23:26](#)):

But I think you bring up an interesting point. I mean, there certainly could be that stigma. And, I mean, definitely, I didn't have... everyone wasn't super keen to sit with me, I can definitely tell you that. There's definitely people who are like, "Yeah. No, I'm good. I don't need anything." And I think we do need to think really carefully about that. One of the things that I think is nice about being in a clinic setting is it's not always a full on physical therapy evaluation. Sometimes, we just sit and have a quick chat with patients. And that, in and of itself, can be really powerful and motivating, especially if people don't want to go down the whole road of physical therapy, a whole physical therapy program over a number of weeks. And, yeah, there's a lot of barriers to that.

Dr. Nora Fritz ([24:19](#)):

One thing I'll add to that is that we did actually look at some qualitative data as part of the guidelines. And really, the goal of that was to understand perceptions of patients and their families about exercise. So this idea about where the exercise takes place didn't actually come up as a theme from any of these articles, but what we did learn was that being part of a group, so if the training is provided in a group setting can actually be really helpful and that patients can gain something from that social interaction and really, that's helpful for building self-confidence and feelings of independence. In addition to the motor benefits of improving balance or walking, it also helps to improve just their overall outlook.

Dr. Nora Fritz ([25:04](#)):

So I thought that was really helpful. And we also gathered from those articles that intensive training is acceptable to individuals. And so I think one of the, when we speak about biases, one of the things that might happen in a community therapist who's not regularly treating a patient with HD, they may under-prescribe the intensity for that patient, not realizing how intensive a therapy could be for a person with HD. And so that's one really major takeaway from the guidelines is that intensive aerobic training, particularly in the early stages of the disease, is not only acceptable, but beneficial.

Kevin Gregory ([25:45](#)):

Yeah, that's interesting. I was curious, and just because I know there's often a mentality with people that, with, let's say, a sports injury, for example, not wanting to go to physical therapy just because you can deal with it or it's not bad enough, and what that ends up doing is just kind of delaying and making it harder for you to recover. And I think, although Huntington's is a long-term disease, really, you're trying to repair those movement issues. And I was really just kind of curious on that front.

Dr. Lori Quinn ([26:25](#)):

Yeah. I'll just say, I think that's a really good point. And this is maybe potentially a branding issue within physical therapy, and we're here at a physical therapy conference and there's a lot of discussion about this, is that physical therapy is often thought of as if people have these impairments or are very sick or have really significant problems, activity problems, but there's a whole push in physical therapy, and we are really experts at wellness. And there's this push in Parkinson's disease, and then a lot of others, especially the generative diseases, to have physical therapists utilize their expertise to not just treat problems, but to help prevent some of these problems.

Dr. Lori Quinn ([27:10](#)):

And with Huntington's disease, we have a very well understood, to some degree, progression of the disease. We can well predict to a large degree the balance impairments that are coming, the potential musculoskeletal problems that are coming down the road, the gait and postural problems, and if we can do some things early on to help prevent those and mitigate some of those problems, we're not going to completely prevent them but sort of change the course of the progression and to help head them off, I think that's incredibly powerful.

Speaker 1 ([27:44](#)):

We'll return to the interview on the HD Insights Podcast in a moment. We hope that you're enjoying this episode. As a nonprofit organization, the Huntington Study Group relies on the generous support from the community and listeners like you to continue bringing you in-depth content on HD, like this podcast series. If you like what you're hearing and are interested in supporting HD Insights through a grant or

donation, please contact us through our email address, info@hsglimited.org, or by calling toll free at 1 (800) 487-7671. We greatly appreciate your support. And now, back to our episode.

Kevin Gregory ([28:33](#)):

I'd like to piggyback on what you said about the approach of physical therapy for HD patients versus kind of any other setting, and can you kind of elaborate more maybe the general listener listening to the podcast right now, things of physical therapy is a short-term intervention to fix a problem. I hurt my shoulder, I go to physical therapy. In a few weeks, it's fine. But physical therapy for an HD patient or somebody with a long-term or chronic issue, it's more than that. And I think for Huntington's disease patients, what you're saying in your research is you have to customize it. It's not the same thing over and over. You're going to have to customize it as the disease progresses and changes course, correct?

Dr. Lori Quinn ([29:32](#)):

Exactly. I mean, you sort of nailed that. And to be fair, this is something physical therapists are still working on. We're adapting to this sort of a new model of care, and there's just work really in the last five years that had been discussing this as physical therapists sort of working across disease progression. I think for us, sort of, well, one of the things that we have done in the PACE study, as an example, is it's a 12-month intervention, right? You don't see many physical therapist interventions that are 12 months long. So we are seeing people over the course of the year, we're seeing them for 18 sessions over that time period.

Dr. Lori Quinn ([30:16](#)):

So 18 sessions is about what most insurance companies would allow for someone to get physical therapy in the course of a year. It's actually below what would be typical. But kind of the idea is instead of having eight weeks, twice a week, rather do we not spread that out over the course of the year and help people manage their disease symptoms over a longer period of time. And that's a shift in thinking for physical therapists but it's something that I think a lot of us who are working in neurodegenerative diseases really see a potential benefit of.

Dr. Nora Fritz ([30:55](#)):

Absolutely. The other thing that, that really does is build sort of a culture of wellness within that family. So we think about HD as a disease of families. If we can instill wellness as an important factor in one person, then that can potentially change the way other family members view their disease or potential disease and how they manage their wellness. I think that could be critically important.

Kevin Gregory ([31:22](#)):

Yeah. And health insurance, which you brought up, is a huge issue, particularly here in the United States. But in your experience or what you've seen, what other obstacles should patients or families be aware of ahead of time in terms of health insurance coverage that they may need to consider if they're looking at physical therapy intervention?

Dr. Nora Fritz ([31:55](#)):

Well, that's a very challenging question. As you mentioned, insurance is quite different in the U.S. than it is in other countries. Just by way of an example, several of the studies that we reviewed as part of the guidelines, that were included in the guidelines utilized a training program where individuals with HD team to a rehab center and stayed for three weeks at a time, three times a year, I think?

Dr. Lori Quinn ([32:24](#)):

Mm-hmm (affirmative), some of them.

Dr. Nora Fritz ([32:24](#)):

So nine weeks total every year of intensive training with physical and occupational therapists managed by a medical team. So when we think about ongoing care the way that Dr. Quinn was mentioning, that is taking it really to an extreme level that is something, a care model we would never see in the United States. So just a very big difference in how insurance is managed around the world. But within the U.S., this is an ongoing battle that I think the advocacy groups of the American Physical Therapy Association are fighting to get ongoing and preventive care for degenerative diseases. So we have groups that are on Capitol Hill really advocating on behalf of the physical therapy profession with Medicare and Medicaid to get ongoing coverage for these patients so that they don't reach a limit on their insurance coverage throughout the year.

Dr. Lori Quinn ([33:22](#)):

Yeah. Yeah, I think it is a really challenging issue. And I think most people are able to get some level of physical therapy services, and we are certainly not advocating that they should be seen by physical therapists twice a week for the rest of their lives, right. I think we also need to be part of the solution in being innovative at how we provide these services. And I think your initial question was what else do people need to be aware of in this regard. And I think it's that they can fight and sort of argue and provide evidence for within their insurance companies that these services are needed and therapists can really help with that.

Dr. Lori Quinn ([34:09](#)):

So I don't see that too much. I think a lot of the times, it's more the difficulty of getting them in the door in the first place, and I'm going to turn it on to something else, which is the issue of apathy and motivation. And this is something that Nora has studied. The kind of difficulty that I think patients have to get motivated to engage in exercise and to be proactive is something that we really don't understand as well as we should, and we're really trying to develop strategy is now that we know that exercise is beneficial, trying to develop disease specific strategies to help people overcome apathy and to engage in exercise. Because exercise is only good if you actually can get off the couch and do it for any of us.

Dr. Lori Quinn ([35:02](#)):

And for people with HD, they've got many more hurdles that are really related to their disease, there's some inherent apathy issues, which I think are really contributing.

Dr. Nora Fritz ([35:16](#)):

So one thing that I always tell my patients when I refer them to physical therapy is that it's really important for them to think about at least two things that they would like to be better at doing. So what are two things that are really important to them that they would like to do better. Maybe that's climbing their stairs at home, maybe that is walking a certain distance, whatever the case might be, because really, what it comes down to is making therapy important and relevant to that particular individual makes it more motivating.

Dr. Nora Fritz ([35:51](#)):

And the other thing that we found through the review of this literature and looking at some of the qualitative literature is that having a really supportive caregiver or supportive support person in your life makes you more successful at doing exercise and maintaining exercise long-term and can actually help to overcome that issue of apathy. So finding that support person is just critical.

Kevin Gregory ([36:15](#)):

Yeah. I was just going to say, I was going to ask you about the caregiver role because that's been a common theme with just about everybody I've spoken with on these podcasts is having the right care team is crucial and having caregivers that can keep you on track and can carry over that work into the home is crucial. In terms of physical therapy work, is it critical that your caregiver be able to perform the same things or do you think it's the caregiver just really needs to be as much of a coach and a cheerleader or somebody who can help perform those same types of tasks.

Dr. Lori Quinn ([37:03](#)):

I would say that it is very individual and as you know and I've heard on some of the podcasts, right, there's a lot of complexity to family dynamics. So I've had, just in some experiences with individual patients, where it's the caregiver who's the one really pushing the patient, saying, "Come on, you should do this," and sometimes, that works but sometimes, that just makes them sort of shut down initially. So it's sort of complex I think in traction and we really take it patient by patient and family by family and thinking about what's going to work optimally. Sometimes, it's not the family member, it's a friend, it's engaging somebody else.

Dr. Lori Quinn ([37:54](#)):

Children often work really well. We had in one of our studies, we had one of the patient's daughters who was 16, she was sort of her exercise partner. And even sort of Nora's point about group versus individual, there definitely is a benefit to group classes, but some people definitely don't like that either. So doing sort of individual, we have some exercise videos that we've put out, really creating a wide range of different options and similarly, having a wide range of options for a support structure for exercise. And that's really what you need.

Kevin Gregory ([38:39](#)):

Going through the recommendations that you put out, there's a couple of things that I wanted to circle back to and have you speak to a little bit more. When people think physical therapy, I think they naturally think stretching your arms, doing walking practices, working on gait, but one of the other things that you looked at specifically was breathing, breathing exercises, and I don't think that people generally would make that connection or that association. How important is that for HD patients?

Dr. Lori Quinn ([39:14](#)):

Yeah. So I would say, that was not one of the strongest levels of recommendation we have because there's only a few studies that have [inaudible 00:39:24], which is unfortunate, and I hope it's an area that's going to continue to build, because we know from very early on, some of just of the cross-sectional work that's been done is that there are real limitations in capacity and in lung function. And this has such tremendous effects in terms of endurance and walking and functional abilities.

Dr. Lori Quinn ([39:49](#)):

We don't really know to the degree that specific inspiratory and expiratory muscle training can really have a significant effect, but there's some preliminary evidence to suggest that it is. But it really, there's a lot of linkage between respiratory function and functional abilities that I think we need to be paying a lot more attention to.

Dr. Nora Fritz ([40:14](#)):

I will say that respiratory training in general and care respiratory function by physiotherapists is much more common in Europe than it is in the United States, and both of the primary studies that we gathered information from for the guidelines came out of Europe. But in addition to functional limitations that occur with airway clearance, we also have secondary issues that can occur, things like pneumonias and just cough, ability to cough and swallow. And so all of that can play into declines in persons with HD. So you can kind of see how respiratory function could be really important in a whole host of domains.

Kevin Gregory ([41:01](#)):

The majority of the recommendations that you came out of the research with relate to encouraging larger scale clinical trials to examine these areas. You talked about the PACE-HD trial, are there any other trials that people should know about or that you're aware of that are kind of in the design phase or maybe will be coming soon that they should watch for or where they can go to get more information potentially about those?

Dr. Lori Quinn ([41:30](#)):

Yes. So there's two studies that I'm aware of. So there was an NIH funded study I believe out of Iowa that there should be results coming soon that was done in pre-manifest individuals, and I believe they did imaging with that. And that, I believe, is registered at clinicaltrials.gov. And so there should be some results coming from that soon. And I believe also in Australia, they are working on a larger scale clinical trial. And we're constantly working on trying to think about the next kinds of exercise studies that we're going to be doing, and I think a big push for us is trying to think about mechanisms of exercise. So kind of that by what means is exercise, an aerobic exercise in particular, potentially exerting its effect on disease progression. And I think that's a really important next step I think for us.

Dr. Lori Quinn ([42:33](#)):

And I think the other thing is some of the balance work that was done. There's, I don't know if you want to talk about the group that [inaudible 00:42:42] that balance work, Megan? Yeah? Yeah, so there's the Be Fit program?

Dr. Nora Fritz ([42:50](#)):

Oh, yes.

Dr. Lori Quinn ([42:51](#)):

Yeah.

Dr. Nora Fritz ([42:51](#)):

I'm so sorry.

Dr. Lori Quinn ([42:51](#)):

That's okay.

Dr. Nora Fritz ([42:53](#)):

So, yes. So there are some efforts to develop more individualized programs that could be, I guess maybe the way I would want to say it is a framework for a program that could be individualized to many different patients. And so there was some nice work that came out of Bellarmine University in Louisville, Kentucky called the Be Fit program that really focused on different areas, including balance and fitness, and they developed this really nice framework of how this could be applied to persons with HD, but it has yet to undergo kind of a rigorous clinical trial, to my knowledge.

Dr. Lori Quinn ([43:34](#)):

Yeah.

Kevin Gregory ([43:36](#)):

Well, Dr. Quinn and Dr. Fritz, again, I really appreciate you being on. I guess there's one last question I'd like to ask of each of you, and Dr. Quinn, I'll start with you. In terms of the research that you did for these guidelines, what is the top thing, the single biggest takeaway that you would like to convey to people that are listening to this podcast as to why this research is so important and these guidelines are so critical for HD patients?

Dr. Lori Quinn ([44:07](#)):

Yes. So I would say the top line takeaway that I would say is that aerobic exercise and strengthening, specially in the early stages of the disease, may have an effect on disease progression and improving functional outcomes in patients. And I think that incorporating that and thinking about exercise as a frontline intervention in the newly diagnosed and as early as possible, I think we can utilize exercise as an intervention alongside pharmacological interventions to potentially have a really powerful additive effect. So that would probably my take home. Nora, how about you?

Dr. Nora Fritz ([45:00](#)):

I don't think I can top that. I think you said it all. I think she said it all.

Kevin Gregory ([45:07](#)):

All right. Well, again, this has been great. This is a topic that we haven't really covered yet with the podcast series. I think the guidelines are outstanding and they'll make a great addition to all the research that's being undertaken. And I hope too that this, just getting the word out, helps foster interest in getting more of those clinical trials up and started to help assess those physical issues for you. So again, thank you again. I really appreciate you joining us.

Dr. Nora Fritz ([45:43](#)):

Thank you very much.

Dr. Lori Quinn ([45:44](#)):

Thank you so much.

Kevin Gregory ([45:49](#)):

Well, that concludes this latest episode of the HD Insights Podcast. I can't thank Dr. Quinn and Dr. Fritz enough for setting aside time to speak about the role of physical therapy for those with HD and the clinical recommendations that are being published to guide physical therapy practice for Huntington disease. It was really great and especially convenient that we could get them on the podcast while they're both together attending the annual PT conference in Denver.

Kevin Gregory ([46:13](#)):

I also want to thank you, our listeners, for your continued support for what we're doing on the podcast, and we certainly hope you enjoy the content that we're able to provide. If you've missed any episodes or would like a copy of each episode's transcript, please visit the Huntington Study Group's website at www.huntingtonstudygroup.org. We'll see you next time on the HD Insights Podcast.

Speaker 1 ([46:41](#)):

We hope you enjoyed this edition of the HD Insights Podcast. Remember to subscribe to this podcast to make sure you automatically get the latest episodes to your device. Please rate and review this podcast with your feedback so we can continue providing the best possible content.

Speaker 1 ([47:00](#)):

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