



**Live Well Today Webinar Series:
Non-binary and Transgender People and Parkinson's**
Davis Phinney Foundation

Jenna Deidel (Director of Community Engagement, Davis Phinney Foundation):

Hello, everybody. Thank you so much for joining us today for our webinar covering issues that affect trans and non-binary people living with Parkinson's. My name is Jenna Deidel and I am our director of community engagement at the Davis Phinney Foundation. And I'm so thrilled to be welcoming Dr. Wissam Deeb and Dr. Roy Lin today to discuss this topic. This is actually the third webinar in a series that we've been producing for the last few months about sexuality, gender, and Parkinson's. And so, if you've missed the other two that covered more in-depth issues that affect women and men living with Parkinson's, we definitely recommend you go back and watch those as well. And today we're excited to talk about this other community. So, I think without further ado, we will dive right in, and I would love actually to start by just inviting each of our panelists to give a quick introduction of themselves, you know, the work they do day to day, and also sort of what has brought them here to talk about this topic as advocates. So, Roy, do you wanna kick us off first?

Chi-Ying (Roy) Lin, MD, MPH (Movement Disorders Neurologist and Assistant Professor, Baylor College of Medicine Parkinson Disease Center):

Sure. Hi everyone. My name is Dr. Roy Lin. I am a movement disorder neurologist at Baylor College of Medicine Parkinson Disease Center. I'm glad to be part of the LGBTQ ally, thanks to the Foundation for the invitation, it's a great pleasure to be here to share with everyone about my experiences and learning with everyone.

Jenna Deidel:

Thanks so much. And Wissam.

Wissam Deeb, MD (Movement Disorders Neurologist and Assistant Professor, University of Massachusetts):

Wissam Deeb, I am also a movement disorders neurologist, and I work at University of Massachusetts in Western Mass. And I got interested in the field of looking at the interaction of being LGBT and the neurology through the Academy of Neurology and then working with my patients where I saw that there is a need for us to know more about this interaction and the fact that it is not very well studied and not very well investigated. One of the main impetuses for me to continue with this was Dr. Rosendale who you, some of you might have met last year when she presented this webinar. And she has been a good force in this field in general, trying to trail-blaze a lot of these things. So that's my story and how I came here. And thank you again for having me.

Jenna Deidel:

Well, we're so thrilled to have you both here and use the word trail-blaze, which I think I would apply to both of you as well. As we've gone through this series discussing kind of the whole person implications of looking at sex and gender, whether that's from a physiological standpoint, from a social standpoint and everything that goes with that. I think it's been a theme that's come up quite a bit as we've looked at this, that this is something that when it comes to how we treat people as whole people living with Parkinson's, a lot of what we are operating on is not particularly well researched yet. But we're lucky to have a number of people in our field, both of you being them, Dr. Rosendale being one, and many others who are committed to shining a light on this important piece of what it takes to treat someone and to live well.

And so, I'm really grateful that you both are here today, grateful for your advocacy and your work. And so, you know, as Wissam mentioned last year, we produced a webinar that was a bit more of a general overview around the LGBT community and Parkinson's. And so, we'll share that link in the chat. And I definitely encourage folks to look back at that. But again, one of the themes was sort of that lack of research and a little bit of that caveat of, you know, we know this is important and we're trying to figure out how to sort of advocate and best move through that. And so, I suspect now, as we zoom in a little closer into people who are transgender or non-binary that that I would guess is still the case. Is that fair to say Wissam, that you know, we're still sort of operating a little bit without that research net in some respects, or how would you talk about that?

Wissam Deeb:

Yeah, what I would say that because research takes time, so I wouldn't expect a huge change in that one year, but the major difference that has happening is that now there is more interest, not just from neurology, the neurologist themselves, and the patients themselves, but also from funding organizations, including national organizations to improve our representation of the patients involved in the research and determine what we call social factors in health. So, and that includes not simply sex and gender, but also other factors. So, thank you also for patient organizations like Davis Phinney Foundation for also trying to highlight this and then show it's important. So, all of this momentum is the thing that will drive and encourage people to research this, dedicate their careers to trying to improve that, and then expand our information in the field.

Jenna Deidel:

Wonderful. And the more we do this in all aspects, I think we can agree that while there are specific elements that we need to research and better understand to serve all the different kinds of people, as you said, you know, this is just one element that we look at by advocating and saying that that's important for, you know, all these different communities, ideally that improves care overall and understanding of what it actually takes to help someone live well and to treat, you know, something as complex and as a part of every part of your life as Parkinson's

can be. So, thank you for that and appreciate that advocacy and also that sort of background and glad to hear there's some momentum continuing, that's really exciting. So, one of the pieces we talked a lot about last year was this idea of inclusion and both from the standpoint of how people who might be care providers or people like us who are creating, you know, spaces for education, different things like that, how we can create more inclusive spaces and what that actually means but also how someone who might be seeking an inclusive space, what sort of clues they might look for to decide if a space is gonna be safe for their sort of whole person care and things like that.

So, I'd love to hear a little bit more from, you know, whoever wants to kick us off around, what do we mean when we talk about inclusion, particularly for this community and what are some ways that individuals who are seeking it can look for it, some clues, and what are some ways that we can create that? So, anyone who wants to kick us off with that.

Wissam Deeb:

Just going to like interject a tiny tiny bit, if that's okay with you Jenna, just a quick, quick reintroduction to some of the terminology we're using, just in case somebody wants to like, refresh about that.

Jenna Deidel:

That's actually a great way to create a more inclusive space today. Thanks to Wissam, good point.

Wissam Deeb:

So, I just want to like review the terms. So, when we speak about sexual orientation and gender identity, it's important to remember there are two different ideas. Sexual orientation speaks about physical and emotional attraction to a certain person of either the same or different gender or other genders. And then gender identity, the term gender is a complex term. And the definition of it has evolved over the years, but our current understanding of it is a complex interplay of biologic, social and psychological factors that create a person's perception of themselves as it relates to a social construct of what constitutes a man, a woman, or even neither, or combination or a mixture between the two that is fluid and variable. So, this is what we call the term gender identity, it's effectively how this person views themselves in relation to this idea of gender in society and that can be very binary, male, female, or it could be between the two. It could be something not even, not related, not socially normative, let's say.

And between these terms, there are other terms that we think about, we think about sex, which is this biologic idea of combination of chromosomal effects, as well as external and internal sexual organs. We have legal gender and that's the stuff you have on your ID. And then also there's gender expression, which is how the person chooses to show themselves, which might link or might not link with their gender identity and might change in different settings, depending on how comfortable they feel or how they want to express themselves. So, these

are like, I wanted to go through some of those words. There's also the term cisgender and transgender.

We use these all the time and also the term gender non-binary or gender diverse. So, cisgender is a person whose gender identity matches with the gender that has been assigned to them at birth. And then transgender is a person whose gender, it's an umbrella term, and it means that it does not match with the gender assigned at birth. Gender non-binary are individuals who don't, their gender identity does not fit in that binary distribution is like male and female. It's more fluid. And also, it is an umbrella term that can also sometimes be called gender diverse, which is a bigger term, which means individuals then are effectively not in the binary. They don't, they are not cisgender individuals generally that will include these terms. I'm going through them very quickly, just like as a quick recap, I think people can, if they want to learn more, they can review the other webinars from, from last year and people who are transgender and gender diverse still get like a lot of discrimination in our field, even in the medical field and the neurology and Dr. Rosendale has done some research to show that there is a discrepancy in the care that we give, or like how much we understand the impact we as neurologists of being gender diverse and gender minorities on the care that people receive.

And many individuals have received negative experiences in neurologic and general medical care from like people not refusing to treat them or people not refusing to touch them or take care of them. So, I'll let Roy speak about what can we do to help patients feel more comfortable when they come to see us so that I don't speak all by myself.

Chi-Ying (Roy) Lin:

Oh, no, thank you for sharing. And absolutely. I wanna answer Jenna's question about my definition of inclusion and inclusivity. To me it means that a group or a place that is willing to provide access, friendliness, opportunity to people with different backgrounds and these backgrounds include demographic, cultural, and socioeconomic backgrounds. And most importantly, by providing this access it will help everyone in a group, in a place to reach the goal of equity, not just equality. And along the way, we also need to check whether the decision makers or the stakeholders of these groups are distributing resources in a fair manner and willingness to customize it for different people inside the group to reach again, the equity, and in terms of what we should be looking for. I think most commonly we should be looking for what we call like when, for example, when you are entering a clinic, a hospital, you should looking for whether there's any, what we call visual affirming queues provided such as the LGBTQ friendly stickers and signs. And also, the flyers provided, any directions in terms of how you can navigate yourself inside the healthcare system. Those would be the top thing to look for.

Jenna Deidel:

That's great. So I think, you know, already demonstrating a couple ways to create these spaces Wissam, walking us through language, the importance of language, and also the importance of

understanding the difference between different dimensions of sex and gender, and even sexual orientation, which people can inadvertently lump together, or even step aside thinking that might not actually have much of an impact on how well someone is treated or living with Parkinson's. But so much of the work you both have done is to say it is important. It's important to know the difference and to understand all the dimensions of the person you're treating and the ways that their past experience with the medical system and also with their community could be affecting how well they're living. And I appreciate that idea of visual cues and you know, things that we can look for and also provide to say, you know, if you're coming in this perhaps at a deficit of trust or a feeling of safety, what can we do to say, we are committed to doing our best to create a safe space.

We recognize that this is important and things like you said, stickers even, I've seen you know, when you're filling out a form, making sure that there's an opportunity to self-identify, that people are willing to ask, you know, if you use a different name than might be on your legal driver's license, things like that. So, all of that's great stage setting, I think to say, this is important, it's complex, and really the goal with these kinds of conversations and this education is to help all of us understand that this is needed, like the understanding is needed and that yeah, it's specific. We wanna be fair. And in order to be fair, we have to be specific to the unique individuals that are in front of us, no matter kind of what dimension we're talking about.

So, thank you all for doing that, that stage setting. I think it's really helpful as we dig into some more specific pieces. So, we've talked a bit about you know, we're talking about the idea of finding safe spaces and often when we are giving advice to people living with Parkinson's a lot of what we talk about is a care team. So, I would imagine this means that someone who is transgender, non-binary, gender diverse, it's not a one-time moment where it's just about finding your MDS or a neurologist, but that actually must happen again and again and again and again, as you're putting together your care team. So, I'm curious a little bit about how you've seen, you know, is that the case? How have people, you know, that sounds like a burden to me to carry, to have to kind of seek those safe spaces all the time. Are there any tools or ways of navigating that you've seen advocates put together to make that a little easier for folks, you know, as they're trying to create a whole team of people who they can trust.

Chi-Ying (Roy) Lin:

So, to my understanding, it's actually not very common, unfortunately. Different institutions would have different LGBTQ sensitive or friendly provider list. Most ideally this list would contain providers from different specialties, but it is also not uncommon to see some of the specialties are lacking to the list up there. Yeah. And I think there are, I actually had an offline discussion with someone before I think with someone who has identify some good resources about like, how do we identify the LGBTQ friendly providers?

Wissam Deeb:

Yeah. And I think, yeah, it is tricky. There are resources like lists, some organizations do those. There are also national organizations like the GLMA, they have their own list also that providers can list their names on them, but it doesn't include all the stakeholders in the care for persons with Parkinson's disease. And that has been known in studies to be a problem where people in nursing homes and the rehab facilities, when they are asked, do you have any transgender individuals, or do you have any gay individuals who you take care of? And most of the times the answer is no which doesn't make any sense and that means that these individuals are not aware of the concept effectively, or of the fact that these individuals become older or have Parkinson's disease.

So, in order, I don't think the onus should be just on the person who has Parkinson's to do this. It's a lot of work that we need to do in institutions. But one thing that the person can do would be to ask around, word of mouth is very, very important. Another thing that can happen is also when they call the clinic, they can ask about their non-discrimination policy, about how many in the facility are individuals who are out, LGBT out, whether transgender or gay and lesbian. So whichever question they want to ask, and that can give a certain sense of the institution. They can come and visit the institution, not as patients, but as visitors and get like a sense from the space, as Roy mentioned about like these nonverbal cues that can help.

But in many cases, it might not always be easy. And in that situation, this is why one of the things that we are interested in is to make sure that we advocate in our own institutions and then also regionally and nationally through like our professional organizations to develop guidelines to make sure that all individuals and gender and sexual minorities to be respected at all the levels of interaction, including the clerk at the front desk to the medical assistant, to the nurse, to the pharmacist to the physical therapist, occupational therapist, speech therapist, because it could be nice that I can be inclusive in my clinic, but then that experience is not the same throughout the organization. That's going to be tough. And again, it shouldn't be on the patient to try to navigate this and try to find these resources. I think we need to do a better job at making sure that people feel included.

Jenna Deidel:

Absolutely. And you make a good point. It's not, there's a lot of people we interact with before we ever get to see our provider. And so, if we're listening to this as advocates or people within institutions, keeping that in mind, that it's not just about your direct colleagues, but about the entire environment of an organization that may need a little bit of help to understand how to create a space that's gonna feel welcoming and make sure that anybody can walk through the doors and come back and receive the care they need. So that's helpful. So, you know, you mentioned already that idea that, you know, in some studies and surveys, you'll ask, how many patients do you have that identify as gay or transgender? And people will say, oh, none, we don't have that at all. Which is possibly the case, but more than likely what you've pointed out is there's a disconnect between collecting that information or someone feeling comfortable to give that information. So, I'm a little curious about digging into the issues that that causes, or

sort of you know, why is it important for that kind of barrier or that disconnect to be removed so that we have that information and are able to share it freely?

Wissam Deeb:

So, one of the things I think we need to think about is that first of all, the person needs to feel comfortable. So that's important in medical care in general to create that rapport, to feel comfortable about discussing everything in terms of medical care. And then, so that initial portion feeling that a person is accepted as their whole being is important. So that's one aspect. Another aspect could be related also to the fact that Parkinson's disease is a complex syndrome and requires usually multiple care team members, including a caretaker or a family partner, or could be a friend, somebody who's going to help that person in their trajectory with Parkinson's disease or their life with Parkinson's disease. So, being capable of including people in their family, in their environment or in their group would be also very important.

And given individuals who are sexual and gender minorities might not feel comfortable sharing who is their significant other, or who is their caregiver, or who is their person who's next to them. And in that case, we might not include all the caregivers in that team and that can be a factor. The other factor also are factors that are related to how being a sexual and gender minority can interact with the Parkinson's disease itself and then the care that we're giving to patients. So, I'm going to mention a couple, and then I ask Roy to also give us some of his recommendations, but some of the things could be related to possible education about certain risk factors or absence of certain risk factors and how they interact with the disease, with disease occurrence, or the chance of having a disease, for example.

And for example, we know in gay men and transgender individuals, the risk of smoking is higher. So how does that interact with the risk of having Parkinson's disease, or how would that affect the disease progression itself? We don't know that information yet, but, and mainly we don't know a lot of this information also because we have been very poor at collecting the information about sexuality and gender identity before, but I'll leave it to Roy to discuss some other aspects too, if you have any other things you want to add about this interaction.

Chi-Ying (Roy) Lin:

For sure. So, when it comes to disclosure of sexual orientation, gender identity, I just wanna highlight that if I were the person with Parkinson, the process of disclosure is actually something that I'm helping myself to create a comfortable environment. I need to feel like myself first before talking about my medical conditions and from the provider's point of view, if a person with Parkinson's is willing to share the SOGI, the sexual orientation and gender identity with me, that means a lot, because that means a certain level of trust and this trust can actually further facilitate our future communications and care plan. And exactly like what Wissam just said, after knowing the gender identity, sexual orientation of the patient, we can better identify the potential factors that affect the health outcome based on what we know

from the current limited science level. And it will be helpful to monitor the disease trajectory along the way.

Jenna Deidel:

That's great to know. I think there's a lot of dimensions to that, that you just shared. You know, and I think one of the most salient pieces, you just said, Roy, that you need to be able to show up to the best of your ability in a safe space as yourself in order to get the actual care you need. And that, you know, as Wissam said means allowing your care team, your family, or your care partner and so, there's all of that sort of emotional and trust piece, as you're saying too, to be able then as a provider to look at the cross sections between different communities and different risk factors and understand, well, maybe I should ask a question of this individual knowing, you know, a bit about those risk factors or these things that I might not have been prompted to ask, but could actually really help inform our way forward.

That's really interesting. The other piece of this, and I think we're getting close to it is the issue of mental health, which we talk a lot about in general with people living with Parkinson's. And when we think about those cross sections of our LGBT community, and our Parkinson's community, mental health and risk factors and issues and higher prevalence of mental health issues is certainly one I think we look at. So, I'm curious to hear a little bit about, you know, for this community of trans and non-binary people we've already talked a bit about, you know, the idea that there could be issues of being discriminated in different social spaces, things like that, but why do you always make sure you always talk about mental health in particular with these communities, what's so important? What are the things you're most aware of, most concerned with, most hoping, you know talking about this will be able to change for people?

Wissam Deeb:

So we all know that people, oh, sorry Roy, that people with Parkinson's disease have a higher probability of having anxiety and depression and other mood disorders. And as you mentioned, individuals who are gender diverse already have faced not simply in the medical field, but in society in general, and can start at their family level, discrimination and then as a result, they have a higher chance or a higher probability of increased risk of anxiety and depression, especially if discrimination persists, and then usually from individuals who are close to them, and that can sometimes unfortunately lead to increased risk of suicidality in individuals. So, I think one of the things that we need to screen for, and that applies anyways to all Parkinson's patients, but maybe also we need to pay attention to our trans and gender diverse individuals to make sure that the mental health situation is well controlled and then they're getting the services that they need to get.

It's also important to remember that many individuals who are transgender and gender diverse are also very resilient and that can also be a strength. So, it's not always a weakness or like a negative thing. They can also have significant resilience from dealing with all that discrimination before that can lead to some good compensation or good strategies of dealing with stresses of

chronic diseases that other individuals who are not trans or gender diverse might not have the tools or the skills that those individuals have. So I think it's always good to look, for me, at least as a doctor, when I'm having individuals who are gender diverse, I look at it from both ways, there's an increased risk of possible depression and anxiety, but also there can be also certain skills that they might, they have that can help them deal with this situation, with this adverse situation of having Parkinson's better than other individuals.

Chi-Ying (Roy) Lin:

Definitely. And I think that along this line, that also highlights again, the importance of disclosure because that can help us understand a person with Parkinson's, a non-binary transgender person with Parkinson's household structure and support system better so that we can further assist the care and making relevant plans. And also like under the spectrum of the mental health issue. So, I previously worked on an article and we realized it's important to specifically consider, which is the self-image of people with Parkinson. I think for non-binary patients, non-binary people with Parkinson it would be very important to understand the factors that might potentially affect their self-image, either from the motor symptoms of the disease itself or from the additional like procedural surgery, like DBS, with battery replacement in front of the chest, would that affect their self-imagining? Would that affect their thoughts of their gender expression, their so-called manhood or womanhood. Understanding these factors are very important to address their mental health as well.

Jenna Deidel:

That's a great point. And one that throughout this series has come up. You know, I think we started with the kind of helpful overview from Wissam about, you know, even what is gender, how do we talk about it, how is it expressed? And we know that many people struggle with that self-image and their ability to present themselves in the way that feels most true to who they are, no matter sort of, you know, what dimension of identity they're thinking about. And so really respecting that that's a big part for all of us, but particularly our community of people who are transgender or gender diverse, that that self-expression is important and to give importance to it and to make sure we're caring for that as well as we're caring for, you know, the Parkinson's, that's a really great point. One other topic that as we were kind of preparing this we talked about the importance of the cross section piece is advanced directives. And so, this isn't a topic I know as much about, and I'd love to hear, you know, as we prepared, why was it that that was a topic that you really put a pin in to say, we need to make sure we talk about that. Why is that so important as we consider that for this community of people?

Wissam Deeb:

For me, it came from a patient encounter initially. That's how I was alerted to the situation. It was a patient encounter, a trans man coming to the hospital. And then I realized that, and they were elderly, and I realized that there was no guidance. There was no form. There was nothing that says what their wishes were in terms of their because they couldn't speak, they were intubated. So, we relied on their daughter and then we were not sure if she was really

expressing what they really would have wanted. So, I researched that topic a little bit more. And we worked out here in the institution to try to develop some guidelines in terms of how to deal with, what we call advance care directives.

This is something in the field of chronic disorders. We deal with it all the time. It's not something that we wait for like the last, the more advanced stages. We speak about it early in terms of planning in terms of person's wishes that can include resuscitation, but also includes like how to deal with the body after death. In terms about will and other things that are important. So, there are certain features here though, that can be more specific to gender diverse individuals and transgender individuals. And there are some legal documents that have been developed in the last decade to help people, to help people like make sure that they write a certain document that can help them. So, some of the things that are important first of all, is to identify healthcare power of attorney, a healthcare proxy who's going to be capable of speaking on their behalf when they cannot speak, but I would recommend always that they have stuff, their opinion in writing in addition.

And that would include information about what we call them advance directives, about how about their gender identity and expression. So, because many individuals don't go through the legal trouble of changing their legal gender and then changing stuff on the paper, on the official paperwork. So having that written there will be helpful. And then clearly stating that this is the name, this is the pronouns, this is my gender identity, and this is my gender expression. And then hospitals usually, it changes from hospital to hospital, but usually many hospitals are respect people's gender expression and then make sure that individuals are not stripped of gender expression if they cannot speak for themselves and then give them like non-descript clothing or clothing that doesn't really match with their gender expression.

Also make sure that these individuals are inhouse in a room that's appropriate to their gender identity and expression and not something that's based on their legal sex or legal gender. Other things that would be important also is after death happens, because that form that you have is called adverse advance directives completely becomes null when a person dies. So having a form for after death, there is a form a special legal form for after death about what to do, it has a very legally name of human remains. That's the name that paper, but it's effectively when the body is shown for mourners which way they're going to show it, and then what's going to be written in communications, how that person is going to be communicated or like, discussed about what's the name that's going to be used because their family member or the next of kin might not respect their wishes.

And so, it's important to have that in writing. So that's something that if we didn't think about, and we didn't ask our patients and we didn't give them the space to feel comfortable to disclose to us and disclosure should be completely voluntary. I never force people to disclose. If we didn't give them that space, we would have missed that opportunity to make sure that they have the tools to empower themselves both now and later when they cannot speak for

themselves and even after death. So that's where this came to for me and then I think it is important to highlight so that people know to empower themselves that way.

Jenna Deidel:

Yeah. That's great. Oh, go ahead, Roy. Excuse me.

Chi-Ying (Roy) Lin:

I just wanna say I totally agree. And then, I think it's also especially important when it comes to Parkinson, people with cognitive disorders, the most recent stats around 50% of the people with Parkinson in our non-binary group, trans group are not excluded, could have combined cognitive orders to either a mild cognitive impairment or dementia. So yeah, setting up the advance directive care plan is like extremely important.

Jenna Deidel:

Absolutely. Absolutely. And while it can be difficult to think about these topics and to think this far ahead, the notion of being empowered, you know, to know that your care team, the people around you will be able to continue to respect your identity and who you are throughout the course of all of that, is really critical. I'm sure. And it's a shame that that's the case, that Wissam, you were in that space to say, I actually don't know if this person in their family is aligned with exactly what they want. And so, to be able to take control of that and ensure that, you know, your care team can know what you need and want is really important for all of us and in particular for this purpose.

So, I wanna shift just a little bit our conversation into some of the more kind of physiological implications of, you know, care that may come along with being transgender or gender diverse and how that might kind of coincide with our Parkinson's care. And so of course, you know, certainly gender affirming treatments, surgeries, medications are not at all part of every single person's life who is transgender or gender diverse, but it's part of life for many people. And I'm curious, what do we know about how these kinds of treatments, whether you are continuing treatment or whether you might actually be choosing to transition while also living with Parkinson's? What do we know about how these kinds of treatments interact with Parkinson's symptoms or Parkinson's treatments or what are we hoping to learn actually, what should we be looking at?

Chi-Ying (Roy) Lin:

I can try starting first.

Jenna Deidel:

That's a big question when we've already acknowledged that research is lacking. So, thank you for giving it a shot.

Chi-Ying (Roy) Lin:

Sure. So, I think first of all, as a provider who takes care of people with Parkinson, I think providers need to at least know the basics of all the like common terms for like gender affirming, hormone related topics. Like what does it mean by gender dysphoria? By gender affirmation, some terminology like vocal feminizing surgery or vocal feminizing services, what does that mean? And how does that affect you making plans for the patient and also some fundamental process of gender affirming hormone prescription. I gotta admit that I'm still learning at this time, like to start with Aldactone followed by estrogen, et cetera. And in terms of the role of the estrogen or hormones in people with Parkinson, my understanding is that even in cisgender group, at this time there's no clear conclusion, most of the study will show protective role for estrogen in people with Parkinson while other studies shows different results.

And Dr. Subramanian from UCLA actually recently published an article about women in Parkinson. She highlighted that maybe the reason why these results are so inconclusive was because it's related to the time of exposure of the estrogen along the Parkinson's disease trajectory. So, with that in mind, it actually reflects how important to investigate this part in transgender and non-binary group, because counseling the hormone therapy in cisgender will be very different as opposed to in transgender, especially the gender affirming therapy is a medical necessity. So yeah, that's my current understanding.

Wissam Deeb:

And we're all like still learning because data is very minimal or lacking. And I agree with Roy that the translation is not there. Like there's no easy way to say, okay, is this gender woman experience is this way, because even a postmenopausal woman who might be taking estrogen replacement therapy the dose is very different, the formulation is different, the physiology is different. So, I think we need to do more, but in terms of like some other things we can estimate right now from the information we have, we know that there could be drug to drug interactions. So, some gender confirming hormone treatments can interfere or like are metabolized through the liver and there are multiple medications we can use that can affect the metabolic, the degradation of these hormonal products. And that can have an effect of either decreasing their effects and then just eliminating their benefits for these patients or worsening some side effects by increasing some of their breakdown products, for example.

So that could be a factor. Other things could be some side effects. So, a trans man might still have a uterus and might be capable of getting pregnant. And then in that situation, what is the effect of these medications on a fetus? So, we know, for example, some Parkinson's medicines are teratogenic, which means that they cause fetal malformations, like amantadine. We use that a lot. If we didn't ask that question, the patient didn't feel comfortable with us. We didn't ask organ inventory to see what's going on. We might miss this and then not advocate for the patient properly and put them at risk. Also, people with Parkinson's tend to have low blood pressure they can have orthostatic hypotension. And then Roy mentioned the Aldactone or Spironolactone, that's an anti-androgen medication, but also is an anti-hypertensive.

So, people can become more hypotensive on those medications than outside without them. So that can help us be aware. I'm not saying that, as Roy mentioned, the treatment is lifesaving, and we shouldn't just stop it because we felt like it from one side. But it will be important to be aware of it and then have a good discussion, including the patient, including endocrinology, primary medicine, in order to be capable of determining what is the appropriate regimen for managing the Parkinson's symptoms that would not interfere with their gender affirming care or will minimize that interaction. So, these are some of the things we know, but as you can guess, there's so many other things that we still have no idea how the interaction is.

Jenna Deidel:

Yeah, there's a gigantic knowledge gap that we are hearing repeated here, that we also discussed in depth when we, as you mentioned, covered women living with Parkinson's. And it's one that I hope through advocacy like yours and webinars like this, that we start to, and Dr. Subramanian's and many others that we start to close that gap and acknowledge that it is pretty critical to understand this and to dig deeper. As both of you just acknowledge you're doing this learning largely on your own and helping to lead some of this learning. If someone is listening to this or watching this, that is a provider who is in a position to treat someone who's looking to transition or continue gender affirming care, or any of these kinds of things that you just mentioned, what do they do? How do they, you know, how do they help that person in front of them? What do you recommend to folks in that position? I guess, what are you doing? You're both doing it.

Wissam Deeb:

So, I think one of the things is right now is more expert opinion in terms of the evidence. There is some work at the American academy of neurology to put some statement for best practice guidelines. It's in the work right now to post some best practice statement, not really a guideline about management. As far as we know, there is a paper from Dr Rosendale and colleagues that summarize the state of knowledge in terms of the studies about the different interactions. The other thing also, there is a gender minority working group in the American academy of neurology, LGBT section that also for me and a lot of our members act as like a professional sounding board. These are individuals who are gender diverse and neurologists. And usually, we defer to them sometimes for many of those questions that can help our patients as well as help people in the profession.

And the other thing would be trying to make these connections with different people. Through this space myself, I have connected with multiple people, some of them in Europe, some of them here in the United States, some of them are researchers, not clinicians and trying to see, like making a consortium of people who have interest in developing the space to try to see if we can develop certain projects. And as I said, there is some momentum right now, which wasn't there few years ago. So, I'm hopeful for the future that we'll be capable of answering some of those questions.

Chi-Ying (Roy) Lin:

Yeah. For me, an ally is really important and I think more and more centers are aware of this importance, like BIDMC at Boston. They also, I think they have, from what I recall, they have the like webinar and then support group meeting on the regular basis. And that's one of the example. Yeah, and putting all these relevant information in the clinical settings are to make it like readily available are also crucial.

Jenna Deidel:

That's great. So, as we're coming somewhat close to the top of our hour here, we have just a couple more pieces that we wanted to make sure we covered. And one of them is a little complicated and in the context of this conversation. So, we discussed a little bit some of the issues that can present as a change, perhaps in gender expression or sexual preference or things like that, that can occur in people living with Parkinson's. And we discussed that we thought it would be important to talk to acknowledge what those are for any person living with Parkinson's, how those might show up how we've seen them, how you know, people and care partners can navigate them while also acknowledging that these are, they live in a similar space, this idea of gender expression, but they're not exactly related, exactly connected. So, I wanna kind of toss it to both of you to share a little bit more about, you know, what it is, what I'm talking about here, what those specifics are, and also kind of how people can navigate them and understand the potential differences between these symptoms or expressions showing up. And the difference of, you know, a lived gender experience.

Wissam Deeb:

So, something in Parkinson. So that is when people are getting treated for Parkinson's disease, we hear about something called impulse control disorders. So, these are disorders of impulsivity, and they usually manifest as hyper eating hypersexuality, hyper gambling and can be also like repetitive purposeless behavior or picking up a hobby and spending eight hours doing it all of a sudden. So, the major feature there is like a change, a break from that person's identity as a side effect of the medication. And one of the side effects that falls under currently we put it under the huge rubric of hypersexuality, although it's not really the same, is cross-dressing that can happen in Parkinson's disease as a part of an impulse control disorder. So, these are not common. There are few cases reported in the literature and they are associated.

They are usually very alarming to the person themselves. It feels different than themselves but they cannot stop themselves from doing it. So, this is the major feature that's different and let's say a transgender individual or gender diverse individual for that person, unlike the person with impulse control disorder, that feels right. I've heard people who are gender diverse or gender non-binary say that it feels right the way I'm speaking about it. Whereas the other one, it just, it feels wrong. It feels like this is not me. I'm being pushed by something to be something different. And that's the difference. So, some people might look at that as like, hmm, how do we explain this? What do we do with that? And at this point we think it is more of a medication

side effect that causes the person to similarly to how they would, a person would go and buy a hundred scratch tickets.

They would be impulsively wanting to cross-dress for example. We don't think it is related to a shift in their gender identity or a change in their core identity, more work would need to be done for this. Most of the work right now is mainly a little bit just retrospective or looking back into the cases, there hasn't been a lot of deep dive into the features, but that's something that's published, but would need more work, but from the information we have, it seems to be more of an impulse change, a change that people find distressing unlike gender identity, where it is something that a person feels fulfilling or feels right. So that's why we thought it would be important to mention because in the Parkinson's field, that's something we discuss about, and then that's something that some people have might have to go through.

Chi-Ying (Roy) Lin:

Exactly. In terms of impulsivity and compulsivity and Parkinson's, although it's very well documented, people are still learning about it, like it's mechanism and how diverse it could be. And recently people with another movement disorder, which is called cerebellar ataxia were also found to have impulse control disorders, and the presentation could be different compared to people with Parkinson. So totally agree with what Wissam say, the cross-dressing issue could happen, but it should not be taken as a phenomenon to under power, the significance of trans and non-binary people.

Jenna Deidel:

Yeah. Thank you for that. I am thinking at, you know, the earlier part of our conversation, again, the importance of having language, having clarity, having, you know, disclosure, if that's, you know, comfortable that as someone who is a provider, you know, on the flip side to help make sure that they're in a position to understand what's happening with the person in front of them and ensure that their advice is in alignment with that person's, you know, core self. I think I would imagine is a pretty critical piece of this puzzle to understand. This could happen, but how do I understand whether it's something to be addressed or something to be affirmed, I think would be pretty important. So, you know, I wanna thank you both as we're kind of wrapping up for, again, really, it's very evident that this is currently a field where what we know is coming from individuals like you and others who care to ask the right questions and seek knowledge.

So, I just wanna acknowledge that and thank you both for not just this hour of sharing what you've experienced and what you're hoping we see change in the future, but for years of commitment to this work and advocating and beating the drum to say it's important, and to find like-minded people to start to build those coalitions and create the momentum. So, thank you both so much for that. And for those that are listening, you know, today or later on who similarly care about this and want to learn more, whether it's for their own care or as advocates, what are some, you know, resources or recommendations you might offer to folks who are listening for ways to learn more or ways to get involved?



Chi-Ying (Roy) Lin:

Thank you all, it's a great pleasure.

Wissam Deeb:

Yeah. And thank you again. I think like there is the Trevor project they have very, very nice resources for gender diverse and transgender individuals. I recommend people who take care of patients or even advocacy and at the local level or community level, they offer a lot of great resources that can be very helpful. There's also in terms of clinical practice, there are resources developed by the Fenway Institute, as well as the HRC, the human rights campaign. They have a lot of resources about how to structure your clinic, how to structure your inpatient service. All the things that we touched on quickly, like how to be welcoming, what are the policies. There is also in terms of the legal documents I mentioned this was developed by the Whitman Walker Health National Resource Center on LGBT aging, for example. So, there are certain organizations that have developed certain strategies that and each local is different. So, I don't think one thing would work, but using those principles can help a person or an institution develop and then help us advocate to develop in a more inclusive space that will allow us to grow in this field and then help our patients and make sure that we respect the diversity of our people.

Want to Watch a Recording of the Webinar?

You can access the recording [here](#)

Want More Practical Articles Like This?

Much more can be found in the Every Victory Counts® manual. It's packed with up-to-date information about everything Parkinson's, plus an expanded worksheets and resources section to help you put what you've learned into action.

[Request Your Manual Now](#)

Thank you to our Peak Partners, Amneal, Kyowa Kirin, and Sunovion for making it possible for us to print, distribute, and ship the Every Victory Counts manual.