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Speaker 1: Navigating Parkinson's disease can be challenging, but we're here to help. Welcome to The Michael J. Fox Foundation podcast. Tune in as we discuss what you should know today about Parkinson's research, living well with the disease, and the Foundation's mission to speed a cure. Free resources like this podcast are always available at [michaeljfox.org](http://michaeljfox.org).

Soania Mathur, MD: Welcome everyone to another episode of The Michael J. Fox Foundation's Parkinson's podcast. I'm Dr. Soania Mathur, physician and patient, having been diagnosed with young onset Parkinson's disease over 25 years ago, at the age of 28. I now serve the PD community as a speaker, writer, advocate, and a very proud member of the Michael J. Fox Foundation's Patient Council, and have the very great privilege of being your guest host today.

The topic we're going to tackle in this podcast is women and their experience of living with Parkinson's disease. PD is often thought of as being a disease affecting a specific demographic, that is, older white gentlemen, and studies have shown that women do make up a smaller percentage of the Parkinson's community, the age-standardized incidence of Parkinson's being about 1.4 to 1.5 times higher in men than in women. But women still constitute a substantial percentage of those diagnosed, and the stats are complicated by what is likely a significant delay in diagnosis or under-diagnosis in women of this neurodegenerative disease. Yet most of the management guidelines have been developed based on research in men, not women.

Today we'll talk about the unmet needs of women with Parkinson's, the unique experience of what it's like to live with this disease, and hopefully offer some practical ideas that may be helpful to other women in our community. While we'll be talking about women's experiences today, this perspective is valuable for the entire Parkinson's community as we work together to improve the quality of life for everyone living with this disease, raise awareness, and ultimately end Parkinson's.

Let's start by introducing our guests in today's podcast. Richelle Flanagan comes to us from Dublin, Ireland. She's a Parkinson's advocate, registered dietitian, and co-founder of the Women's Parkinson's Project, and a digital health startup, My Moves Matter. Richelle was diagnosed in 2017 at the age of 46, a few months after giving birth to her second child.

Joining us from the UK, London to be exact, is Omotola Thomas. Omotola was diagnosed with early onset Parkinson's in 2016, at the age of 35. She's the founder and director of Parkinson's Africa, where she works to support, connect, and empower those affected by Parkinson's.

Kat Hill is an author, speaker, and advocate currently living in Portland, Oregon. She was diagnosed at 2015, at the age of 48, after a long career as a nurse

practitioner and midwife. She also is a co-founder of the Women's Parkinson's Project.

A warm welcome to you all. I'm actually so excited to be sitting here amongst women that I consider friends, women that inspire me, and for who I have actually learned a lot over the past several years. And I'm also excited to be able to share this conversation with our listeners today.

Among us, it's no secret that there are unique challenges that women face, from the way the disease presents, its impact on our life experience, our quality of life, social stressors that are unique. So I'd really like to discuss with you how life with PD is different for women, both on a personal level, and what you know is the experience of the women in our community. So let's start with the earliest part of this journey, the time of diagnosis. Women in general seem to have a delayed diagnosis compared to men. Was that true in your situation, and why do you think that is? Maybe, Kat, I could get you to start that off.

Kat Hill:

Sure, Soania. Thank you so much for that delightful introduction. It's really an honor to be here today. Thank you. I think for me, I was my biggest obstacle in getting diagnosed. It wasn't on my radar, and I wrote off a lot of my symptoms early on for being perimenopausal. I was 48, I was busy raising teenagers, I was in a demanding job that required long hours, and I was caring for an ailing mother. And I just simply didn't have the time to think about what was going on with me. And it was really until my tremor came and didn't go, that my hand literally was waving in my face, before I went in. And I was diagnosed fairly quickly, and I think because I delayed going in, although I had been diagnosed for many years with anxiety, which really wasn't adequately treated until I started taking carbidopa-levodopa, ironically, it was some of that internal tremor. So I was my obstacle, even though I had a dad with Parkinson's, it should have been on my radar, but I was much younger than my dad was. My dad was diagnosed in his mid-seventies.

Soania Mathur, MD:

Right. And those nonspecific symptoms I think are something we hear quite often from the peers in our community.

Kat Hill:

Mm-hmm.

Soania Mathur, MD:

Richelle, what was your diagnosis like?

Richelle Flanagan:

I suppose mine was, I suppose, kind of unusual. Well, it's not that unusual now that I've met many women through the Parkinson's community. And likewise, I'm delighted to be here having the conversation together. But I was pregnant, three months pregnant at the time, and I work as a registered dietician, and a patient had come back to see me after a large gap in time. And when I went to write on my record card for that patient, I noticed that my handwriting was a lot smaller than it had been five years prior, and I thought that was strange. And then I tried to make it bigger and I couldn't. And I thought, okay, that's really odd.

And then I was actually skiing... Well, I wasn't actually skiing, my husband and my son were skiing, but I was waiting at the bottom of the slopes, and I was having a hot chocolate. And my hand wouldn't stop trembling. And I remember specifically saying to my husband, "I hope it's not Parkinson's." And then the penny dropped between the small handwriting, the tremor, and then I had very subtle things like couldn't twist my fork very easily eating spaghetti. And I was at a Bruce Springsteen concert, and you're shaking your hands up in the air, and I noticed my right hand wouldn't move as well as my left. So they were very subtle.

But I went to the GP and I said, "Look, I'd like to see a neurologist." When I saw the neurologist, he felt I was a very fit, healthy, pregnant woman. My symptoms were very minor. And he said, "There's always the possibility of Parkinson's." And I have to say, I was like, "What?" I couldn't believe that he actually thought it might be, even though I'd surmised it was a potential.

So I was sent for a brain scan and a trapped nerve test, which I realize now many people are sent for, but I couldn't have a DaT scan until my daughter was born and I'd finished breastfeeding, which was seven months after that. So I basically had to wait 16 months, I think that's the right calculation, before I got the official diagnosis.

But on reflection, as I know many people with Parkinson's do, I basically was... There's symptoms I can think about many years prior, now that I understand the various symptoms of Parkinson's. So I'd say it was probably in my thirties, and possibly even earlier, that it presented. But I suppose the fact that I couldn't get a DaT scan delayed the diagnosis.

Soania Mathur, MD: Right. It's interesting, a lot of what you said rings true for me too. I was pregnant with my first daughter when I was diagnosed. And again, at that time we chalked things up to, like Kat was saying, perimenopause or pregnancy, and you don't really want to see what the diagnosis actually could be. And I'm surprised that you were able to surmise it ahead of time. Is there Parkinson's in your family, or is it just from the people that you knew or from your educational background?

Richelle Flanagan: I think it's probably just as being a dietician and a health professional and science background. I just researched, and it kind of... Micrographia... Parkinson's is the main condition for micrographia, no matter how hard I looked for something else. So that was probably... I thought this is potentially it. I was hoping it wouldn't be, but... Yeah. It was.

Soania Mathur, MD: It was. Yes. Omotola, how was your journey to diagnosis?

Omotola Thomas: Like everyone else, I'm really, really excited to be here amongst friends. It's such a joy and a pleasure. My diagnosis, for me, I think my symptoms started when I was 29. And what I attributed it to was a slight twitch in the forefinger on my right hand, and I just thought it was quite a stressful period in my life. A family member was getting married, and if anybody knows anything about Nigerian weddings, it's a whole event. So I just attributed the tremor to stress and I didn't think anything about it. I was living in the US at the time.

And to cut a long story short and fast-forward five, six years, I finally got diagnosed about six years later. The year before I got diagnosed, we were living in South Africa, and I remember very clearly the doctor who saw me there said, "Look, it looks like you are presenting with some Parkinsonism-type symptoms, but because of how young you are, because of your race, your age, and your gender, it's very difficult for me to diagnose you with Parkinson's, because we typically see this in old white males, and you're a young Black African female. That's not the usual demographic that fits this Parkinson's profile."

So eventually I came to the UK, which is where I live now, and I went to UCL, I got a DaT scan done, and that confirmed my diagnosis following the clinical assessment. But for me, I think it was a combination of factors, not just the gender, the age, and the race.

Soania Mathur, MD: Right. And I guess it's important to note that six years is a long time...

Kat Hill: It's a long time.

Soania Mathur, MD: Between your symptoms starting and diagnosis, for sure. But this is not just a problem that you were in South Africa at the time of your diagnosis. Unfortunately, we hear a lot of that even in North America, where women will present with symptoms that are really, because of age and gender, are not really taken into account.

Omotola Thomas: Yeah. I spent the first three years of my journey in America, in the US from 2000 and [inaudible 00:11:16] for a while, but my symptoms started in 2009, and we're in the US from then until 2013. So about three, four years of my Parkinson's diagnosis journey was actually in the States. So you're right, I went to see many doctors there. One doctor actually told me, "You have essential tremors and you have nothing to worry about." He was quite wrong.

Soania Mathur, MD: Right. Yeah. So what I'm picking up is that, in terms of just our four journeys, that sometimes women can present with nonspecific symptoms, sometimes maybe even more anxiety or depression symptoms, and they're not really considered as being prone to develop Parkinson's disease by physicians. And perhaps for that reason, we have more of a delay in diagnosis. Is there any other perspective that you think is important?

Kat Hill: I also think that, for me, my symptoms pre-diagnosis were very much exacerbated by my cycles, my hormonal cycles. And we've heard that consistently in the women and Parkinson's realm. And so we know that lots of things can be exacerbated or changed when women have hormonal cycles. But a lot of the stories that we've heard reported in the female community around diagnosis, often it's pooh-pooed if it changes with your period. That's interesting. Or it's dismissed as something else. And I think we're going to dive into some of the literature here, which is really fascinating.

Soania Mathur, MD: Absolutely, we will. Yes, Richelle.

Richelle Flanagan: Yeah. I suppose just coming on the back of that also, I think the menopause, the perimenopause definitely around the menstrual, pre-menopausal, but going through the perimenopause and menopause, definitely a lot of the symptoms are very like Parkinson's symptoms, particularly obviously the non-motor symptoms. So I think there's potentially... It seems that the research would show that more people are diagnosed post-menopausally, and the question is, are they being delayed diagnosis? Back to your point, Soania, that because they mentioned that they have anxiety, depression, and the research shows that women are put on anti-anxiety medications, anti-depressives, et cetera, more regularly than men are. So is it that that's masking some of the diagnosis?

And just back to Omotola, in terms of the research that I did around the app that I've developed, in terms of access to care for women with Parkinson's and women with neurodegenerative conditions in general, Black women in America are the bottom of the pile in terms of delay to diagnosis and delay to access to care, by a long mile. So there's huge disparities in terms of access to care.

Soania Mathur, MD: Yeah. That seems to be a global phenomenon, for sure, disparity in access to care, and access to information. So if we go back to that, so once diagnosed and after the initial shock, I think that we all go through, how did you find your information at that point in time? Now we've done all our research and we're very involved in the cause, but was there information on Parkinson's disease as a woman readily available as you began to inform yourselves about the disease?

Kat Hill: Absolutely not. Universally not. And especially in the literature. As a clinician like you, Richelle, I tend to dive into the literature, and I was really very shocked at the dearth. There just was nothing, especially about pre-menopausal women. And actually I found your website, Soania, in my searches, and that was helpful just to know there was somebody else out there, because I think it felt very, very lonely at the beginning, and searching for information about how to manage symptoms, and it was very frustrating to try to make really informed decisions about navigating things. And even providers would say, "We just don't have information." And so I think, if nothing else spurred me to action, that was part of what lit my fire.

And I don't think this is totally unique across the board with lots of conditions where women are affected differently than men. The literature is heavy on how men respond to medicines, and very little is published. So while we are talking really specifically about Parkinson's, I do want to say that it's not uncommon in other disease states to find the same thing. So we've got to change that.

Soania Mathur, MD: Absolutely. 100%. We're here to do that.

Kat Hill: Yeah.

Soania Mathur, MD: Richelle, you and I were involved in authoring a paper on the unmet needs of women in PD. And while researching for that paper, like Kat, we found there wasn't much out there, but we came up with a list of symptom differences, motor, non-motor, that women experience compared to men. Could you please share with our listeners some of those differences?

Richelle Flanagan: Yeah, absolutely. So we found that the literature seemed to indicate from a motor point of view that women suffer from more tremor-dominant Parkinson's, suffer more from facial masking. So I know my son said to me, "You don't smile as much any more, Mom." And that was before my diagnosis. And there's a lot of women have reported that in terms of interactions with their kids or family. They tend to suffer from more levodopa-induced dyskinesia, which is the rocking and rolling in terms of a side effect of levodopa. Restless leg syndrome, which without Parkinson's is higher in women anyway. And from the motor point of view, women seem to have slower disease progression than men.

And then on the non-motor side, women suffer from more mood and sleep disturbances, anxiety and depression, fatigue and apathy, pain and urogenital symptoms, but less cognitive impairment, less hallucinations, less gastro symptoms, and less issues with sexual dysfunction.

And then on the psychosocial issues, women suffer from more psychological distress, self-reported disability, their quality of life at presentation or diagnosis was worse, they have a more negative destructive self-image, they have a sense of loss of femininity, suffer more from impaired sexual intimacy, and a certain feeling of not being heard, which I think is part of the problem around the diagnosis, and as a result of not being heard, tend to downplay their symptoms, because they just get fed up with being told it's in your head or it's your hormones or... And actually, women have less social support for their Parkinson's, and we know that they tend to end up in nursing homes earlier than men with Parkinson's as well.

Soania Mathur, MD: Lots of differences, but a lot of that rings true, for me anyway. What about you ladies? Do you find that a lot of what Richelle cited is your own experience?

Kat Hill: I would agree with that. I think that the non-motor symptoms are certainly the ones that seem to impact me more. Pain was really clear early on. I had had a shoulder issue before my diagnosis, like so many of us, and upper back pain that I attributed to lots of other things, which is actually cervical dystonia. So, Om, I don't know about you. Is it mostly motor, non-motor, for you, love?

Omotola Thomas: So my Parkinson's is tremor-dominant, which is my most visible symptom. And that used to affect me from an aesthetic point of view at the beginning. But as the disease progressed, and I started becoming more and more aware of the non-motor symptoms and how they were actually impacting my life, the tremors actually pale in comparison to the apathy, the fatigue, the pain, the cognitive challenges, the memory issues. But in terms of... I think when, Soania, you were asking about the unmet needs of women, for me, I was very surprised to eventually learn, I don't know how many years ago it is, that my medication is impacted by where I am in my monthly cycle. And so when I found that out, I started actually charting it on a calendar, and it was so predictable. My symptoms would be exacerbated, my tremors would be really... They'd get really worse.

Soania Mathur, MD: I think that you're right. I mean, the variations in women's PD symptoms and how effective their medications are do vary with menstrual cycles. I was not as

smart as you. I didn't catch on until very late in the game that mine too were varying in terms of where I was in my cycle.

Omotola Thomas: What is painful is that, why... I mean, this is public knowledge now. Why weren't we told about this when we got diagnosed? Why wasn't there information for us? Why did we have to go through the long road to get that information? And even now...

Soania Mathur, MD: I agree.

Richelle Flanagan: I mean... Yeah. I was the same. And I heard other women, it was after the World Parkinson Congress, and Kat and myself and Sree, our other co-founder of the Women's Parkinson's Project, we noticed that we were saying the same thing. And when you look at some of the Facebook groups, the closed Facebook groups that women are in, I mean, literally every day you'll see someone asking the same question.

But when we asked, we did a survey of women, about 240 women around the world, about whether their neurologist asked them about their hormones, their menstrual cycle, perimenopause. It was like an overwhelming no. 90% of the women said that their neurologist did not ask them. And the Michael J. Fox Insight survey that we did showed a very similar result. So I think it's a whole area that a lot of consultants, whether it's neurology or other, are not trained in. It's bizarre, when 50% of the population are women, that they don't think that this is something that would impact us. So it is incredulous, really.

Soania Mathur, MD: It is.

Omotola Thomas: Yeah. I agree, Richelle. That's the word. It's actually... I find it bizarre, because of how much it impacts my daily life. I'm working full-time now and [inaudible 00:22:22] I've had to have this conversation with my employers, because of the impact that this week has on my ability to do my job, because during that time I can't function. My productivity, which was impacted by Parkinson's generally, is now further impacted by the hormonal fluctuations. And I think it's just incredible that this is not getting more air time.

Richelle Flanagan: And the other thing as well is, the research showed that our medication doesn't work as effectively. So the Hebron group it's a group in Spain, did a survey in follow-on from ours, and it showed that the medication wasn't as effective, and the Michael J. Fox Insight survey showed the same. So there's something actually going on. And so we don't have any clinical guidelines to deal with that.

Soania Mathur, MD: What do we know about the significance of hormonal changes, either menstrual cycle fluctuations, the effects of menopause, what do we know?

Richelle Flanagan: We do know that anecdotally there are women who are given extra levodopa during that. So we know that 80% of women report that their symptoms are worse the week before their menstrual bleed, and then about 50% during their menstrual bleed. And we know that estrogen drops and progesterone drops before

your menstrual bleed, and you have estrogen receptors in your brain, and that seems to be impacting the dopamine. So whether it's the dopamine receptors or how well the levodopa is taken up... But we know that some women who are given extra levodopa in that week, that helps them, because obviously their dopamine is lower. But also there's some women who are put on the oral contraceptive pill without a break. So normally you have a break in your four weeks, which allows your estrogen and your progesterone to drop. But what they do is they stop that break so it doesn't drop, and women who are given that do better in their symptoms. But there's no consistency around it, and there's not really any research.

Kat Hill:

And that's very similar to how we would treat PMDD or premenstrual dysphoric disorder. So women, and now we're talking, this is my clinical background as a midwife, people that have more depression and anxiety the weeks before their period may take an anti-anxiety medicine or treatment for depression, and that helps them get through that drop in estrogen, or estrogen depending on who you're hearing it from. I'll just translate for my dear friend and colleague.

So we know that about other states, in terms of being female, and it's not surprising to make the leap to treating a chronic disease that way. We just need to be talking about it. We're starting to lay the foundation with these surveys, and I think as women, as one of the takeaways, I'd just like to say, we need to be talking about it. We need to bring it up at our appointments if we're not being asked. If you are a young woman with Parkinson's disease, and you find that the week before your period or of your period you are really struggling and your medicine is not working as well, have a discussion about that. And it is a safe, appropriate place to talk about that with your movement disorder specialist. And if they don't ask you, you need to say something. We don't need to yell and scream all the time, we can be polite, but get it in at the beginning of your appointment. "I really want to talk about the week before my period, because my medicine isn't working. What can we do?"

Soania Mathur, MD:

Right. I think that's really important. I mean, I don't think progress is going to be made in this area until clinicians become more aware of the situation, become educated, and also patients. Because you're right, we do have to advocate for ourselves in a lot of instances.

I just wanted to mention, Richelle, you mentioned the online study survey. It was done through Fox Insight, which is the Michael J. Fox Foundation's online longitudinal study of people with PD and their experiences, which is a great way to actually participate in research, and that's where we actually launched our surveys on women and PD.

Kat Hill:

In several sections, and there will be some more sections coming up, so you can look for that one. That's my teaser.

Soania Mathur, MD:

That's great. Omotola, we talked a lot about the North American and European experience, but I think it's really vital for us to look at the global community as well, especially those underrepresented populations. What is the experience of



women that you have worked with in parts of Africa, that maybe we're not aware of?

Omotola Thomas: I think I will speak for those who I have come in contact with or communicated with from my home country, which is Nigeria. And I think just generally speaking, there's lack of access to information, there's a lack of access to support, there's lack of access to care. And I think it's particularly challenging, because in certain parts, particularly in the rural parts of the country, women take on more of the home roles, taking care of the family, and it becomes really challenging.

So I'll give you an example. Maybe you have a typical setting where there's a husband, a wife. The husband typically goes to work, and the wife is home with the children. So if she's not able to do her part of... What happens in that instance is then she starts to feel... The woman starts to feel really inadequate, really starts to feel like she's not enough, inept. And it's a real struggle, not being able to... I think maybe I'll even personalize it and use myself as an example because when my symptoms... When I got diagnosed, I wasn't working. So the example I'm giving is actually... It's a typical example. It's not just happening back home [inaudible 00:28:34].

So my husband go to work, bless him, travel, do all these things, and then I'm sitting at home and I'm unable to do my share of the responsibilities. Again, I don't want anyone coming for me, I'm not saying that it's a woman's job to take care of the house. I'm not saying that at all. What I'm saying is, he would go out to work, and then I would be home, and before Parkinson's I was able to do certain things, and then with the onset of Parkinson's disease, it became more and more difficult. So personally, I felt inept, I felt inadequate, I felt like I was not enough. And it was very painful to... It was sad to watch him come back home late, or come back from travels, and still have to do things around the house. I didn't think that was fair. But I'm blessed with a husband who does so many amazing things, so I'm fortunate in that regard, but it's not the same for many people.

So going back to Africa, to Nigeria, there are many women there who have to deal with this on their own, who don't have access to information, to support, care, to healthcare resources. And sometimes [inaudible 00:29:49] many of the people that we've had to support from Parkinson's Africa don't have access to medication. They can't afford it. In many areas it's not available, and when it's available, it's not accessible, it's not affordable. So there are many layers of challenges and barriers to being able to deal with this illness.

And I think the last thing I would say is, because... Mental health is becoming more of a thing that's being talked about, but issues like anxiety, depression, there's not enough information available to women and men in Africa.

Soania Mathur, MD: Yeah. I agree. And I just want to say that... You're talking about lack of access to information and care, and I just wanted to say, you at Parkinson's Africa are doing such a tremendous job in trying to attack what is really a very barrier-filled situation, and you really need to be commended for your work there. It's amazing, what you're taking on and what you're trying to do.

Omotola Thomas: Can I say something? I'm about to put myself on blast here. So this is that week, my PMS week, and my... Don't want to get emotionally [inaudible 00:31:11] it's really challenging. You have the words in your brain, but it's difficult to... I can't believe I'm doing this. Anyway, you have the words in your brain, but it's difficult to connect them to your mouth. And at this time, this particular week, it's the absolute worst.

Soania Mathur, MD: Well, friend, we all are here to support each other, and I think that's really important. We're not going through this alone. You're not going through this alone. We're here as a supportive community.

Richelle Flanagan: I think as well, there are women who've reached out to you, Omotola, and myself, who've shared exactly what you've shared right now. And I think it's actually going to be comfort to women to know that they're not going mad. I mean, I've had women saying that they literally thought that they were losing their marbles because of exactly... And I know exactly that feeling of just not being able to... And when you compare yourself to pre-Parkinson's, when you were on the money and quick and... I find it sometimes in a conversation, I'm literally just there going, I cannot think of the word. And if you're working or whatever, that's... You really feel lesser than. So I just thank you for sharing and...

Kat Hill: And being vulnerable.

Richelle Flanagan: Yeah. Yeah.

Kat Hill: Because I think that we feel that way, and we feel really isolated. I think it's really easy for us to shut down and pull away from everything when we're feeling that way. And it doesn't feel good. I find that the tremor... I feel like the ideas get lost in my brain as they bounce around, and they can't ever make it out my mouth. The words are in there, but they can't find their way, because everything's getting shaken.

Richelle Flanagan: I have to say, sometimes I have my son talking to me, my husband talking, and my daughter, and I literally have to say, "Just stop for a minute. I can only deal with one of you, one at a time." And I know my son gets really frustrated with me sometimes, and I can't remember... "I told you that." And I go, "Yeah, I know. I'm sorry." And that is, I think as a mom, sometimes I feel that's really hard, that I can't remember, or takes a while to... Or I have to... I can't multitask quite the same way, in terms of executive functioning. That really frustrates the hell out of me. And especially when you go off with your symptoms, and obviously as Omotola said, when your hormones worsen that even more, it's just like... Yeah.

Omotola Thomas: It feels like a double whammy. On one hand, the symptoms are exacerbated. On the other hand, medication isn't working quite as well. So it's like you're literally being hit on both sides. And I know we're going to delve into roles and responsibilities, but Richelle just touched on that. As a mom, it is so hard not being able to do all the things that I want to be able to do for my children. And sometimes I've had to learn to just live with it and accept it, but it's difficult. It's

difficult not being able to attend all their games, all their plays, all their school and social events. And then when you add working on top of that, just having to balance and manage all these things is particularly challenging for women.

Soania Mathur, MD: Indeed. Absolutely. And I think I myself had to change the way I looked at parenting, because like you, I thought, I have to go to every game, I have to bake all the stuff for the bake sale, I have to keep on top of their homework, a lot of physical... Drive them around. And I had to make a very conscious change in the way I think about parenting. And parenting really is about raising children that are well-adjusted to society, that have integrity and love and compassion in their hearts and are productive members of society. And that doesn't always need the physical aspects. But it is a hard thing to let go of when you felt like you should be able to do things.

Richelle Flanagan: Yeah. And actually, one of our friends, Annelien Oosterbaan, who's a gynecologist who has four kids, she did a survey on women in terms of working and... And it showed that the majority of the young onset women still did the majority of the work in the home, and still had that responsibility. So I think in terms of society, it's still a problem that women still take that majority of care, and you can't just suddenly change that when you get a diagnosis. So it's difficult, and it's a whole having to change the whole dynamic of the family in terms of responsibilities. But probably some good can come out of it in terms of, rather than... Maybe I feel it's about, as you say, handing back some responsibility to your family. Maybe that's not such a bad thing.

Soania Mathur, MD: So, since there is sparse research and limited guidelines on how to manage women with PD based on our unique needs, what advice do you have, based on your own experience and those in your network of women? How should women living with Parkinson's address these things in their own life, regarding their own treatment and how they cope with this disease? Do you have any words of wisdom for women that are starting this journey?

Omotola Thomas: No, I think it's been echoed earlier, all throughout this chat that we've had, and which is you have to be an advocate for yourself. You have to speak up at your appointment. And I think the second or the last thing that I would say is, you also have to be... We were all talking about the lack of research, and how research is predominantly male. We have to put ourselves up there to participate in research as well. We have to join our voices [inaudible 00:37:32] the voices of the other women, otherwise who is going to do the research? Who...

Kat Hill: Yeah. Beautifully said.

Richelle Flanagan: Yeah, I suppose from a personal perspective, talking about hormones, I personally went on HRT, and it definitely made my life a lot easier. And I suppose in terms... That's not advocating that women with Parkinson's go on HRT, because there isn't evidence to show that it necessarily slows progression or anything, but there is some research to show that it might actually reduce the risk of developing Parkinson's. It does definitely show reduced risk of getting Parkinson's if you have an early oophorectomy, where you have your ovaries removed. But in terms of a lot of the menopausal symptoms, or as I mentioned

earlier, like Parkinson's symptoms, so sweating, overheating, brain fog, executive function issues, it's like the premenstrual syndrome on speed, because you're losing all of your estrogen. So for me, that was just like a game changer in terms of being able to sleep properly, stopping the sweating, my executive functioning, the brain fog, fatigue was reduced. So that for me was a really important thing around the hormonal change.

And I suppose the other thing is advocating. So I would say to people to download the unmet needs paper, I've actually said to a number of women, bring it to your neurologist, if they're saying that's not a thing, because we've done research with women around the perimenopause, and a lot of the comments were that the neurologists were like, "That's not a thing. It doesn't impact." Well, we know through the research, it definitely does.

And in terms of the research that Om talks about, that was actually one of the things came out of our paper, was having a tool for women to be able to advocate for themselves. And that is why I developed the app initially, the My Moves Matter app, was to actually generate research. So we wanted to generate prospective research for women, young onset women could track their Parkinson's symptoms across their menstrual cycles, so that we can actually see a correlation. And is that basically... Because obviously the surveys don't count enough in terms of research to do clinical guidelines, so we need prospective data. So I think that's really important. We need to get the data to get the care.

Kat Hill:

And we also invite folks that the data in the Fox Insight is available to researchers. If you're out there and you're listening and you know somebody who's doing research in the Parkinson's area, let them know there's data available to start asking some questions. We are collecting more and more information, we're advocating, but we need researchers to think about it and start tackling some of the questions too.

Soania Mathur, MD:

So true.

Richelle Flanagan:

And I suppose just to give a little plug, we're actually doing a study at the moment with the University College Cork, and it's open to women in Europe and in the USA, and hopefully we'll get it extended a bit further. So we're looking for women to take part in that study, so where they will do a... There's a couple of surveys that they'll do, but then they take part and track their symptoms for a four-month period. And it's actually not just for young onset, we've actually extended it now for women who are pregnant, perimenopause, or post-menopause, because we want to look at the different hormonal stages and see if the symptoms differ between the different stages. Because we know, like for example, in a study by Bas Bloem, showed that women who were post-menopausal had much worse symptoms than the pre-menopausal [inaudible 00:41:30] in a survey.

So we need the data, so we don't have to keep on... I'm fed up, to be honest, having to... I feel like the little girl in the corner, jumping up and down about my hormones. And there's this woman called Lisa Mosconi who's done huge research around Alzheimer's and the menopause, and she's coined a term,

neurosexism. And I actually feel that there is neurosexism in... Where it's just, I feel like... Yeah. It's just this annoying woman giving out about her hormones.

Soania Mathur, MD: Well, you're not an annoying woman, let me assure you of that.

Kat Hill: No.

Soania Mathur, MD: As we can see, there's lots of work to be done, and it's going to be through increasing awareness, through continued advocacy, and really a united voice that we can really push this forward and make changes in terms of how we manage women with PD, and hopefully resulting in improved quality of life for everyone.

Thank you so, so much. I can't even express how grateful I am to you for sharing your thoughts and your feelings. I think our listeners are going to really gain a lot from it. For blogs and other resources on this topic, visit the Ask the MD page on our website at Fox Foundation, or connect with others, ask questions, and share your experiences via the online form, the Parkinson's Buddy Network. While on the Buddy Network, you can sign up to join a private group for women in PD, and links to these resources are in our show notes. And also, please rate and review this podcast. Until next time, Dr. Soania Mathur.

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