



Health Disparities and Parkinson's: Bridging the Gap between Urban and Rural

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Davis Phinney Foundation

Melani Dizon (Director of Education and Research, Davis Phinney Foundation):
Hello and welcome everybody. My name is Melani Dizon. I'm the Director of Education and Research at the Davis Phinney Foundation. And today we are here for a webinar on health disparities and Parkinson's: Bridging the Gap between Rural and Urban.

I'm going to hand it over to Soania. Soania is a part of our Board of Directors. She does a lot of our moderating. We love having her here and we think it's going to be a super great discussion. So, Soania, take it away.

Dr. Soania Mathur, MD (Davis Phinney Foundation Board of Directors member and YOPD Women's Council Leader):

Thank you, Mel. Good afternoon. Afternoon, I guess, depending on what part of the world you're in. My name is Dr. Soania Mathur. I'm a family physician and Parkinson's patient having been diagnosed well over 21 years ago, 22 almost. I have the privilege of serving on the board of directors for the Davis Phinney Foundation and I have the pleasure of being your moderator today. So, today, as part of our "Health Disparities and Parkinson's" series, we're going to be addressing the concept of the urban and rural divide, the disparity between the care and outreach, the patients with Parkinson's disease face depending on where they live.

All of this is somewhat the case, but there is also another side of this issue, where those concerns are not as polarized as one might think. In fact, for some shared experiences to help us explore this topic today, I will be joined by four remarkable women who work hard to support our Parkinson's community.

So, first, I'd like to welcome Wendy Lewis. Wendy is the CEO of the Parkinson's Council in Philadelphia. She has a long successful career in working with nonprofits having received her master's in nonprofit leadership and has been with the Parkinson's Council since 2000, so welcome Wendy.

Next, is Amber Winter. Amber is executive director for Parkinson's Nebraska. Although relatively new to her current position, and as a sole staff member, which I still can't get over, she brings us a wealth of knowledge and a degree in nonprofit management. Thank you for joining us today.

Amber Winter (Executive Director, Parkinson's Nebraska):

Thank you, Soania.



Soania Mathur:

Also with us today is Holly Chaimov, the executive director for Parkinson's Research of Oregon. Her involvement with PD really extends beyond the great work she's done within the community. She serves as a member of the unified Parkinson's Advocacy Council, which focuses on really advancing policy changes for all of us with Parkinson's disease, so thank you Holly, for joining us as well.

Holly Chaimov (Executive Director, Parkinson's Resources of Oregon):
Glad to be here. Thank you.

Soania Mathur:

And last, but certainly not least, we introduce Kathleen Crist, executive director of the Houston Area Parkinson Society with her degrees in social work and extensive experience, she's been responsible for creating and implementing many service initiatives, support groups and educational programs. We are so glad you could join us today.

Kathleen Crist, LMSW (Executive Director, Houston Area Parkinson's Society):
Thank you. Thank you for having me.

Soania Mathur:

So, it's a real pleasure to be speaking with you all about this topic in the field of health disparity. As I mentioned, we sort of talked about the existence of this urban, rural divide in Parkinson's care, or actually medical care in general and that divide is real in a lot of ways.

I mean, there is a disparity between retention and medical professionals, access to care and access to technological advances, the influence the different regions have in policy changes, and so forth. But there are also many similarities, particularly as we look into certain communities within the urban setting.

So, let's just start off today by asking each of you a question. And maybe you could share a little bit about the communities you serve and the top one or two issues that you face when trying to provide equitable and comprehensive care to those in your regional community.

And I'd like to start with Amber. Amber, when we spoke, prior to this webinar, you mentioned that you have been kind of doing this from the beginning; getting to know what services are needed and what community outreach should look like in your area. So, what have you found challenging?

Amber Winter:

So, here in Nebraska... well our organization in Parkinson's Nebraska serves the whole state. So, we serve both people living in the urban setting, here in Omaha and in Lincoln, as well as people in rural communities all across the state.

We see some similarities with, well obviously the type of services that people need access to, such as support groups, exercise classes, access to movement disorder specialists. One of our biggest challenges is really reaching out to those rural communities and getting them connected with the statewide network. We have found that one of our best ways to work through that is through partnerships with people all over the state. As an organization and as a single employee, there's only so much capacity that I have. So, that in and of itself is a big challenge that we face and so I find myself working really closely with people here in Omaha, really great relationships, to be able to connect people with resources, as well as leveraging on national resources, statewide resources and building relationships with people in outer parts of our state, because we can't do everything. So, we really do rely on people all across the state, to be able to learn how they can make an impact and really provide them with those resources to help them.

Soania Mathur:

So, you provide resources to people that you partner with in the community. Are there specific people that you do tend to reach out to, like support groups, or are there individuals involved with Parkinson's Nebraska?

Amber Winter:

Yeah, so, the type of people that we reach out to, we're really focused on the person with Parkinson's, so what does that person with Parkinson's and each community need and how can we help build wellness programs in communities that either don't have all the aspects of wellness, like therapy, access to a physician, support groups and education. So, if there's a support group that we have a relationship with, we work on really strengthening that relationship and then using their information and their knowledge on their local community, because they're the experts, we're not the experts of Norfolk, Nebraska, for example, so we really do rely on the exercise professionals, you know, the physicians, the speech therapists that work there to help us know who has Parkinson's, what does their community look like, specific to their area. What do they need? And then what can we do? What resources can we connect them with, via national, via providing funding for them to help their communities grow, but really relying on the professionals, as well as the people with Parkinson's that we develop relationships with to tell us what they need, and we work with whatever resources we have available to us, to connect them to what they particularly need. That's a big part. And a really important part, when you're talking having this conversation, is, like you mentioned, even within an urban community there are multiple smaller communities that might have certain disparities that that they face.

For example, here, we are working towards a new program for people who don't speak English as a primary language. English is my primary language, and I don't know any other languages, so, by partnering with other community members, other organizations, that do have access to that, we can provide something and we're able to really make a bigger difference and reach more people that way.

Soania Mathur:

For sure, and Wendy, I know that I'd like to ask you specifically about that, about the challenges you've faced, because recently, the issue of inequity has come into focus in our world, and rightly so, in the way that we look at the world. Inequity is real, it's pervasive, and in all areas of healthcare including Parkinson's care. For example, I believe when we spoke before, you mentioned that the Houston area population is about 40% black, but only 8% makeup those visiting Parkinson's institutions. So, I know that all aspects of our PD community, you know the people of color, indigenous black communities have not been traditionally reached, so why is that and what challenges do you have to overcome to get there?

Wendy Lewis (CEO, The Parkinson Council):

Thank you, Soania. So, we actually, in the Philadelphia area, are rich in resources in terms of experts in the field of Parkinson's. We have two major centers, Jefferson and Penn. One across the river at Cooper in New Jersey. Then, we have a center in Delaware, as well, that deals specifically with people with Parkinson's, so, our region is really rich with experts.

The challenge, however, has been having communities of color access that care and a lot of it has to do with education and outreach to those communities. A lot of communities of color are dealing with other issues that take prevalence and priority. If you've got a community of color that's dealing with issues, let's just to say COVID right now, a lot of communities across the country, where people of color are probably the first or the hardest hit, and they're the last to actually have access to the vaccine. That's similar in Philadelphia.

One of the things I think that is unique about our region, though, is that the centers recognize that we need to do more. And despite the competition they have with each other, have decided to come together to work collaboratively to address those issues. So, there's a lot of outreach that we, as a collaborators group called Diversity PD, are doing to educate community health workers, because I think that's where it's going to start, about Parkinson's. Their clients are dealing with, as I said, a lot of issues, from obesity to diabetes, heart disease, and so Parkinson's falls down on that list of things to take care of.

So, we actually have done a really, or tried to do a better job than we've done previously to reach communities of color, but it doesn't mean that that all institutions have to stop addressing the systemic reasons why this is happening in our community. The Philadelphia region, we're talking 44% of the population in Philadelphia is African American, yet of the clients that visit those centers in the metropolitan area, 8% are African American, which is astounding.

Again, we have to do a better job of educating people who are reaching and working with those communities of color. Also, the biggest issue that we face is trust in our community. We recently had a huge fiasco rolling out the vaccine, and it's something that I think the city is trying to rectify by making sure that the experts who know the docs who know about how to deal with infectious diseases reaching communities of color and



have the bill to trust or the frontline staff to initiate and implement the vaccine program in the city.

So, trust is a major issue and I think across the board, just as a national initiative, I think that the country has to do a better job in reaching communities of color when it comes to anything having to do with working with big institutions to provide care.

Soania Mathur:

Yeah, I think you're right. I think it's a hugely complex issue. And, you know, there's not going to be a short-term solution to a long-term problem. We have to definitely work towards it. Has anyone else had issues with reaching certain underserved communities? I mean they don't necessarily have to be communities of color, they can be socioeconomic issues, distance issues, other basically under-served communities in your area.

Kathleen Crist:

Well, I can speak for what's happening here in the Houston area, and when I say Houston area, we serve eight county regions, which is somewhere around maybe 6 million people. So, it's a big area, and it's pretty geographically spread out. We don't have mass transit systems that are helpful in terms of people and access. Houston's also very richly diverse, culturally, and so, within populations of our community, access tends to be a problem. Like Wendy mentioned, we too, are very fortunate to have a wonderful movement disorder clinic. We have a pad rack here with the VA. We also have four different movement disorder clinics and upwards of 15 movement disorder specialists, just located right here in our Houston area.

But we also find that folks in the outlying area, don't have the same access to care, and experience barriers, not only in terms of physical access to it, but also in some of the support that they have from their healthcare professionals in those areas, as well as some cultural barriers that they're facing, just in terms of stigma, trust, and shame from within. So, you know, certainly, there's a lot of work that needs to be done in the outreach efforts to groups that don't have kind of the same accessibility or the same access that other populations have.

Soania Mathur:

And are there specific things that you're trying to do as an organization in order to reach out to those individuals, those communities?

Kathleen Crist:

For us, one of the things that we're really trying to focus on is a lot in terms of education. So, trying to help folks, figure out education that takes into consideration cultural issues, cultural barriers, cultural norms. Education that takes into consideration urban versus rural, location, education status, income level. So, we're really trying to figure out ways that we can communicate that help folks understand better what Parkinson's is, and what's aging. What is it that we can tell you in terms of symptoms that we can start a dialogue about and that we can start getting resources to you? Some of those things

that really carry a little bit more stigma associated with it, that create, you know, barriers for people to want to reach out for help.

So we're really trying to focus on how can we best, educate, spread the word about Parkinson's, you know, what is it that we can do even with, even in terms of providers, I mean, I think, you know, one of the things we discussed them internally here is kind of how the UPDRS, which is, you know that Unified Parkinson's Disease Rating Scale is not very culturally competent, it's also, you know, for folks who have a higher education level to the part where you have to self-assess or the part where, as, as the interviewer you're assessing someone else. We're looking at how, you know, how can you adequately or appropriately assess assets that influence someone's quality of life and get them connected to resources they need when the tools that we're using aren't really even adequate or appropriate just on, on, you know, on face value there.

Soania Mathur:

You're absolutely right, there's so many nuances to this issue I mean culturally, there's so many, so many nuances I mean I know from my East Indian background that that that my family politics, a little differently than may say someone else's but yeah it's harder to navigate but it's necessary, you know as our world becomes our country's become more and more multicultural we have to not let certain communities slip, you know, it's, it's, they deserve just as they deserve the same level of health care and access to health care as anyone else. So, I'm glad that you're all working on that Holly did you want to add something.

Holly Chaimov:

I was just going to kind of underscore the, the rural issues for a lot of our state, the rural areas are really not densely populated at all like the county seat isn't even a large town. And so, we run into challenges where, when we talk about providers and bringing providers together for some of our counties there's not a neurologist, let alone a movement disorder specialist, counties apart.

And so, this creates for many people this really significant burden of traveling to get medical care, which is compounded when we, as a as an organization and as a community talk about the importance of specialty care for your Parkinson's disease, when some people are struggling just to get a primary care doctor that is willing to work with them to treat their Parkinson's.

So, I just, I think that we can't leave behind really some basic care and the need for really some basic care within, within many of our counties across the country here.

Soania Mathur:

And I mean diagnosis itself is out of reach for a lot of people.

Holly Chaimov:

It is. It really is. You know one of the things that we've been pleased to be a part of is our local Center of Excellence does do some outreach to primary care providers and



provide training for them on Parkinson's disease, so we leverage our local support groups to help identify who the docs are in the communities and try to use the patient population to encourage the medical population to rise up and do just a little bit better.

Soania Mathur:

Holly that the access to care and the distance that some of your constituents have to travel kind of kind of reminds me of, I guess, any one good thing came out of this pandemic. Well, I guess, any one good thing came out of this pandemic. Is that we've seen sort of the rapid progression and the development of internet resources and telemedicine that really has come along, far away in a very short period of time.

You know, writers support groups and educational groups exercise classes, and more. And what thing I remember you saying at our prep call was that you thought that this would be the kind of, you know, great leveler, equalizer which makes sense to me I would think the same thing but in reality, you said it wasn't so much. Is that right?

Holly Chaimov:

Yeah. So, just to elaborate on that. I think the, the hope that we had, and the expectation was that with all the wonderful virtual opportunities for people that these geographic barriers would no longer be what kept people from having access to an exercise class or their support group or, or even an appointment with a movement disorder specialist.

However, Broadband Access Oregon is 36th in the country. And, and this affects a great portion of our geography. We have counties that there's nobody in the county that has high speed internet access. It just doesn't exist.

And so, this idea that we were going to see people from our outlying regions, being able to engage much more than when we're live and in person, just really didn't transpire for us, at least not here in the northwest, having everything to do I believe with internet access.

Soania Mathur:

Amber, is it the same for you in Nebraska?

Amber Winter:

Yeah, so I would echo a lot of web Holly just mentioned on the geographic barriers that that people out in central and western parts of Nebraska face are very real. We have a, we are lucky here in Omaha to have the University of Nebraska Medical Center and Nebraska medicine, we have a comprehensive multidisciplinary Parkinson's disease clinic with some world renowned on movement disorder specialists, but they're all here in Omaha. And so, when you look out to central and western parts of Nebraska, you are seeing a lot of places don't even have neurologist or if they do, they're traveling between many towns.

And so, people are going to their primary care physicians or their family physicians with symptoms that oftentimes you know we see here a lot that people are getting, if they're even getting diagnosed, they're getting diagnosed really late and the disease progression on because they're not catching those more subtle, non-motor symptoms.

So, by the time they are diagnosed, it's, you know, they've really progressed quite a lot, so we do see that a lot, and we have really been focused on outreach to rural communities that's just been a really big part of our strategy over the last two years and we've made really great progress. However, there was definitely we also were very excited for zoom and had all these great ideas for connecting groups and sending them up on zoom calls and huge oversight on our part with the hundreds of people that across our state that no matter how great their internet is about how motivated they are how great their computer is how motivated they are to learn there, there's a lot of people who just don't have access to internet or quality internet where if we were talking right now, it'd be super choppy and bouncy and I would probably exit out of that as well. So we have been trying to determine what's the next step to that, you know, internal, you know that statewide structure that infrastructure and I think for us that's really going to be and probably every state facing this is going to be, you know, we're not the only group that's facing these issues, there's schools that are facing these issues during COVID on other types of diseases or medical providers so while zoom and an online and telehealth absolutely has helped a lot of us reach a lot more people, it's also, thankfully brought to our attention on a huge gap in meeting the needs of people without internet access.

So, I'm grateful for that though because before all of this, we weren't even thinking about that as a barrier. So, now at least we know, and we can try and partner and find ways to meet that.

Soania Mathur:

You know I think you're right identifying barriers for stuff, but it must be frustrating because especially when you're talking about large geographical distances that I mean that would be primed to be able to have a really good telemedicine network that people could access I mean, it would just be revolutionary for a lot of people.

Kathleen Crist:

Oh, I was going to say I might add that one of the interesting things is Texas had very limited laws related to telehealth and telemedicine. And so, the onset of covert really forced this issue. So, all of these kinds of excuses that the Texas legislature had about why we couldn't have telehealth and telemedicine really had to be, you know, there was a lot of pushback, and they had to allow you know and make accommodations for folks, because people, you know, I mean, when everything was well, as shut down as things got here in Texas, that they were able to you know that people had access, regardless whether it was primary care or specialty physicians, but this, this whole pandemic really did kind of open some of the gates and kind of push that forward little bit here in the state of Texas, because it was very limited. There were a lot of restrictions, a whole lot of excuses why it couldn't happen and what we have learned, because even though we



do have upwards of 15 movement disorder specialists here, we have people coming from Mexico and Louisiana and Oklahoma and all across the state of Texas, and but even just here, you know from one end of our service area to the other could be, you know, a two-hour drive. But getting into the medical center which is where the majority of these folks are you know how.

There's a lot of traffic if anyone's ever been to Houston you are well aware; our traffic situation is expensive to park. It's difficult to navigate we now have light rail down in the medical center which has been, you know, kind of an ongoing issue for people to navigate and so it, you know, so this is really giving people an opportunity to have access in ways that I don't think many of us thought we would see, you know, as soon as we did.

Soania Mathur:

It's interesting how the pandemic kind of cut a lot of red tape very quickly. Yes, collaboration between scientists and the development of vaccine particularly. And, yeah, issues like you were saying about the telemedicine Wendy How are things in your neck of the woods?

Wendy Lewis:

So, Philadelphia is the birthplace, and headquarters of Comcast, and Comcast has, I think of the last maybe 10 years has tried to make it a more affordable for access to internet access to broadband internet. There are places around the city that students are set up for students and designed for students to go to do work.

I do know that for some families, even though the small fee that that is sometimes required, I think it's like \$10 a month, it's still a stretch for a lot of families who are facing issues like food insecurity or housing. A lot of families who, you know, not only are they not able to afford access but they don't have the technology, even if they, you know, have a place to go, they won't necessarily have the technology to actually initiate access, so you know Philadelphia is unique in that way. One of the things that I think, just a little bit of background about our organization is that you know, even though we are an organization that has been around for since 1987 and one of our founders, is one of the three co-founders of Comcast, we still have, you know, some challenges in helping and navigating that relationship with Comcast to ensure that they recognize some of the barriers associated with people living with a disability who may have really a tough time accessing care.

Again, they're doing what they can do. Everybody wants a piece of you know what they were able to provide financially. And so, I think one of the biggest, for us as an organization, is to continue to identify access points that businesses, partnerships that businesses can do with local nonprofits and work in a collaborative fashion to ensure the local families have those needs met.

I've mentioned this before that, I think Amber mentioned the fact that neighborhood to neighborhood are very different. If you've been to Philly, our neighborhoods are very

different. People are very loyal to their specific neighborhoods, folks who live in the north Philly area may not want to travel to center city to see a movement disorder specialist maybe they just want to go to a neurologist nearby. The neurologist may not be as equipped to be able to provide a comprehensive care but they there's access to something.

So, people are very loyal to their neighborhoods, they're very loyal to their providers they, and some folks may not even have ventured even farther than their neighborhood for you know pretty much all their care, everything that they may access is right there. So, I think that having big institutions do that outreach as I mentioned before, to create a level of trust, to be able to, you know, say this is what we can do for you. And this is, I mean, not only are we talking about people who are living in, I mean Philadelphia has some pretty poor neighborhoods, and then they have we have an area that has pretty wealthy neighborhoods, so it's pretty segregated racially and in terms of economically, and so there's, you know, we've got to work really closely with our business and our business sectors to help identify ways to partner with community-based organizations. We've got folks who live two miles away from, less than five miles away from a big service center of Philadelphia where you'll see the difference of life expectancy of seven years, a difference within five miles so you know it's a lot of work to be done in our region we are big metropolitan area, we have, we are regional organization so again we work very closely with those across the river in Delaware in Jersey. So, it's a big thing to handle and manage but I think that there was a lot of commitment from those providers to ensure that that we're not leaving folks behind in care.

Soania Mathur:

It's so interesting you all sort of travel in this very complicated world in some ways because it's not just about identifying say there's not enough moves or specialist. Increasing access to them doesn't necessarily solve the problem because there's all sorts of issues that lead to the problem in the first place that you have to solve along the way so even like you're saying, you put educational classes up on the internet and you think that would reach more people but yet there's, you know, there are barriers to get them even to be able to log on or to afford to log on which is, which are real life problems and things that we have to look at in order to really truly, truly get sort of more equity in terms of access to care.

One of the questions that someone who's watching put forth is, what lasting value if any, do you see for both rural communities and minority communities resulting from the virtual forums that have been developed to deal with the limitations required by COVID? I guess, beyond the, as long as they have internet access, I guess, as I've been a successful way to reach people for any of you.

Kathleen Crist:

Well, just from a human perspective I can just say that prior to COVID who did nothing virtually. And so now that we have virtual programs, which clearly people have been very receptive to. We actually have a much greater level of participation from the outlying counties that we serve. So those areas that maybe we didn't have programs in,



we were doing some beginning some outreach pre COVID. We now will continue those, those virtual programs so that will be reaching people.

We're also doing support groups, virtually. We're doing educational programs, virtually. We've, you know, had the opportunity to serve people kind of in you know that are coming to Houston for various reasons, but don't necessarily live here.

And, but consider this kind of their home base. So, we've been able to serve them in ways that we hadn't prior. And I think that that was, you know, that was, that was pretty extraordinary for us it was something that we necessarily were expecting.

We had a maybe a little bit different experience than like Holly and Amber maybe I have had with in terms of internet access. We also had, interestingly, a number of kinds of multigenerational homes that have said because their grandchildren have access to internet and have now been given devices that they use for school that they can join in on things and see their doctors, using that technology just kind of on off school hours and things.

So, we've tried to, you know, we've been able to implement some, some evening some weekend. Some other things that we weren't doing that this technology, gave us the opportunity or this, this kind of forced, use of technology gave us the opportunity to do.

Soania Mathur:
That's great.

Holly Chaimov:
I think we're going to end up in some kind of a hybrid after, after COVID, where we will continue to be offering some of our services virtually, but we'll be moving back to as much as we can, that we're offering live with the rural outreach that we had initiated in 2019 and we're continuing rolling out into 20, we'd had really some great impact with education and out in communities bringing staff, local experts, as well as folks from our Regional Medical Center out to talk and provide education on Parkinson's disease.

What we learned was that many of those people that got engaged because of that outreach didn't continue their engagement in a virtual setting. And whether that's because there hadn't been enough time to really forge those relationships or not, but for us it really highlighted that boots on the ground and being present in a community and having the respect and, you know, Wendy talked about this trust level. Trust is a real big issue in an urban, rural divide. Certainly, here in Oregon it is something that, that we read a lot about that, there is great mistrust between folks who don't live in our urban settings, who look to our more urban communities as having all the resources and how there's just great disparity there. So, it is going to require us to be back out in the field. Again, as soon as we're safe to do so.

Soania Mathur:

Yeah, I mean virtual is, is tremendously helpful sometimes but there's nothing that kind of replaces that rapport that you feel in your sort of one on one with somebody. Amber you're going to do sort of a hybrid as well then?

Amber Winter:

Yes. Yeah, absolutely. So, before 2019 we kind of started at the same time on really being intentional about rural outreach. There was very, very limited services available we've actually in the last two years quadrupled, the amount of exercise classes support groups on, etc. Available in rural communities. So, on through zoom, we do have this issue, a barrier issue of access to internet.

However, we have seen on a lot more people. I guess people in central Nebraska, and western Nebraska, have been so underserved for so long that they are so eager to get access to these there are boots on the ground.

Just organically, who have been really wanting for a long time and just really needing to be that leader in their community and being able to provide you know like this webinar, for example, out to those communities.

It's the local support groups that are sharing this information so there is a little bit of, you know, we're really trying to work with the local leaders who have that trust there and providing them with a lot of resources, connecting them with national resources, we're able to get movement disorder specialist to do webinars with support groups in Alliance, who have never spoken with a movement disorder specialist before.

So, as much as there is that, you know, internet access issue, we have seen, a really great, welcoming response from people in central and western Nebraska.

And that's been really, really great to see, we do plan when COVID started, you know, our first challenge was how do we transition everything online? What does that look like?

And I think the next step of this is going to be, how do we transition from virtual to hybrid, because it's been so successful, we have people tuning into programs from like a small-town Beatrice who join our UNMC support group, who never had access to that support group before COVID because it was all in person. So, to be able to offer things in person, as well as still maintain the importance of that online kind of hybrid.

That's kind of the next step that we're going to be approaching with professionals as in person classes resume is, how can we keep offering this to these communities outside of here, while also, you know, building that in person, local community as well?

Soania Mathur:

Right. That kind of ties into the next question that someone has submitted, and they said they're asking, what can a person with Parkinson's like me who has access to

resources and information and treatment and support do to reach out to those who don't? Does anyone have any ideas about that?

Wendy Lewis:

I guess the thing I would say is, how much do they know about their community? I mean, get to know what the needs are in the community. If you have access and you have resources if you have knowledge if you have time and expertise that you could share, you know, find a way to volunteer that to create a sense of community even if it's virtually I think that's one of the biggest challenges that this, the COVID has seen you know that a lot of facility with Parkinson's has experienced because Parkinson's is already an isolating disease, anything that you could do to create community and build awareness and build visibility about what's available, I think you should take that opportunity to do that so I would say to that person is to connect with those health professionals, and I'm sure they would love to have somebody to come in and take on a role of the support group leader, somebody who could facilitate a gathering of some source where people can share ideas and tools and thoughts I think that would be just a huge way to give back to the community and also you can actually get something for yourself as well.

So, every relationship is a give and take, but I think that if you have all of those things and you have the time and you have the expertise and you have the energy to do that, you know, reach out and to those experts and asked him, what can I do to give back to help support the work that you do? So that's kind of what I would recommend.

Soania Mathur:

Yeah, and that whole concept of reaching out is so important particularly now as you said, with Parkinson's, you tend to sometimes actually isolate yourself because the disease and then on top of that the pandemic has not helped in that way. Does anyone else have some suggestions for the person..

Holly Chaimov:

To follow on to it Wendy was just saying, I think that for those that they're getting really good care and they have the resources. One of the things that any of us can do is to just be very public about what we're dealing with and what you're living with, I think that anything that you do to help raise the profile of Parkinson's disease, and to help normalize the experience and other people to appreciate and understand that there's this great range of experiences is only going to have ripple effects throughout the community, and you may be living in a resource rich town, but you don't know who you know who knows somebody who's living much further away. We all have these impacts that are unknown until you change somebody's life just by sharing your story.

Amber Winter:

I could kind of add on that as well is to be on really intentional with your time and who you're reaching out to find out who are those therapists in the town over from you, who maybe doesn't have a support group.

Who are those therapists that might be trained in a Parkinson's specific program that has access to that community in that town and work with them to identify what those needs are and maybe start a support group or they know someone with Parkinson's, talk with them, start a relationship with that person so that they can build a support group. Here in Nebraska, we have a group in North Fork, which is about 100 miles north of Omaha, and they have people from O'Neill which is another even smaller town, maybe about an hour west of there, and those people in O'Neill have been traveling to North Fork for services, and they just reached out to me recently for help with, well how can we just get something going in O'Neill, we have stuff here in North Fork, there's no reason for them to drive all the way here if we could just get them set up with resources and meet the needs of their community. So, just reaching out specifically to the people who can really make an impact in the local communities you're trying to impact.

Soania Mathur:

Yeah, that makes a lot of good sense. It kind of ties into the question that I have for each of you. And that's really these calls to action for our patient community. I mean I've always been big about people having to be an active participant in their management, in order to optimize the quality of life and to live well with this disease. We can't be a passive bystander and expect to thrive. You'll just basically survive instead and that goes for medical management goes for wellness or self-care. And luckily, we have support organizations and dedicated individuals like yourselves to help us along the way to help guide us, a sincere thank you for that.

But in that spirit of being an active participant, how can we as patients, help you and support the work that you are doing and, really, we're helping the whole Parkinson's community if we do so. Who wants to start?

Wendy Lewis:

I'll start. I would say that, how people living with Parkinson's can help organizations is to help the organization, build its capacity to do this work so organizational readiness to take on these, you know these different roles that we play every day as organizations and community also to, you know, support our work, you know, volunteer time, donations are always welcome. We're all you know the nonprofit sector is, you know, particularly smaller nonprofits are hit the hardest because a lot of the monies that are given during this time of the pandemic is given to frontline staffing, our services don't stop services and increase, and then, you know, fundraising diminishes there's, there's a bigger gap. So, I would say that, you know, help the organization build readiness and capacity to be able to take on these roles in the community because we're all wearing different hats as leaders to ensure that our community has what they need. Also be a conduit and a facilitator for those opportunities.

You know, if you see an opportunity out there is nothing that will, you know, keep you from reaching out to another organization to partner on something, even if your mission's a little bit different, to partner with something that can bring together. So that's kind of what I would say.



Holly Chaimov:

I would say a really easy thing for any person to do is to reach out to your local organization and get a supply of brochures or business cards and liberally litter them everywhere you go for services. You know make sure that your dermatologist knows that there's a Parkinson's organization that serves this area. And I can't tell you how often we get a call from someone in an outlying area that is inquiring about services, and when we let them know there is no boxing class in in your town and the answer is, well I know have six people that would sign up.

Well, that's amazing. But if those six people aren't organized are using an entity to help organize them then it's really six remote individuals and so any of us can be helping to coalesce a community, either by distributing information and helping funnel people back to a consolidated resource base or stepping forward as the volunteer to start that group in your own community. Absolutely.

Soania Mathur:
Excellent.

Kathleen Crist:

I would say, to build on both what, Wendy and Holly has said, and I'm sure, you know, Amber will also have something kind of associated, is the connection aspect let's don't be afraid to connect whether that's with other, you know, to each other. I think that, you know, not only individuals with Parkinson's but care partners as well. All have their, you know, common and then you know overlapping and unique needs.

But also, you know, don't be afraid to reach out as Holly said to the local resources because even if you've looked at something and go well there's nothing really there that I'm interested in, or they have nothing for me, I can speak on behalf of my organization and my team, we thrive on education we, we, we are not in if you build it, they will come kind of organization.

So, we, we are looking to guidance and we're very grassroots, very needs based, you know, kind of thumb on the community and so if there's something that that you need, help us by educating us. I mean I think the education piece is so important because that's where we can really work together and I think that, you know, just broad education of Parkinson's, but that, but that also just the more people that we connect together, the better we can spread the word about Parkinson's, and how it affects individuals, and how it affects families and how it affects communities. And I think that we know that you know timely identification leads to improved quality of life, delay and disability, and hopefully you know potentially improve survival and those are things that, you know, that I think that everyone benefits from, but it has to be collaborative.

Amber Winter:

Yeah, I would definitely kind of piggyback off of that, um, especially what Kathleen kind of said about, we want, you know, I could be an expert on the overall resources of what's available on a national statewide level that I don't know I'm not the expert of local



communities across Nebraska, you guys are the experts of those communities, everybody listening today you're the expert of your own community and your own wellness needs and the wellness needs of people around you that have Parkinson's disease. And really that education goes both ways. We are all here everybody you know on this panel we're here for the purpose to help and strengthen our communities, but it is collaborative both ways, it does require us to kind of rely on those local communities and leaders to tell us what the needs are so that we can collaborate.

Find what partners, you know help you identify the needs, help you identify what partners and, you know businesses and organizations could help you on that local level.

And I would also just like to say, you know, over these last two years, we again I've been really intentional about rural outreach, and we've really seen on a lot of success in our rural communities, being strengthened and that has to do with those people at that local level so I'm here to say that you can make a difference, you can make an impact you don't have to work for a nonprofit, you don't have to know everything about Parkinson's disease.

It starts with forming relationships with, with other people with Parkinson's, with your service providers, with your doctors and just know that you really do have the power to make a really big impact on a lot of people's lives really no matter where you are in your journey, and I hope that's something you can really take away today that you are super powerful.

Soania Mathur:

That's so cool. Yeah, I agree, just, we're sort of still at the beginning of the new year and we're all hoping for a better year this year for sure.

But just to briefly ask each of you what sort of makes you excited about the coming year? What in your organization, what particular project or initiative gets you up in the morning so that you're like, yeah this is going to be fun?

Wendy Lewis:

Yeah, I think that the fact that I can bring my whole self to my role, which is very different because of all the social justice issues that happened last summer, I can really walk into a space and identify myself as a woman of color and the unique talents needs.

And I can bring my knowledge related to aspects of my community, because I can't speak my entire community, to my work that it wasn't done before so I get really excited about being able to, to make a difference with those communities that are often unseen, and underrepresented, in our region. So, the collaboration across all of our centers has been just a phenomenal opportunity for all our docs, all of our providers, for me, for my board, for my community, just to really, that's what makes me really excited about my work in 2021. Forget about 2020. Everybody wants to give, you know, the big f- to 2020, but 2021 is a lot of promise and I'm very excited about that.



Holly Chaimov:

I think I'm excited about figuring out this hybrid. And I think that we are going to be virtual through the summer, and then maybe they'll be slowly some gradual lifting.

What I think is going to be important for an organization for all of our organizations, is to be paying attention to this telemedicine and the digital divide, I think that if, if, virtual is going to continue and it is there's kind of no going back that genie is out of the bottle here.

We need to find a way to make sure that that new universe is inclusive, from the beginning, so that we're not having the same issues just being replicated with access and access barriers, going forward, and we're having the same conversation again.

Kathleen Crist:

Last year was such a bad year. But, you know, having the perspective of someone who's been with the same organization for nearly 20 years. What I saw last year was a lot of change, and the ability to change, and the ability to accommodate people's needs, and I think what I'm most excited about is the resilience of the community and the resilience of the Parkinson's community globally, but also just the resilience of our local community and how much they've given during, you know, and I don't mean monetarily but I mean how much they've given of themselves to figuring this out and continuing their journey and living proactively with Parkinson's, and that's really exciting. I look forward. We will obviously be having a hybrid model going forward. But I look forward to seeing people in person but at I also look, we have done over the last year, thousands and thousands and thousands of phone calls with people.

And so, it was, it was great to strengthen and deepen some of those relationships with people on a very different plane, and I look forward to more of that as well, but I think that in some ways, you know, this being apart has brought us together.

And, and so that's something that I find is kind of the spillover excitement for me.

Amber Winter:

I would definitely kind of echo that. One thing I like to do a lot in my own life and in my role is find the silver lining and everything. If you receive the Parkinson's Nebraska newsletter you get that line a lot, we always are looking for the silver lining and as awful as 2020 was for a ton of reasons, it allowed us to identify different barriers that we're facing, it's allowed us to get into new communities, and so I'm really excited to work towards on, you know meeting these new needs that have been identified, continue to identify new ones, and strategically or on a bigger scale for our particular organization, we are looking to hire an additional staff member, which will really be great for me personally, obviously, but also for the organization as a whole because that's really going to, you know, expand our capacity, like Wendy was saying, to be able to meet these needs there's only so much you know manpower woman power, you know behind us, and I'm really looking forward to what you know, with what we've been able to accomplish over the last few years, what are we going to be able to accomplish with an



expanded capacity and now that we're, we know these new needs and these new barriers.

There's a lot. I could talk all day about all the things that we're looking forward to in 2021. But that's going to really help us out.

Soania Mathur:

Well, the hour has flown by so we're coming to the end of our time together and I just want to thank you all so much for your insights, your experiences, and sharing them with us. It's greatly appreciated.

I also wanted to thank everyone who tuned in for joining us today and hope that you found your time with us helpful and educational and always remember you may not have control over your diagnosis, but how you face the challenges of what this disease brings is yours to determine. So, focus on optimizing the quality of life. Educate yourself, empower yourself, and celebrate your victories. I also like to just thank Dance for PD for partnering with us on this webinar series, their support is appreciated. So, thank you.

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