

# **Healthy Parkinson's Communities® Grant Recipients**

### **New Orleans Ballet Association**

**Davis Phinney Foundation** 

Note: This is not a flawless word-for-word transcript, but it's close.

Kayla Ferguson (Grants Program Manager, Davis Phinney Foundation):

Awesome. Well, thank you, Milette and Jaelyn for being here on this Zoom call with me today. We're talking with these two women at the New Orleans Ballet Association. They are one of our 2022 grantees doing some outreach to some underserved communities in their area and we're going to learn more about that through this interview. So, I'll just jump right in with the first question. Can you tell us briefly about the project that you've received funding for?

Milette White Lin (Education Manager, New Orleans Ballet Association):

Yes, absolutely. We're super excited for this project. I'm very grateful to the Davis Phinney Foundation. The project is called Championing Movement, and it is a community building and outreach project. And through the project, we're aiming to provide critical support for both underserved groups as well as rural areas in southeast Louisiana during these really, what continues to be, very challenging times. I mean, I feel like we've definitely made some progress through this pandemic, but it's not over. And I feel like this is like now more than ever a really important time to reach out in whatever ways we can to provide some support and resources for folks dealing with Parkinson's and their families.

## Kayla Ferguson:

You kind of touched on it a little bit in your answer but, or in your answer to the previous question, but how did you identify the needs and some of the barriers in your community that you're specifically focusing on with this funding?

#### Milette White Lin:

Yeah, so again, you, I will edit this out, but originally when we heard about this grant we, you know, we never want to just come up with an idea that's just out of the blue. We've always kind of go to our community that we've been working with now, the Parkinson's community here and the greater New Orleans area, for now, five years, we've been operating this dance for Parkinson's program completely free in the community. And I think over the years, I would say what spurred us to really kind of dream up this project with you all's help is just the contacts that we've made over the years at different advocacy events that we've been able to be part of. So, such as like the, actually the Phinney, one of the Victory Summits back in 2016 was one of my first experiences at all with Parkinson's.



It was when we were building the program and trying to launch a class here in this community, we really don't, didn't have at that time any programming for Parkinson's, I think other than just the local support groups. And they had the Rock Steady Boxing. So, people were asking about it, and because we're a dance organization, it was a natural fit. So, when we were meeting people from other communities that were coming to these regional events from other areas in southeast Louisiana, such as Thibodaux, you know, Baton Rouge, other areas, they were asking like, oh, do you know a class like this in my area? And unfortunately, we had to tell them no. And we didn't even have a program yet. So, through this project, now that we do have a program that's been successful through the national Dance for PD model and curriculum, we're really excited to be able to respond to some of those requests to actually now have the ability to go out into these communities that we have not been able to go to so far because our funding has been so specifically allocated for Greater New Orleans at our Metairie class and our New Orleans class.

## Kayla Ferguson:

And Jaelyn, anytime you want to, I don't want to speak too soon and cut you off from any answer, but some pop whenever you want or not. That's okay too.

Jaelyn Robinson (Outreach Coordinator, New Orleans Ballet Association):

Okay.

## Kayla Ferguson:

So, okay, so, you obviously, you just kind of talked about how you address some of the, or how you kind of got to developing this grant in the way that you did. What are some of those specific needs and barriers within the community that you're hoping to address by being able to expand your reach a little bit further?

## Jaelyn Robinson:

So, in terms of needs, we know that Parkinson's patients, they need advocacy, and they need resources. And because it is a movement disorder, we know that they also benefit from exercise. So, there's so many geo, like Ms. Milette said, there's so many geographically and demographically isolated groups across Southeast Louisiana and they're not receiving the Parkinson's tools and the programs that they need to live well. And so, the champion movement project is aiming to not only spread awareness about Parkinson's and the rising prevalence of it but to also disperse Parkinson's educational tools and health literacy. And we plan on also sharing our dance for Parkinson's model of movement to areas that haven't been able to gain access to those tools before and that need that critical support. So, we're trying to overcome some of those geographic barriers and those demographic barriers and provide actual onsite resources for people that otherwise would not gain them.



## Kayla Ferguson:

Wonderful. That's exactly what we were hoping our grant funding could do. So, way to go. Okay. So, what are some of the short-term goals for this project?

## Jaelyn Robinson:

for each one of our workshops, we plan on, like I said informing Parkinson's communities in the areas that we touch. We want to increase awareness, of course, and knowledge about available Parkinson's resources. We know that of course, the Davis, Davis Phinney Foundation has a ton of resources and people might just not be aware that those resources are available. So, we plan on just kind of dispersing that information and to not only educate but also encourage people to embrace movement as a crucial form of treatment for the condition as well. I have been a dancer most of my life and I'm most fulfilled when I am moving. And so, it, dancing increases and just movement in general increases your, your balance and your mobility. And specifically, dance really works on your mental awareness, which are all things that people with Parkinson's need. So, we just hope that we can provide a more holistic approach to treating Parkinson's, not just providing resources, but giving people practical information that they can use and using the long term as well.

### Kayla Ferguson:

Awesome. So, the obvious follow-up question to that is, on top of those short-term goals, what are some of the long-term goals you all are trying to accomplish?

### Milette White Lin:

Yeah, I would definitely tag onto what Jaylen shared, and I have to brag on her cuz she actually did come up through our dance training program, known her for a really long time, and we're really excited to have her on board as our outreach coordinator for this project. She brings just a wealth of dance experience, but also she majored in public policy in college and she's just going to be amazing with helping connect with these communities. So I think like tagging onto her short-term goals of like the actual things that we're working on with this particular project, just in this one less than a year now I think our long term goals still are that, you know, overall that we really want to pair it with the Finnie Foundation and other organizations throughout southeast Louisiana to really continue to empower people of all backgrounds with Parkinson's to really inspire them to give them the tools like Jalen said, to thrive and live well today and into the future.

Again, during these times where it's really easy, I feel like for people to just continue to stay home and be isolated to really provide opportunities to come back and gather and even if they're not comfortable gathering, to then provide those virtual resources that are still out there, which are so amazing. I think that's really important to connect them with virtual



resources that the Davis Phinney Foundation provides and other Parkinson's advocacy groups as well as you know, our, the program that our teachers are trained in the dance for PD curriculum, they continue to provide amazing virtual resources for live classes, pre-recorded classes. So, there's just so much to share with folks. I guess that's our long-term goals in a nutshell.

## Kayla Ferguson:

Yeah, those are great. And I mean they're, they're exciting to think about the impact it could have short term and long term on the community. So, going off of that, what excites both of you, I guess, or one of you the most about doing this work for, I guess the short term and then the long term as well?

#### Milette White Lin:

Yeah, for me, I think it's planting seeds and continuing to do that in a really impactful way and a way that is very much community and heart-first space, which is what our organization really stands on. We're a very tiny organization. We have about five full-time staff, but an amazing faculty of teachers that care a lot about dance and the healing power of movement. So, I think, you know participants in the program, just hearing their testimonials about what this type of program provides for them, and not just our program, but other similar programs that support folks with Parkinson's and their entire families. It just excites us to be able to plant seeds now in other communities throughout southeast Louisiana so that if this is something that sparks them and gets them excited, that it might even inspire them to create and team with their local community to build more regular consistent opportunities in their own community.

Because that's really what it takes is, you know, we won't be able to go there repeatedly, but we've seen it happen. We've one of our teachers did a sample class in Ruston a few years ago in Dance for Parkinson's, and that community was so inspired that they were able to, you know, find someone with a dance background that was passionate enough and wanted to start a chapter of dance for PD out there as well. So, it's just exciting to kind of continue just building that community. I think locally, regionally, and I mean nationally and internationally

#### Jaelyn Robinson:

For me as a dancer, I like to say that there's no criteria for dance. There's nothing that you need to bring except for your body, I guess, maybe, or just an arm if that's all you have. And for so long it's been one of the most empowering experiences that I've had, and I've been able to attend some of the dance for Parkinson's classes we've had in New Orleans, and it's phenomenal to see the way that people move through their symptoms and don't let symptoms keep you from dancing. And it almost, it kind of silences symptoms sometimes when you're dancing and you're focused on the movement, it, everything else goes away. And so, there is definitely a healing effect, and I know people are looking for treatment and it's just so



empowering to see that treatment come through, dance of all things. And there are other ways that you can move and move your body and heal yourself. So, it's very empowering.

## Kayla Ferguson:

Yeah, that is exciting. Even just talking here on Zoom about it, so there's obviously lots of excitement. And then I guess the other thing we like to, to, I guess talk about even if it's not as fun, is what some of the challenges are that you expect to encounter, you know, reaching groups that have been historically hard to reach, you know, bringing in new people to this healing modality as you said. What are some challenges that you foresee existing in this project?

## Jaelyn Robinson:

Yeah, so we know how successful that the dance for Parkinson's has been and how, you know, we have people that can speak on behalf of that, but it is difficult to get people to buy into a program and get interested in trust in something that they've never experienced before, or maybe not have seen the immediate effects of it. So, I think one of the things is when we do our workshops is making sure that people feel that there is a, there is a positive response from dancing and moving. So, I think that'll be a big challenge is getting buy-in and getting trust and also making sure that we're reaching people that may be, you know, kind of isolated. We're still in covid like we've said, and people might not be accustomed to coming out of their houses too, but we do have lots of virtual resources like Ms. Mu talked about where we can disperse that information. And so, I think just the challenge is kind of reaching the communities that we know we need to be reaching those underserved communities.

#### Milette White Lin:

Yeah, I can tag a little bit onto that too. I think one challenge that's always an inevitable in community programming is, you know, just like Jaylen said, just making sure that if we're connecting with folks, we're also respecting that, you know, we may not, some folks might not be interested, That's the bottom line and that's okay. So, we certainly want to make sure we're never going to barge in and force ourselves on any one community. But I mean, just to give a little example about some progress we've already made the local Vietnamese community here in New Orleans East, this is about it's still technically in the greater New Orleans area, but it's an area we haven't really reached yet. We've been able to connect with the director of the Vietnamese community, a hub there, and she's really excited about us coming and doing some movement workshops and also engaging with some of the local health professionals and some of the local folks that she already knows that are affected by Parkinson's.

So, I think like just making sure that we're having conversations and exploring things in ways that, again, like Jaylen said, are building trust. So, I think that's really important is that it takes, I mean the challenges that it takes work, it takes, it takes sometimes getting rejected. We, we



may get rejected from some communities we reach out to who just might not be interested or maybe the particular person in that community we reach out to first may say no. But then I think going beyond that and going to find someone else in that community and trying again, like not giving up, I think that we've proven over the years that we don't give up. So, we'll, we'll continue trying as best we can to go into those communities and have those conversations and at a really grassroots level. So, I think, yeah, there's definitely challenges there, but we are ready to ready to work.

## Kayla Ferguson:

Awesome. Yeah, there's any of these big projects that are trying to change things at a pretty large level. There's always going to be challenges which, we face them too, so, of course. So now for my last question, why are projects like this so important in the work of building healthy Parkinson's communities and beyond that, you know, healthy communities in general?

#### Milette White Lin:

Well, I wanted to actually share, if it's okay as a response to this question, one of our testimonials from our participants who I was hoping could be on this call, but she wrote in a really beautiful testimonial a while ago, and I won't, you know, share the entire thing. But I mean, she and I had conversations about this project as we were kind of building it and dreaming it up and writing this grant and figuring out what our goals would be and, you know, what our, what our tasks would be, what our steps would be to make this happen and what we wanted to achieve. And she, you know, we talked about the Phinney Foundation and coming up even with the name. And she just, she basically flat-out told me that she would love to see in these classes more people that look like her.

She's African American and she comes to one of our classes weekly. She's very regular and she just, you know, she shares the word in her community, and she's been very, very supportive in helping us to connect with communities even in New Orleans and then outside of New Orleans that we haven't reached yet. And I think, you know, her testimonial about her experience with movement and dance for Parkinson's, in particular, is really powerful. She just stepped forward and she said, I will be one of your champions. I will be one of your program ambassadors. She participates weekly, sometimes twice weekly in our freed dance for Parkinson's classes. And you know, she shares with she shared with us a while back a really beautiful testimonial that dancing is power for the per person with Parkinson's. It promotes self-determination and living the best life that you can have. And she just really shares that it's a blessing to have agencies like the Davis Phinney Foundation who are interested in willing to help crucial programs like this continue and initiatives and projects like this actually happen and reach further into underserved communities. And you know, she even shares that she was diagnosed back in 2013, I think she's probably about in her seventies now.



And she feels like she's back to where she was before she was diagnosed, while she's participating in the class, that she's during the class intentionally healing. And it's a way for her to get her body to do what her brain is telling it to. And she feels joyful that it's purposeful movement and then it's holding back the advancing symptoms of Parkinson's and then it's joyful. That's, that's something I think we all need right now is a little joy in our lives and more connection to, more connection to folks around us and support that this disease does not define you and that you are much more than a diagnosis.

## Kayla Ferguson:

What an amazing testimonial. And I like how you had that. She said she would champion the program. Then you have the name of the program Championing Movement. I like how it all ties together. So yeah, That's perfect.

## Milette White Lin:

So yeah, she's wonderful. So, I hope she will, I hope, you know, if we ever have another opportunity, she went on the news with us a few months ago, so she's great speaking and she's fabulous.

## Kayla Ferguson:

Well, well I'm sure have another opportunity to talk with all about the program, how it's going, all that sort of stuff. So, we'll get her next time. Oh, so wonderful speaking. So, I guess, you know, those were all the questions that I had set up this, this interview, but I wanted to make sure if there's anything you all want to share about the program, about the association, anything that we might have missed touching on. It's kind of an open floor for you to share it with us now.

#### Milette White Lin:

Sure, yeah, I can, you know, Trevor, people who might be curious about, you know, what New Orleans Ballet Association is and what ballet might have to do with Parkinson's. Can I just share a little bit about our organization? We were founded back in 1969 and we were founded as a presenting organization, which we still present dance companies from around the world. Like Alvin Alley, American Dance Theater, and Joffrey Ballet Dance Theater of Harlem. So, we have an amazing season coming up even this year but back in 1992, in partnership with the city. So that was our big our first community partnership was with the city of New Orleans back in 1992. So over 30 years ago now. We started teaming up with them to provide completely tuition-free dance programming for children. Then post-Katrina had expanded to senior citizens based on an express need from the city for more programming for seniors.



And then, you know, fast forward now we're in our fifth year of our dance for Parkinson's program, which was launched thanks to lead sponsorship from the Oscar J Tolmas Charitable Trust and then expanded to our Metairie location through some amazing seed funding that we actually received from the Davis Phinney Foundation several years ago to help launch that. And then additional support from Parkinson's Foundation as well. So, it's just we're very much about community and providing resources for folks through movement, through that Art of healing movement for folks now as young as four, four years old through our early childhood programs that we offer all around the New Orleans community at recreation centers and neighborhoods, pockets of New Orleans all the way through our senior dance fitness and our dance for Parkinson's program.

## Jaelyn Robinson:

And I just want to, you know, give my praise too, because NOBA has been one of the most inclusive and adaptable, and flexible programs I've ever been with. It's like the way that they can tailor a class specifically for those that are attending it and want to attend it. It's incredible. And I think that's what makes them so unique dealing with this Parkinson's project, is their ability to understand what a community needs and give them that. And so that's my appreciation for the program and why I've been here for so long.

## Milette White Lin:

We're very excited to have Jaylen on board. And actually, you know, when we had applied for this project she was, I don't know, were you back in town yet, Jaelyn? I don't know, but it just, when this came up and we received the great news that we received, the funding, like Jaelyn had started to work with us a little bit and I was like, it has to be her if she will do it, but she's amazing. So, we're excited and we already have meetings next week with some communities who are excited about starting our first workshops next month.

## Kayla Ferguson:

I wanted to just give kudos to the inclusivity that you talked about, cuz you said from four to senior citizens you have programming. And I read somewhere a long time ago, you know, the eight to 80 role, if you have spaces and programs for people from age eight to age 80, you have really a very good foundation for a very inclusive community. And it sounds like you have all done exactly that and are really just getting started. So huge kudos to NOBA for all that you're doing.

Milette White Lin:

Well, thank you.