“One of the Best Things I’ve Done with my Life”

Duluth Teacher Dances with People with Parkinson’s

BY EMBER REICHGOTT JUNGE

Wanted in Minnesota: Dance professionals to teach people living with Parkinson’s Disease at least weekly and transform quality of life for hundreds of individuals. Training available. All styles of dance welcome.

Just over ten years ago Jessica Roeder, a modern dance and writing teacher from Duluth, saw a video email about Dance for PD through the Mark Morris Dance Group, one of her favorite dance companies. Tears streamed down her face; joyful tears. It was Christmas Eve. She signed up online that very night to volunteer if this was happening in Minnesota. Within a half hour of hitting “Send,” David Leventhal responded. “It’s not happening in Minnesota yet. Would you be interested in training to teach?”

Jessica obtained a grant through the Arrowhead Regional Arts Council and headed to Brooklyn, New York, to the Mark Morris Dance Center. “I was really nervous, but I felt so at home there. David is a very kind person; he is warm; he remembers people. I can’t say enough about him as a teacher. It’s amazing, because he is such a wonderful dancer, and he also has this gift for teaching.”

Somehow it was meant to be. At the end of the training, Jessica’s Dance for PD class was joined by people with Parkinson’s. David paired up people to massage each other’s hands. “So here is this man with Parkinson’s from Manhattan, I’m massaging his hands, and he tells me he is from Duluth, Minnesota!” recalled Jessica. She returned home to start a class. At a local wedding, she met Joan Setterlund, a woman with Parkinson’s who wanted to participate and help. Together, Joan and Jessica got the word out and found accessible space at the newly-built Unitarian Universalist Church in Duluth. There was no start-up funding, but it didn’t matter. “Just start the class, because you are going to love doing it,” a friend who started the class in Chicago told Jessica. “Just get it started and worry about the rest later.” The 75-minute classes started once a week. “I think that was great advice,” said Jessica.

Ten years later, Joan Setterlund still attends the weekly dance classes, now an hour long. Classes are currently 6-8 students, though numbers were in the high teens to low twenties pre-pandemic. “Usually when people dedicate to it, they stay and don’t miss a whole lot of classes,” said Jessica. But sadly they lose members due to progression of illness. Jessica, now 55, continues to volunteer her time. There is a suggested donation of $3 per person, or $5 for a family group to partially cover expenses. No one is turned away if they can’t pay.

“It’s one of my favorite hours of the week every week,” said Jessica. “There’s a lot of preparation that goes into it, but it is always worth it. No matter how many people attend, there’s a joy of connection and dancing. I love dancing whenever I do it, but this class is special. They are dancers. It’s one of the best things I’ve done in my life, one of the things that has meant the most to me. You can’t beat it, really. I will continue this as long as I’m around, and as long as people still keep coming.”

Jessica loves the community that forms with it. “Everyone supports each other so beautifully, and they celebrate each other, too. It’s something they often look forward to; it’s something that people as a couple or with their


People with Parkinson’s show their joy and movement as they dance in classes through the Dance for PD program. Photo by Amber Star Merkens.

children can do together every week that is not a doctor's appointment. This is different; this is just for fun." Remarkably, she found her dancers willing to explore all styles of dance and "jump into" improvisations.

Duluth is just one of 300 sites around the world of the international award-winning program Dance for PD. While Jessica teaches unpaid in Duluth, most programs are financially supported by organizations and institutions, as occurred for several years in the mid-2000s at Bethesda Hospital in St. Paul. Libby Lincoln of Minneapolis taught that weekly class.

Libby was an in-house lawyer in Minneapolis for almost thirty years. She also was a trained ballet and jazz dancer who taught jazz dance during law school and her first several years of law practice to maintain "her sanity." While attending a conference in San Francisco, her husband handed her a newspaper article about David Leventhal and Dance for PD. Libby's mother was living with Parkinson's, so Libby was familiar with her symptoms and movement issues.

"I called David, and he said 'we're doing a workshop in New York, come on out.'" She did. Bethesda had contacted David about starting a program, so the match was made.

"It was wonderful," recalled Libby. "We had everyone from young and recently diagnosed to people in wheelchairs. You just adapt what the movement is to fit what everybody is able to do. We did tap routines, we did Broadway complete with top hats, and we had a flamenco teacher come in." The class, supported by Bethesda as part of their Neurology and Parkinson's program, ranged from 2 to 20 people per week, and caregivers were often involved.

"I think one of the biggest things was the camaraderie," said Libby. "The sense of support, the laughter. Everyone was able to appreciate and laugh at the challenges we faced. We were not looking at this as therapy, we taught it as a dance class."

The program lasted for about two years at Bethesda, when they lost the person administering the program. Libby didn't have the bandwidth during her law practice to take on the program. "I just wanted to teach," she said. The program ended, and in 2020, Bethesda Hospital closed. But Libby is still involved as an advocate for her husband, who currently is living with Parkinson's, and as a member of the Patient Advisory Board at Struthers Parkinson's Center in Golden Valley. Struthers is also the center where Linda Muir, another dance teacher trained by David Leventhal, began conducting periodic Zoom classes for their clients during the pandemic (See the August issue of *Sheer Dance* for more about Linda's story).

Photo by Amber Star Merkens.

Opportunity: Bring Dance to Twin Citians living with Parkinson's

These three Minnesotans have helped lead the way. But so much more can be done. According to the Parkinson's Foundation, it is estimated that nearly one million people in the U.S. are living with Parkinson's Disease; this is expected to rise to 1.2 million by 2030. Minnesota is one of the highest incidence states per capita, with approximately 13,400 people living with Parkinson's. Yet, Duluth is the only location where a regular weekly class exists. There is no local nonprofit structure or institution that has yet hosted a regular dance program for people with Parkinson's in Minnesota. We can change that!

According to David Leventhal, there are two levels of teacher training. One is an introductory training process that "is really getting teachers on board. They learn the fundamentals of how to teach this class. Then we send them out. We say 'try this. Do a pilot in your community. We are here for you; we are here to support you.'"

When teachers are ready, they can return for a certification process. They must teach at least 50 hours to qualify for certification. That process is designed to measure the quality of their teaching, evaluate their class, and do a peer review of their class by video. Candidates take two online exams, and there is some reflective work. "Once they pass all of that, they are officially certified and we license their program," said David. At that point they are allowed to use the Dance for PD trademark and brands, and are featured on the website. Certification is lifelong, with professional development required every two years. The annual license can be renewed if the local program meets the license standards.

According to David, certified teachers are professional teachers of dance of any style and the license holders are often the institutions that employ them. Current licensees around the world range from sole proprietor studios, to dance companies, to presenting organizations like theatres, to medical clinics and hospitals. The licensed entity can call their program Dance for PD, as long as they have a certified teacher teaching.

Currently there are 26 certified teachers, with 30 more certified teachers in the pipeline around the world. There are also more than 700 active trained teachers around the world who are not certified. Jessica, Libby and Linda all fit the latter group of trained teachers. "It's like having a Bachelor's Degree vs. a Master's Degree," explained David. "Certification is like the next level. It's not like you don't have the skills to teach. A lot of teachers just don't have the time to go through certification and we don't pressure them. They don't need the brand. They just love what they are doing."

Finally, there is an Educational & Professional Enrichment course designed for people without a dance teaching background who want a comprehensive overview of Dance for PD approaches for their own enrichment. Participants might include therapists, caregivers, medical professionals, or people with Parkinson's. Others, including recreational dancers, may wish to assist in classes or become trained assistants in Dance for PD classes.

As a nonprofit founder and leader, I am personally inspired about the possibilities of creating a sustainable structure to support this amazing work in Minnesota. I hope others are as well. Similar possibilities exist for bringing the benefits of dance to people with dementia. Yes, our ballroom and broader dance community can give back in a meaningful way. And it may be "one of the best things [we've] done" with our lives, together.

Ember Reichgott Junge is an amateur competitive ballroom dancer and co-founder of the nonprofit Heart of Dance. She has served as legal and development coach for nonprofits around the country for over 30 years. She invites you to contact her at ember.reichgott@gmail.com if you are interested in bringing dance to people living with Parkinson's and dementia here in Minnesota. E

People with Parkinson's show their joy and movement as they dance in classes through the Dance for PD program. Photo by Amber Star Merkens.

"There are No Patients, There are Only Dancers"

BY EMBER REICHGOTT JUNGE

THE DANCERS ON THE STAGE OF the famous Mark Morris Dance Center in New York City form a large circle, holding hands, gliding back and forth to the classical music of Mozart, reminiscent of a Minuet. They "scallop" as they weave through the circle to hold hands with new partners, nearly all of them older adults. Reggie is among the group of about twenty dancers.

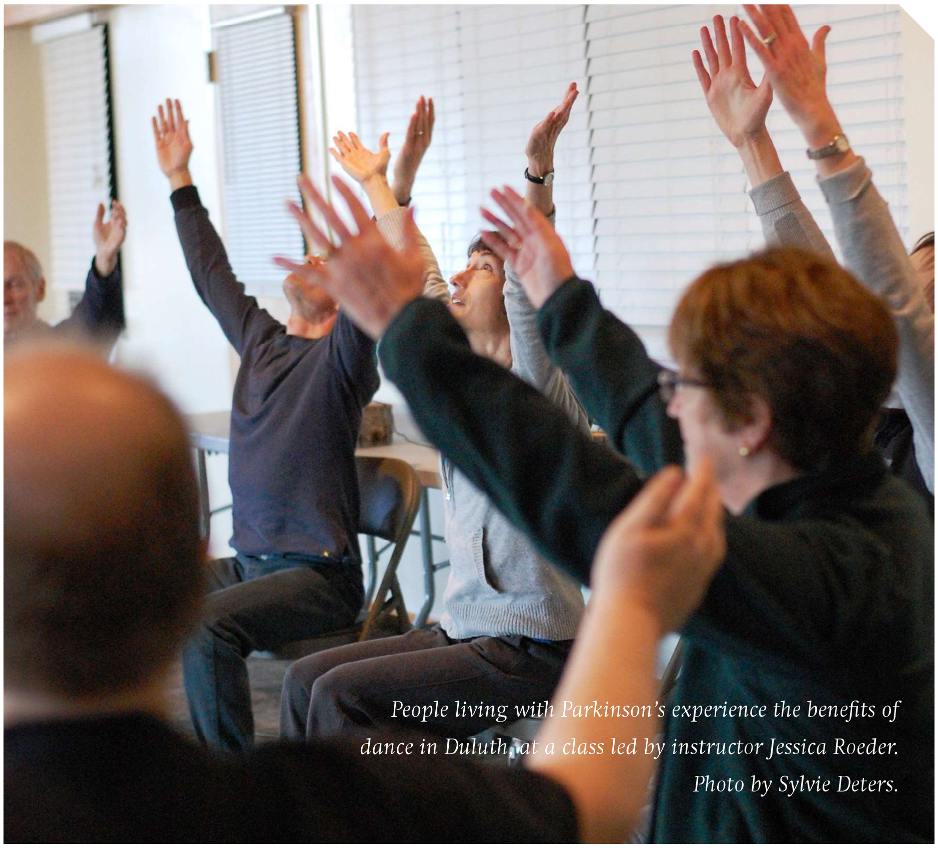
Later, all are seated, using their arms and legs to improvise small movements, then using their entire bodies to stretch in all directions, opening up their bodies and their hearts to the audience, the community, and the world.

Soon, Manny and Joy come out to an empty stage. Manny is seated stage left in a tux with an untied bow tie hanging around his neck. Joy comes from the right in a slimming, long red gown. As the waltz music begins, they slowly come together, as if making up after a fight. They elegantly dance together in a waltz frame then dance separately, seemingly conflicted as to whether or not they want to be together again.

Near the end, Cyndy does an exquisite solo performance, turning, twisting, bending, reaching to the sky, using every limb to its fullest extension.

The audience in this premiere dance theatre is mesmerized. They cheer wildly after each segment in the hour-long show. For good reason.

Nearly all the dancers on stage are living with Parkinson's Disease (PD). Some are newly-diagnosed, some have been diagnosed for twenty-plus years. All of them attended dance classes for a full year through Dance for PD, with teacher and founder David Leventhal, formerly a lead ballet dancer with the Mark Morris Dance Group.



People living with Parkinson's experience the benefits of dance in Duluth, at a class led by instructor Jessica Roeder. Photo by Sylvie Deters.

Says David, "It's not like the experience of dance is in any way a cure, but it transports them to a completely different level. In that state of flow and fluidity, Parkinson's is nowhere in the room. It's miles away." As Reggie says, "There are no patients, there are only dancers."

This is the story of a project that took place in 2011, as told in the award-winning documentary *Capturing Grace*, directed by David Iverson and filmed in collaboration with the Brooklyn Parkinson Group, the Mark Morris Dance Group, and Dance for PD.

In the film we meet Cyndy, the solo dancer diagnosed with Parkinson's 24 years prior. "Sometimes I can't walk, but I can dance," she says. At home, she shows a tremor in her hand; she shuffles as she walks in short, halting steps. She presents the characteristic Parkinson's movements of jerky, unpredictable movements in her torso and arms. Then she dances. The tremor is gone, her arms are outstretched, she sways them side to side, she lightly glides across the living room floor, almost sweeping and sliding her feet around the room. There is no jerkiness, just fluidity and elegance. Her joy is unmistakable. On performance day, Cyndy reads her personal note from David: "When you dance, you bring the whole world in and reveal your whole self. Enjoy today."

Joy tells us that "Dance works against the natural inclination that Parkinson's has to constrict and hunch over. Dance straightens you up and extends your arms." Said David to Joy in her note: "You take light and turn it into movement. The photosynthesis of sorts. You dance with clarity and honesty." And to Manny he writes: "You dance with your heart and soul. And share so much of yourself with all of us. Enjoy today, savor it."

The Mark Morris Dance Group first offered classes for people living with Parkinson's in 2001. Today, the award-winning Dance for PD initiative is global, offering research-backed dance classes for people with Parkinson's Disease and their families online, in New York City, and through a network of partners and affiliates in more than 300 communities across 26 countries. Classes are offered in English, Spanish, and Mandarin Chinese.

David says he often sees dramatic transformation in a dancer even in a one-hour class. "Dance seems to fit Parkinson's like a glove," he began. "Parkinson's is a disease of subtraction, so over time, things get taken away. Strengths or skills you used to have, particularly the 'automatic' ones, are more difficult to access. But the thing is, Parkinson's is more than just a movement disorder. It's a quality of life condition—it affects all aspects of an individual's life. So it's also about self-esteem, confidence, sense of connection to others, sense of self-identity, and self-efficacy, the feeling that you have power to do something. It also affects mood; more than 50% of people with Parkinson's are living with some degree of depression. It creates anxiety. All of these elements percolate through every component of somebody's life. What's remarkable is that dance has a way of addressing each of those things through this art form, but it does it almost unconsciously."

Dance for PD includes all styles of dance. "We are nondenominational in terms of dance. Each teacher teaches what they know. Whether you are a Salsa expert or traditional Chinese dance teacher, it is not the style that makes this program effective," explained David. "It's the fact that dance of whatever form shares a common DNA. It's like humans. Though we may look and sound a bit different, depending on our background, we share 99.9% of DNA. Dance is like that too. When you look at the fundamentals of any dance technique from the motor skill level, the imaginative level, from the music and storytelling levels, we share it all. The DNA is there. It is that DNA that is so powerful for people with Parkinson's."

So what is that DNA? "We see a couple things happen. First is fluidity

People with Parkinson's show their joy and movement as they dance in classes through the Dance for PD program. Photo by Eddie Marritz.

of movement. The sense of one movement leading into the next, like the way we speak, as opposed to stopping at every word. Parkinson's movement is absence of flow. So one of the first things I see as we start to piece movement phrases together, is that a sense of flow comes back into the body. People are thinking about how to create a movement sentence that has a flow to it," David said.

Along with that comes a focus on movement quality. "People with Parkinson's, and even the general public, are focused on the steps. Do I go right, do I go front or back, which leg is it? Our classes focus on the How. It doesn't matter whether you go left or right, but HOW you are stepping. Are you stepping through water? Are you escaping from something? Are you reaching to someone you love? What is the motivation behind your movement? When you do that, you start to engage the imagination, and you start to engage the emotions behind the movement. It's like an actor."

David uses imagination in service of a story. "That part of the brain is very much active and is able to generate or spark movement even though the mechanics of that movement may be cumbersome," he said. "And by doing that we see people accessing movement that they had trouble accessing before." In the music from a Broadway show like West Side Story, "we see the movements become strong, powerful, and rhythmic, and they are able to travel in that character because they are fully invested in the story they are trying to tell with their bodies."

Forty-five peer reviewed scientific studies on the website www.danceforparkinsons.org provide evidence that underpins the effectiveness and benefits of the Dance for PD teaching practice. Research shows that the Dance for PD model may relieve debilitating symptoms, aid short-term mobility, significantly improve stability, contribute to social inclusion, improve overall quality of life and self-efficacy, decrease rigidity, and improve facial expression. A longitudinal study published in 2021 showed that weekly participation in Dance for PD classes over three years significantly slowed the progression of motor symptoms in people with PD compared with a non-dance cohort.

Anecdotally, there are other benefits. The fun and interaction of dance provides exercise benefits much more fun than a treadmill, and people generally don't realize they are doing something therapeutic. It also changes how people think about living with Parkinson's. "The class is not at all about living with Parkinson's," explained David. "We don't talk about PD, we don't talk about how a specific movement will address a specific symptom. So in some ways it is an escape from Parkinson's, or a reconfiguration of one's identity. Dance gives people a sense of freedom and joy and confidence that fights against everything going on in their diagnosis."

David continued. "Dance is like a perfectly designed movement modality and activity for people with Parkinson's, and it is also an escape from 'patient-dom.' For that hour and a half, people are processing information differently, they're thinking differently about their bodies, and they're thinking differently about their relationships to themselves and to others."

And David's vision for the future? "The key word for us is access and inclusion. How do we make this program available to as many people as we can? And once available, how do we make sure they have a sense of belonging in that experience?" Currently Dance for PD is on multiple social media channels, video on demand, and DVDs, and they conduct in person and online classes in English, Spanish, and Mandarin. A major focus for David is making the classes culturally responsive to those in the room. For example, the music and movement should reflect the Hmong cultural traditions if working with the Hmong community. To that end, Dance for PD is offering training for teachers around the world. That training is about structure and approach, but the content is locally created.

David's goals go beyond cultural inclusion. He wants to see the program

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offered as standard intervention throughout the dance community, through dance studios and companies, and university dance programs. And he wants dance embedded in standard clinical care, making access as common as physical therapy.

To make all that happen, more formal research is necessary to influence medical professionals who are making choices about their patients' care. Funding is needed to better meet research standards of randomized control studies and larger cohort sizes of 300-600 persons. Said David, "I would love to see in the next five years a multi-center study on the impact of dance on PD, particularly as it relates to motor skill, quality of life, and reduction of fall risk. Falls are so detrimental to quality of life and morbidity and mortality numbers. Falls are the most acute cause of hospitalization among people with Parkinson's. If we could reduce those numbers considerably, we are improving quality of life for people with PD and we are reducing the burden on health care providers." And if studies show reduction of fall risk (as seen in some other populations) for people with Parkinson's, perhaps health care providers and insurance companies would honor dance programs like Dance for PD as an effective, low-cost way of significantly reducing the burden on the health care system.

The tools are here. The need is great. We need more of this in Minnesota! Some Minnesotans are already leading the way (see a feature of some of those Minnesotans in "One of the Best Things I've Done with my Life" in this month's issue of *Sheer Dance*). Do you want to help?

As David Leventhal told his dancers before going on stage in New York: "You know what to do. It's all there." And so it is. We can make it happen.

Ember Reichgott Junge is an amateur competitive ballroom dancer and cofounder of the nonprofit Heart of Dance. She invites story ideas for her book-in-progress, Life Stories of Resilience from the Ballroom Dancer's Heart.

Brooklyn Parkinson Group volunteer takes class at the Mark Morris Dance Center. Photos by Amber Star Merkens.