

On *Top* of *Their* Game

Parkinson's disease notoriously robs the body of its ability to move. Some patients can no longer walk, and many feel 'frozen' in their bodies. The five men and women portrayed in these pages slowed the excruciating creep of the disease in the most challenging way possible: They decided to move more — and with more determination — than ever before.

By SHERRY ANGEL
Photography by AUSTIN HARGRAVE

Tremors, slow movement, and rigidity are among the leading signs of Parkinson's disease. People usually do not start moving more fluidly — with grace, speed, and force — after receiving this diagnosis.

But that is what happened when five individuals decided to fight this progressive disease by doubling down on their passion for athletics.

"What these patients are doing is remarkable and inspiring," says their neurologist, Michele Tagliati, MD, director of the Cedars-Sinai Movement Disorders Program. "They used their diagnosis as an opportunity to take charge of their lives. They are champions."

Now, 200 years after James Parkinson first described the condition, studies are beginning to document the benefits of exercise that

Tagliati is seeing in the clinic. A growing body of research suggests that exercise may improve brain plasticity by repairing damaged circuitry that underlies motor and cognitive impairment in Parkinson's patients.

"We still have a lot to learn, but we see that vigorous exercise seems to alleviate symptoms and slow progression of the disease for a number of Parkinson's patients," says Tagliati, one of the nation's leading investigators and treatment specialists for Parkinson's and other movement disorders. "We're now treating this disease earlier and more aggressively with a variety of medications so patients can move as freely as possible."

Read on to see how five men and women are redefining what it means to live with Parkinson's by practicing and excelling at the sports they love.

THE SKIER: ADI ERBER

A Kid at Heart

Adi Erber was 4 years old when he put on his first pair of skis. Born and raised in the heart of Austria's Kitzbühel Alps, he discovered his life's passion early. Fast, flexible, and strong, his body seemed made for the sport he loved. He tested himself as a racer and ski jumper while developing an elegant skiing style that others wanted to emulate.

The rush of adrenaline Erber felt on the slopes eventually carried him across the globe to Sun Valley, Idaho, where he has been a ski coach for nearly 40 years. Skiing sometimes fills him with such joy that he startles those around him by yodeling.

"I have so much fun," he says, adding that he can't resist doing small jumps over ridges because "it feels good."

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But several years ago, he started noticing that his energy was sapped. Parkinson's disease was blunting his edge. While medication alleviated some symptoms, he wasn't bouncing back. "He wasn't the smiling guy I knew," his girlfriend, Di Anna Tonello, says.

Normally, Erber is easygoing — as comfortable having a bowl of soup with a movie star after a skiing lesson as he is hanging out with the guys at the coffee shop. With a playful glint in his blue eyes and a wicked sense of humor, he earned the nickname "Naughty Adi." "He's a 19-year-old trapped in a 75-year-old body," Tonello says. "He'll always be a kid at heart."

Seeking to regain his youthful spark, Erber visited Michele Tagliati, MD, at Cedars-Sinai to explore the possibility of undergoing deep brain stimulation surgery to improve his condition. During a battery of tests before the procedure, Arnold Schwarzenegger — a close friend whom Erber has long coached — was at his side, helping him stay positive. And when he underwent the surgery in 2015, Tagliati stayed with him as he awoke. "He squeezed my hand and I squeezed his," Erber recalls. "He told me everything had gone perfectly."

Erber still coaches several days a week during ski season and goes to the gym six days a week year-round. He often looks out the window with a sense of wonder that his "office" is a snow-covered mountain. "Not bad," he says.

THE RUNNER: BOBBIE POLEDOURIS

Her Race Against Time

Bobbie Poledouris is always eager for the next leg in life's marathon. At 70, she just needs a good pair of running shoes — preferably neon pink.

For the past decade, medication has enabled this youthful grandmother to stay nearly symptom-free from Parkinson's. Refusing to let the disease slow her down, she runs faster and farther than she did before her diagnosis.

Poledouris was 59 when she noticed the first signs of Parkinson's. She'd watched her father suffer from the disease, so her initial reaction was fear, but her vigorous nature prevailed. "I decided the disease was not going to become my identity," she says.

One day in 2013, while walking along the beach with her dog, Lucy, Poledouris felt an impulse to pick up her pace. She went with it, running a short distance with the terrier at her heels. Soon she was leaving Lucy at home so she could go farther — 1 mile, then 2, then 3. Now she does 3-mile runs several times a week and says she has never exercised with so much drive.

It's not easy. "There's always a point

in a run where I say to myself, 'You can stop. You don't have to do this,'" she says. "But then another voice says, 'Yes, you do.'"

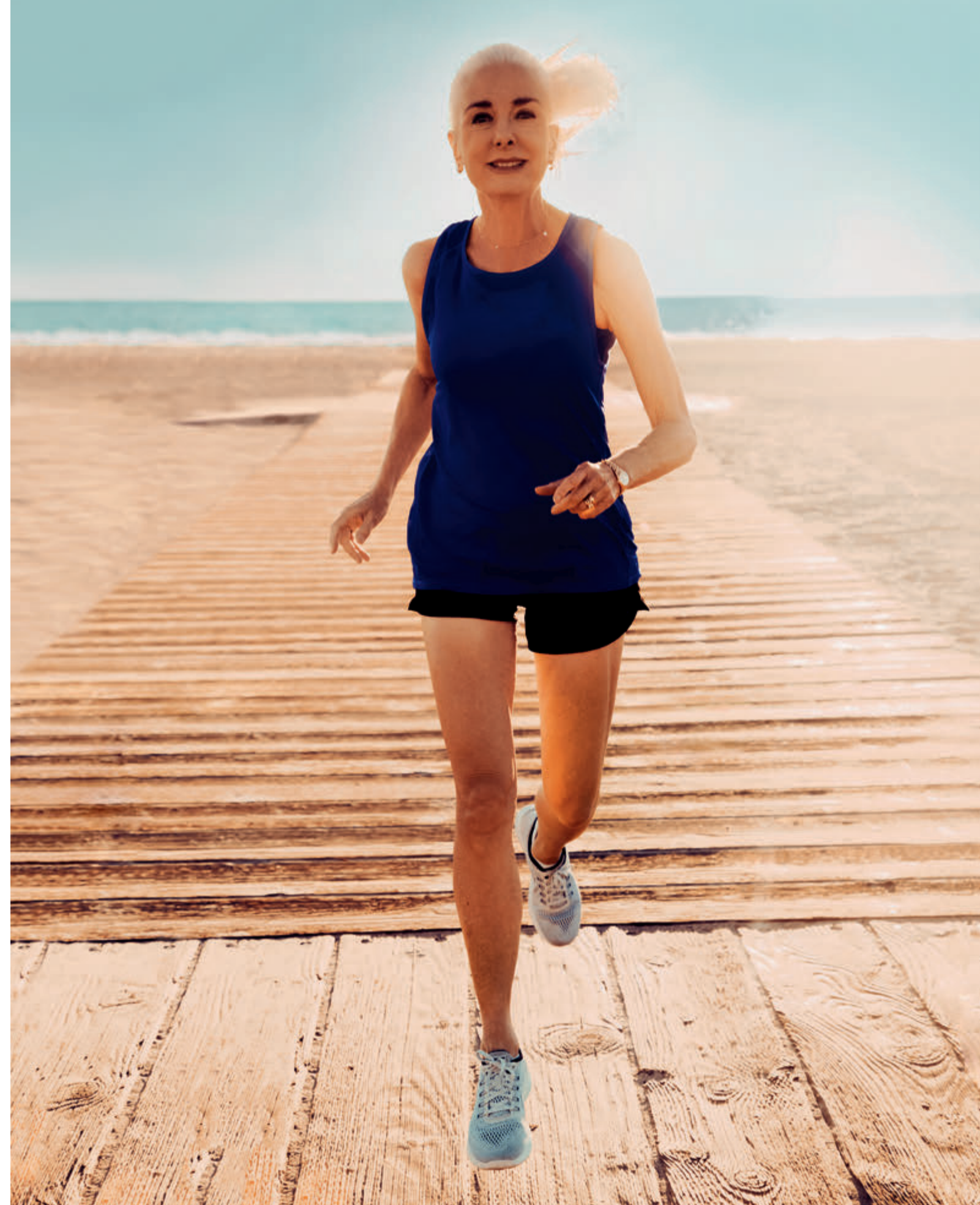
Running awakened her competitive spirit. Poledouris has participated in more than two-dozen 5K races and taken home many first-place trophies for her age group. After each race, she studies a printout of results, seeing that she not only is improving her time but also beating runners as young as 18 — despite her illness.

Her determination and high level of fitness impress her neurologist, Michele Tagliati, MD. An avid runner himself, Tagliati joined her in a Santa Monica/Venice 5K last December. "His support over the past few years has definitely helped me stick with running," Poledouris says.

So far, her very active retirement years are unfolding just as she hoped. "Parkinson's gave me a gift. It gave me running, and made me more determined," she says. "Maybe I can outrun this disease."

"Parkinson's gave me a gift. It gave me running, and made me more determined."

— *Bobbie Poledouris*



THE DANCER: LINDA BERGHOFF

Grace and Gratitude

Ballet. Jazz. Tap. Hip-hop. Linda Berghoff does it all — with grace and gratitude. She defies and resists her Parkinson's diagnosis with elegant arabesques or Bob Fosse-style routines.

Despite watching the progressive disease immobilize her mother, Berghoff believes it doesn't have to be the same for her. Instead, she channels the resilience she also inherited from her parents, who were Holocaust survivors. "They lost everything but were never bitter," Berghoff says. "They were grateful for simple things every day."

Her lifelong love affair with dance has kept this warm and willowy retired teacher on her toes — literally — since her diagnosis 11 years ago. At that time, she was having difficulty with balance and coordination. "I was terrified it would keep getting worse and I would not be able to dance," she says. Medication brought her symptoms under better control, enabling her to build strength, flexibility, and endurance by doing what makes her feel most alive.

Now she shares the benefits of dance with other Parkinson's patients. With

help from Laura Karlin, artistic director of Invertigo Dance Theatre, and Sofia Klass, an Invertigo dancer, she brought the Brooklyn-based Dance for PD program to Southern California about six years ago. People at all stages of the disease participate in the Invertigo Dance Theatre "Dancing Through Parkinson's" classes that Berghoff leads. Some with advanced symptoms sway, tap their feet,



"I've learned to be humble. Just finishing a dance class is a triumph."

— Linda Berghoff

and follow her elegant arm movements without leaving their seats.

"Everyone has rhythm and joy inside of them," Berghoff says. "After an hour of dancing, you walk out stronger because you're doing something to help yourself."

Parkinson's has taught Berghoff to accept certain limits — a valuable lesson for coping with aging as well as illness. She doesn't let herself get down about her footwork not being as fast or her kicks as high as they once were. "I'm learning to modify the way I move and to be humble," she says. "You can make a dance out of life by moving through challenges in a graceful way."



THE TENNIS PLAYER: BERNIE LESAGE

Boomer Is Back

Self-taught tennis player Bernie LeSage, who has made a comeback on the national tournament circuit despite Parkinson's disease, feels best about his game when he hits a "crisp shot down the line." But if he could

relive the day he played world champion Jimmy Connors, "I'd hit a few more put-away volleys," he says.

They were matched in the 1971 NCAA championship at the University of Notre Dame when Connors was still a relative unknown. LeSage, now 68, was

a senior at Notre Dame and the varsity team's captain and star. The thundering echo of his serve earned him the nickname "Boomer."

Connors was a UCLA freshman who would become one of the best tennis players in history. He won against LeSage, 6-1 and 6-2, and went on to take the NCAA singles title and lead UCLA to the national championship.

"I wasn't happy with my performance at the time, but now winning a few games against Connors seems okay," says LeSage, who has played competitive tennis off and on since college.

Returning to tournament play after his Parkinson's diagnosis seven years ago required patience. He was having difficulty with his toss when serving. Then he began to experience tremors, weakness, and trouble walking.

"I had to learn to play tennis all over again," he says.

"There were lots of misses," his wife, Joan, adds. "It was painful to watch."

Medication and rigorous daily training eased LeSage's symptoms and improved his game. He battles fatigue but doesn't give in to it — he hits tennis balls instead of napping. In 2016, Boomer was ranked 19th in Southern California and 85th nationally among players 65 and older. He remains competitive but has relaxed his attitude toward winning since retiring from a long career as a business litigator. On the tennis court, "There are people I used to beat easily who I can't beat anymore, but that doesn't stop me from making a fool of myself," he says. "Having a good match and hitting the ball where I want it are more important to me than winning."

He has good days and bad ones, just as he has good matches and bad ones. "I only remember the good ones," he says.



THE BOXER: VINCE HENDRICKSON

They Call Him ‘Bulldog’

Like Clark Kent removing his glasses, Vince Hendrickson just makes one small wardrobe change to summon hidden strength. Twice a week, he pulls on bright-red boxing gloves to push through Parkinson’s symptoms and complete demanding workouts at a Los Angeles boxing gym. He hammers the punching bag with such tenacity that his coach calls him “Bulldog.”

“Vince is ferocious. He works really hard,” says Lauren Von Bernuth, a coach in the Support and Training to Overcome Parkinson’s Disease (stoPD) program. Hendrickson, a 65-year-old retiree with a slight build but strong will, works out alongside others in fighting Parkinson’s with gloves on.

Hendrickson was diagnosed in 2002. He sought treatment at Cedars-Sinai

after he and his wife, Helene, moved to Los Angeles from New Jersey about four years ago to spend more time with their two grandchildren. He underwent deep brain stimulation surgery to treat his motor symptoms and takes medication, but he still struggles with gait and balance issues, low energy, and depression.

Before hitting the gym, the disease has a grip on him. His gait is unsteady, he leans forward, and almost stumbles. After he warms up, though, Hendrickson responds instantly to his coach’s commands and the shaky gait is gone.

“Move around the bag. Give me speed. Fast hands. Fast,” Von Bernuth urges.

Hendrickson is breathless when he stops for a break. He learned about the boxing program from his Cedars-Sinai neurologist, Michele Tagliati, MD, who

“Boxing trains me to think about how I’m moving.”

– *Vince Hendrickson*

had seen other patients benefit from intense exercise.

Hendrickson says the concentration required for boxing’s footwork helps him avoid falls in his daily life. “It trains me to think about how I’m moving,” he explains.

When he puts his gloves on, he’s in the zone, focuses on the bag, and pushes himself to punch harder. “I’m a power hitter, and the intensity of the training gets results,” he says. “It is helping me cope emotionally, too. I get my frustrations out on the bag.”

A DIABETES DRUG FOR PARKINSON’S?

Studying the brain has long been the chosen approach for understanding and treating Parkinson’s disease. But now investigators are looking beyond that gray matter to identify underlying causes and find new treatment targets.

Some investigators are studying a gut-brain pathway that may lead to neurodegeneration. Others

address the role of genetic defects. At Cedars-Sinai, experts are leading research into the idea that insulin resistance could be a major culprit implicated in Parkinson’s.

“There is growing evidence that the metabolic changes that occur in diabetes may impact brain degeneration associated with Parkinson’s,”

neurologist Michele Tagliati, MD, says.

Tagliati, director of the Cedars-Sinai Movement Disorders Program, is conducting a Phase II clinical trial to test a Type 2 diabetes drug as a potential treatment for Parkinson’s. The drug, liraglutide, has not previously been tested in Parkinson’s patients, though studies in England have shown

promising results with a different diabetes medication.

The trial involves 57 Parkinson’s patients and will run for two years. It focuses on how liraglutide, which regulates blood glucose levels, affects motor, non-motor, and cognitive symptoms. The trial is part of the Linked Clinical Trials initiative, which accelerates develop-

ment of new Parkinson’s treatments by identifying neuroprotective drugs that have been approved for other conditions.

“This is a revolutionary approach to treating Parkinson’s,” Tagliati says. “We want to find out whether liraglutide can relieve symptoms and also whether it can change the trajectory of the disease.”