



Leading With Compassionate Care: Stories And Updates

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NFL Coach Brings Experience To Bear On Parkinson's

“In fourth grade they had us write a letter to our mother detailing our goals for life,” shares Dave ‘Red Man’ Redding, retired NFL strength and conditioning coach. Redding listed three goals: playing football for his dad, earning a spot on the football team at the University of Nebraska, and becoming a Green Bay Packer. **“Those were my lifetime goals, and I reached them,”** he says.

In the process, Redding paved the way for strength and conditioning in the NFL. His accolades include Coach of the Year, USA Strength and Conditioning Coaches Hall of Fame member, and a Super Bowl XLV victory with the Green Bay Packers.

During these same decades of success, his body began to fail him. His athletes started to wonder about his hand tremor. “I would stop and stick my hand in my pocket, hide it,” Redding says. “Then I started falling down. That’s when I went to the doctor.” Redding was diagnosed with Parkinson’s disease; it was devastating.

He was finally coaching the team he had idolized since the fourth grade, yet “I was so depressed all the time,” he admits. **“I was in denial for five years. I knew I had it sooner.”** Redding expresses regret over that denial. He encourages anyone who may experience symptoms of a movement disorder to seek out a diagnosis, **knowing early treatment can make a huge difference in preserving quality of life.**

Redding retired with the Green Bay Packers in 2010, capping a career that began in 1982. Now, he keeps himself moving to manage his Parkinson’s. Redding owns two dozen acres surrounding a house tucked along the Platte River in Nebraska. “I started building my home in 1995,” he says. “This wood has got my blood on it. I like to get outside, do everyday chores.” He also goes for a half-hour walk most days. During rough Nebraska winters, he lifts dumbbells and enjoys boxing, “to get my hands active,” he says. He also prioritizes naps and adequate sleep, saying



Photo used with permission and courtesy of the Green Bay Packers

“with Parkinson’s, rest is very important to reboot.”

About four years ago, Redding began Deep Brain Stimulation therapy, or DBS, to help with tremor. The surgery connects wires inserted into the brain to a pacemaker on the chest, something that reminds him of the movie *Men in Black*. All joking aside, the procedure helped. **“I was shaking really badly before,” Redding shares. “After the [DBS] surgery, I’m not shaking anymore. I’m glad I had the operation.”**

Even with the success of DBS, living with Parkinson’s remains a daily battle. Redding struggles with how the disease affects his mobility and now his voice. “I would love to get back out in the yard and work,” he shares. “Use my woodshop. **I still have a lot to say — I just can’t get it out.**”

Exercise Kicked Up A Notch For Young-Onset Patient

When David Goni received a young-onset Parkinson's diagnosis two years ago, he decided to battle the disease — **boxing gloves raised.**

As a long-standing account manager for sporting goods company Riddell, David already liked to stay fit himself. But he took up a more rigorous form of exercise once diagnosed: boxing and kickboxing. **"I figured I need something harder to exert a little more energy,"** he shares. "Kickboxing involves using your feet and hands, and requires coordination." Repetitive movements, like those required for boxing, can benefit Parkinson's patients tremendously.

David wakes up at 5 a.m. each weekday to be at the boxing gym early, stretching and warming up. Then his class begins, "which involves eight rounds of kicking and punching a bag for an hour," he explains.

In addition to boxing, David also incorporates hiking, weight lifting, meditation, acupuncture, and intermittent fasting into his routines. Sleep and hydration make a daily difference in how he experiences the disease. **"I notice some days are better for me when I'm really hydrated. It helps a lot,"** David says.

It was while reaching for a glass of water that David first noticed a little shake, "almost a shiver," he describes. Then it was the way he gripped a pen so tightly. As shaking in his left arm became more noticeable, David remembers thinking, 'What is happening here?'

Knowing he was a baseball pitcher in college, a physician friend speculated that it could be a nerve problem. So did his general physician. After all, David was merely 38 years old at the time. No one expected Parkinson's.

In fact, it is common to mistake Parkinson's symptoms for a sports injury or other minor ailment in younger patients. **An estimated 10-20% of those with Parkinson's experience initial signs and symptoms before age 50.**

When a neurologist reviewed scans of his brain, diagnosis became clearer: David had young-onset Parkinson's disease. David knew nothing at all about it. "No family history of it," he shares. "Just kind of strange."

Fortunately, David connected with a well-known activist for Parkinson's care in the San Francisco Bay Area, where David was born and raised. He strongly encouraged David to pursue care at PICC.

"You don't need to be with your normal neurologist anymore," David recalls him saying. **"You need to get to the Parkinson's Institute and Clinical Center."**

Every four months, David meets with a compassionate PICC neurologist who is a movement disorders specialist. David finds her very knowledgeable and deeply invested in helping him get better. **"Dr. Andruska is really trying to help me out, see what's going on and what new studies are being done,"** he says. **"I appreciate that she sees me as a person, not just a patient."**

His support network also includes family and friends, "and two nephews who keep me busy," he says lightheartedly. "They're all great. I say, 'If you have any questions, just ask.' Otherwise I go about my life and my days."

“**Stay positive and stay active. Take care of yourself; that's the best thing you can do.**”

—David Goni, age 40, young-onset Parkinson's patient at PICC

David hopes to participate in a PICC clinical trial focused on genetic research, which may help him and his team of doctors learn more about the root of his disease and fast-track him toward new therapies. Doctors can often tailor treatment differently for young-onset patients, especially because of their brains' higher neuroplasticity.¹

In the meantime, David keeps to his early-bird boxing routine and focuses on what is going well. His message to other patients: **"Take care of your body and your mind. It gets frustrating but stay positive even when days are bad."**





Letter From Our CEO

Dear PICC family,

While Parkinson's and many other neurodegenerative diseases don't yet have a cure, a substantial body of research—including learnings from the Parkinson's Institute and Clinical Center—guide the way to slow disease progression. Regular exercise is near the top of the list.

In the last decade, PICC participated in a comprehensive study through the Parkinson's Foundation called The Parkinson's Outcomes Project. We learned that spending at least 2.5 hours a week staying physically active can slow decline in quality of life.²

Quality of life is at the center of what we do here at PICC. Our physicians insist on the best quality of life for each patient under their care, which is why they take the time needed to customize treatment plans—

including exercise regimens—and discuss clinical trial opportunities for each patient.

We continue to advocate exercise classes such as our LSVT® Graduate Class, PD Choir, as well as classes focused on flexibility, strength training, gait and balance, and more.

You play a role in helping each patient successfully manage their Parkinson's in a positive, relational environment. Thank you for the difference you make in their quality of life.

Sincerely,

Brian R. Coulter
Chief Executive Officer

PICC Partnership With CENTOGENE

New genetic testing is underway at the Parkinson's Institute and Clinical Center, part of a rare and exciting partnership with genetic diagnostic company CENTOGENE. A large, 68 gene customized panel has been carefully selected to identify important genetic variants for those affected by Parkinson's, atypical parkinsonian syndromes (such as Multiple Systems Atrophy and Dementia with Lewy Bodies), ataxia, dystonia, other movement disorders, and Alzheimer's. Patients at PICC are tested through a simple blood draw.

CENTOGENE, known as "The Rare Disease Company," is a worldwide leader, with outreach in over 100 countries. The CAP/CLIA-certified CENTOGENE labs characterize samples collected from each participating patient at PICC and return confidential genetic reports to the patient's physician.

Many commercially available tests only look for changes in a few genes. The proprietary Parkinson's Institute CENTOGENE panel tests for 68 genes that are known to cause Parkinson's, Alzheimer's, DLB, MSA, dystonia, ataxia, and related disorders. This large panel is far more

useful for the patient, their families, and the doctor.

This partnership with CENTOGENE provides another example of how the Parkinson's Institute and Clinical Center conceives and pursues innovative opportunities to improve the lives of our patients. The test reports offer physicians at PICC the ability to make better-informed decisions about the treatment of each unique patient. It also empowers each patient to know their genetic make-up, relevant information helpful for family planning, and or genetically based treatments or cures!

The Parkinson's Institute and Clinical Center considers this test something valuable to offer patients, and that's why our leaders actively negotiated its pricing. We are pleased to share that PICC secured an over 80% reduction in cost. We look forward to seeing how patients will benefit from this opportunity!



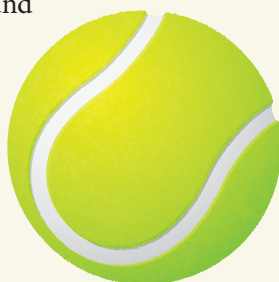


Handball And Tennis Preserve Patient's Health

Several times a week, 76-year-old Karen Lloyd meets up with ladies ages 45 to 80 to play tennis. Many of these women suffer from major health issues, including Karen, who was diagnosed with Parkinson's 11 years ago. For all of them, tennis improves their quality of life.

A Denmark native, Karen grew up playing team handball (think: basketball court with small soccer nets for goals, using only your hands to score) and became a member of the Danish all-star handball team in 1960. During her handball career, she traveled throughout Europe, where handball ranks second only to soccer in popularity.

Karen is a patient at the Parkinson's Institute and Clinical Center. According to her general physician, she still has the bone density of a 20-year-old woman! She feels fortunate that Parkinson's progressed more slowly for her, crediting much of it to staying physically active before — and after — her diagnosis.



People facing Parkinson's and other neurodegenerative diseases deserve personalized, holistic care from top experts in the field. Caregivers and family members need resources and support. This and more is offered at the Parkinson's Institute and Clinical Center.

Since its founding over 30 years ago, PICC has:

- Helped thousands of Parkinson's patients better manage symptoms of the disease.
- Conducted more than 135 clinical trials, medically evaluating more than 95 different drugs and therapies for Parkinson's.
- Been involved with testing nearly every drug on the market today addressing Parkinson's disease.
- Published hundreds of articles about Parkinson's care, treatment, and research.
- Hosted three renowned research laboratories led by expert scientists using state-of-the-art equipment and tools.

Please consider making a gift online at parkinsonsinstitute.org or by telephone at (650) 770-0201.

Thank you!

Parkinson's Institute and Clinical Center is a 501(c)(3) non-profit organization. Financial donations are tax-deductible in accordance with United States IRS rules and regulations.

Debunking Parkinson's Myths (Part Two)

We continue our series addressing common myths around Parkinson's and other movement disorders with PICC Medical Director Dr. Kristin Andruska.

Myth #1: Only rigorous and specific exercises help with Parkinson's

"We encourage patients to engage with any and all forms of physical activity — because it all helps!" Dr. Andruska says. "Exercise slows down motor symptom progression and can also improve non-motor functions such as mood, cognition, and stamina."

In order to gain the most functional balance and mobility, commit to an exercise regimen for six months or longer, at whatever exercise intensity. To stay consistent, pick something fun like hiking, cycling, tennis, boxing/kickboxing, dancing, yoga, walking, or resistance training.

Myth #2: If someone with Parkinson's looks fine, they must have a good quality of life

Symptoms of movement disorders fluctuate in intensity and duration. Some days can feel more normal to a patient; other days are frustrating and difficult. "Early diagnosis is critical; in the early stages of the disease, we have more treatment options," says Dr. Andruska. "We also encourage our patients to take note of how long it takes for their medication to wear off, what activities seem to help their symptoms, and even whether or not they're having a 'good' day when they come for an appointment."

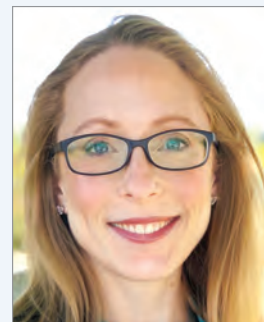
Being under the care of a movement disorders specialist, like those at PICC, can make all the difference for someone with Parkinson's or another neurodegenerative disease.

Myth #3: My condition isn't bad enough to necessitate Deep Brain Stimulation (DBS)

DBS is not a surgery done as a "last resort" for those with advanced Parkinson's. It is best for people with good general health and with good thinking and memory. "DBS can be a helpful and highly personalized therapy for those who would like more consistent symptom relief than with medication alone, or who experience side effects," says Dr. Andruska.

In the past few years alone, several studies have been published specifically illuminating the advantages of undergoing DBS in the earlier stages of Parkinson's, finding patients showed improved motor outcome, more frequent "on" time (when their medication worked well), and better quality of life.⁴ PICC collaborates with excellent neurosurgeons to perform DBS surgery.

Check back in future newsletters as we debunk additional myths related to Parkinson's, and please consider donating to PICC today using the enclosed reply envelope or at www.parkinsonsinstitute.org



Dr. Kristin Andruska
MD, PhD

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Powerful Ways To Support PICC

Both the level of exceptional care our patients receive daily, as well as the innovative, cutting-edge research we perform, are unique to the Parkinson's Institute and Clinical Center and only made possible through your support. We want you to know about the variety of ways you can give to PICC.

- Write a check or use your credit card today
- Give a gift from your Donor Advised Fund or family foundation
- Give a gift of stock or other appreciated assets
- Have your gift matched by your employer
- Include us in your will or estate plans

1. "Young Onset Parkinson's," <https://www.parkinson.org/Understanding-Parkinsons/What-is-Parkinsons/>

2. Young-Onset-Parkinsons "Parkinson's Outcomes Project," <https://www.parkinson.org/research/Parkinsons-Outcomes-Project>

3. "Neuroprotective Benefits of Exercise," <https://www.parkinson.org/Understanding-Parkinsons/Treatment/Exercise/Neuroprotective-Benefits-of-Exercise>

4. "Spotlight on Parkinson's Disease: The ABC's of DBS," American Parkinson's Disease Association, <http://www.aaic.net/APDA/APDA18123arc/>