

MORE THAN MOTION™

PARKINSON'S DISEASE. SHARE, LEARN, ACT.

2017, ISSUE 2

PD Warrior

Jimmy Choi

The clinical-trials enthusiast went from physical therapy to marathon racing. What are you waiting for?

Kids and PD

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Get active and build a community
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{ **ALSO** }

**WOMEN'S
ISSUES**

**PUBLIC
POLICY**

**SMALL
SUCCESSES**

 **TEAMFOX**
FOR PARKINSON'S RESEARCH

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Focus on Fitness

Physical fitness is an important part of the management of symptoms of Parkinson's disease (PD). Tremors, muscle stiffness and a change in your gait may make you feel like you don't know the body you live in anymore.

The good news is staying physically fit—or getting fit, as the case may be—may not only help you feel stronger and more limber but may also help your brain understand your body in space. Exercise also helps reduce stress levels that come with managing a chronic disease. It may even impact you psy-

chologically in ways you didn't expect, like it did with Jimmy Choi, featured on the cover. He started running after his diagnosis. Now he inspires people with PD—and beyond.

Kimberly Rogers, also featured in the magazine, says that her diagnosis inspired her to take charge of her life: She started her own online group and found a passion for fitness coaching.

In this issue, you'll find PD news, tips for being with kids, motivating stories, and more. Whether or not you're an athlete, we're on your team.

MORE THAN MOTION

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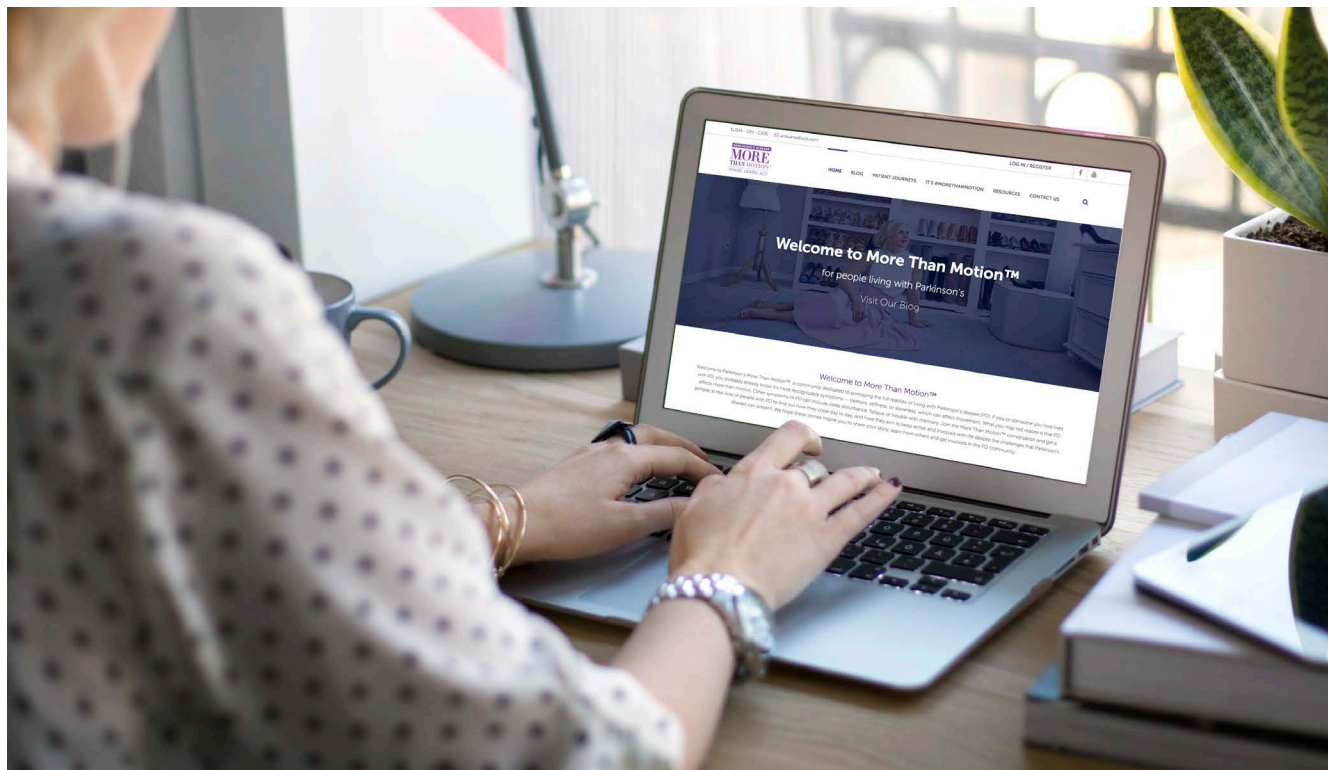


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New! Visit Us Online

THE NEW *MORE THAN MOTION*™ WEBSITE FEATURES NEWS AND INSPIRING STORIES FROM EARLIER ISSUES OF THE MAGAZINE.

If you like what you see in *More than Motion* magazine, you'll be happy to know that you can now find articles from the publication online. The redesigned *More than Motion* website includes recent cover stories on subjects such as blogger **Tonya Walker**, novelist **Martin Cruz Smith** and former NBA star **Brian Grant**, all of whom

are inspiring others with their stories of strength and advocacy. In the Blog section, you'll find recent news as well as interviews with movement disorder specialists to help you understand how these specially trained neurologists may aid your treatment. In Resources, you'll find fun puzzles to help keep your brain sharp and previously published

issues of the magazine in their entirety.

And since *More than Motion* is a community dedicated to portraying the full realities of living with PD, you can also participate in awareness initiatives, such as sharing your story on social media and tagging it #MoreThanMotion.

Go online to get all the details, and while you're there, check out everything the new website has to offer. After all, you can help take control of your journey by learning as much as you can about Parkinson's. **parkinsonsmorethanmotion.com**

DID YOU KNOW women are less likely to visit a specialist?

Did you know that women may react differently to medication than men? Genders respond differently to Parkinson's research and care, and in the country's first effort to address these disparities, the Parkinson's Foundation has received a \$250,000 grant to support its initiative, "Women and PD Teams to Advance Learning and Knowledge (TALK)." Over the course of two years, the project will task leadership teams of experts with creating recommendations to help advance healthcare for women, and those teams will be made up of experts from the patient, research and healthcare communities. For more information, visit **pdf.org/womenpd_talk**.

PD and Public Policy

READ ON TO LEARN HOW THE MICHAEL J. FOX FOUNDATION AND THE FORMER PARKINSON'S ACTION NETWORK HAVE JOINED FORCES.



In June 2016, two big groups formed one cohesive organization focused on public policy as it impacts the Parkinson's community. The Michael J. Fox Foundation for Parkinson's Research (MJFF) absorbed the Parkinson's Action Network (PAN), which formerly had served as the voice of the PD community on government regulations and legislation. The result—a unified effort that covers the full spectrum of causes, from research development to drug approvals—magnifies the push of advocates to effect change.

MJFF works across the aisle, with both political parties, says Ted

“Every person has a voice. And it is the job of the elected official to listen.”

Thompson, senior vice president of public policy: “Your strongest opposition on one issue may become your greatest champion on another one.”

Through this process, the MJFF policy team celebrated a victory in December, when the 21st Century Cures Act was signed into law. One provision, which would create a national data collection system for brain diseases, took nearly a decade to enact.

HOW CAN YOU BE PART OF THE CHANGE?

By connecting with lawmakers, you could help to increase federal funding for research and affordable access to healthcare.

Visit the MJFF website to learn how to contact your elected officials (see box below). Tell them what you think about topics such as healthcare changes and biomedical research.

Though engaging with elected officials may feel intimidating, advocating for public policy issues “is not magic,” says Thompson. “Every person has a voice. And it is the job of the elected official to listen.”



Share Your Story with Policymakers

The Michael J. Fox Foundation for Parkinson's Research (MJFF) offers helpful tools to get you started.

- Through easy online forms, compose your own message to elected officials or contact lawmakers on various issues, get handouts for in-person meetings and much more: advocate.michaeljfox.org.
- Connect with policy and advocacy volunteers across the country: michaeljfox.org/policy.
- Keep up with research updates and public policy news on the Foxfeed blog: michaeljfox.org/policyblog.
- Sign up for action alerts or notifications to contact your lawmakers when important issues affecting the PD community arise: michaeljfox.org/act.

PEER-TO-PEER

Q+A

WITH **KAREN JAFFE, M.D.**, RETIRED OB/GYN AND COFOUNDER OF THE WELLNESS CENTER INMOTION, DIAGNOSED WITH PARKINSON'S IN 2008.



Q | How do you stay motivated to work out regularly?



A | Having worked with a personal trainer since before my diagnosis, I can see that I am staying ahead of the game. Taking community classes is a great motivator, and I keep my routine fresh by changing it up. With PD-focused programming, I've seen people gain enough strength to put down their canes and walkers! I've felt and seen the powerful impact that exercise brings to the management of PD.

FIND A PD-FOCUSED PROGRAM NEAR YOU: beinmotion.org, danceforparkinsons.org, rocksteadyboxing.org.

ACTION STEPS by Karen Jaffe, M.D.



You are never too old, and it's never too late!



Find something that will engage you and keep you coming back.



Learn how to work out so you feel safe.



Take a team approach: Enlist friends and care partners.

Good to Know...

50,000

estimated number of Americans diagnosed with Parkinson's each year.

90%

of Parkinson's patients report an impaired sense of smell, and it's one of the earliest symptoms of the disease. A paper published in *Lancet Neurology* proposes that neurotransmitter dysfunction is a possible cause of smell loss in some neurodegenerative diseases, including PD.

15-25%

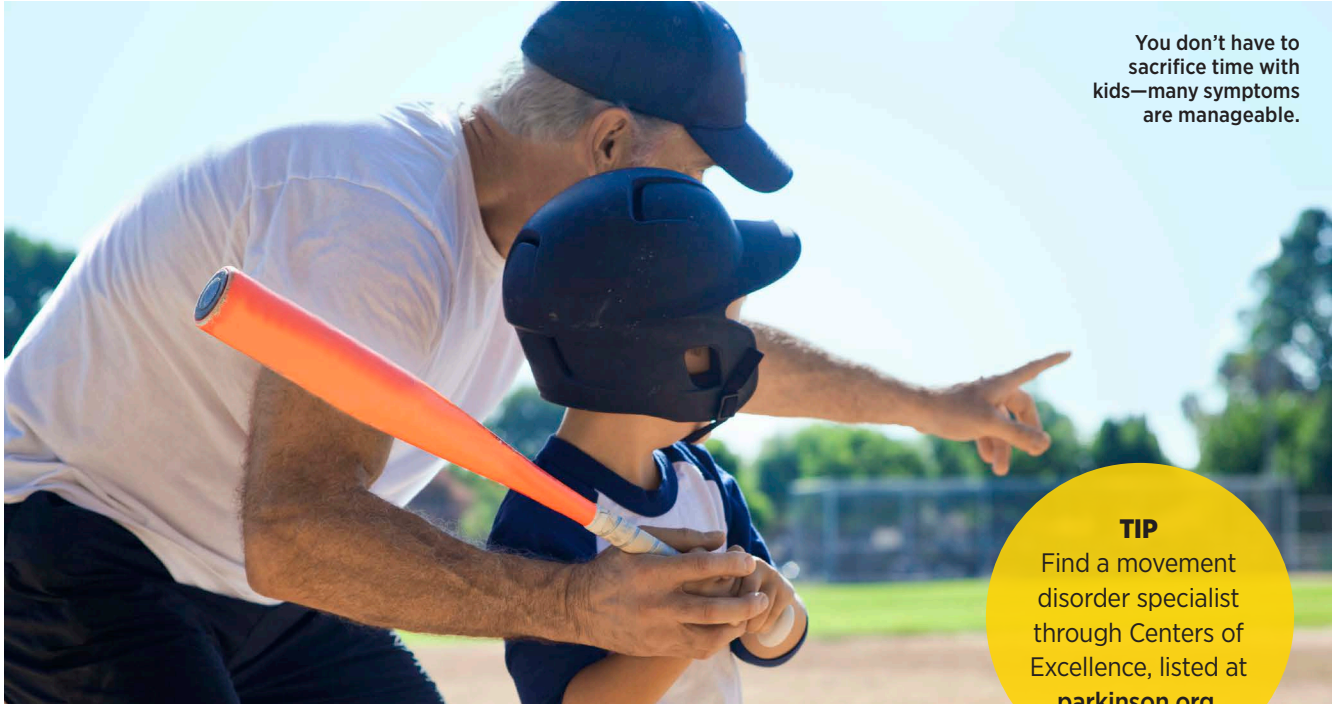
of people with PD have a known relative with the disease.

500+

clinical trials for Parkinson's are open at clinicaltrials.gov.

50%

more men than women are affected by PD.



You don't have to sacrifice time with kids—many symptoms are manageable.

TIP

Find a movement disorder specialist through Centers of Excellence, listed at parkinson.org.

Parenting and Grandparenting with PD

HOW TO BE OPEN AND REASSURING WITH THE LITTLE ONES YOU LOVE.

Spending time with children and grandchildren is a way of life for many people with Parkinson's, but kids may not understand how symptoms of PD can affect the ones they love. We talked to movement disorder specialist Ritesh A. Ramdhani, M.D., at the Icahn School of Medicine at Mount Sinai in New York City, about the challenges that Parkinson's can present when it comes to spending time with kids, how to explain the condition to them, and more.

Q | How can Parkinson's affect my ability to spend time with my children or grandchildren?

A | It depends on the type of symptoms. Gait issues such as shuffling or freezing episodes increase the risk of falls and may make it difficult to negotiate small spaces or walk long distances—limiting the time spent outdoors. Significant

tremor may interfere with the ability to do routine tasks, and the social anxiety it may produce could negatively affect a patient's interaction with loved ones.

Q | What's the best way to talk about Parkinson's with children?

A | Keep it simple for younger children: It may be helpful to explain that the symptoms are related to a low level of a chemical in the brain that helps control movement, and that there are medicines to help substitute and replace that chemical, making it easier to move. It's important to reassure kids that Parkinson's is not a death sentence, everything is going to be OK, and many symptoms are manageable and treatable. Older children might want to know more about the nature of the disease progression in order to help their parents or grandparents with some of the lifestyle

changes that are needed to reduce the rate of symptom progression.

Q | What can teenagers or even younger children do to help?

A | To manage motor and non-motor symptoms well, there are some key lifestyle changes that patients can do in addition to taking medication: Get 7-8 hours of sleep each night; engage in a cardiovascular-based exercise regimen several times a week; eat a healthy diet filled with leafy green vegetables, fruit and water (this will help with digestive health); and reduce stress levels as it can worsen underlying Parkinson's symptoms. I think children and grandchildren can help with many of these changes and help reinforce them. It's important that there's support from everyone in the family, as it enables a patient to feel they're not carrying this burden alone.

COVER STORY

Inspiration in Motion

More than 14 years after his diagnosis, Jimmy Choi is proof that taking action is the best defense against Parkinson's.

Swinging from a rope high above a pool of water, Jimmy Choi, age 41, prays that his grip will hold. His biceps tremble as he digs deep for strength. But the obstacles he faces on this popular fitness-competition TV show are nothing compared with the big hurdle that life presented him 14 years ago: Parkinson's disease (PD).

WRITTEN BY
**BRIGID ELSKEN
GALLOWAY**

PHOTOGRAPHS BY
KEVIN J. MIYAZAKI





Choi adds resistance in the form of his 10-year-old daughter, Karina.

Choi first attributed his minor twitches, stiffness and balance issues to muscle overuse on the golf course. He was only 27 years old when a routine insurance physical led to a diagnosis of early-onset PD. In those first months he kept the news to himself, not even telling his wife, Cherryl. “We had just gotten married, and our careers were just starting,” Choi says. “I thought if I just took the medication everything would be fine.”

Unexpected Discoveries

Eight years later, things weren’t fine. His PD progressed until he couldn’t walk without a cane. Inactivity caused substantial weight gain, which further compromised his mobility and balance. After a fall down the stairs with his infant son, he finally accepted that he needed to take a more active role in his health.

Choi threw himself into research, determined to find a cure. He was

“It’s important to stay positive and keep moving. You never know who you’re going to inspire.”

amazed by the number of clinical trials being conducted and saw an opportunity to contribute. “I felt that the best way to fight back was to give my body to science,” he says. “I signed up for as many clinical trials as I qualified for.”

One of the trials required physical therapy. After the workouts, Choi noticed that his body responded better to his Parkinson’s medication. He also

trimmed down and built muscle. In 2012, he decided to run his first 5K. He was hooked.

“I felt great after running,” he says. “I had more control of my off periods. In September, when I crossed the finish line at my first half-marathon, I decided to run my first marathon.”

But there was one slight problem: The Chicago Marathon was less than a month away. “I thought he was crazy,” Cherryl says. “But I encouraged him, because when he started running, his outlook and the way he lived day to day changed. He had a positive mindset.”

Choi joined Team Fox, the fundraising initiative at the Michael J. Fox Foundation, to help him register for the already-closed Chicago Marathon. This resulted in two positive outcomes: He became more public about his PD, and the team provided a much-needed support network. “Team Fox has become

a second family for us,” Cherryl says. “They just know how to help.”

Cycle of Inspiration

Over the past five years, Jimmy Choi has run 13 marathons (including several Chicago and New York City Marathons); 90 half marathons; countless 5Ks, 10Ks and Gran Fondos (over-100-mile bike competitions); and an ultra-marathon. All told, he’s raised more than \$100,000 for Parkinson’s research.

Choi’s dedication to exercise and advocacy inspires people with and without PD. (See sidebar below.) But his 10-year-old daughter, Karina, who is an obstacle-course champion at the local gym, inspired his latest accomplishment. At her insistence, he applied to be a contestant on a popular network television competition and was selected.

With only six weeks before the air-date, Choi’s rigorous workouts became even more intense. A combination of cross training, distance running and cycling, and obstacle-course training helped him prepare. Karina did too. “She became my barbell,” Choi says with a grin. “I did overhead lifts, pull-ups and push-ups with her on my back.”

When Jimmy Choi appeared on the show in July, the entire family was there, cheering him on. At home,



Above: Choi with his wife, Cherryl. Right: The Choi family hosted a lemonade stand in support of Team Fox.

millions of viewers, including his Team Fox family, watched on the edge of their seats as Choi competed. Although he didn’t win, his victory was far greater: He changed perceptions for millions of viewers about what it means to have PD. “It’s important to stay positive and keep moving,” he says. “You never know who you’re going to inspire.”



New Kicks for The Shoe Maven

In November, Parkinson’s advocate and “The Shoe Maven” blogger Tonya Walker will (temporarily) exchange her stilettos for sneakers. Thanks to inspiration from Jimmy Choi, she and husband Chad are running with Team Fox in the New York City Marathon.

Walker, who was diagnosed with PD at age 34, met Choi at a marathon in 2016.

“Jimmy has inspired so many people to run and become physically active,” she says. “We have a saying, ‘Jimmy made me do it.’”

The always-fashionable Walker concedes to wearing comfortable shoes while training for the 26-mile event, but rest assured she’ll arrive in style when she crosses the finish line in Central Park. She’s been known to finish in a glittering orange tutu.

Read more about Tonya Walker online at theshoemaven.com.

Guide to the Good Life

With humor and heart, Angela and Karl Robb have learned to work happily and live well.

Call up Karl and Angela Robb, and you're bound to hear laughter.

"If that bowl were any bigger, she'd still be drinking," Karl says about Lily, the couple's nine-year-old chocolate Lab, feverishly lapping water in the background. "She teaches me about forgiveness," he adds. "No matter what, I am part of her pack."

The Robbs, married now for more than 20 years and longtime residents of Northern Virginia, have comedic timing fit for a sitcom. But they're content to crack each other up while discussing their new book, *Dealing and*

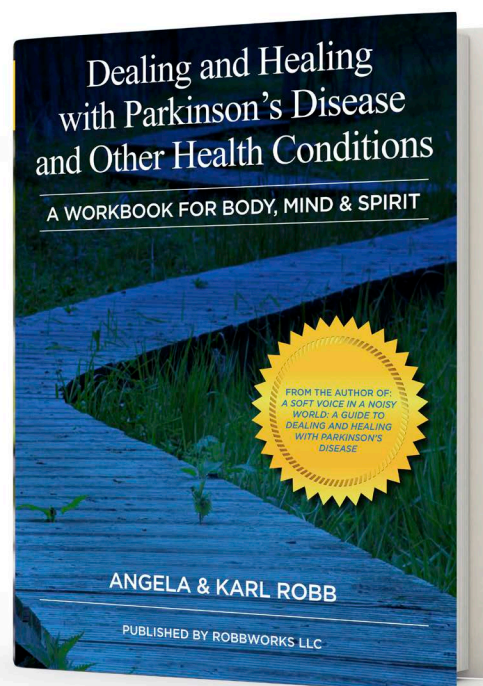
Healing with Parkinson's Disease and Other Health Conditions: A Workbook for Body, Mind & Spirit. In addition to hard-won tips for living well with a chronic illness, the book sets forth a number of thoughtful questions and writing exercises designed to get people thinking. For example, one passage asks readers to reflect on their attitudes. Questions include "Are you an optimist?" and "What do you do to remain upbeat and positive?" And it reminds us, "Positive is a choice."

The Robbs, who coauthored this new workbook, take a holistic approach to wellness. Both practice and teach Reiki, a complementary therapy that focuses on physical and emotional health, in addition to their advocacy work in the Parkinson's community.

Diagnosed with early-onset Parkinson's at age 23, Karl later met Angela in an online chatroom in the mid '90s. "Her name reminded me of sunny days," he says.

"My grammar was a lot worse then," quips Angela. When she learned that Karl had PD, she wasn't deterred. "I fell in love with the man," she says, "not the disease." As for writing together, the process runs smoothly. "I defer to the English major," Angela says. "When it's tense, I say, 'Time to take Lily for a walk!'"

Karl first took to writing about PD in his blog, asoftvoice.com, with the notion that he might help one



"The book sets forth a number of thoughtful questions and writing exercises to get people thinking."

person. Encouraged by Angela, he compiled his notes from living with PD for three decades and in 2012 published *A Soft Voice in a Noisy World: A Guide to Dealing and Healing with Parkinson's Disease*, which went on to become a bestseller.

Inspired by an outpouring of support from patients and caregivers, the Robbs created the corresponding workbook as a kind of homework for others. Everyone has a unique journey, says Karl. "We don't have the answers, but we do know the questions," and that might help you find your way.

Try some workbook exercises on the facing page. To order Angela and Karl Robbs' book, visit pdpatient.wordpress.com.



Angela and Karl Robb, with their dog, Lily, take a holistic approach to health.

BOOK EXCERPT

Positive Daily Living

Use these exercises to talk about your attitude. You might discover something new about yourself!

Positive is a choice.

"Finish each day and be done with it. You have done what you could. Some blunders and absurdities no doubt crept in; forget them as soon as you can. Tomorrow is a new day; begin it well and serenely and with too high a spirit to be cumbered with your old nonsense." —Ralph Waldo Emerson

• How does this quote help you live each day "in the moment"? _____

• Are you an optimist? _____

• Do you find helping others, helps you? _____

• Did any of your teachers/mentors leave a mark or impact on you that has stuck with you? _____

• What do you do to remain upbeat and positive? _____

Are You an Optimist?

• Do you see obstacles as goals and lesson builders? _____

• Do you see the glass as half full or half empty? _____

• Do you worry about things that haven't happened? _____

• Do you focus on the good or the less good? _____

• Are you an optimist? Could you be an optimist? _____

Turning Obstacles Into Opportunities

After her PD diagnosis, one busy mother used fitness coaching to help inspire others.



Always check with your doctor first before you begin any fitness program.

When Kimberly Rogers was diagnosed with early-onset Parkinson's disease in 2016 at age 34, her neurologist warned her that she would need three things to survive: a positive outlook, a healthy lifestyle and a support system. Rogers, who has no formal personal training certification, had always had a love for fitness. But the support system and the positive outlook were a little harder for her to come by.

"I was a 'negative Nancy,'" Rogers says with a laugh. "I saw the glass half empty. But coaching changed that."

Since her son's birth in 2013, Rogers scaled back her fitness regimen. Instead, she started to work out and coach from home as a trainer with a fitness company that helps clients reach their health goals, primarily through social media. When Rogers got her diagnosis, following a year of numbness, tremors and muscle spasms, she continued to coach and encourage her clients through Facebook—but kept the news of her diagnosis under wraps.

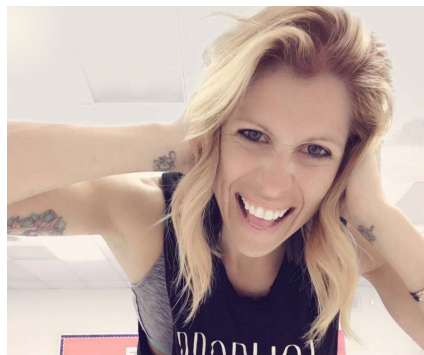
"I was shocked, and I kind of went into a hole," Rogers says. "It's not something you expect to hear at 34." Of the 50,000 people diagnosed with Parkinson's disease each year, only 5 to 10 percent are diagnosed before the age of 50.

Rogers could find few support groups with women her age. Even fewer provided the positive outlook her doctor had recommended. So she decided to make her own. In her private coaching group, Rogers started opening up about her condition and sharing her prognosis through social media.

"For so long, it felt like something I was hiding," Rogers says. "I acted like things were fine, but they weren't. Then I started being really open about what was happening with my body and what I was feeling, and I felt so much better once I put it out there. People were encouraging and positive, and it made me feel better in return."

Before long, Rogers' group was swarmed with women who had chronic

Kimberly Rogers with her husband and son.



illnesses of their own. They were eager for both a positive message and tips on how to get healthy.

Today, it's become what Rogers claims is a "safe space" for people to share their journeys and receive help along the way. Marrying her love of people, her passion for fitness and the desire to spread awareness about Parkinson's, Rogers says that she feels like she's truly making a difference every day.

"I can't save the world, but I can share my story," says Rogers, who now juggles a career as an assistant principal, in addition to her coaching. "And when I share my journey, I have several people every month who come up to me and tell me I'm making a difference. It's really special."

On Instagram as **@diagnosed_not_defined**, Rogers inspires more than 1,500 followers.

EFFECTIVE EXERCISES FOR PD

Some types of exercise may be more beneficial than others. The PD clinic at University of California, San Francisco, suggests:



SWITCH IT UP: Exercise that has you change direction, tempo or

activity emphasizes balance and rhythm, which can be challenging with PD. Such activities include dancing, skipping, marching to music with big arm swings, tai chi, yoga, golf, aerobics classes and walking outdoors, among others.



MULTITASK: To get more benefits from exercises that don't challenge

motor planning—slow treadmill walking, riding a stationary bike, weight lifting—add a simultaneous activity, like reading, tossing a ball back and forth or singing.



THINK ABOUT IT: Learning-based exercise may help with memory, such as yoga, tai chi and dance.

For more: pdcenter.neurology.ucsf.edu/patients-guide

Small Successes

MEMBERS OF FACEBOOK'S *MORE THAN MOTION™* COMMUNITY SHARE THEIR TIPS FOR GETTING THROUGH THE DAY WITH PARKINSON'S, BECAUSE LITTLE VICTORIES ARE WORTH CELEBRATING!

My husband has been battling Parkinson's for almost 15 years. He was diagnosed a few weeks after we found out our daughter was carrying triplets. The grandchildren are his motivation to keep moving. He cycles for 30 minutes 4 times a week on a stationary bike, walks with his stabilizing walker with a U-shaped base, and started taking piano lessons for the first time last year. He turns 80 on September 11.

—JUDI SMITH

My husband was diagnosed five years ago. He is 52. He plays golf almost daily and hits the gym almost daily, too. It helps a ton with his balance and rigidity.

—ROBYN GLADD

I was diagnosed four years ago and am now 60. I have taken what could be a real downer and turned it around with an upbeat attitude, most days, through sharing my art, drawings, paintings—you name it, I try it. I also started a support group where I live—going beyond my comfort zone! Never quit!

—WENDY K. SMITH

I found out that satin sheets help me to move better while in bed.

—CEIL PETRAS

I am a police officer. I was diagnosed at age 43. I'm 47 now. I'm still able to work, but every day is a struggle. What helps me is staying active. Keep moving!

—BRIAN MATNEY

When told I had PD, I made up my mind to get up every day, tackle life's troubles thrown at me and beat this disease—not let it beat me! Attitude can make a huge difference in how you tackle your own war on PD. I plan to go down kicking and fighting it!

—EWING FEARS
BEST

DO YOU HAVE A "SMALL SUCCESS" TO SHARE?

Like us on Facebook and tell us about it in the comments! We're always looking for great suggestions to share with the community. [facebook.com/parkinsonsmorethanmotion](https://www.facebook.com/parkinsonsmorethanmotion)



GETTY IMAGES

TRAIN YOUR BRAIN!

Flex your mind muscles with these word games from nationally syndicated puzzle columnist, and author of 47 puzzle books, Terry Stickels. Find more at his website, terrystickels.com.

Unscramble!

Below are 16 letters that form a common, everyday word. Using each letter just once, can you figure out what the word is?

T	S	R	O
I	G	D	N
T	E	S	S
H	H	E	S

Match the Creatures

Try your luck at matching up the science on the left with the creatures studied on the right. (We added an extra one in the right column just to be tricky!)

- | | |
|-----------------|----------------------|
| 1 Herpetology | a insects |
| 2 Cetology | b legendary animals |
| 3 Arachnology | c snakes |
| 4 Entomology | d spiders, scorpions |
| 5 Cryptozoology | e bats |
| | f whales, dolphins |

Answer key: shortsightedness; 1-c, 2-f, 3-d, 4-a, 5-b.

8 Things to Remember

HERE ARE YOUR TAKEAWAY TIPS FROM THIS ISSUE OF *MORE THAN MOTION*.

- Visit us online.**
More than Motion has a newly updated website with inspiring stories: parkinsonsmorethanmotion.com.
- Get involved in public policy.**
Did you know that MFJJ and PAN joined forces? Get involved on the Hill: Your voice can make a difference.
- Find fitness inspiration.**
Karen Jaffe, M.D., founder of a wellness center, likes to take classes. How do you stay motivated to work out?
- Exercise really can help.**
Jimmy Choi used to walk with a cane! PT helped get him back on track—and now he runs marathons.
- Get involved in fundraising.**
Choi runs marathons and hosts summer stands to raise funds for PD; these are great ways to build a community.
- Nourish your spirit.**
How does your attitude affect your health? A new workbook with a focus on holistic health may show you.
- Pay it forward.**
Fitness coach Kimberly Rogers has found that being open about her diagnosis helps inspire others.
- Share your “small success.”**
We love to hear about the little victories in your day where you overcome PD’s challenges. Tell us!

Click for Community

Visit **Parkinson's *More than Motion***[™] online! The redesigned website includes recent cover stories, news, videos, interviews with specialists and key resources about Parkinson's disease. You can also learn about sharing your story on social media and tagging it #MoreThanMotion. **parkinsonsmorethanmotion.com**

4 REASONS TO LOG IN AND JOIN US ONLINE



1. Great stories, photos and videos



2. Access to a vibrant community



3. A helpful guide to resources and events



4. Sign up for this free magazine

Join our online community at facebook.com/parkinsonsmorethanmotion



Inspired by **patients.**
Driven by **science.**

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