# MORE THAN MOTION™

**PARKINSON'S DISEASE.** SHARE, LEARN, ACT.

2016, ISSUE 3

## Fashion & Passion

Tonya Walker promotes Parkinson's awareness and raises funds with her stylish blog

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Meet *More than Motion*™ at the World Parkinson Congress September 20–23

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# Let's Talk

Talking about Parkinson's isn't always easy, but it's important to know how to communicate about it when you need or want to, especially when you talk to your healthcare provider. The more you know about PD, the more you can advocate for your care.

As such, *More than Motion*™ can help you communicate with doctors (and friends and colleagues) by offering educational, inspirational stories from people with PD and by offering tips to help make life easier. In this issue, in time for the 4th World Parkinson Congress (WPC) in Portland, Ore., September 20–23, we join the conversation by highlighting PD advocates; sharing guidance from a movement disorder specialist; informing you about ways you may save money on medications; and interviewing a speech pathologist. You'll also find a profile of a shoe-loving lawyer who decided to help spread awareness by blogging about her PD experience, and an enlightening story about a Norwegian photographer whose hopeful portraits of people with Parkinson's help beat the stigma. (He'll be at WPC, as will some others featured in these pages.)

**The more you know, the more you can advocate for your care.**

Wherever you are in your journey with PD, *More than Motion*™ can be your partner. We're in this together.

## IN THIS ISSUE

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# Newsroom

Events + Community + Solutions + Resources

## Blogging Out Loud

### THESE BLOGGERS HELP FORGE COMMUNITY BY REMINDING OTHERS THEY'RE NOT ALONE.

In celebration of the 4th World Parkinson Congress (WPC) in Portland, Ore., this fall, WPC Official Blogger Partners share news, experiences, hope—and a whole lot more.

You're stronger than you know, writes Karl Robb in his blog, **asoftvoice.com**. Robb, the author of *A Soft Voice in a Noisy World: Dealing and Healing with Parkinson's Disease*, was diagnosed at the young age of age 23. Now 50, he's an entrepreneur, inventor, writer and photographer who lives with his wife, Angela, in Virginia. "My intent was if I could help just one person through the blog or the book, I could call it a success," he says. "Keep your mind active, body moving and spirit positive," he adds, "and you may see surprising benefits."

Following his diagnosis, Dr. Julio Angulo, a retired psychologist, went through a grieving process. "At one point, however, it dawns on us that prolonged grief becomes unproductive; you have to move on." His blog, **movingforwardwithpd.com**, is an expansion of his advocacy work. He began volunteering at the Muhammad Ali Parkinson Center at Barrow Neurological Institute in Phoenix, and helped launch its *Vida Positiva*, a PD newsletter in Spanish distributed in the U.S. and parts of Latin America. Angulo, who is from Chile and lives in Oregon, says focusing on your abilities and strengths is the first step to a more fulfilling life.

"The blog has given me an excuse to make connections," says Laura Kennedy Gould, whose **magictrickparkinsons.wordpress.com** excels at relaying complicated information in a concise, humorous style. One such example can be found in her post "Eat Your Kale," about her participation in a clinical trial: "What the heck is a free radical?" she writes. Gould, who lives in Washington State, was diagnosed at age 57 and started the blog soon after retiring from her job as a computer analyst. These days, she's like an investigative reporter sent to cover life-altering experiences, and all the magic therein.

**MEET THE WPC BLOGGERS**

Join us at the 4th World Parkinson Congress September 20–23, in Portland, Ore.

*Go to the Partners section: worldpdcoalition.org*

THIS PAGE AND OPPOSITE: GETTY IMAGES

# Her Nose Knows PD

NEW RESEARCH IS UNDER WAY THANKS TO A WOMAN WHO CAN SNIFF OUT PARKINSON'S.

Joy Milne's perceptive sense of smell has researchers looking into PD and skin scent.

Joy Milne can smell Parkinson's. She was a caregiver to her late husband, Les, when she first described the scent to a group of surprised scientists, patients and PD advocates as a musky odor on people's skin.

Edinburgh University researchers have since tested her ability and found it valid. Patient-advocacy group Parkinson's UK has started funding research at the University of Manchester to identify chemicals on the skin's surface (possibly changes in the sebum) that might cause the smell in people with PD. The group's website even credits Milne, "the 'super-smeller' from Scotland," who could identify people with Parkinson's by the scent of their T-shirts.

Despite his worsening symptoms, Milne's husband was always her biggest supporter. "Les wrote down what was happening to him," she says. "When his writing became bad, I helped him." A retired doctor, he also helped direct her to the place where sharing her ability could do the most good. "We had a long talk about it one night. He told me 'You have to talk about this.' A year later, we got an invitation to a research event from Parkinson's UK, and Les said, 'That's where you need to say it.'"

Les became too ill to attend, but the power of their daily talks carried her through. Now, because she was heard, Milne hopes that others will feel they can speak up. "People are doubtful," she says. "I put myself out there." It's a good thing that she did. You never know how advocacy might pay off.

## IN MEMORIAM

# Muhammad Ali, 1942–2016

On June 3, 2016, the Parkinson's community lost a great champion. From Olympic Gold to the Presidential Medal of Freedom, Muhammad Ali was honored around the world. After his diagnosis with Parkinson's disease at age 42, his fighting spirit never faltered. He raised millions of dollars to benefit the Muhammad Ali Parkinson Center and other charities. For these accomplishments and so much more, he was—and will always be—The Greatest.

TOP: COURTESY JOY MILNE; BOTTOM: NEIL LEIFER/SPORTS ILLUSTRATED/GETTY IMAGES

# Good to Know...

## Scientists at Boston University are exploring how Parkinson's influences social connection. Based on early findings, they advise planning activities for when one is most energetic.

According to the *Journal of Physical Therapy Science*, researchers studying PD have introduced a new quality of life measure in which social connections such as family and friends are considered important and "being heard" was revealed as essential.

> Evidence ... suggest[s] that certain activities—exercise, social connectedness and creativity—may not only be therapeutic for Parkinson's symptoms but may actually change brain function.
>
> JULIE H. CARTER, R.N., M.N., A.N.P.

"Dance for PD," a study in the *Journal of Neural Transmission,* found that dance—which combines social, physical and mental effort—helped improve mobility and overall life satisfaction.

## ACTION STEPS

*by Maria De León*

Open up about your diagnosis. Then people can help.

Ditch perfection. Others drop things and fumble, too.

Express yourself. Say, "This stinks!" Laugh. Sometimes you will cry.

This is your life. Make the best of it!

## PEER-TO-PEER Q+A

**Maria De León, M.D.**

Author of *Parkinson's Diva* and movement disorder specialist living with PD

**Q** | **How do you battle the stigma of PD?**

**A** | Red lipstick and great shoes! You need something that gives you extra confidence. Try to change the world around you and pave the way for others. Joining support groups can also help with the stigma—and not just groups for Parkinson's. Relating to people in general about their everyday problems helps you stay connected. You can make a meaningful contribution.

*Read about advocacy and get health and beauty tips at Maria's blog, parkinsonsdiva.org.*

FROM LEFT TO RIGHT: GETTY IMAGES; COURTESY MARIA DE LEÓN

# A Mile in Her Shoes

**TAKING CHALLENGES IN STRIDE, TONYA WALKER UNITES HER PASSION FOR SHOES WITH PARKINSON'S ADVOCACY, RAISING IMPRESSIVE FUNDS ALONG THE WAY.**

Tonya Walker's closet is filled with more than 120 pairs of shoes: sandals, pumps, slings, platforms, stilettos, wedges and more. But for years—because of the effects of Parkinson's disease—she couldn't wear them. For Walker, losing her ability to wear fashionable, sexy high heels was an intolerable side effect, and one that she was not going to accept without a fight.

In 2006, she began experiencing symptoms of Parkinson's. She was only 32. After the birth of her son, Walker's symptoms worsened. Soon balance became an issue, as her feet cramped with dystonia, and rigidity set in during her "off" times. For years she took her medication and chose to keep her diagnosis a secret from all but her closest family and friends. She left her law practice and took a job as a law professor. Reluctantly, she retired her stylish stilettos. Depressed, she thought she'd be relegated to sensible flats for the rest of her life—but she did something about it.

Walker and her husband have raised close to $20,000 for Parkinson's research.

## Best Foot Forward

In 2013, before the first of two deep brain stimulation (DBS) procedures, Walker was relatively quiet about her diagnosis. Fortunately, the procedures were successful, and they brought the worst of her symptoms in check: She regained her balance—and her ability to wear heels.

In 2014, ready to face her condition publicly with her heels on and head up, she stepped into the national spotlight. With encouragement and tech support from her husband, Chad, Walker launched The Shoe Maven (theshoemaven.com), a dynamic blog that embraced her passion for fashion and provided a platform for her Parkinson's advocacy. Even from the home page, it's clear her site is about far more than fashionable footwear. "If I have lived this way, how many other people are living in denial?" Walker asks. "I don't want other people to be held captive by this disease. I believe dramatic strides can be made to change public perception through the power of social media."

Of course, it's no small feat (pardon the pun) to balance her roles of wife and mom and law professor, all while maintaining a social media network, launching The Shoe Maven (TSM) Originals T-shirt line and organizing Parkinson's advocacy events. This year, for example, she presented The Art of Fashion fundraiser held at the Orlando Museum of Art and teamed up with the Michael J. Fox Foundation to launch a social media awareness campaign called Heels On, Head Up. Since 2014, Walker and her husband have raised close to $20,000 for Parkinson's research. By meeting Parkinson's head on, Walker finds that she's empowering herself while helping others.

"I've met some of the most amazing people I know through advocacy and fundraising," she says. "I hope I can make a difference. I want people who are diagnosed to know they are not alone."

> **"I believe dramatic strides can be made to change public perception through the power of social media."**

THE SHOE MAVEN'S TOP TIPS

## Stay Stylish with Parkinson's

**Don't get tied down.** If dexterity is an issue for you, no matter how divine the shoe's design, if there are too many straps or ties, walk away. Consider spending your money on styles that you won't dread putting on.

**Avoid attachments.** "I'm a dress girl; they're easy to slip on," says Walker. "Rompers are stylish but too much work." Pair skirts (without zippers or buttons) with pullovers; for men, try polo shirts or shirts with magnetic closures.

**Be accessory-smart.** "I'm not going to make myself crazy trying to fasten a dainty necklace with a tiny clasp." Instead, Walker favors long necklaces and bangle bracelets that slip on or jewelry with magnetic clasps.

**Keep a spare pair.** Can't concede to wearing flats with your favorite date-night outfit? Pack a more comfortable spare pair (in your fashionably oversized handbag) to slip on if your feet start to ache.

THINGS TO ASK A . . .

# Speech-Language Pathologist

HERE'S HELP FOR SPEECH ISSUES THAT ARE COMMON IN PEOPLE WITH PARKINSON'S.

COURTESY HEATHER CLARK

Speech-language pathologists like **Heather Clark, Ph.D.**, can help Parkinson's patients with common speech difficulties be heard and feel included. These specialists have an arsenal of behavioral therapies and communication technologies at their disposal for treatment, says Clark, chair of the Division of Speech Pathology in the Department of Neurology at the Mayo Clinic in Rochester, Minn. Here's what that means for you.

**Q | How do most Parkinson's patients come to you for treatment?**

**A |** The motor control problems associated with Parkinson's can lead to a speech problem called hypokinetic dysarthria—quiet breathy voice, monotone vocal quality and slurred speech. They may also experience dysphagia (difficulty swallowing). Not everyone gets these, and the timing varies.

Often a family member needs to voice a concern, or the physician can notice it during an exam, because the person with PD tends to be less aware of their speech difficulties than the people around them are. It's not understood exactly why.

**Q | Are speech issues important to catch early on?**

**A |** Speech and swallowing therapy may be helpful even if symptoms are mild. I don't think we know if any of the behavioral therapies we might recommend would help delay or prevent onset of symptoms.

**Q | What can a speech-language pathologist do to help?**

**A |** Symptoms often respond well to an exercise program that emphasizes increased effort, such as speaking more loudly or more intentionally. There are some other therapies that focus on specific or isolated muscle groups, such as the respiratory muscles.

**TIP**
Find help through the American Speech-Language-Hearing Association, asha.org

**Q | Are there any communications technologies you like?**

**A |** Because a soft voice is one of the biggest complaints, some patients use a device that amplifies their voice through a speaker. There is also a kind of hearing aid that offers "delayed auditory feedback," which can help PD patients automatically slow down and articulate more clearly. A newer technology delivers noise in the patient's ear, prompting them to speak more loudly. It's adjustable, so the clinician works with the patient to find a level that is tolerable but also effective.

# Hidden Help for Those in Need

Patient Assistance Programs (PAPs) may help you get medication at a reduced rate. Read on to find out if you qualify.

WESLEY SORIANO

> **Certified care managers are often hired by families to help with complex medical needs.**

How do the 1 million adults with Parkinson's disease in the U.S. afford to pay for their prescription medication? According to Karen Campbell, certified care manager and founder of Innovative Aging LLC in East Kingston, N.H., the cost of medication can often be a struggle.

"Everyone needs help paying for prescription medications," says Campbell, who has been assisting the disabled and geriatric population for 14 years in her role as a certified care manager. "No matter how high someone's income is, it never seems to be enough." According to the Parkinson's Disease Foundation, medications for Parkinson's patients average out to around $2,500 per year—a fee that is, for most families, astronomical. "A lot of people are just barely getting by," Campbell says.

But although the costs of a chronic illness can be steep, Campbell considers herself an expert in saving families money. Certified care managers such as Campbell are often hired by families to help with complex medical needs, usually in the case of a disability or chronic illness. Care managers can evaluate patients in person and can help families with caregiving tasks—anything from helping individuals apply for Medicare and Medicaid to suggesting an elevated toilet seat in the bathroom. The job that she's tasked with most often, actually, is helping families figure out how to afford prescription medication.

## Can't Afford to Pay?

If you are uninsured or can meet certain need-based thresholds, a PAP, or Patient Assistance Program, may offer some relief. Run by a local nonprofit, a state program or a pharmaceutical company, a PAP may provide prescription medications at a greatly reduced rate. Patients do need to demonstrate need, and each PAP has different eligibility requirements—for instance, PAPs are usually restricted to those without insurance, or whose insurance does not cover their needed medication. Patients must also demonstrate financial need, with income limits up to 300% of the federal poverty guidelines. (Medicare and government insurance patients are not eligible for most copay and financial programs.)

For those who are eligible, patients may be able to obtain a one-month supply of medication through a PAP for as little as a $20 or $30 co-pay, "depending on the medication and the company," says Campbell. In cases of extreme financial hardship, medication and co-pay fees are waived altogether. "More often than not, I save people a lot of money," says Campbell.

## Hidden Gems

Finding a PAP doesn't take much effort, thanks to several reliable and free databases. On rxassist.org and rxhope.com, patients can look for PAPs by searching the database by medication or drug manufacturer. The Partnership for Prescription Assistance (pparx.org) provides a database of pharmaceutical and nonprofit PAPs, while medicare.gov has a comprehensive list of state-run programs (called SPAPs).

Applying to a specific PAP, however, is usually when patients get fatigued. Fewer than half of the states provide SPAPs, and nonprofit PAPs may require an additional fee on top of the prescription co-pay. Many patients, according to Campbell, apply for PAPs by doing an internet search for the manufacturer and applying for assistance for each drug.

If needed, care managers can step in during the application process and guide clients through the red tape, from completing the basic application to reaching out to the patient's physician, whose signature is needed on the PAP application form. Once the application is completed, proof of income is attached and a physician signs off. If the program approves the application, patients can start taking advantage of discounted or free medications.

## Ask Your Doctor

For patients who are unable to afford a care manager, physicians can also act as advocates for patients who need discounted drugs. Physicians can sign off on a diagnosis and provide additional documentation for the PAP application if necessary.

A word of advice while you're in the process: "Don't give up," says Campbell. "It's hard to research all the programs and make phone calls, but keep at it. Sometimes you have to keep calling, or you hire an advocate who can help, but it's worth it."

## For more information:

**RxAssist,** rxassist.org
**RxHope,** rxhope.com
**Partnership for Prescription Assistance,** pparx.org

# The Changing Face of Parkinson's

## How a Norwegian photographer gave the age-old stereotype a makeover.

Stark white backdrops draw attention to faces filled with intensity. Looking into their eyes, you seem to see hopes and dreams, pain and disappointments. You can also see the desire to live well and a sense of defiance toward the disease that was not a part of their plans.

Norwegian photographer and videographer Anders Leines created these portraits to help change the stereotype of Parkinson's, a disease that affects more than 10 million people worldwide—including him. While working on location, his symptoms began without warning. "One day, my energy left me," Leines says. "It felt like my cells were trembling inside. My wife noticed my right arm wasn't swinging." He was diagnosed with Parkinson's in 2010 at age 47.

After his diagnosis, Leines researched his disease, trying to find the best path of treatment. He continued to work as an editor, cameraman and producer for a broadcasting company. In his free time, he began producing films about Parkinson's. Four years ago, he hatched the idea to create a photo exhibit featuring people with PD, and it's been a rewarding pursuit.

"When people think of Parkinson's, they think of old people with inexpressive faces," Leines says. "I wanted to change that perception. People with PD are normal people who have lives ahead of them. They still have hope for a good treatment."

### All About Attitude

The Norwegian Parkinson Society helped spread the word about the photography project. Seventeen men and women with Parkinson's showed up for the three-day photo shoot. They were not professional models. The only criteria were that they be people with PD and under the age of 50. (One exception was made when an elaborately tattooed 56-year-old man volunteered. "Eivind was just too good-looking to be excluded," says Leines.)

WRITTEN BY
**BRIGID ELSKEN GALLOWAY**
PHOTOGRAPH BY
**ANDERS LEINES**

No stylists or makeup artists were used on the shoot. Leines wanted to capture each subject's natural beauty and character. "I asked them to think proud thoughts about themselves, to hold their heads up high," he says. "I was most concerned about them having attitude. That's not something you can magically create."

In 2015, the exhibit began touring across Norway in cooperation with the Norwegian Parkinson Society, the Norwegian Directorate for Children, Youth and Family Affairs, and the World Parkinson Coalition. The traveling exhibition has since wowed audiences in London, Phoenix and Grand Rapids, with its compelling portraits, real-life stories and critical approach toward the general status quo image of the person with PD. In September, the evocative exhibit will be featured at the 4th World Parkinson Congress in Portland, Ore. Leines' images can be seen on the WPC 2016 website in a promotional video.

His powerful photography has already helped shift perceptions. The Norwegian Parkinson Society uses the images in its lobbying efforts. "I think the photos have influenced the decision makers more than I expected," Leines says. "The photos allow them to bring the patients wherever they go and speak to their hearts."

## Photo Therapy

You don't have to be a supermodel to have a powerful portrait done of yourself. "Every person on this earth has a good face," Leines says. "Everyone has an interesting story to tell. Everyone can look good on camera." Here are Leines' suggestions for being photographed:

1. **Wear simple clothing, without a lot of patterns.**
2. **Keep the background neutral.**
3. **Sit on a high chair or stand to improve posture.**
4. **Look straight at the camera.**
5. **Think proud thoughts.**
6. **Sit for a lot of photos.**

# 8 things to remember

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

1 **Join community.** Remember you're not alone. These WPC Bloggers found community and a platform for advocacy online.

2 **Share knowledge.** When a woman who could smell PD spoke up about it, she affected new research. It can pay off to be open!

3 **Find support.** Joining support groups (not just for PD) may be helpful; it was for this movement disorder specialist.

4 **Stand tall.** Consider sharing your diagnosis like Tonya Walker did. Empowered, she turned to advocacy and fundraising.

5 **Be vocal.** If motor problems affect your speech, a speech pathologist may be of help. Learn more and find a specialist.

6 **Can you cut costs?** You may qualify for Patient Assistance Programs (PAPs), which may help you get medication at a lower cost.

7 **Battle the stigma.** Remember that anyone can help combat the stigma of PD. Being open about it can bring people together.

8 **Stay sharp.** Puzzles and teasers can help you stay sharp. See how many of these (challenging!) games you can do.

THIS PAGE IN NUMBERED ORDER: GETTY IMAGES; GETTY IMAGES; COURTESY JOY MILNE; GETTY IMAGES; JEFFREY SALTER; COURTESY HEATHER CLARK; WESLEY SORIANO; ANDERS LEINES; GETTY IMAGES

# Train Your Brain!

**Give your brain a workout!** Try these puzzles and challenges from nationally syndicated puzzle columnist and author of 47 puzzle books, Terry Stickels. Find many more at his website, terrystickels.com.

## Name the States

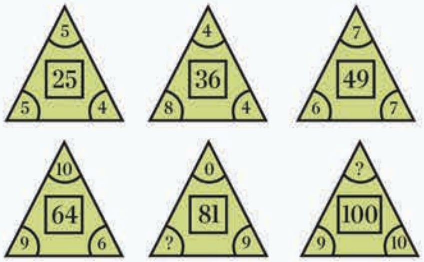
**Below are the names of six states with their vowels removed. How fast can you figure out their full names?**

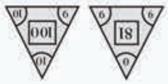
1 **KLHM**
2 **NDN**
3 **H**
4 **LLNS**
5 **W**
6 **RGN**

Answers: 1) Oklahoma, 2) Indiana, 3) Ohio, 4) Illinois, 5) Iowa, 6) Oregon

## Tricky Triangles

**What are the missing numbers in the last two triangles?**

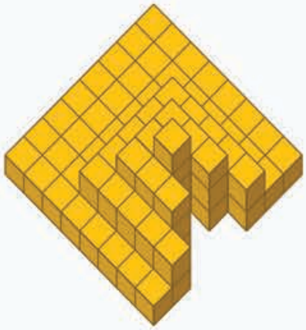




Answer: Multiply the bottom two numbers and add that to the top number to arrive at the number inside the square.

## Count the Cubes

**How many cubes are in the stack below? All rows and columns continue unless you actually see them end.**



TOP: GETTY IMAGES

Answer: 90 Cubes

## Match the Animals

**A group of locusts is called a plague; a group of turtles is a bale and a group of eagles is a convocation. Match the animal on the left with their respective group name on the right.**

1 **Coyotes**
2 **Alligators**
3 **Tigers**
4 **Sharks**
5 **Trout**

a **Congregation**
b **Band**
c **Shiver**
d **Ambush**
e **Hover**

Answer: 1=b, 2=a, 3=d, 4=c, 5=e

# Click for Community

The **Parkinson's More than Motion™ Facebook group** is an active online community for breaking news, event listings and key resources about Parkinson's disease. You can ask questions, get answers and meet people just like you. Visit parkinsonsmorethanmotion.com.

## 4 REASONS
### TO LOG IN AND JOIN US ON FACEBOOK

**1.** Great stories, photos and videos

**2.** Access to a vibrant community

**3.** A helpful guide to resources and events

**4.** A free subscription to MTM magazine

**Join our online community at facebook.com/parkinsonsmorethanmotion**

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

**ABOUT US**
UCB, Inc., is a pharmaceutical company dedicated to bringing cutting-edge science, innovative drugs and practical solutions to patients and their caregivers. We are committed to raising awareness of Parkinson's disease through education and community building.

FROM LEFT TO RIGHT: JOSÉ MANDOJANA, COURTESY WORLD PARKINSON CONGRESS (2 EVENT IMAGES), KYLE JOHNSON