MORE THAN MOTION™

PARKINSON'S DISEASE. SHARE. LEARN. ACT.

2016, ISSUE 1

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Join Our Online Community at Facebook.com/ParkinsonsMoreThanMotion

WELCOME

WE'RE IN THIS TOGETHER

AS WE RECOGNIZE Parkinson's Awareness Month this April, the Parkinson's disease community is also realizing a whole host of solutions that are helping people with PD, as well as their loved ones and caregivers, to become their own best advocates.

As you'll read in this magazine, new opportunities enable people to get involved in a number of ways. Organizations are inviting the general public to submit research topics. Wearable technology is enabling people to track their symptoms—findings that can help improve patient-doctor conversations.

Additionally, PD programs mentioned in these pages help support advocacy and awareness. These are just some of the engaging tools that people in the PD community can use to empower themselves and live their fullest lives.

This magazine is part of these solutions, too. It was conceived as a tool for addressing priorities brought to the forefront by people with PD (and their caregivers)—for those recently diagnosed and for people who've been living with PD for a while. The title *More than Motion*™ underscores the idea that managing PD is more than handling physical problems of movement. It means finding ways people with PD can work together as partners with their caregivers, have better conversations with their doctors, and draw inspiration from the small successes of others with PD—all while navigating the healthcare system. Managing your PD is also about engaging with peers. One way to do that is by taking part in the Parkinson's Unity Walk in New York City on April 23. For more ways to connect, read on—and get involved!

Join Us.
Our Facebook page loops you in to our latest news. Like us at Facebook.com/ParkinsonsMoreThanMotion.

COVER PHOTOGRAPH: KYLE JOHNSON; THIS PAGE: GETTY IMAGES

Make a Web Page for Parkinson's

Here's a fun, easy way to make a difference for yourself or a loved one this April, during Parkinson's Awareness Month: Log on to the American Parkinson Disease Association (APDA) website and create a special web page, which lets you turn a beloved interest or activity into a powerful fundraising tool. Your web page will serve as one of APDA's Personal Optimism Fundraising campaigns, which are helping to raise critical dollars in support of the organization's two-year-long "$1 Million for 1 Million" initiative launched in 2015. You simply fill in the site's data fields to create your personal campaign in a template with a button labeled "Support me." Once a page gets posted, the organization maintains it, channeling donations from friends and family toward APDA's collective goal.

While April is a great time to create your fundraising page, there's no time limit on how long your campaign can run, and you can continue to update your page long after you've reached your fundraising goal. The site also notifies you when people make donations and provides a prewritten thank-you note to make it easy to show others you appreciate their contributions. Proceeds will enable APDA to expand its programs for health, wellness, education and communication, as well as to expedite the pace of research.

Do the ready-made web pages really help? To date, the organization has raised more than $750,000 toward its $1 million goal. Of that, Personal Optimism Fundraising has brought APDA $188,000, with 1,392 participants. Create your page at apdaparkinson.org/PersonalCampaign.

RAISING FUNDS IN 4 STEPS

1. **Create a page** at apdaparkinson.org/PersonalCampaign.
2. **Personalize your page!** Choose one of six template types, with themes such as "Activity," to highlight your involvement in a run-walk event, or "Weddings or Anniversaries," so friends can donate in lieu of buying gifts.
3. **Set a goal.** Pick a realistic dollar amount as your fundraising goal. Then customize your page, to share your reasons for getting involved.
4. **Tell people.** Include the URL in social media posts and texts to friends and family.

Apps That Help You...

	DEVICE	PRICE
...to schedule and track meds **Medisafe Meds & Pill Reminder** > This easy-to-use, medicine-management app provides you with reminders and a calendar.	🤖 🍎	FREE
...to stay sharp **NeuroNation** > Engaging brain exercises stressing memory and attention, with a social feature that lets you rank your scores against those of other users.	🤖 🍎	FREE
...to get quick, simple answers **Parkinson's Central** > Handy source for all kinds of PD information. It identifies symptoms and treatments, and offers tips for structuring doctor's visits, home modifications and insurance.	🤖 🍎	FREE
...to watch for changes in symptoms **Lift Pulse** > Uses a smartphone's accelerometer to track tremors against a baseline, and a journal to record sleep, exercise and stress data to share with your doctor.	🤖	FREE
...to keep your voice loud and clear **Speak Up for Parkinson's** > This app has tools and tips to help you practice volume control. It also provides feedback on how you're doing.	🍎	FREE

GETTY IMAGES

Can Futuristic Sneakers Kick-Start a Cause?

By bringing fictional footwear to life, Nike is attracting cash for PD research.

In 2011, Nike made a sneaker with the same look as the fictional, self-lacing pair it created for Marty McFly, Michael J. Fox's character in *Back to the Future.* Even without the mechanism that would make them lace themselves, the sneakers attracted fans who spent $4.7 million on 1,500 pairs during a 10-day eBay auction to benefit The Michael J. Fox Foundation. The news made philanthropic history, marking it as eBay's largest charity auction ever at that time. Because the auction was positioned to leverage the Foundation's Brin Wojcicki Challenge, proceeds were doubled, bringing the total funds generated to $9.4 million. The $50 million Brin Wojcicki Challenge ran throughout 2011 and 2012.

Now Fox's fans and fellow PD advocates are anticipating a second Nike collaboration, which may raise additional dollars for Parkinson's research: In October 2015, Nike leaked word of its 2015 Air Mag, a shoe that is identical to the movie version and laces itself, just like in the film. Auction details can be found on Nike's website and via Twitter @Nike and @MichaelJFoxOrg.

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4 million

Number of times Michael J. Fox's demonstration of Nike's prototype was viewed on YouTube, as of March 2016.

Lobbying for a Cure

This election year, Parkinson's Action Network—the voice of Parkinson's in Washington, D.C.—is fighting battles big and small. Here's what you should know about them.

What's the agenda of the Parkinson's Action Network (PAN), PD's major lobbying group in Washington? A cure: That's what the group ultimately wants to achieve with its efforts. But to reach that goal, PAN has recently focused on increasing federal funds for Parkinson's research and establishing a national Parkinson's information database. Both are top priorities for the group in 2016, and PAN had some success on both fronts in 2015.

Last year, Congress approved $32 billion in funding for the National Institutes of Health (NIH) to be used this year—a $2 billion increase in funding, which PAN and patient advocacy groups for other diseases had been demanding for three years. That's significant, as the NIH is the single biggest funder of medical research into Parkinson's and pays for much of the basic fieldwork that becomes the foundation of cutting-edge developments by drug companies and private organizations.

As for the database, PAN managed to add a provision to the 21st Century Cures legislation, which would mandate its creation. That legislation passed the House last summer. Such a database would collect information not just about the number of Americans who have Parkinson's, but also about environmental exposures and gender and racial differences in patient populations.

"[Lobbying] is not sexy," says PAN President Ted Thompson. "But in terms of impacting somebody's daily life with the disease, even little provisions can make a huge difference."

GET INVOLVED!

E-advocacy
Sign up for "action alerts" at parkinsonsaction.org and contact members of Congress about priority issues.

Join PAN
Volunteer to be one of PAN's "grassroots leaders" and bring its agenda to schools, support groups and state representatives.

Plant a virtual tulip
PAN kicks off the Tulip Tribute Garden campaign during April, which is Parkinson's Awareness Month. Visit pantulips.kintera.org.

Tweet
Follow PAN on social media to be part of the dialogue at twitter.com/pantweets.

OPPOSITE PAGE: COURTESY NIKE; THIS PAGE: GETTY IMAGES

HOW ARE YOU COPING WITH YOUR EMOTIONS?

Not everyone with Parkinson's faces emotional problems. But if you or a loved one with PD seems glum, there is help, says **Mark Groves, M.D.,** a movement disorder specialist and neuropsychiatrist at New York City's Mount Sinai Beth Israel Hospital.

***Q:* What's a big emotional hurdle you look out for in people living with Parkinson's?**

A: I always look for signs of depression first, because depression has been shown in many studies to be the No. 1 predictor of quality of life. For many, I find it may not be just a reaction to the diagnosis, but part of the illness itself.

***Q:* But anyone might feel a bit down, in reaction to a diagnosis of PD. How do you know when it is depression?**

A: If you're feeling hopeless, experiencing conflict in relationships or having trouble sleeping, these may be signs. Depression can sometimes precede the onset of physical PD symptoms by years. I don't ignore how the caregiver is feeling, either. If he or she feels burnt-out, irritable or hurt, both people may benefit from therapy.

***Q:* How do you know when it's time to get professional help?**

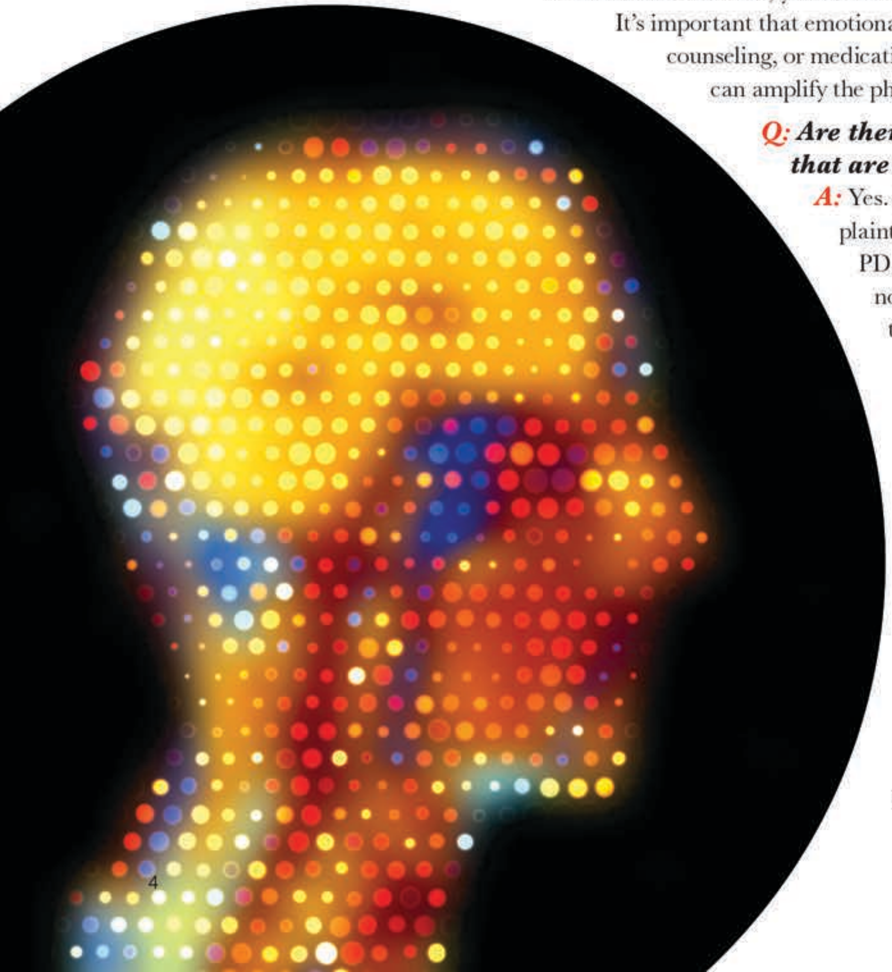
A: If you think you notice any of the symptoms described above in yourself or a loved one with PD, you need to consult your doctor immediately. It's important that emotional symptoms are fully treated with counseling, or medication if necessary, because the depression can amplify the physical symptoms of Parkinson's.

***Q:* Are there other mental health issues that are associated with PD?**

A: Yes. Apathy. That's a really common complaint I hear from loved ones of people with PD. They notice the person with PD is just not as engaged as they once were—a sign that they have less motivation, less drive.

***Q:* How can caregivers help, if they notice these signs?**

A: If there are no signs of depression, only apathy, the best treatment is to schedule rewarding activities, which can help perk the person up a bit. I have to coach people to just show up and see if they enjoy themselves. I'm always trying to distinguish between depression and apathy. So, always communicate shifts in mood or behavior to a doctor, so you're not taking on too much of the coaching or motivating alone.



COURTESY MARK GROVES; GETTY IMAGES

POWERING FORWARD

WORDS BY
BRIGID ELSKEN GALLOWAY
PHOTOGRAPH BY
KYLE JOHNSON

Diagnosed with early onset Parkinson's, former NBA star Brian Grant first thought the disease might kill him. Now he's inspiring others to power through.

Brian Grant is best known for his power and tenacity on the basketball court. The 6-foot-9 athlete enjoyed an illustrious career, during which he went toe-to-toe with basketball adversaries on five different NBA teams. Today, he has a new opponent—Parkinson's disease. Like other people living with PD, he endures frustrating symptoms such as hand tremors and involuntary foot-tapping. But he's taking the same in-your-face approach that he used when squaring off against competitors.

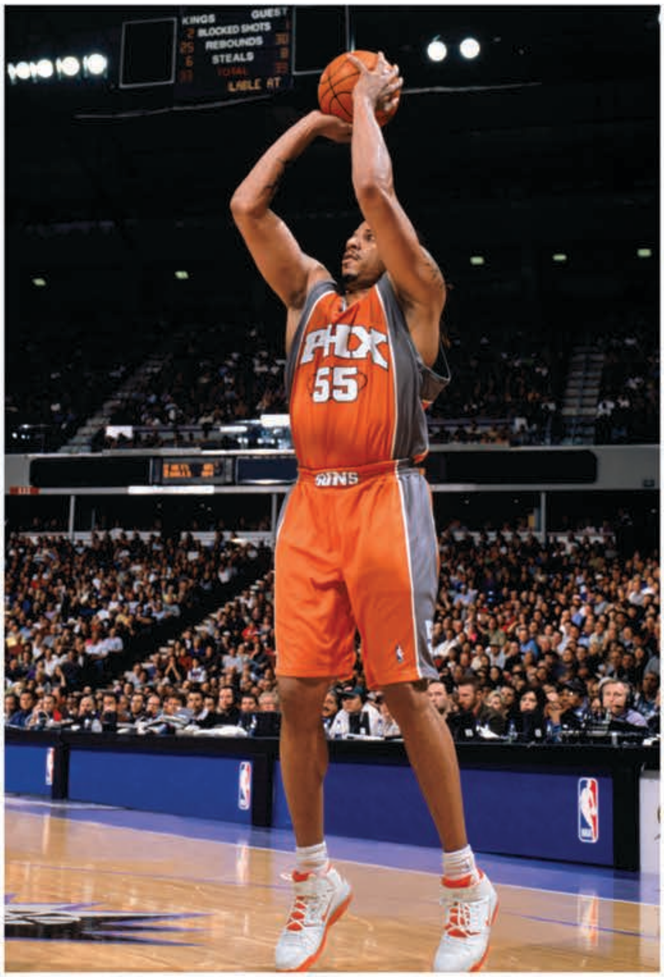
"I wasn't the best power forward on the court, but I never let anyone beat my effort. I always worked hard on the things I could control. I gained people's respect through that hard work," Grant says.

Even after his hand tremors began, he entertained offers to become a TV sports commentator. He bowed out after tremors became more noticeable. He assumed that old injuries were to blame, but in 2008, he was diagnosed with early onset PD. He was 36 years old.

NEW TEAM, NEW MISSION

As a professional athlete who had always depended on his ability to control his body, he was hit hard by the diagnosis. "The first thing I thought was, 'Is this going to kill me?'" he says. "After I found out it wasn't terminal, I wanted to know everything I could about PD."

As a celebrity, he quickly realized he had access to the best resources available, and he wanted to share the information he gathered with others who weren't so fortunate (or famous). He channeled his charisma and the focus of the Brian Grant Foundation into making the organization's website a Parkinson's resource: It provides instructional exercise videos, healthy recipes, and tips to help people with Parkinson's and their caregivers lead active and fulfilling lives. The site also has advice about how to talk to children about PD—something Grant, a father of eight, knows plenty about. "The first time I went to a Michael J. Fox event with my son Jayden, he was a bit overwhelmed with the reality of Parkinson's as he learned more about how the disease was going to impact my life," Grant says. "My son's eyes got big and he squeezed my hand because he was scared. He was thinking 'Is this what my dad has?' But he doesn't think like that anymore."



Clockwise from top right: Brian Grant in his NBA heyday; spreading the word about PD and the Brian Grant Foundation; fishing; and enjoying time with two of his eight children.

True to form, Grant keeps his children informed about his status and his growing legacy as someone who is raising awareness about Parkinson's. His foundation's message to live well now and take control by using the tools he has found helpful is a philosophy he models in his own life. "This is one disease you can manage, to a point, through exercise and nutrition," he says. "I see too many people waiting around for a cure. Although I want a cure, too, I'm more concerned about what you are doing for yourself today."

I always worked hard on the things I could control. I gained people's respect through that hard work.

THIS PAGE, CLOCKWISE FROM TOP RIGHT: ROCKY WIDNER/NBAE/GETTY IMAGES; JOSE LUIS VILLEGAS/SACRAMENTO BEE/MCT VIA GETTY IMAGES; VICTOR BALDIZON/NBAE/GETTY IMAGES; NOAH GRAHAM/NBAE/GETTY IMAGES. OPPOSITE PAGE, FROM LEFT: CHARLES ESHELMAN/FILMMAGIC/GETTY IMAGES; KYLE JOHNSON

Bonding with Michael J. Fox, who featured Grant in the actor's documentary *Faces of Parkinson's.*

BRIAN GRANT WANTS YOU TO POWER THROUGH

IN SEPTEMBER 2015, the Brian Grant Foundation and the World Parkinson Coalition launched the Parkinson Power Through Project: Montreal to Portland (PTP), a global exercise initiative marking the countdown to this year's 4th World Parkinson Congress (WPC 2016) in September. The initiative encourages those with Parkinson's—and people in general—to exercise. Using an interactive online app, you create a profile, then log any forms of physical activity you enjoy. The activity gets converted into miles to represent a virtual journey from Montreal (site of the 2013 WPC) to Portland (site of WPC 2016). The point is for people with PD to feel empowered as they move through this challenge on their own terms. Grant even enlisted the help of the 2016 NBA All-Stars to promote the virtual event during the All-Star game in February. To sign up, visit powerthroughproject.org.

TECH SOLUTIONS

Collaboration between researchers, physicians and people with Parkinson's is making wearable tech the ultimate accessory.

Named for its built-in gyroscopes that resist the wearer's hand tremors, the GyroGlove is being tested in the United Kingdom.

COURTESY GYROGEAR

Dan Kinel's smartwatch—a computing device worn on his wrist—vibrates as he finishes a phone call with a client. He checks the notification: time for his meds. He notes that he has walked 16 miles this week, his sleep cycles are a bit off, and that he has an appointment with his neurologist on Thursday. While it's top of mind, he sends an email to his doctor, attaching the biofeedback report gathered by his watch.

Kinel's take-charge attitude is a big shift from how he felt three years ago when first diagnosed with early onset Parkinson's disease. Initially, the 43-year-old attorney was shocked and distressed, believing all he could do was wait for the disease to take its course. But with encouragement from friends, family and colleagues, he decided to be more proactive.

When his neurologist offered him the opportunity to participate in a telemedicine clinical trial through University of Rochester—using a wearable device to help him track and report his symptoms—he signed up. The experience provided information about himself that he'd never noticed before. "I never really thought of myself as having on/off periods with my medication, but I noticed an increase in tremor within a half hour of the time I was scheduled for another dose," he says. "It was useful for me to recognize that."

The idea that wearables are tools, which people with PD can use to help themselves, is a recurring theme. Kinel also joined the online Fox Insight study from The Michael J. Fox Foundation, and is one of the first testers of its smartwatch-syncing app for iPhone.

"People want to do something to help themselves and their family members who might develop Parkinson's," says Claire Meunier, vice president of research engagement at The Michael J. Fox Foundation.

PEOPLE POWER

People with PD also like to feel they're helping their peers. "There are a lot of people working toward a cure, but they can't do it without patient participation," Kinel points out. Although wearable technology for healthcare has been in development for almost 20 years, there had not been widespread use of it to help with PD research. In 2000, Intel started working with The Michael J. Fox Foundation to explore ways that the technology could be used to advance Parkinson's research. Those efforts led to the partnership between the foundation and Intel now called Fox Insight, and to the sub-study Fox Insight Wearables.

"The traditional research paradigm excludes a lot of people. Wearable, mobile technology provides a means of virtual participation," says Meunier.

Intel developed a system for collecting data through wearable and mobile technologies, and then analyzing it "with an aim to make it accessible to any researcher in the world," says Ron Kasabian, vice president, Data Center Group, and general manager of Big Data Solutions at Intel.

The Fox Insight online study was launched in March 2015 and, to date, the wearable substudy has outfitted approximately 600 participants in the United States and 110 in the Netherlands with a smartwatch. The watch collects data using a built-in accelerometer, which can detect a sudden increase in motion. Different measurements are extracted using machine learning algorithms, which determine the severity of the patient's motor symptoms. This data is securely collected, de-identified, and then matched up with patient-reported information, such as medication intake and other general information, and stored in a cloud platform for future analysis by researchers.

> **The smartwatch is a lot more than just a nifty gadget.**
>
> *—Dan Kinel, a Fox Insight study participant*

In addition to those in the wearables substudy, 3,000 more people with and without PD have enrolled in the Fox Insight online study. Participants are asked to complete a questionnaire on their disease progression every three months. This year, Intel plans to expand the study with an additional 3,000 devices, and enable patients to share the data collected with their movement disorder specialist or neurologist.

"I use my wearable data when talking to my neurologist about the intervals between my medications," Kinel says, explaining why he finds the device useful. "It's a lot more than just a nifty gadget."

WEARABLES TO WATCH

Recording symptoms, calling for help, assisting your steps. Devices are being designed to empower wearers by giving them greater control.

Kinesia 360

Great Lakes NeuroTechnologies in Cleveland launched a PD-specific wearable with an app: Kinesia 360. Sensors you wear on your ankle and wrist transmit information to the app and measure PD symptoms such as tremor and bradykinesia. The data is available to clinicians and researchers.

PDShoe

An ordinary beach shoe equipped with a mechanism that vibrates in the heel is being developed by two research teams jointly in India and at the University of Delaware. Although it is still in the testing phase, the robotic shoe aims to help PD patients who walk with a freezing gait to walk more steadily.

ActivePERS™

Developed by Boston-based BioSensics with funding from the National Institutes of Health, ActivePERS™ is a medical alert solution that can detect falls with the use of acceleration sensors. The device distinguishes between an actual fall and a non-fall action such as sitting down. In an emergency, it issues an alert to a call center, which calls 911, if needed.

BEDROOM MAKEOVER

A safe, comfortable and inviting bedroom for someone with Parkinson's is achievable, no matter how small the budget. One resource, the nonprofit Rebuilding Together, provides critical home repairs and accessibility modifications for people with disabilities through its network of affiliates across the country. Contact a local affiliate by visiting rebuildingtogether.org. Or, find help to pay for a do-it-yourself update at disability.gov. Making your bedroom restful and easy to use can be fun. Some of our tips may help you enjoy it more tonight.

ROOM TO WALK

Remove barriers and tripping hazards such as magazine racks and footstools throughout your home. The bedroom likely won't suffer from one less ottoman.

QUICK FIX

Donate all furniture with casters or wheels. Chairs and tables must be sturdy enough to stay put, if you need to rest a hand on them as you walk by.

MOTORIZED BLINDS

Daylight is healthy and key to safe movement. Automated blinds you can operate with a remote will let you control natural light without having to grip and pull drapes and shades.

QUICK FIX Install so-called easy-lift shades, which have no pull cords and are designed to adhere to the tops of window frames, tools-free. Find them in most home stores.

REMOTE-CONTROLLED LIGHTING

For real ease and control, you could install lighting that you activate with a clap or your voice to replace lamps that may have hard-to-grasp switches.

QUICK FIX

Get a lamp with a touch-sensitive base that you tap to turn on and off. National home stores sell them for prices starting around $40.

GETTY IMAGES

A BED THE RIGHT HEIGHT

A safe, comfortable bed is one that allows you to place your feet flat on the floor while you're sitting on the edge. Satin or smooth cotton sheets also make it easier to turn over, as you work to get out of bed.

QUICK FIX Install a bedside handrail for support in pulling yourself upright, if you experience spontaneous losses of mobility or freezing. Many attach without tools and may be paid for using a Flexible Spending Account.

SLIP-RESISTANT FLOORS

Flooring that comes labeled "non-skid" (and removing loose rugs) can provide a durable slip-resistant surface. Wood, vinyl or rubber tiles may be more forgiving than nonporous ceramic tiles in case of falls—and they feel more cozy in a bedroom.

QUICK FIX Apply a nonslip finish to an existing smooth and level floor. A list of treatments certified by the National Floor Safety Institute is available at nfsi.org.

Join Us.
Our Facebook page loops you in to our latest news. Like us at Facebook.com/ParkinsonsMoreThanMotion.

YOUR 8 THINGS TO REMEMBER

Here are your takeaway tips from this issue of ***More than Motion***™. Discuss some of them during your next doctor's visit.

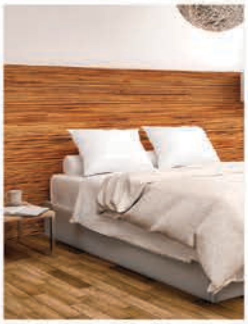
1 **Make a web page** that helps fund PD research, by using the American Parkinson Disease Association's tools and templates at apdaparkinson.org/PersonalCampaign.

2 **Become an advocate!** Add your voice to those of lobbyists for the Parkinson's Action Network. This year's agenda could be a step toward a cure. Visit parkinsonsaction.org.

3 Look out for news of Nike's auction of **self-lacing sneakers**. Purchases will raise funds for PD research. Get updates at news.nike.com/news/nike-mag-2015.

4 Speak to your physician, or a specialist, at the next appointment, if you think that you or a loved one with PD might be experiencing **symptoms of depression or apathy**.

5 Visit the **Brian Grant Foundation** website to participate in the Parkinson Power Through Project, or explore other ways to get inspired and stay active at briangrant.org.



6 **Try these tips** to create a safe, comfortable and attractive bedroom. Review our roundup of best practices. Keep it as a reference for planning your next home improvement.

7 Discuss **wearable technology** with your doctor at your next visit. Communicating your interest is the best way to find out if he or she would recommend a solution that might be a right fit for you.

8 Ask your doctor about clinical trials or **patient-led studies** that you may be eligible for. You can find out about clinical trials that might be a match for you by visiting foxtrialfinder.org.

Notes: ______________________________

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CLOCKWISE FROM TOP LEFT: GETTY IMAGES (2); COURTESY OF NIKE; GETTY IMAGES (2); COURTESY OF GYROGEAR; GETTY IMAGES; KYLE JOHNSON

GETTY IMAGES

The Age of Patient Power

Patients are being empowered to speak up about which aspects of PD are most important to them. Their voices are steering research.

People living with Parkinson's quickly become authorities on their bodies, given the self-monitoring that they do. As they increasingly communicate their priorities, doctors and researchers are hearing them speak up as their own care advocates: They need a cure, but they also want solutions they can use now. The result? "Our goal is to create innovative research projects with strong patient involvement," says Arthur Roach, M.D., director of research for 37,000-member, patient-led charity Parkinson's UK.

THE NEW RELATIONSHIP

It's important to point out that this patient-led approach to research is emerging on the heels of earlier patient-driven efforts, such as having people with PD participate in advisory boards. At Parkinson's UK, for example, the official line on their website is "Everything we do is driven by people with Parkinson's."

In keeping with that mission this year, the group launched a Patient and Public Involvement guide for scientists, in order to help them involve people with PD in research at all stages.

DIRECTING RESEARCH

In 2015, Cambridge University Hospitals created its own Patient Led Research Hub on its website to collect patient-generated submissions. The hub's goal, according to the hospital's statement? To "turn patients' own research ideas into rigorous clinical trials."

Stateside, the Parkinson's Disease Foundation (PDF) holds its Community Choice Research Awards, which in 2013 led PDF to identify two symptoms of Parkinson's disease—fatigue and gastrointestinal dysfunction—as priority issues for which they are now funding studies. This fall, PDF will again ask people with PD and their caregivers to submit their ideas for PD research. An advisory board will select two of those issues for further study and invite the individuals who submitted them to join PDF in finding answers.

EMPOWERING PATIENTS

For people battling PD, these opportunities to steer the direction of research may help restore a sense of control. Parkinson's UK reports that roughly 2,000 of its members are also involved in the group's Research Support Network—a subset of people with PD, their family, friends and caregivers, and doctors and nurses, all interested in research. The message is simple, but profound: Patients understand their disease, and they may know which solutions should be addressed first.

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.

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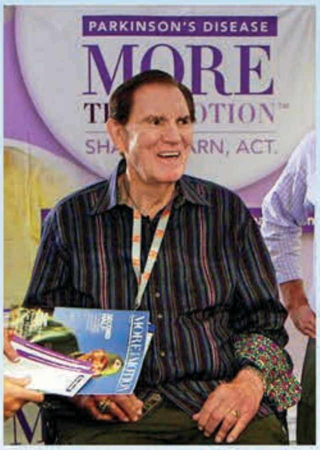
4 REASONS

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

"THE GREATEST DANGER FOR MOST OF
IS NOT THAT OUR AIM IS TOO HIGH AN
WE MISS IT, BUT THAT IT IS TOO LOW A
WE REACH IT."
– MICHELANGELO

4. A free subscription to MTM magazine

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.