

MORE THAN MOTION™

PARKINSON'S DISEASE. SHARE, LEARN, ACT.

2017, ISSUE 1

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Martin Cruz Smith

The novelist adjusted to life with Parkinson's—and kept on writing.

{ ALSO }

RESEARCH
NEWS

“SMART”
CLOTHES

SMALL
SUCCESSES

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Stay Positive

It's not always easy to stay positive in the face of adversity, especially with the physical and emotional challenges presented by Parkinson's disease (PD). Here at *More than Motion*™, we want to remind you that you are more than your disease. With inspiring stories from other people with PD, as well as news about breakthroughs and treatments, this community can be considered one of your partners in treatment.

In this issue, we encourage you to stay positive. Our cover subject, the prolific novelist Martin Cruz Smith, reveals his optimistic take on life since being

diagnosed with Parkinson's. "This too will pass" is one of his mantras. Read more about him and his healthy attitude, beginning on page 4.

There's more help for the spirit in our feature about mindfulness, on page 8. A neurologist who specializes in Parkinson's talks about the damage that stress can cause, and how mindfulness can be used in conjunction with other treatments in a holistic approach to treating PD. A good mood can help the patient overall, he explains. He also has recommendations for mind-body exercises such as yoga and tai chi.

Boxing is another great exercise, and gyms around the country now offer classes exclusively for people with Parkinson's. On page 10, we talk to coaches, doctors and patients about the benefits—not surprisingly, the strength that some of these boxers build is not only physical but also psychological.

No matter where you are in your journey, the *More than Motion*™ community can aid in your wellness. Like your team of doctors and caregivers, we're part of your holistic approach to managing Parkinson's, and we're with you every step of the way.

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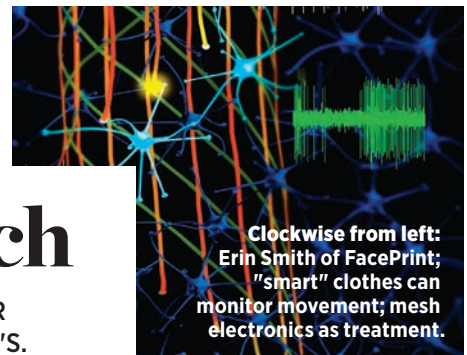
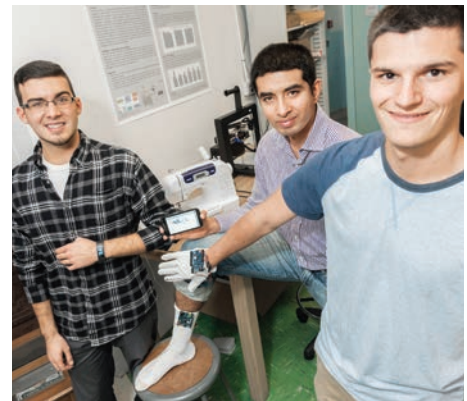


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Newsroom

Events + Community + Solutions + Resources



Bright Ideas in Research

THREE EXCITING ADVANCES IN RESEARCH PAVE THE WAY FOR EARLIER DETECTION, BETTER TREATMENT AND FURTHER STUDY OF PARKINSON'S.

1 A website analyzes facial muscle movement to detect PD symptoms.

Restricted facial expression is an early symptom of PD. What if facial-recognition software could help with a diagnosis? Leave it to a high school student in Kansas to find the answer. Science star Erin Smith has been working to develop FacePrint, an app that recognizes biomarkers, or differences in facial muscles, to detect those displayed by Parkinson's patients.

Smith's site uses a computer's camera to analyze movement and compare the data with other subjects, with the goal of providing early and inexpensive detection. The Michael J. Fox Foundation for Parkinson's Research launched the web-based study through its Fox Trial Finder: foxtrialfinder.michaeljfox.org/trial/4726.

2 Textiles interwoven with sensors can monitor movement in the wearer.

Researchers at the University of Rhode Island are developing "smart" clothes such as gloves and socks that are made from textiles interwoven with electronics. The gloves have embedded sensors that measure symptoms like tremors and rigidity, and are connected to a smartphone that records data and delivers it to doctors who can monitor treatment while the patient remains home. The socks evaluate a person's gait, noting movement that might indicate a need for therapy.

The university is working to partner with companies that can create these products, which have the potential to improve a patient's quality of care.

3 Mesh electronics in the brain may alleviate tremors and other symptoms.

A new device—mesh electronics made from polymer—may revolutionize treatment for Parkinson's disease. The wire meshes, which are thin and flexible enough to be injected by a needle, are connected to a computer that delivers electrical jolts to alleviate symptoms of Parkinson's, such as tremors. The rigid implants currently used in deep brain stimulation (DBS) can degrade over time because of chronic tissue damage. This does not occur with mesh electronics, however. Developed by Harvard chemist Charles Lieber, the mesh stimulates individual neurons as well as measures the activity of neurons, which is a groundbreaking advancement in this area.

CLOCKWISE FROM LEFT: JENNIFER LEAHY/COURTESY ERIN SMITH; MICHAEL SALERNO; COURTESY LIEBER GROUP/HARVARD UNIVERSITY

A Focus on Movement

Movement disorder specialists play a key role in treatment for patients with PD, and one medical society devoted to the field holds its first congress this winter.



Dr. Cynthia Comella is organizing the first congress of the Pan American Section of the International Parkinson and Movement Disorder Society

If you have Parkinson's and haven't visited a movement disorder specialist, you may benefit from a visit. These specialists are neurologists who receive an additional two years of training so that they can offer critical knowledge and skills to the Parkinson's patient that a general neurologist cannot. It's important to try to seek out a movement disorder specialist early on in a diagnosis, even if there isn't one in your immediate area, says **Dr. Cynthia Comella**, a professor of neurological sciences and a member of the Movement Disorders clinical team at Rush University Medical Center in Chicago.

"First of all," she says, "it may save you money, because we know which tests to order. Second, we treat as indicated, so it may help reduce the need to try many different medications."

For example, there are no tests that can diagnose Parkinson's disease. The movement disorder specialist is trained to recognize the clinical fea-



1st Pan American Parkinson's Disease and Movement Disorders Congress

Feb 24-26, in Miami,
pascongress2017.org

tures and obtain the relevant history.

When patients are further along with Parkinson's, a movement disorder specialist can assess whether they are candidates for deep brain stimulation (DBS) and can work with the neurosurgeon to optimize electrode placement and subsequent programming.

The best way for you to find a movement disorder specialist is through your neurologist, patient organizations or professional associations such as the International Parkinson and Movement Disorder Society.

Meanwhile, we can hope to see improvements in the field soon. Comella is organizing the first congress of the Pan American Section of the International Parkinson and Movement Disorder Society (MDS) in Miami in February, which is open to neurologists and nurses as well as other specialists, and will feature breaking news.



Find a Movement Disorder Specialist

Use the Movement Disorder Specialist Finder tool at partnersinparkinsons.org/find-movement-disorder-specialist, provided by Partners in Parkinson's in collaboration with the International Parkinson and Movement Disorder Society.

Search the Centers of Excellence listed at parkinson.org, or call the toll-free Helpline at **1-800-4PD-INFO (1-800-473-4636)**.

To read more about movement disorder specialists, visit the International Parkinson and Movement Disorder Society at movementdisorders.org.

Good to Know...

10%

Percentage of people who have early-onset PD, which often begins before the age of 50.



The Nobel Prize in Physiology or Medicine 2016 was awarded to Japanese biologist Yoshinori Ohsumi for his work in autophagy, which pertains to cells and means “self eating.” Disrupted autophagy has been linked to Parkinson’s.

“A new study: “Gut bacteria in patients with [PD] are different from those microbes found in healthy individuals. When we transplanted the microbiome from [PD] patients into mice, we found that symptoms like motor deficits and neuroinflammation were more severe.... This suggests that there is a fundamental relationship between bacteria in the gut and the disease.”

JULIE H. CARTER, R.N., M.N., A.N.P.

NRF2

Researchers have learned more about this key cellular protein that could lead to treatments for neurodegenerative diseases, including Parkinson’s, according to the *Proceedings of the National Academy of Sciences*.

ACTION STEPS

by Peter Dunlap-Shohl



Join a support group. You help others as they help you.



Keep doing things you love, even if you don’t do them as well.



Do what you can to try to reduce stress.



If you freeze and can’t walk forward, try walking backward. Surprisingly effective!

PEER-TO-PEER

Q+A



Peter Dunlap-Shohl

Cartoonist, blogger, and author of *My Degeneration*, a graphic-novel memoir about Parkinson’s

Q | How does a sense of community help you with PD?

A | Social isolation can be a serious problem for people with PD. Symptoms like difficulty with speech and loss of facial expression hinder communication. You have substantial incentive to hole up. Engaging with others, say, through a support group, can help relieve the sense that you are battling this difficult disease alone.

Find Peter’s blog and his humorous comics at offandonakpdrag.blogspot.com.

Revising the Plot

Despite PD, novelist Martin Cruz Smith carries on with vigor and light, producing best-selling books.

“I had fun,” says Martin Cruz Smith, on researching and writing his latest novel, *The Girl from Venice*—a romance set in Italy at the end of World War II.

Fun is a word he uses often.

But his life is not all clear sailing.

While Smith has written many novels, including *Gorky Park*, the literary thriller that introduced Russian detective Arkady Renko to fans, he also has Parkinson’s disease, which presents its own challenges.

His description of those challenges, however, centers on play, comparing his lack of focus with an inability to follow instructions for putting together a child’s toy. Also, he says, “I can’t skip. If you can—congratulations.”

While Smith concedes that “denial has thousands of stages,” his relentless optimism seems like a choice. Then again, fun runs in his family. His father was a jazz musician, his mother a nightclub singer. They met at the New York’s World’s Fair in 1939. She was a Pueblo

Indian girl who was there to represent New Mexico.

“They were an attractive, romantic couple,” Smith says. “Eleanor Roosevelt once had them thrown out of Washington Square, where she rented an apartment, for making noise at 2 a.m. Too much fun.”

As children, Smith and his brother and his sister, Jack and Beatrice, lived with their paternal grandmother in Pennsylvania when their parents toured the East Coast. Later, Smith studied creative writing at the University of Pennsylvania, where he met his future wife, Emily “Em” Arnold.

The pair married and lived in New York City while Smith edited a men’s magazine before focusing on writing novels. He turned out bread-and-butter projects while carving out time to work on what would later become *Gorky Park*.

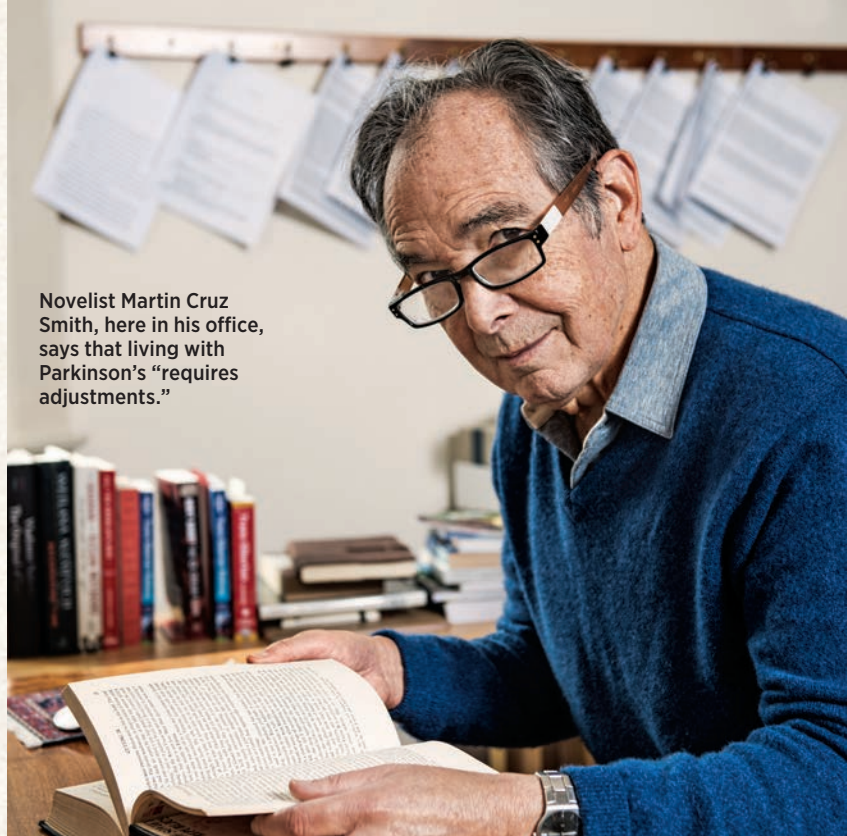
With the success of that book, the Smith family, which by then included two daughters (and later a son), turned the corner financially. Smith went on to produce eight books in



WRITTEN BY
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PHOTOGRAPHS BY
WINNI WINTERMEYER



Novelist Martin Cruz Smith, here in his office, says that living with Parkinson's "requires adjustments."



the best-selling Arkady Renko series and other acclaimed novels, including *Rose* and *December 6*.

A Diagnosis—and DBS

"I had about as lucky a life as one could have," Smith says, describing the time before he was diagnosed with PD in his mid-50s. As tremors, slowness and rigidity set in, he tried medications, concealing his condition for 18 years while continuing to write, even as he struggled to take notes and sketch, both instrumental to his research process.

When he could no longer type, Em stepped in, taking dictation as he paced the room. After Smith submitted *Tatiana*—a book inspired by a Russian journalist who was murdered after aggressively reporting on political corruption—his editor praised the manuscript. Smith then revealed his Parkinson's. "At a certain point you owe it to people," Smith says. "First, I had to prove that I could write."

He also fought back medically. When the book was finished, Smith underwent deep brain stimulation (DBS). Doctors customized the surgery, planting electrodes in a specific region of the brain

to preserve verbal fluency while still controlling tremors.

In 2013, he began to speak publicly about Parkinson's, giving interviews to major news outlets that published videos and articles about his diagnosis.

Some writers have wondered how he can write without typing. During one interview, an author suggested to Smith that typing is how writers think. Smith responded, "There was a time I thought I could not write unless I had a cigarette in my mouth. You adjust. Living with PD requires making adjustments."

Focus on the Fun

As Smith continues to work, family members help. He recently went to Siberia with Em and his daughter, Luisa, who took photographs for her father's research. Smith says that "if anything," the struggle with Parkinson's "adds a certain grit to the writing."

At age 74, Smith is still doing what he loves, working on a novel, sometimes facing rough spells, as we all do.

"There are days when you feel floored," he says. "You might think, 'Good day to crawl under the table.' Tell yourself, 'This too will pass.'"

Martin Cruz Smith shares advice for beating the blues.

When you hit a wall: Get out a good book, or watch a great movie. Go for a walk and appreciate the day.

Sign up: "I joined a therapy class," he says. "Seeing other people with PD is like looking in a mirror. Some will be in a much more advanced stage than you are, but they won't be deterred."

Exercise: Get moving. Nothing helps the PD body and mind more than physical exercise.

Come to terms: "Accept that it's going to be difficult," says Smith. "But a lot of time may go by—make the most of it!"

Try something new: "I was in a log cabin in Siberia singing 'Streets of Laredo.' That, I promise, was a one-time event."



THINGS TO ASK A ...

Neurologist

WE SPOKE TO AN EXPERIENCED NURSE—ONE WHO KNOWS THE INS AND OUTS OF THE PATIENT-DOCTOR EXPERIENCE—ABOUT JUST HOW NEUROLOGISTS CAN HELP WITH PD.

Checking in regularly with a neurologist can help you control Parkinson's symptoms. We talked to an advanced practice nurse specializing in Parkinson's, **Mariann Di Minno, R.N., M.A., C.N.S.**, at the Department of Neurology at the University of California, San Francisco, about neurologists, movement disorder specialists (who are specialized neurologists; see page 2), and more.

Q | Why see a movement disorder specialist instead of a general neurologist?

A | Movement disorder specialists are neurologists who focus on PD and related conditions and, thus, are experts on symptoms, medications and other treatment options; they can connect patients to other specialists, such as speech or physical therapists, when needed. If you must travel to see one, they will do an assessment and may suggest medication tweaks and such to your local general neurologist.

Q | Why might my medications need tweaking?

A | PD medications often work effectively for a period, but as time goes on and the disease progresses the same medication may not treat symptoms as well. That's when it may be time to add medications that can prolong and improve symptom control. We now have many more medication options than in the past, and there are other treatments, such as deep brain stimulation, that can also be considered.

TIP

The Parkinson's Disease Foundation can help you find a neurologist: [pdf.org/en/resource/link](https://www.pdff.org/en/resource/link)

Q | How often should I have an assessment to review my treatment plan?

A | It depends on the individual. If symptoms are stable, then every three months might make sense if the patient and the movement disorder specialist are in the same locale. If starting a new medication, the patient should see the specialist earlier. If a patient must travel, then consider an annual check-in with a follow-up from a local neurologist. A review is also indicated when a patient or caregiver feels symptoms have changed significantly; the patient is having more trouble with walking, balance or speech.

Q | How should I prepare for an assessment? What should I bring to an appointment?

A | Be ready to provide all current information about your medications: the dosages and when and how you're taking them—with or without food, for example. You'll also be asked whether you're having any specific problems and what your best and worst times of day are. If you're under stress, share that as well; stress can make symptoms of PD worse. Caregivers often have good information and perspective that can help paint a more complete picture, so ask them, too.



Positive Thoughts

Mindfulness can lead to less stress—and better outcomes.

Could your own brain help you in the fight against Parkinson's? More and more often, patients are turning to mindfulness-based treatments like yoga, deep breathing and meditation to help curb stress and anxiety, which in turn can help make a chronic disease like Parkinson's a little more manageable. In a recent study published in *BMC Neurology*, for example, researchers studied the impact of a six-week mindfulness program in an assisted living community of adults with stage 2 Parkinson's disease. As part of the mindfulness program, patients met once a week for two hours and practiced "attention to breath" and "letting go of negative thoughts." Participants were also encouraged to

"explore personal meaning" in their lives and were given a guided meditation CD to use over the course of the program, according to the study synopsis.

At the end of the course, researchers tracked the patients' progress and found, six months after treatment, that the patients were more mindful and less anxious, and were even choosing healthier behaviors (like added fruit intake) as compared with the control group. In an earlier study, where patients underwent a similar mindfulness-based lifestyle program, some Parkinson's patients actually had improved motor performance and lessened tremors.

Doctors Agree

In his own practice, Jerome P. Lisk, neurologist and director of Movement

Disorders at CHRISTUS® Trinity Mother Frances Health System, has noticed how a patient's mood can affect his condition—for better or for worse.

"The patients who have more anxiety and more stress do worse in this disease than the ones who don't," says Lisk. "Many patients will complain that when they're stressed, they feel like that worsens their condition. They have a reactivation of old symptoms."

Tremors and muscle stiffness, for example, can worsen when patients are anxious or depressed, he notes. On the other hand, experiencing a deep sense of joy or peace causes the secretion of a chemical in the brain called dopamine, which is responsible for regulating mood and improving motor function. Mindfulness-based activities like



Seeds of Serenity

How to implement mindfulness into daily life

Yoga “Exercise is very important for people with Parkinson’s, because it helps release dopamine,” says Dr. Jerome P. Lisk. Not only is yoga associated with stress and tension relief, but it also helps muscle elongation and flexibility. According to Lisk, this can lead to fewer falls for PD patients by improving their anticipatory reflexes. “It not only keeps patients stretched out, but it helps them with balance and posture.”

Meditation It’s simple, it’s free and it works—studies have shown that meditation can help manage chronic stress, lower blood pressure and even boost concentration. Surprisingly, one study showed that people who meditated for an average of 30 minutes a day for eight weeks actually exhibited changes in the brain: The amygdala, which regulates the body’s “fight or flight” response, had reduced activity in patients who completed a mindfulness program.

Tai Chi This Chinese meditative practice involves slow, guided movements, and a 2012 report in the *New England Journal of Medicine* showed that tai chi may improve balance for people with PD, as well as prevent falls. Lisk recommends tai chi to his own Parkinson’s patients who have anxiety. “People are able to move better, and they’re more relaxed and at peace,” he says.

yoga, gentle stretching, deep breathing, or meditation can all potentially release dopamine by blocking outside stressors and focusing the patient on the present moment. “We doctors don’t really use the word ‘mindfulness.’ We say ‘stress reduction,’” Lisk jokes. “If people are meditating and they improve their stress level, then it improves their health, absolutely.”

Lisk recommends that mindfulness therapies be used in conjunction with other treatments, like antianxiety medications or antidepressants, for best results. It’s also important to talk to your doctor. In the end, anything that improves a patient’s mood will help the patient overall, says Lisk.

“The better you feel about yourself,” he explains, “the better you are.”

Parkinson's — on the — ROPES

Boxing delivers a one-two punch against a formidable foe.

For some people with Parkinson's disease, fighting their symptoms has taken on new meaning. Around the U.S., PD warriors are lacing up their boxing gloves and going more than a few rounds with the disease that threatens to limit their mobility. It seems that noncontact boxing may be an effective form of physical therapy.

Jorge L. Juncos, M.D., a movement disorder specialist at Emory University School of Medicine and the Emory Brain Health Center in Atlanta, discovered the benefits of noncontact boxing through his work with PD Gladiators, an organization that promotes fitness in people with Parkinson's. "Boxing gives you a vigorous workout and can alleviate PD motor symptoms as well as the secondary disabilities that come from aging or sedentary habits, such as acceleration of age-related stiffness and loss of joint and muscle elasticity," he says. "Through exercise, you can slow down symptom progression."

Improving Balance

The popularity of PD boxing classes has spread since the first program of its kind, Rock Steady Boxing, was introduced in Indianapolis in 2006. More than ten years later, there are hundreds of Rock Steady Boxing classes around the world.

In 2016, after a friend's uncle was diagnosed with PD, Scott Anderson, fitness coach and owner of Element Athletix in Meridian, Idaho, attended Rock Steady's training for instructors. He was impressed. "When they throw a combination of punches, it can improve concentration and can help prevent freezing," he says. Now, on weekdays, more than a dozen men and women in varied stages of Parkinson's do the 50-minute workout. Anderson and his trainers provide one-on-one instruction. He's found that boxing helps increase mobility both in and outside of class. If his boxers begin to freeze, Anderson calls out code words. "It helps change their thought process. If they get stuck outside of class, they can think of the code words to restart."

Confidence Booster

The effects of noncontact boxing on PD symptoms caught the attention of Pennie Seibert, Ph.D., a neuroscientist and chief research scientist at Saint Alphonsus Regional Medical Center and professor at Boise State University. "I've seen people come in using walkers and after they step onto the exercise area, they look like different people," she says. "The instructors teach participants a way to plant the feet and hold the body that provides greater stability."

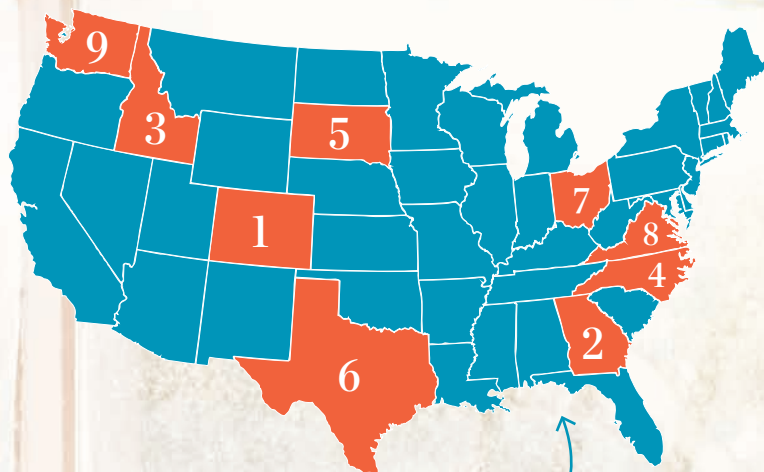
Anderson's Rock Steady class is the subject of Seibert's clinical study on the efficacy of noncontact boxing therapy for PD. Although her research will not be complete until next year, initial findings are looking positive. "Not only does boxing seem to help the physical symptoms of PD but it also improves the sense of self," she says. "I've heard over and over again that people believe noncontact boxing has changed their lives."

"I'm a better person for it"

Allen Rabinowitz can attest to that improvement. He attends boxing training for Parkinson's disease at Delgado Boxing & Fitness in Atlanta, Ga. Rabinowitz was diagnosed with Parkinson's in 1999 at age 47. The loss of his ability to take part in sports was one of the frustrations he's faced over the years. Boxing put him back into the ring, literally and figuratively, and he's not looking back. "My hand-eye coordination has improved, and the footwork has helped my balance, plus I'm not as angry," he says. "I have a working body. It feels good knowing that I can do this."




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GALLOWAY**



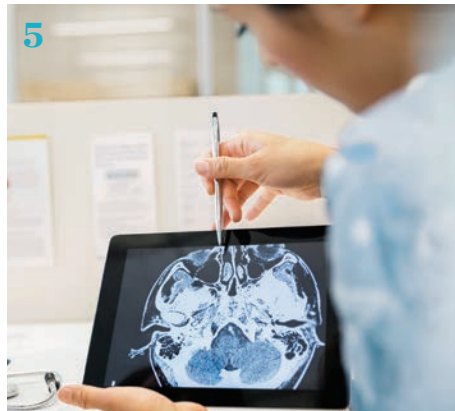
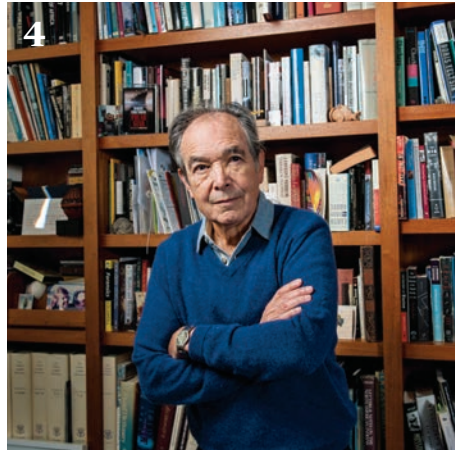
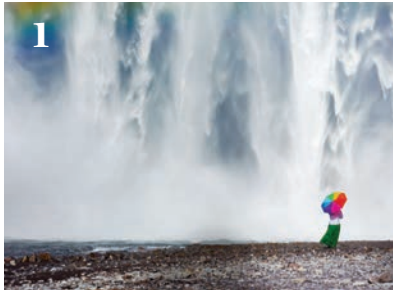
Pick a Fight

Here's a sampling of boxing classes around the country for people with Parkinson's. Consult your local PD organizations for more listings. To find Rock Steady locations in 44 states (and abroad!), search "Find a Class" at rocksteadyboxing.org.

- 1 Boulder, Colo.:** Power Punch Parkinson's Boxing at various locations, parkinsonrockies.org
- 2 Atlanta, Ga.:** Boxing Training for Parkinson's Disease at Delgado Boxing & Fitness, pdgladiators.org/atlanta-boxing-program
- 3 Meridian, Idaho:** Rock Steady at Element Athletix, elementathletix.com
- 4 Boone, N.C.:** Parkinson's Boxing Class at Paul H. Broyhill Wellness Center, wellness.apprhs.org
- 5 Hot Springs, S.D.:** Parkinson's boxing classes at Bodies in Motion, facebook.com/Bodies-In-Motion-1589601481303064/about/
- 6 Fort Worth, Texas:** Punching Out Parkinson's at Paulie Ayala's University of Hard Knocks Gym, punchingoutparkinsons.org
- 7 Toledo, Ohio:** Knock Out Parkinson's at International Boxing Club, ibctoledo.org
- 8 Springfield and Falls Church, Va.:** Boxing for Parkinson's at Title Boxing Club, titleboxingclub.com and parkinsonfoundation.org/virginia
- 9 Seattle, Wash.:** KO Parkinson's at Arcaro Boxing, arcaroboxing.com



PD Gladiators, left, is an organization devoted to battling Parkinson's with vigorous exercise.



8 things to remember

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

1 Have hope.
Researchers are continuing to work on advancements in diagnosing PD and treating it, so tune in to news.

2 Get involved.
Studies for people with PD are available online, and by participating, you might be helping advance research.

3 Talk to specialists.
It's a good idea to talk to a movement disorder specialist, a neurologist with training to help you with PD symptoms.

4 Accept changes.
Novelist Martin Cruz Smith says it's important to make adjustments. When you have PD, it's a requirement.

5 Follow up.
Check in regularly with your neurologist. Parkinson's symptoms change, so your treatment plan may, too.

6 Be mindful.
Practices such as deep breathing and gentle exercises can help you reduce stress and feel better.

7 Box it out.
Gyms around the country offer boxing classes for people with PD. Consider trying one near you.

8 Take it easy.
Take note of all the little ways that you overcome challenges in your daily life. Your strength may surprise you!



Little Wins

Living with Parkinson's, you learn to champion the small successes. On this closing page, we share Facebook comments from some of our fans whose posts told us how they work through the challenges of PD with humor and grace.

Do you have a "small success" to share?

Like us on Facebook and tell us about it in the comments! facebook.com/parkinsonsmorethanmotion

Remember to Breathe

"Sometimes I get so tongue-tied I have to just stop talking and breathe. It's quite embarrassing when it happens in public. I try to laugh it off."

—Nikki Davis

Color-Code Cues

"My hubby's eyesight has been affected. He couldn't find the handles on the inside of the car, so I put bright green duct tape on the handles."

—Patricia Durden

Wellness at Home

Day-to-day activities may be easier with these suggestions for around the house.



Cooking: Have you noticed that modern-day utensils and cooking tools tend to have bulkier handles now than in the past? If you're using products from years ago, consider buying new ones. Thick handles and nonslip materials are your friends.



Drinking: If you have tremors and are prone to spills, consider filling your glass half-full (not half-empty!). You can also drink from a plastic water bottle or a sports bottle with a narrower opening that can be sealed shut.



Cleaning: You may find that it's easier to use a dustpan that has a long handle, so you don't have to stoop to sweep up the mess.

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

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

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