

Rabbi Moshe Yitzchok Gruskin speaks candidly about his 18-year battle with Parkinson's

# Flare of Hope

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The phone buzzes on speaker as I pace the airless, boxed-in cubicle—Monday vibes at their best.

“Hello?” the voice rings through, vibrant and strong. It’s Rabbi Moshe Yitzchok Gruskin, founder of LifeSpark Jewish Center for Parkinson’s. I snatch up the phone. “Hi, how are you?”

“I’m doing amazing, *baruch Hashem*. Just fantastic. How are you?”

I introduce myself, telling Rabbi Gruskin I’m reaching out for an interview.

“Here’s the problem,” he tells me. “Tomorrow morning, I’m going to Robert Wood Johnson to meet a doctor on behalf of the Parkinson’s community. After that, I have to take care of my car. On Wednesday, I’m undergoing outpatient surgery. I’m not sure how I’ll feel the day after. Do you mind calling my secretary to schedule a meeting?”

Without knowing his background, I would never have guessed that Rabbi Gruskin has been battling Parkinson’s for the last 18 years.

## Warning lights

Our virtual meeting kicks off as soon as there’s a slot in Rabbi Gruskin’s packed schedule, a few weeks after my initial call.

The Zoom screen displays a smiling Rabbi Gruskin and his wife, Mrs. Kaila Gruskin, who plays a key role in LifeSpark, and in another display box, Paulette Laniado. A medical assistant and LifeSpark patient liaison, she’s usually the first friendly face patients see when they come to LifeSpark for support and advice.

Once introductions are made, Rabbi Gruskin shares his story. “When I was 56 years old, my left foot started dragging when I walked. I ignored it.”

A fundraiser by profession, he would visit his hometown in Detroit, Michigan, every summer. “When my friends there saw me for the first time in a year, they said, ‘We don’t like the way you look. You need to see a doctor.’”

I went to a neurologist, who told me, “I think you have Parkinson’s. Here’s some medicine. Take it and see if it makes you feel better.”

Mrs. Gruskin, who brings her experience as the wife of a Parkinson’s patient to LifeSpark families, leans into the narrow frame. “My husband brought the prescription home and put it away in his drawer, and that was that. He insisted, ‘I don’t have Parkinson’s.’”





A second doctor thought the rabbi had a slipped disc in his back. Months of exercise and \$8,000 in physical therapy copays yielded almost no improvement.

“Other symptoms began to crop up that were, in hindsight, caused by the Parkinson’s. Still, I refused to believe I had the disease. I thought, *I’m getting older. This is how it goes.* And by 2012, three years after my initial diagnosis, I looked like a 75-year-old man when I walked.”

Paulette explains, “The first Parkinson’s indicator is most commonly a tremor in the hand or a shuffle in the foot. But the disease has over 40 symptoms, many of which overlap with regular aging or common conditions. Initially, symptoms like loss of smell, memory lapses, sleep issues, or anxiety can be dismissed or

gathering of researchers, doctors, therapists, caretakers, and patients. Researchers and doctors didn’t fully understand the perspectives on the patient and caregiver journey; to address this gap, they organized the gathering to foster mutual understanding between the two sides. Hearing about the latest medical developments gives hope for people who have Parkinson’s. At the same time, it helps doctors understand what’s going on in patients’ lives.

In 2013, the conference was in Montreal.

“There, I found a lot of hope, a lot of inspiration, and a clear sense of the practical steps I should take to navigate this journey of Parkinson’s. One of the main takeaways, which is still the main advice today, a decade later, is exercise, exercise, exercise. That’s the proven way to lessen—and even reverse—the effects of Parkinson’s. Interestingly, scientists found that it makes a big difference if you exercise to lively music.”

Paulette highlights the difference between seeing a neurologist and a movement disorder doctor. “The analogy that I give is this: If your child has a stomachache, you assume it’s a virus. You wait a few days, and when it doesn’t go away, you take him to the pediatrician. Now it’s time for labs. Let’s say the results come back, and it’s Crohn’s. Do you ask the doctor to perform a colonoscopy

## There’s an expression in the Parkinson’s community, “If you met one person with Parkinson’s, you’ve met one person with Parkinson’s.” Every Parkinson’s case is unique

mistaken for something else. Even when clear signs are present, patients are often very slow to accept the diagnosis. Parkinson’s involves a dopamine deficiency affecting the chemicals in the brain, so the denial we see so often in patients actually makes a lot of sense.”

### Reality sinks in

After three years of decline, Rabbi Gruskin’s family took a stand. “Enough is enough,” they said. “It’s time to see a doctor.”

“As soon as I walked into the neurologist’s office, he told me, ‘You have Parkinson’s.’ He saw it in my smile, which was bigger on the right side than the left.

“I then saw Dr. Stanley Fahn, the movement disorder guru who trained many of this generation’s best doctors. Unfortunately, as soon as he saw me, he too confirmed the diagnosis and prescribed Sinemet.”

The gold standard of Parkinson’s treatment, Sinemet helps manage Parkinson’s symptoms by replenishing dopamine levels in the brain.

“It was depressing. The fear of the unknown was huge. But after denying it for all those years, I was finally ready to do something about it.”

While in the waiting room, Rabbi Gruskin noticed a brochure about the World Parkinson’s Congress, a

and put the child on medication, or do you say, “Thank you so much, doctor; could you refer me to a gastroenterologist?” You’re not going to your PCP for Crohn’s treatment.

“Similarly, it’s often the general neurologist who will be the one to diagnose. Once a person gets a Parkinson’s diagnosis, it’s extremely important to follow up with a movement disorder specialist because that’s their field. They’re the ones who will control the daily medication, establish a baseline, and see what should be done.

“One of our biggest struggles in LifeSpark is convincing patients to see a movement disorder specialist instead of continuing with their general neurologist. Unfortunately, many neurologists try to handle the case on their own even though it’s out of their scope.”

### Defying decline

“As soon as I came back from the conference, I called my kids together for a meeting. ‘You’re on duty as my cheering squad,’ I said, ‘If you’re going to be behind me and encourage me to exercise, I’m going to be okay. If you don’t, then after three or four months, I’m going to lose my motivation, and it’s going to be over.’

“We made a schedule, and everybody had a turn to be with me for my exercise. For a person who has symptoms of Parkinson’s, it’s really very hard to do exercise at the

beginning because their limbs are usually very stiff. It's like putting a 50-pound bag of sand on your feet and saying, 'Now do your exercise.' In order for a person to do the intense exercise at the beginning, they really need to be encouraged.

"I exercised for 50 minutes straight six days a week, nothing less, for three years. Today, with the Ribono Shel Olam's help, it's 18 years later, and I'm reaping the benefits of that time.

"The early years of Parkinson's are called the 'golden years.' It's important to do regular exercise then. This effort can make a big difference in how well you manage the condition later on. Think of it like *shanah rishonah*—if you build a strong foundation at the start, you have a strong foundation to handle challenges better down the road. By focusing on exercise and healthy habits early on, you'll benefit in the future.

"Don't get me wrong; you still have to do exercise after those first few years, but it doesn't have to be as intense."

Paulette sits down with patients after they hear the devastating diagnosis. "We explain that Parkinson's is a disease where there's a lack of dopamine in the brain. How do we combat Parkinson's? Unfortunately, there's no cure yet, but in most cases, there are ways to slow its progression.

"There are three ways to add dopamine into the system. At LifeSpark, we've named each approach so that they're clear to the patients:

- **Synthetic dopamine**, through medication such as Sinemet.
- **Natural dopamine**, which comes from the food we eat. There's a specific brain-healthy diet that increases dopamine levels.
- **Active dopamine**, which we generate through intense exercising.

"There are many different trials and experimental drugs to slow the progression of Parkinson's, but they all have potential side effects. Exercise is the only treatment for Parkinson's that doesn't have any negative side effects. The earlier you start exercising, the better off you are. *Baruch Hashem*, in most cases, exercise helps slow the disease.

"Whenever we advise patients about exercise, we always tell them to confer with their physical therapist before doing any exercise. We don't want muscle fatigue or a broken hip *chalilah*. Everyone has a different baseline, and we want to make sure that they're not doing anything that's going to harm them."

Exercises that emphasize aerobic activity—such as brisk walking, cycling, or swimming—as well as strength training, stretching, and balancing exercises are crucial.

"Doctors said many times at different conferences that when you feel you're finished with the exercise, it's too much and you can't anymore, if you do another three or four minutes of work even though it's very, very

hard, that's when the dopamine is released," Rabbi Gruskin shares. "It's not just the extra three or four minutes after you feel you did your share, it's the intensity with which you're doing the exercise the whole time. The more intensely you do it, the more you're going to reap the benefits. If you do it properly, with the intensity and the time you need, it either delays the disease from progressing or brings you back to the earlier stages of Parkinson's."

### Building LifeSpark, building hope

"By 2016, I was finally comfortable being open about my diagnosis. It's interesting; when you're open about something, it stops defining you. It becomes just a fact, a piece of your story. Yes, I have limitations, but it doesn't define me.

"Parkinson's is very prevalent in the Ashkenazi community; it's become almost an epidemic. I couldn't believe there was nobody there for us; it made me furious. At that point, I decided that it was time that I took on this organization.

"It's a very devastating diagnosis, and whoever gets it usually feels completely lost and doesn't know what the journey will bring," Rabbi Gruskin shares. "How will I go on with life?" they wonder. "Will I be able to work?" They don't know how they'll be affected, and the uncertainty is terrifying.

"That year, I brought 28 people to the World Parkinson's Congress. They all got very excited about the power of exercising and started taking it very seriously."

As word of LifeSpark spread among Parkinson's patients, Rabbi Gruskin and his expanding team adapted to their needs. They began offering consultations, helping individuals navigate the daunting early days and weeks following their diagnosis.

The organization soon introduced an advocacy branch, followed by informative Zoom classes and a newsletter. In time, support groups emerged where patients and caregivers could find understanding and friendship. Through the commitment and boundless passion of the Gruskin family and the LifeSpark team, the organization grew from a small group of 28 into a multifaceted global network in just eight years. Today, LifeSpark provides vital support to Parkinson's patients and caregivers in cities such as Los Angeles, Chicago, Montreal, and Toronto and across countries including England, Switzerland, Australia, and Mexico.

"When I first started LifeSpark, a man called me with a devastating





question. ‘I heard you help people with Parkinson’s,’ he said. ‘Tell me, when do I go to the *beis hachaim*?’

“I almost cried. I said, ‘You’re completely wrong. There’s a lot of hope, there’s a lot you can do, and there’s a lot that Hashem helps us do.’

“From the time that a person has the guts to call our organization and on, it’s a positive experience. That, I insist on. They find a community, a network. We give them the gift of hope and the will to live the best lives they can. They feel the warmth, the care, and the support, and they know they’re not alone in this journey. That’s the most important thing.”

### The best thing

“In the beginning, there’s so much unknown, and that causes a lot of stress. Stress is very bad for people with Parkinson’s because it brings the symptoms forward. When you alleviate stress, the symptoms usually subside somewhat,” Rabbi Gruskin notes.

“When people come to the LifeSpark center for a consultation, the first thing I tell them is, ‘If you want to know what’s going to be, don’t look at anybody else. If they have a certain limitation or symptom, it doesn’t mean you’re going to have it.’ There’s an expression in the Parkinson’s community, ‘If you met one person with Parkinson’s, you’ve met one person with Parkinson’s.’ Every Parkinson’s case is unique.

“You really don’t know what you’re going to experience. You might as well leave it to the *Eibershter*. He’s going to take care of you. Don’t look at the future. Look at what you can do now, with the *Eibershter*’s help, to lessen the symptoms and slow the progression.”

Framed that way, it sounds simple.

“Don’t think it’s easy to accept,” Rabbi Gruskin warns. “It took me ten years of working on myself, of studying the *Chovos Halevavos Sha’ar Habichon*, of learning to accept and trust that the *Eibershter*’s plan is the best, to realize that Parkinson’s is the best thing in my life.

“You might be thinking, *Are you crazy? Come on, it’s Parkinson’s*. The answer is that Parkinson’s has caused me to be more empathetic, more understanding, and more relaxed. It taught me to leave myself in Hashem’s hands. Hashem will take care of me. Since I know that nothing I do in life is more important than helping others, I choose not worry about anything else.”

### Early-onset spreads

Unfortunately, since covid, doctors have seen an enormous influx of Parkinson’s diagnoses and cardiology issues. No one’s quite sure if the wave is due to quarantine, the vaccine, or covid itself. Especially in the Parkinson’s field, they’ve seen many more early-onset cases than ever before.

## Feedback

Rabbi Gruskin shares a letter a patient recently sent, one of many, many similar grateful messages.

*Lchvod Rabbi Gruskin, dear Paulette,*

*I cannot describe to you how much chizuk we received from our visit to you.*

*The wealth of practical information you gave us was so meaningful because it was presented with background information and an understanding of the sickness itself. The potential, *b’ezras Hashem*, of exercise to augment and support the depleted level of natural dopamine was exceptionally meaningful.*

*This understanding has made all the difference in the stamina that it takes to exercise a few times a day, as it has lifted it up from a mere *eitzah tovah* to something much more significant. Your warmth and understanding of the challenges that I’m experiencing and your openness about the sickness, along with the positive and upbeat tone of the whole meeting, was in itself a source of tremendous chizuk.*

*The sheet with the information on dietary recommendations was also useful. The knowledge that I can connect back with you makes me feel that I’m not locked alone in my situation. May Hakadosh Baruch Hu give you only brachah in the *zechus* of your outstanding chessed and support.*

“They find a community, a network. We give them the gift of hope and the will to live the best life they can”

## The LifeSpark lifeline

### Support and resources for the Parkinson's journey

When someone first walks through LifeSpark's doors, they're welcomed with a free initial consultation where the focus is solely on understanding their unique needs.

"For that block of time," says Paulette, "there are no ringing phones and no interruptions, just complete focus on the patient and the relatives they've brought along.

"We begin by exploring the science behind Parkinson's disease and explaining the potential symptoms. We then discuss the patient's specific difficulties and challenges. Finally, we review their treatment plan and the doctors and therapists they're currently working with. We explore the needs of the patient—should they prioritize speech therapy? OT? PT? Is there a specialist we can involve? We offer ideas and suggestions, calling doctors and therapists for their view or referral."

LifeSpark staff is constantly meeting with new doctors, new researchers, and anyone in the medical field who can help improve Parkinson's treatment. They also actively engage in advocacy, working with the Michael J. Fox Foundation and other support organizations.

The LifeSpark team has even participated in Congressional meetings. "Most recently, we were honored to be chosen as our district's representatives to discuss advocacy and the best use of the allotted funds to advance Parkinson's research," says Paulette.

The organization offers a wealth of educational resources.

Monthly Zoom events feature specialists in cardiology, pain management, urology, psychology, and more. "Any

issue that we see a lot of patients dealing with, we bring to the forum," Paulette says. The Zoom events feature live Q&As so participants can ask any questions they have. These classes are available globally and are later accessible on the LifeSpark website for ongoing learning.

They also send out bimonthly newsletters with the latest news in the medical world of Parkinson's along with anything they feel might benefit patients, like Parkinson's grant opportunities, for example.

Patients are constantly reaching out for guidance.

"One of the things we pride ourselves in is that during business hours, with Hashem's help, we call everybody back within 24 hours. We don't like to keep anyone waiting."

Medical referrals, a resource library, support groups for patients and caregivers, and expedited doctors' appointments when necessary are all services designed to support those navigating this overwhelming challenge. The website features a submit-your-question option, which on-staff doctors and therapists are available to address.

"Anything that can help patients and caregivers, we try to provide," Mrs. Gruskin says. "Two years ago, we hosted a relaxing *Shabbaton* for patients and their caregivers. We had various doctors and therapists come along or Zoom in and speak. People were just blown away. Many of them told me, 'I finally felt like a part of a community. I went to shul, and I felt like I belonged. The people here understand me; they know what I'm going through.'"

Unfortunately, with a growing demographic and heavy overhead, they don't have the funds to do it again.

Paulette says, "Parkinson's used to be a common geriatric condition. I spoke to a 42-year-old patient yesterday. Unfortunately, that's not uncommon these days. We see plenty patients today who are in their early 40s or late 30s."

LifeSpark used to receive one to three new patients a month. Now, the monthly norm has leaped to 16 to 20. Rates have surged to an average of 100 to 150 new patients per year. There's nobody in this community that doesn't know someone who had Parkinson's.

"It's going to be a challenge if we're not prepared for it. Parkinson's is a chronic disease that's showing up more and more in our community, with over 200 cases in Lakewood alone, many of them young men and women. If we don't step up now and help them manage the disease, it can become a real challenge in the future for patients, their families, and the community as a whole."

#### The cure is coming

Says Rabbi Gruskin, "I always tell LifeSpark patients that it's our job to do our *hishtadlus* with the proper eating habits, the proper therapy, the proper exercise, and the proper medication if needed until a cure is discovered. We believe that Hakadosh Baruch Hu can make a cure for this just like He can cure anything else, and we just have to hold onto that positive mindset that we're doing our *hishtadlus* just until a cure is found. And with all our *davening*, I'm confident that there will, *b'ezras Hashem*, one day be a cure. I don't know if it's going to be now or in 20 years, but I'm confident it will happen."

May the founders' deepest hope and belief—that a cure will soon be found—render LifeSpark's role as a crucial support system unnecessary.

Until then, LifeSpark and its unstoppable founder will continue to be a beacon of support and inspiration. ●