

FESPARK NEWSLETTER

ELUL - STAYING YOUNG AS TIME GROWS OLD

Rosh Hashanah, our New Year, is celebrated on the first day of the month of Tishrei. However, our Avoda and our efforts towards renewal are the distinctive work of the previous month, Elul. Elul is referred to in the Torah as the אחרית עונה, the end of the year, its essence being the extreme and farthest point from the year's start. At the beginning of the year, a sense

of vitality and freshness pervades, while

גליון זה מוקדש לעילוי נשמת הרב שמעון יהודה בן הרב אברהם יעקב עפשטיין זצ"ל

THIS EDITION IS DEDICATED

L'ILUI NISHMAS RAV SHIMON YEHUDA BEN RAV AVROHOM YAAKOV EPSTEIN ZT"L

FOR SPONSORSHIP OPPORTUNITIES,



at the tail-end in Elul, stagnation and apathy tend to kick in. The closer we are to our source and essence, the more alive and vibrant we feel, while from a distance, we fade, our feelings and souls withering, listless. Elul's struggle to maintain a genuine sense of potency and renewal is of great challenge and significance.

Elul's unique requirement is the daily blowing of the Shofar, aside from our obligation to blow the Shofar on Rosh Hashanah. The Midrash says that the source for this is the Shofar that Klal Yisroel blew when Moshe went up to Har Sinai during Elul (for the third and final forty days, concluding with the atonement of Yom Kippur and the receiving of the second Luchos). It says that during the days of Elul, there was a particular concern that Klal Yisroel would revert to serving Avodah Zarah, and the Shofar served to deter them from doing so.

At other intervals during the year, while we are still connected to the year's beginning, the lure to serve Avodah Zarah is not as great. Our association with the source, our sacred portal of time, Rosh HaShanah, is a powerful spiritual bond that keeps us grounded in the faith and genuine service of Hashem. However, when that bond is tenuous, and our identity with our sacred source weakens at year's end, we need reinforcement to ensure and strengthen our devotion and commitment.

The Shofar is the tool that awakens, inspires, and reconnects. It stimulates us to return to our core vitality and rekindles our relationship with Hashem. As the Rambam tells us, in the sound of the Shofar lies a compelling subliminal message: "תקיעת שופר... רמז יש בדבר",

the Shofar contains within it an allusion. It hints to Man: Wake up and do Teshuva - do not slumber in your physical world pursuits, listen to your Neshama, return to Hashem and be enlightened.

Our unique work in Elul is to find vitality, freshness, and a sense of new beginnings, even from a distance; to commit ourselves anew to nurture physical, emotional, and spiritual health - even when life seems worn, stale, and tired. The struggle is daunting and challenging, while the dividends are extraordinary. Our work to achieve the elusive renewal of Elul is what stands in our merit to secure the divine gift of renewal on Rosh Hashanah, granting us dynamic life and genuine vitality for a whole blessed year.

בברכת כתיבה וחתימה טובה,

Rabbi Tyviki Fener

We are proud to announce that we have recently been enthusiastically accepted as an American Brain Coalition (ABC) member! The ABC has an overarching goal of improving treatments for all Americans affected by brain conditions, and we share that commitment to improving treatments for our Parkinson's patients.

In recognition of this special collaboration, we now have a unique ABC Member Seal prominently displayed in many of our communication channels. ABC will officially announce us as a new member in their next eNews Update, sent to all ABC members and observers. There will be a link on their website to our organization's website for those who wish to learn more about us or require more information, and our logo will be added to nearly 200 organizations on ABC's website.



HOSPITAL TRIUMPHS: RABBI GRUSKIN'S HOSPITAL EXPERIENCE

Our founder, Rabbi Moshe Y. Gruskin, has dealt with the challenges of Parkinson's Disease (PD) for the past 18 years. He knows the importance of adhering to a strict medication regiment to keep his symptoms at bay. He understands that both anesthesia and surgery affect the brain and may not be the safest option for someone with Parkinson's.



Nevertheless, on June 19, 2024, he was required to undergo gallbladder surgery. Now, having experienced surgery as a Parkinson's patient, he wants his voice and story to be heard and to give significant tips to any other PD patient who needs to undergo surgery.

The journey began when he was vomiting and in pain. He was hospitalized, and after a few tests, they had an MRI done to observe what was going on in the gall bladder. The MRI showed no obstruction, but the hospital wanted him to undergo gallbladder surgery because of the risk of an obstruction later on in his life. The hospital was extremely assertive, but Rabbi Gruskin was determined not to go ahead with surgery until he was confident that it was absolutely necessary and the benefits outweighed the risks. While he understood the urgency of his need for surgery, especially because his liver was involved, he was also extremely concerned about how it might affect his Parkinson's.

TIP 1: Always make sure to have someone at your side so that you are not vulnerable to any pressure from medical staff to decide before you are ready.

TIP 2: Before deciding to proceed with surgery, speak to your Movement Disorder Specialist and anyone else involved in your care.

Before deciding that surgery was the right option for him, Rabbi Gruskin spoke to 4 doctors.

- ▶ Urologist Dr. Yekutiel Sandman
- ▶ Gastroenterologist Dr. Wael El-Nachef
- ► Movement Disorder Specialist (MDS)-Dr. Sanders-Pullman
- ▶ Pediatric Gastro Dr. Marcus Alfie (family friend of the Gruskins)

He also discussed it with his Rav at length. He began the scheduling process only when all professional opinions concurred that he should proceed with the surgery. The surgeon he used was Dr. Aron Gornush, who wanted the movement disorder specialist to be involved. The procedure in Brick Hospital was laparoscopic, which, when feasible, lends itself to an easier recovery.

Rabbi Gruskin was told to be NPO [i.e., nothing can be taken by mouth before the surgery]. Still, when he brought up the issue of his Parkinsons' medications, he was told that they all MUST be taken, even the morning of the surgery. The only medication he was told not to take was the aspirin 80 mg so as not to have his blood thinned.

TIP 3: It is very important to discuss medications with the surgeon before the surgery as it is crucial for PD patients to continue to take their meds. If your surgeon brushes you off, do not hesitate to involve your neurologist.

▶ Dr. Fiona Gupta wrote an excellent book on this topic, bringing many good tips and information. The book is titled Parkinson's Disease for the Hospitalist and can be purchased at https://www.amazon.com/stores/author/Bo7K1X4Q2G. Please read this book, bring it to the pre-op appointment, and show it to your provider to ensure they know the compulsory medicinal needs of the PD patient. If they still insist that you can skip your meds, offer to have them discuss it with your neurologist. If this is proving difficult, don't hesitate to get in touch with our office so we can help you coordinate that.

Rabbi Gruskin's surgery took place on a Wednesday. When he woke up, they told him to take his medications immediately because they were aware of the importance of being timely. He was still weak at

discharge, but that was to be expected. However, he had a very rapid progression of his PD symptoms. By Friday morning, he was still very weak and kept losing his balance, and eventually fell on Friday evening. His voice was also weak. By Sunday night, he was unable to urinate, and by Tuesday night, his pain was so unbearable that he went to the ER.

He had elevated liver enzymes and a Urinary Tract Infection. They inserted a catheter, his levels went down, and they sent him home, but he was in terrible pain. Per med-



ical advice, his catheter was likely twisted because he was in severe pain, but the urologist he went to, Dr. Freddie, told him it still needed to be inserted. By now, he had been immobile for 8-9 days, but on the Monday after the surgery, he had told his PT, Haim Nesser, about his surgery and what was going on. Dr. Nesser came to him on Wednesday and reassured him that he would be doing the movement exercises with him while in the hospital so that he could keep on moving while not overdoing it. This was crucial for his limbs to not stiffen up further and helped increase his strength even while resting so that he could heal. By the following Thursday, the urologist removed the catheter, and his pain lessened, but he was still so weak and still needed so much rest!

TIP 4: Before the surgery, inform everyone on your care team, including your PT and OT, about your surgery and how long the recovery is expected to take. Ask them what exercises can be done from the bed to keep your body mobile. Sometimes, therapists can perform the movements on the patients while in the hospital, assuring that the neuroplasticity is as open as possible.

TIP 5: Anesthesia can cause a temporary progression of PD symptoms, from which it usually takes up to six months to recover fully. The diagnosis of Parkinson's must be mentioned to the anesthesiologist so that they can give a local anesthetic, if possible, or the lightest sedative if general anesthetia is warranted.

It is now 3 months post-surgery, and Rabbi Gruskin finds that it has caused different imbalances in his body, and his mood and verve have not yet fully recovered.

TIP 6: The need to rest in order that the body can heal is vital, but so is the need to be mobile and get back to yourself. Get yourself motivated and push yourself! It would be best if you had a mission pulling you to be mobile. Rabbi Gruskin's daily motivation is LifeSpark, so he knows he must get his energies back! Find out from your doctor how much it is safe to push yourself. It may be 'easier' to recuperate from your bed, but it is much healthier in the long run if you keep as mobile as you can. Generally, after most surgeries, they want to see the patient moving as soon as possible, even if it's painful, for the following reasons – 1. To avoid pulmonary embolism, and 2. Studies show that the sooner the patient is mobile, the quicker they heal, and the more it will stave off a continued progression of PD.



NEW YEAR, NEW BEGINNINGS

Living with Parkinson's disease can be a challenging and unpredictable journey. However, with the right mindset, support, and strategies, thriving and finding new beginnings is possible. Let's take advantage of this new year and get a fresh commitment towards our health! This article will explore the importance of therapy, nutrition, and medical care in navigating life with Parkinson's.

GOING BACK TO THERAPY

Therapy is a powerful tool for managing Parkinson's symptoms and improving overall well-being. Physical therapy can help maintain mobility and balance, while occupational therapy can assist with daily activities and independence. Speech therapy can address communication challenges.

Recommitting to therapy can be a new beginning, allowing you to:

- Improve balance and coordination

- Rebuild strength and flexibility

- Enhance cognitive function

- Develop coping strategies

EATING RIGHT

Nutrition plays a crucial role in managing Parkinson's. Incorporating Parkinson's-friendly foods such as leafy greens, berries, nuts and seeds, and fatty fish into your diet is essential. A balanced diet rich in whole foods, fruits, vegetables, and omega-3 fatty acids can help:

- Promote energy and vitality
- Reduce inflammation
- Support brain health





MAKE A DOCTOR'S APPOINTMENT

Regular medical care is essential for monitoring Parkinson's progression and adjusting treatment plans. Schedule an appointment with your neurologist to:

- Review medication and dosages
- Discuss new symptoms or concerns
- Explore alternative therapies

EMBRACING NEW BEGINNINGS

13. Sinew

12. Billfold

Cold

10. Potholder

Newspaper 11.

Living with Parkinson's requires resilience and adaptability. By recommitting to therapy, eating a balanced diet, and prioritizing medical care, you can take control of your journey and discover new beginnings. Remember, every day brings new opportunities for growth, learning, and connection. Embrace this journey, and find hope and empowerment in your new beginnings.

Shana Tova!

.8

Goldfish

Newborn

Newton

Solder

bloM

Newt

blofbnila

Scaffold

MEDICAL MOVEMENT



PARKINSON'S UK WILL INVEST IN A CLINICAL TRIAL OF A POTENTIAL TREATMENT THAT COULD PROTECT BRAIN CELLS

Parkinson's UK will be providing £1.25 mil. through their Virtual Biotech program to help test a potential treatment called MTX325 in people with Parkinson's. Together with The Michael J. Fox Foundation for Parkinson's Research (MJFF), they will partner with Mission Therapeutics to research whether MTX325 is safe, gets into the brain, and improves energy production in brain cells. If this small, early-stage clinical trial is successful, then larger trials would be needed to continue and uncover the potential of MTX325 to protect the brain cells that are lost over time in Parkinson's.

It is currently being tested in healthy individuals to understand its safety. The preliminary data shows a good single-dose safety profile for MTX325. The funding will help carry out the next stage of research, which is investigating its safety and potential in people with Parkinson's. The trial plans to recruit 50 people with Parkinson's from the UK and other European countries to test out the drug

over 28 days and will hopefully start at the beginning of 2025.

How does MTX325 work?

Brain cells need energy to function correctly. Within the cells are the mitochondria, which are the energy-producing powerhouses of the cell. In Parkinson's, mitochondria inside dopamine-producing brain cells stop working correctly. These faulty mitochondria cannot produce enough energy and leak harmful chemicals, causing damage that affects cells' ability to make dopamine and contributing to the death of brain cells over time. MTX325 is in pill form and is a compound that has been designed to help get rid of faulty mitochondria. Hopefully, by removing 'problem mitochondria,' dopamine-producing brain cells will be protected and ultimately slow or even stop the condition's progression. Lab-based research has so far shown that it allows brain cells to remain healthy and prevents them from dying.

CREXONT – NEW DRUG APPROVAL FOR PARKINSONS' PATIENTS

As per the Michael J. Fox Foundation, the U.S. Food and Drug Administration (FDA) has approved a new, long-acting oral formulation for treating Parkinson's disease (PD). Developed by Amneal Biosciences, Crexont is an extended-release formulation of levodopa/carbidopa that aims to alleviate symptoms longer with fewer doses and offer patients improved symptom control and a better quality of life.

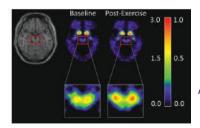


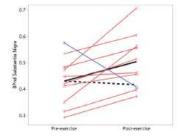
HOW EXERCISE SLOWS PARKINSON'S

Parkinson's disease is a neurodegenerative disorder characterized by the loss of dopamine in the substantia nigra area of the brain. Many studies have shown the benefits of exercise in controlling motor symptoms of PD, which can vary based on the type, intensity, and duration of the exercise. Moderate-to-high-intensity exercise

multiple times per week for prolonged periods (e.g., 6 months) has been shown to lighten the motor severity of PD in clinical trials. Indirect evidence suggests that the exercise may be neuroprotective, and postmortem examinations have shown links between physical activity and brain health. PET studies and MRIs in people with PD have also demonstrated that a single bout of vigorous cycling by habitual exercisers released significantly more dopamine in the brain than the same activity performed by those who were sedentary. Additionally, Neuromelanin (NM) is a by-product of dopamine, and therefore, its absence can be used as a biomarker for disease progression in the brains of people with PD.

In this study, the authors used PET imaging with 18F-FE-PE2I, a dye that can show dopamine transporter (DAT) protein levels, to measure changes in







2024 YEAR WRAP-UP

The FDA Reviewed Four New Parkinson's Medications in 2024

- •Under-the skin, continuous apomorphine infusion, given through a pump, like an insulin pump used by people with Diabetes Mellitus Type 2
- •Under-the-skin, continuous levodopa/carbidopa infusion, also given through an insulin pump-like device
- •Under-the-skin, continuous levodopa/carbidopa infusion given through a pump-patch that attaches to the skin
- •Crexont a reformulated, potentially longer-acting levodopa/carbidopa pill

All these medications temporarily replace or mimic dopamine, the brain chemical that decreases in Parkinson's, causing movement difficulties. The infusions aim to provide a consistent medication level to help smooth out symptom fluctuations—when times of little or no symptoms alternate with times of significant symptoms and/or extra movement (dyskinesia) throughout the day. The new pill, Crexont, which was just approved in August 2024, aims to potentially provide better symptom control with fewer daily medication doses. It is now the 19th new treatment approved in the last decade.

Updates on Potential Approvals

Each new device-based drug application received a letter from the FDA outlining areas for drugmakers to address about the devices or manufacturing process. While this delays the approval process, the good news is that these medications could still gain approval. The drugmakers are working with the FDA to address outstanding matters and potentially resubmit their application. In August 2024, Supernus Pharmaceuticals announced it had resubmitted its application for the continuous apomorphine infusion.

A HOLISTIC APPROACH

RECRUITING VOLUNTEERS

In addition to conventional medicine, there are various alternative approaches for Parkinson's disease. We are reaching out to all our members to explore the possibility of sharing your success stories with others. If you have tried holistic approaches to manage your Parkinson's disease and have experienced successful outcomes, we would love to hear from you. Holistic approaches are not one-size-fitsall as they have not undergone the rigorous testing process for the FDA, and what may work for one individual may not work for another. Keep in mind that any natural supplements on the market for Parkinson's can increase dopamine at an inconsistent pace and may cause a fluctuation of symptoms and erratic off times and in some cases, it may cause kidney or liver damage. Be sure to discuss any supplements with your neurologist so he can verify that there are no interactions with your medications or medical conditions.

Your experiences and insights can help us better understand what works and what doesn't, allowing LifeSpark to provide more effective guidance and support to the PD community. By sharing your story, you can help us help others. If you are willing to share your story, please get in touch with us at paulette@lifesparkpd.com or 732-806-1133 ext. 301.

Thank you for considering this request. Together, we can create a community that supports and uplifts one another on the path to wellness. Hatzlacha Rabba! dopamine levels. They imaged the effects of 6 months of high-intensity exercise on the dopaminergic system in patients with PD, with the outcome that there was a significant change in the DAT availability in the brain. A secondary outcome was the change they saw in the NM concentration in the substantia nigra. The study began with 13 subjects with early and mild PD, but 3 had to drop out for reasons unrelated to the study. Six months of high-intensity exercise induced visible brain changes on the imaging tests. They observed a consistent increase in available DAT sites, compared to the natural declines in comparable PD populations. These results not only support the inclusion of high-intensity exercise early in the treatment plans of PD patients but also suggest a role for exercise as an effective non-invasive neuromodulatory therapy. These observations could also have far-reaching implications for the neuroprotective effects of exercise in PD, but further work would be needed to validate them.

Our take: The findings are intriguing; however, they do not translate into neuroprotection or disease modification alone. Furthermore, this study included only 13 subjects with high-functioning mild Parkinson's, and there was no control group. However, we strongly agree with the authors that there is an 'improved functionality in the remaining dopaminergic neurons after exercise.' The most exciting finding was that 'sustained intense exercise' produced brain changes in areas of interest to all of us in Parkinson's disease research and care. Let's see where this imaging work goes next.

something *old*, something *new*

body...but not in a steak_



All the answers in this word definition game contain the letters OLD or NEW.

IC	tters OLD of NEW.
1.	A type of salamander
2.	That furry green stuff that grows on cheese that's been around too long
3.	Low melting alloy that is used to connect metal to metal
4.	A fig cookieor seventeeth generation physicist
5.	Another word for infant
6.	This decorative fish, which comes in all shapes, sizes and colors is actually a carp
7.	A temporary structure on the outside of a building often used by construction workers
8.	You'll need this to play pin the tail on the donkey
9.	You can always find horoscopes, classifieds and op-eds in one of these
10	. You don't want to take a pan off the stove without one of these
11.	This word can precede war or turkey
12	. It's just another word for wallet

answers on page 4 7

13. A piece of tough fibrous tissues that connects muscle to the bone or bone to bone. It's good have in the

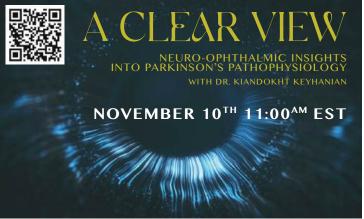


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SAVE THE DATE! OCTOBER 30, 2024

PARKINSON'S AND FAMILY:
CHALLENGES, TRIUMPHS, AND STRATEGIES FOR SUCCESS
OCTOBER 30, 2024, 6:30 PM
DUE TO OVERWHELMING RESPONSE, GLORIA LEBEAUX WILL BE SPEAKING FOR US ONCE
AGAIN, ADDRESSING THE DIFFICULTIES THAT FAMILIES FACE WITH A DIAGNOSIS OF PARKINSON'S.
SHE WILL DISCUSS ISSUES FROM THE PERSPECTIVE OF BOTH
YOUNG AND ADULT CHILDREN,





SUPPORT GROUP

We are pleased to announce that iy"H we will be starting a ladies' support group for patients with the highly acclaimed Social Worker, Gloria Lebaux. You may have heard her speak at our July Virtual Education Event for which we received astounding feedback! The group will start after Sukkos. Please get in touch with our office for more details and to join this exciting new venture! We are available Monday thru Thursday 11:00-4:00.

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