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LifeSpark
igniting victories for parkinsons

NEWSLETTER

TU B'AV – FORTRESS OF HOPE

לא היו ימים טובים לישראל כחמשה עשר באב וכיום הכיפורים

There were no greater Yomim Tovim for the Jewish people as the fifteenth of Av and as Yom Kippur (Taanis chap. 4) The festival of Tu b'Av is of epic significance, even greater than the שלש רגלים. Furthermore, tradition has it that the third, final Beis Hamikdash will be built on Tu b'Av. Nonetheless, we do not celebrate Tu b'Av outwardly at all (aside from not reciting Tachanun and other limited laws concerning prayer). What is the dominance of the Tu b'Av celebration, its connection to the Beis Hamikdash, and our lack of celebration? Most of all, what is our Avodah, our inner, spiritual work, considering this Yom Tov?

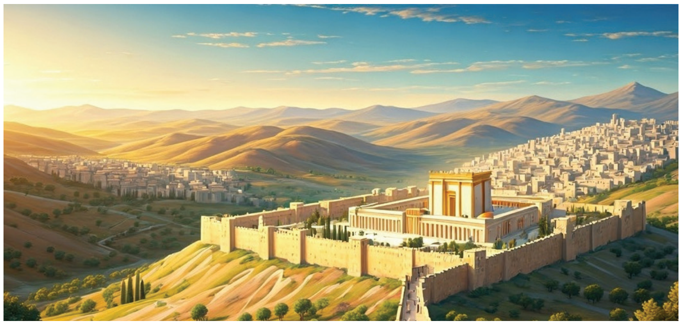
The Gemara (Taanis 30b) lists a few rationales for celebration on Tu b'Av. The Rambam (ibid.) says that the foremost event is the fact that the דור המדבר ceased to die. Each year, many perished as punishment for the חטא המרגלים, until Tu B'Av of the final year, when the decree was rescinded, and the dying ceased. Rambam writes that on that day, "They sensed that Hashem's anger had withdrawn, they secured hope and confidence in themselves, their future, and their relationship with Him." This was Klal Yisroel's seminal moment of hope. From within the darkness of sin, distant from הקב"ה, helpless, hopeless, and dying, they found renewed faith in Hashem and the promise of hope in a better future.

This original Tu b'Av laid the roots for Klal Yisroel's description as 'prisoners of hope'. The Navi Zecharya says (9:12): שובו לבצרון אסירי התקוה; Return to the fortress (the Beis Hamikdash), Oh prisoners of hope. We are considered 'captives of hope' because even in our most desperate moments, when we seem locked in misery and despair, we are liberated by confining ourselves to the 'prison of hope'. We go faithfully to where we are enveloped in light, a 'prison' where we sense with undying certainty that Hashem will bring salvation, and nothing but hope exists! Our perpetual spirit of hope, our being prisoners of faith in a brighter tomorrow, lies in the primal hope experienced on that fateful Tu b'Av.

Our conviction to be שובו לבצרון, to return to the Beis Hamikdash, is grounded in our being אסירי התקוה, prisoners of faith. The Beis Hamikdash is our fortress of faith, wherein we find connection even after the abandonment of sin, hope after the despair of transgression. This fortress of hope can only be built by our conscience and constant choosing to be prisoners of hope. Facing life's challenges with hope in the heart, not focusing on the seemingly dire and hopeless, but instead on the unlimited possibilities that Hashem can bring.

While every Mikdash was built upon these valiant instants of faith, the final Beis Hamikdash even more so. That fortress of hope is the culmination of millennia of hopeful moments that we generated, like a strand of pearls, stretching from our primal hope on Tu b'Av in the Midbar to the end of times. Every time we chose hope over despair, faith over doubt, in the face of insurmountable challenges and obstacles, we built another brick in the fort, another column of support, until the final Beis Hamikdash stands in all its magnificent glory.

The Yom Tov of Tu b'Av is indeed distinct, its celebration beyond all others. Its joy begins when all other Yomim Tovim cease, as its festivity is reserved for the Yemos Hamashiach when the final Beis Hamikdash will be built. Therefore, we don't celebrate it in our world, as its whole essence is a festival of the next, when we celebrate the accumulation of all our hopes, transformed into the fortress of the future.



Our work is cut out for us. Being involved in the building of the Beis Hamikdash means learning to tap into the hopeful energy of Tu b'Av, one hope at a time. Let us hope, no matter what, and may we soon see the culmination of all our hopes,
בבנין בית המקדש במהרה בימינו. אמן.

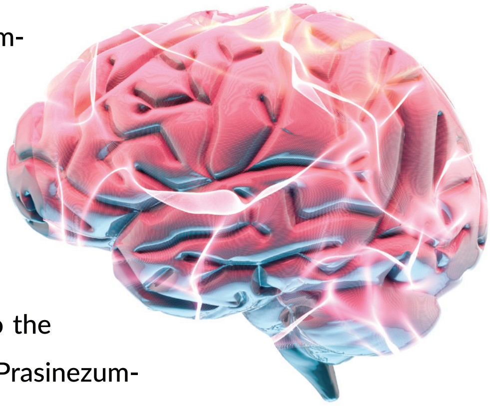
Rabbi Tzviki Feuer

NEWS *flash*

Prasinezumab

Drug With Potential to Slow or Stop Parkinson's Moves into Next Phase of Clinical Testing

The earliest known physical markers of Parkinson's Disease (PD) are the clumps of misfolded alpha-synuclein proteins in the brain. As they clump in the brain, they become toxic and destroy dopamine neurons. Alpha-synuclein is therefore a priority biological target for pharmaceutical companies, and numerous therapies directed against alpha-synuclein are currently under investigation. There are currently around 15 drugs in the pipeline that seek to target the production, spread, or clearance of PD-related alpha-synuclein clumps in the nervous system.



One of these drugs, Prasinezumab, is being developed by the Swiss pharmaceutical company Roche. It aims to stop the process by binding to those toxic alpha-synuclein proteins, limiting their damaging effects on the brain that cause Parkinson's symptoms to get progressively worse over time, or possibly even halt the disease entirely, so that symptoms could be minimized or potentially never emerge. Evidence suggests that after 18 months, it appeared to help slow the progression of Parkinson's motor symptoms, in addition to being safe and well-tolerated. This drug is now moving into the critical Phase III stage of clinical trials, which will aim to answer the key question: Does Prasinezumab achieve the goal of slowing or delaying the progression of the biology that leads to Parkinson's symptoms, so that patients can experience slower worsening of symptoms and maintain their quality of life for longer than they would without the drug?

Phase III will likely require thousands of people, and its safety and effectiveness will be assessed over a prolonged period, possibly several years. If Phase III is successful, they will be able to request approval from agencies such as the US FDA, potentially making Prasinezumab one of the first disease-modifying medications for Parkinson's to become available to the public. Approval itself could potentially take years, so we are still looking at some time before the drug is available commercially.

Drug development is an incremental process, and these early steps build knowledge and move the field forward, creating opportunities for a cure. It may take several studies to refine the science before we have a clear understanding of how a drug targeting alpha-synuclein can have a meaningful impact on PD. We continue to see significant momentum in developing effective, next-generation drugs. There is growing energy among researchers, as well as robust industry interest and investment in Parkinson's. Our *tefilla* to the *Boirei Oilam* is to send us a complete cure *b'mheira* for this complex and devastating disease.

SUPPORT GROUPS

Look out for reminders from our office for dates and times!

Our support groups serve as a dedicated space for individuals with Parkinson's and/or their caregivers to come together, share, and gain understanding in dealing with and coping with PD. They are not in person; they are conducted via zoom or telephone.

Ladies' Caregiver Support Group *Moderator* Mrs. Tehila Weisberg, LCSW	**Ladies' Patient Support Group** *Moderator* Gloria Lebeaux, LCSW	**Men's Patient Support Group** *Moderator* Rabbi Dr. Fishel Mael, PhD

For more information or if you are interested in joining any of these groups,
please reach out to Rivka at rivka@lifesparkpd.com or 732.806.1133 ext. 302

HYGIENE

Summer is here, and along with it come warmer temperatures. Everyone ends up sweating more, and this is particularly true for people with Parkinson's, as they tend to sweat even more than the rest of the population. Combine that with more time spent outdoors, and the need for frequent showering, laundering of clothing, including *tzitzis*, and more meticulous care in the area of hygiene is necessary.

What do you do if someone you love has Parkinson's and you notice that their hygiene is not up to par? It is always challenging to discuss sensitive topics with others, so it is essential to determine what hinders their self-care.

- Are we dealing with concrete, practical things that they physically can't manage on their own, such as showering & dressing?
- Do they have tremors or limited range of motion?
- Is it depression or apathy that is causing the issue, or is it a cognitive issue that they do not remember to shower, how to shower, or why they need to shower?
- Are they self-aware?
- Is it medical, such as a urinary issue, and they need to speak to their doctor?
- Do they have Orthostatic Hypotension, or are they afraid of falling in the shower?

As a caregiver, don't be afraid to ask some hard quedtions, yet do so in a thoughtful way. Be candid and sincere, but also wait to see what they bring to the table. It can be tough to separate the person from the disease, and to accept that your loved one might have limitations that they never had before, and that they not doing this on purpose. Recognize that maybe they need assistive devices to help them with their ADLs, such as a shower chair to reduce the risk of fainting or falling, or perhaps they would benefit from an aide. Speak with their doctors or OT to discuss what the options are, provide psychoeducation for you, and work with them on it.

MIND GYM

CAN YOU SOLVE THESE TRANSPORTATION-THEMED RIDDLES? THINK CREATIVELY

1

I stretch without a spine or bones,
Yet carry weight from every home.
I vanish at the edge of maps,
And echo with a million paths.

2

I speak in shape and silent red,
No mouth to warn, no hand to spread.
Obey my face, or chaos wakes –
I'm where the engine hits the brakes.

3

I race with lights that flash and gleam,
A roaring engine wakes the dream.
I carry hope on every street,
To bring relief when dangers meet.

4

I cross the waves, but I'm not a boat,
I carry cars that cannot float.
I go one way, then turn around,
A moving dock without the ground.

5

I roar along with two strong wheels,
My engine's voice, the road reveals.
I lean and turn with graceful flight,
A rider's thrill in day or night.

6

I fold but do not break,
Reveal the world, yet stay in place.
I know each road, though none I've walked,
A silent guide when paths are talked.

7

I float through skies without a wing,
My fire helps me rise and swing.
You'll find me drifting way up high,
A basket sailing in the sky.

8

I wait without a name to call,
Yet strangers flag me, one and all.
I move for meters, not for fame,
Each trip unknown, yet much the same.

9

Silent steps that mark the earth,
No engine hum, no wheels to turn.
A steady pulse beneath the sky,
The oldest path where feet still fly.

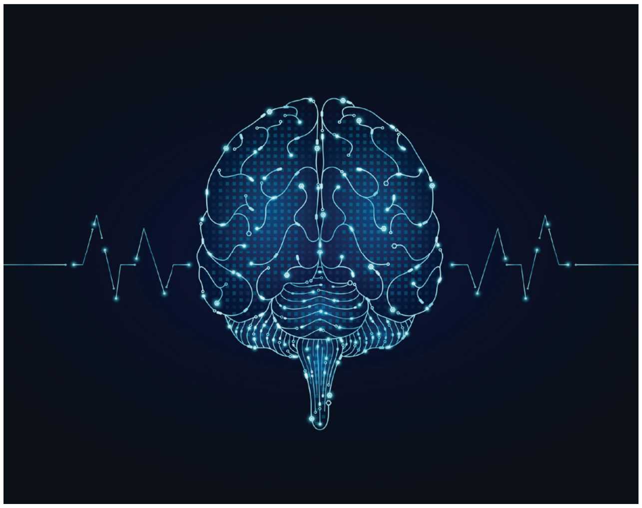
10

I live for loops and fly on ground,
My breath is fuel; my voice is loud.
I chase the clock but never age –
Built for speed, not for the stage.

ANSWERS TO MINDGYM ON PG 4

Medical Movement

Research Charting Brain Waves to Help Treat Levodopa-Induced Dyskinesia



A common medication prescribed for people with Parkinson's Disease is levodopa, a dopamine-replacement medicine, to help them improve their quality of life. However, continuous use of levodopa often leads to new movement symptoms called levodopa-induced dyskinesia (LID). Dyskinesia is characterized by involuntary, erratic movements that can affect various parts of the body and become increasingly uncomfortable as they worsen. Although the majority of people who take levodopa for PD symptoms develop LID, the neurological reasons behind this phenomenon are still not well understood. Now there is a researcher who is trying to dig deeper so that we can help these patients even more. Jeroen Habets, MD, PhD, a recipient of a Parkinson's Foundation Postdoctoral Fellowship, is aiming to identify brain wave biomarkers of LID by highlighting regions of the brain that go awry during an episode by using a non-invasive recording technique to try to understand what happens at the surface of the brain. He wants to understand better how the whole movement network functions and what happens when they move involuntarily. Then, he hopes to use magnetic stimulation therapy to reduce or eliminate LID completely.

> **We hope to create personalized magnetic stimulation treatments that reduce or eliminate dyskinesia — and improve life for people with Parkinson's.**

Dr. Habets is using a machine called a magneto-encephalograph to study participants with PD and visualize the brain wave activity that occurs during bouts of LID. By measuring their brain wave patterns and how they change during LID, the doctor hopes to identify regions in the brain that could be targeted for treatment. During dyskinesia, specific brain processes at the surface are more active than they usually are. His study will utilize non-invasive transcranial magnetic stimulation (TMS), which involves directing magnetic waves to alter brain wave activity. Previous research has shown that, with this magnetic stimulation, patients developed less dyskinesia over the hours that followed. He is hoping to be able to create personalized TMS treatments that alleviate debilitating levodopa side effects. Although finding a way to implement this treatment into patients' daily lives is still a challenge, he is hopeful about the potential of this research.

MIND GYM

ANSWERS TO MINDGYM, PG 3

1. Highway or Road
2. Stop Sign
3. Fire truck
4. Ferry
5. Motorcycle
6. Map
7. Hot Air Balloon
8. Taxi
9. Walking
10. Race Car

SHIFTING GEARS

Transitioning From the Driver's Seat to the Passenger's Seat

Summer is here, and with it come thoughts of travel, both near and far, alone, or with family and friends. Cars hit the road as people take welcome breaks from their year-round routines. But is it still as safe for everyone to drive as it used to be? Driving is a highly complex task that must not be taken for granted, even though it is such a universal skill. The car or motor vehicle is probably the most dangerous and potent machine we all operate.

As people age, it is usually not a sudden event that they stop driving, but rather, most will gradually begin trying alternative means of transportation. People typically end up stopping to drive about ten years before their passing. For individuals diagnosed with Parkinson's disease (PD), the thought of giving up the privilege of driving can be emotionally distressing. However, Parkinson's, a progressive neurological disorder, significantly affects the motor and cognitive functions essential for safe driving. As PD patients age, many of their issues can seriously affect their driving skills. Understanding the risks associated with driving while living with Parkinson's is crucial for patients, families, and healthcare providers alike.

- Tremors, rigidity, or bradykinesia (slowness) can make it difficult to brake, steer, or accelerate in a timely fashion.
- Unstable posture can distort or impair their awareness of all their surroundings.
- Cognition issues can severely affect attention, memory, focus, and decision-making abilities. Multi-tasking, even for simple things like turning on the AC, can be very complicated.
- Executive functions and visuospatial abilities may be impaired.
- Psychomotor speed has slowed, yet quick, almost instantaneous decisions are very often required during driving, especially when making turns or merging onto a highway.
- Some older adults experience diminished proprioception – understanding where their body or parts of it are, e.g., Is your leg on the gas or brake pedal?
- Motor planning and range of motion are reduced.
- Vision –
    - Dry eyes, double vision, and visual movement skills all affect driving.
    - Dynamic visual acuity, which is how well we understand what we are seeing, slows as we age. This includes peripheral and rear-view vision.
    - Reduced contrast ability mainly affects night vision.
    - Glare recovery also becomes more difficult as we age, especially when it is raining.
- Diminished strength and endurance, which are vital, especially on longer drives.
- Medications and their side effects, such as drowsiness, dizziness, blurred vision, dyskinesia, on/off times, and fatigue, can also affect all of these issues.

PD is a slow, progressive disease, making it difficult to determine when individuals may become unsafe drivers. Physicians' ability to determine driving ability is limited to short observations in a clinical setting. There is a need for efficient screening with good predictive validity of passing or failing an on-road exam. Some studies were done with PD and non-PD persons who used driving simulators and real on-road situations; PD patients were on medication and feeling well. Those with PD committed more at-fault safety errors in the categories of lane observance, stop signs, urban conditions, intersections, roundabouts, hesitation before turns, not accelerating, and so much more.

Yet, making the decision to stop driving can be physically and emotionally wrenching. It can feel like a loss of independence and contribute to social isolation. It's essential for families to approach this topic with compassion and empathy. Replacing driving with supportive alternatives—such as ride-sharing services, community transportation, or rides from loved ones—can help ease the transition.

Suppose family members are the ones noticing slower or varying driving speeds, hitting both accelerator and brake simultaneously, slow reaction times, near misses and accidents, getting lost or confused, poor attention, or fatigue. In

Continued on Page 6

STRIVE PD

A new App Designed with Parkinson's Patients in Mind

StrivePD is a free app that passively collects and records daily resting tremor, mobility, gait, and dyskinesia data via Apple devices – an iPhone or Apple Watch. It also tracks how medication, physical activity, and daily life influence your symptoms and plots the information on clear charts. It compares and contrasts any symptom changes over the previous two months. This helps you learn from patterns in behavior to manage your conditions more effectively. These personalized reports can be shared with your care team. They will help improve communication with them, enable them to view your symptom data, and assist them in tailoring treatments specifically to you.

For an added level of support, a subscription-based service, StrivePD Guardian, is available for $50 per month. They assign a dedicated coach who tailors the app to your specific needs and gives expert advice focused on your progress and care goals. The symptom data it collects helps your coach understand your needs and make data-driven decisions to optimize your care. There is also real-time technology that offers daily insights into your unique PD experiences. This comprehensive service helps you optimize your care plan, track medications, and prepare for doctor visits, ensuring you are ready to discuss key concerns and keeping you one step ahead. StrivePD Guardian also monitors essential indicators and provides timely alerts for any changes that may require attention.

We here at LifeSpark are very excited about this new technology. There is so much potential here to help all of our members with PD and their caregivers to be able to handle this disease so much more easily and effectively. However, we do understand that many of our members are reluctant to purchase and own Apple devices. We are working with the company to determine how we can incorporate our members' sensitivities while still benefiting from this incredible technological tool. Meanwhile, those who can make use of this app, please get in touch with them at support@strive.group • www.strive.group/guardian

They have even thoughtfully provided a code for 25% off their StrivePD Guardian for LifeSpark members. Please use code LifeSpark.

Continued from Page 5

that case, they may need to broach the topic. This is a complex and delicate conversation to have. However, it is essential for the safety of the driver and those around them to reevaluate the capability of driving as time moves on. Ideally, the conversation should be done early, before it really becomes a safety issue. Earlier on, Occupational Therapy or some adjustments may help them be able to continue driving for a bit longer. When having the conversation, remember that it is, in essence, an act of love and caring for someone; not a confrontation or intervention – that's why cars have passenger seats. It is crucial to convey the message that they are whole people, and even if we don't drive, we are still very vital, productive people as we age. Explain how you love them and want them to be as independent as they can be, yet you care so much about their safety. Explore options – independent transportation networks such as taxis and buses, gradual transitioning into not driving (i.e., keeping their car and others will drive them in it). Try to find as many opportunities to give rides to the person, even when they are still able to drive themselves, and enlist the help of any family members or friends who can offer rides. Take your time when having the conversation, and don't expect this to be only one conversation; several short ones can be more convincing.

Conclusion

Driving with Parkinson's disease poses serious and often underestimated dangers—not just to the patient, but to others on the road. As difficult as it may be, recognizing when it's time to stop driving is an act of responsibility and care. With proactive planning, compassionate dialogue, and support systems in place, patients can maintain dignity and autonomy while prioritizing safety.

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LYFT offers discounts to seniors.
ITN America has a hotline that helps refer people in need to customized transportation opportunities. 855-607-4337
or their website www.itnamerica.org or www.ridesinsight.org
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Wrap-up of the Zoom Educational Event on June 29, 2025 // By Dr. Joseph H. Friedman

FATIGUE IN PARKINSON'S DISEASE

What it is,
what it isn't,
and can anything
be done about it?

Dr. Joseph Friedman holds the Stanley Aronson Chair in Neurodegenerative Disorders at Butler Hospital in Providence, RI. He is a professor of Neurology at the Warren Alpert Medical School of Brown University.

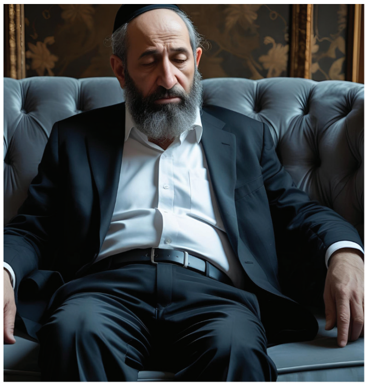
Fatigue is an intrinsic problem in Parkinson's Disease, yet it is one of the problems that others can't see. Fatigue is a sense of tiredness, but not sleepiness. While it is normal to feel fatigued after strenuous activities, the fatigue should not last for an entire day. Some cases of fatigue are due to depression, but a large majority of fatigue cases are unexplained. In PD, however, the statistics are much more severe. 50% of PD patients listed fatigue as one of their three worst problems, and 1/3 of patients listed fatigue as their single worst PD problem. They fatigue more easily than they used to, and it impairs their quality of life.

Subjective fatigue is when there are plausible reasons for the fatigue. The reason can be physical – because you have just worked hard, mental – because you are using your mind for so many other things, such as writing a book or making work decisions, or emotional – because you are anxious, frustrated, or feeling resentful. However, if there is no subjective reason for your fatigue, it would be considered pathological, meaning that a physical or psychological disorder is causing it. For example, radiation therapy can cause measurable fatigue – it typically starts and ends at specific times after treatment. Fatigue from an illness, such as a bacterial or viral infection, is widespread, including those caused by malaria, flu, or COVID-19. Heart or lung problems, anemia, chronic pain, or even some medications, tire people out, but then getting better or fixing the 'problem' stops the fatigue.

Yet, with PD, we don't know the pathology of the fatigue – why there is fatigue, nor what aspect of PD is causing fatigue. Similar to depression, treating the PD does not necessarily remove the fatigue. Fatigue is frequently an early symptom, and as PD progresses, the fatigue may get worse, but not necessarily. Additionally, as motor symptoms worsen, this does not necessarily predict an increase in fatigue. Furthermore, fatigue is part of depression, and depression is part of PD, but helping the depression does not necessarily remove the fatigue!

All fatigue appears the same, and there is no way to distinguish between them. It is assumed that it is most likely related to the release of chemicals. There is also a connection to apathy, which is a less emotional reaction and a loss of motivation. We know that exercise helps fatigue, but you can't exercise because of the fatigue, and since there is a lack of motivation, the cycle continues, and you don't exercise! Fatigue is a natural part of PD, yet we don't fully understand it.

So, how do we treat fatigue in PD? We don't know how. But here are a few ways you can help yourself. Firstly, gradually increase exercise and set realistic goals to improve endurance. This will also improve mood, memory, and physical function, so it is essential to force yourself, no matter how you are feeling. Since doctors can only treat underlying illnesses, the next step is to look for other reasons why you are experiencing fatigue. If you think you are depressed, you are! Some antidepressants may help. Maybe dopamine agonists will help you. There are many vitamins on the market. Although there is no proven data on any of them, if it helps, you can use them. Some examples of vitamins are Vitamins A-Z (!), ginger, turmeric, ginkgo, CoQ10, and Magnesium. Stimulants – drugs like Adderall, Ritalin – can speed up adults a bit. They are safe, but there are no studies that prove they help for fatigue. A CPAP machine is the most effective treatment for sleep apnea, so use it if possible.



In summary, we currently lack effective treatments for fatigue; however, it is essential to recognize its significant impact on people's lives. Doctors and families often misinterpret it as indicative of an emotional problem, but it is likely an organic reason, physically related to energy perception in the human brain.

LifeSpark
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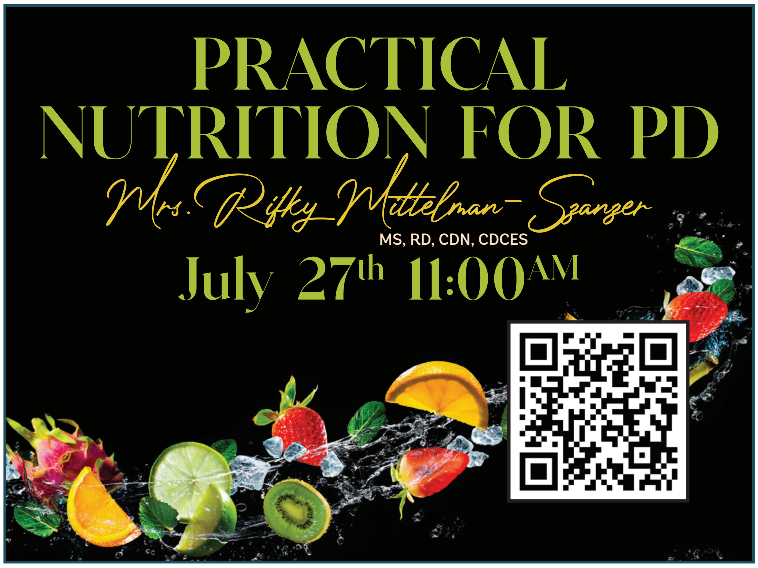
Smart Spark

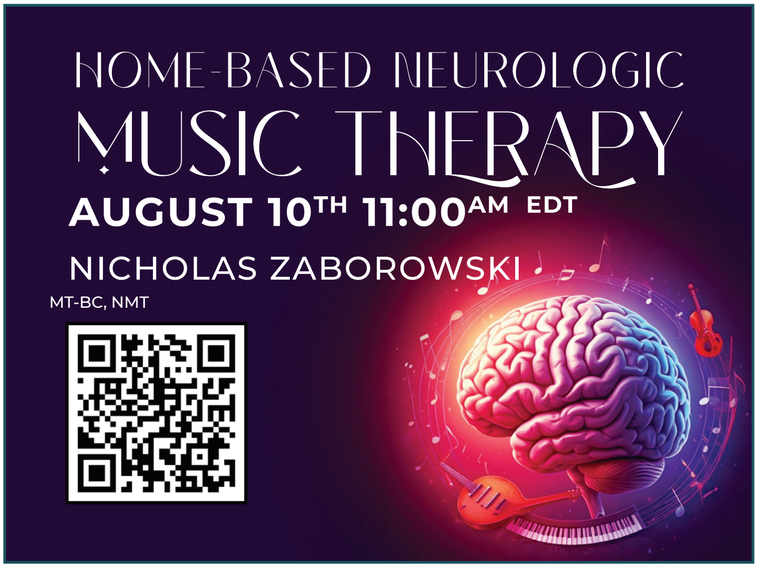
DID YOU KNOW? WHILE PARKINSON'S MAY IMPACT DRIVING, MANY STAY INDEPENDENT WITH ALTERNATIVE TRANSPORT & COMMUNITY SUPPORT.



PRACTICAL NUTRITION FOR PD

Mrs. Rifky Mittelman-Szanger
MS, RD, CDN, CDCES
July 27th 11:00AM

ATTEND VIA: ZOOM: **MEETING ID** 822 1861 0926
CALL IN: 646 558 8656 **ID** #822 1861 0926



HOME-BASED NEUROLOGIC MUSIC THERAPY

AUGUST 10TH 11:00AM EDT
NICHOLAS ZABOROWSKI
MT-BC, NMT

ATTEND VIA ZOOM: **MEETING ID** 859 9988 2500
CALL IN: 646 558 8656 **ID** #859 9988 250

Keep in Touch

We just received the newsletter and we are so, so impressed by Tania's article. It was so powerful, so special, and displayed so much strength. We are so inspired. Keep printing articles like these! D.F.

My husband really appreciates the depth and clarity of your editorials by Rabbi Feuer. They are always timely and so relatable. Please keep them coming! M.S.

Just reaching out with hakoras hatov for the beautiful Nuttery platter in honor of Shavuos that you sent to my mother. It really gives chizuk to my mother, father, and our extended family! E. L.

Thank you for the newsletter. It was put together beautifully. A.G.

Drop us a line: info@lifesparkpd.com Subject line - Editor OR text 732.534.6388