LIFESPARK, igniting victories for parkinsons

FEBRUARY 2022 SHEVAT EDITION ISSUE #5

A Time to Reflect

The month of Shvat falls in the deepest cold of winter. The fields and pastures seem frozen in time, as crops and produce are stilled by the ravage temperatures of the season. Yet, it is then that we revel in the beauty of the trees and the pleasure of its fruits. On Tu B'Shvat, the fifteenth of the month (according to Beis Hillel, while on Rosh Chodesh, the first of the month, according to Beis Shamai) we celebrate the the month, according to Beis Shamai) we celebrate the the month 'ום טוב אילן (as per the custom of a ום טוב) that falls on a weekday), and we indulge in the consumption of all types of delicious, exquisite fruits.

This all begs the question. Why now? Why celebrate the tree and its yield when there are no fruits to be seen on the trees, and even the trees stand frozen and hardly alive? Wouldn't it make more sense to celebrate when the trees are vibrant and pulsating with life? When the fruits are ripe, dangling plump from the tree and ready to be picked?

Tu B'Shvat serves as a lesson, an import regarding how to go about enjoying the pleasures of life. Sometimes life is 'a bowl of cherries', as the proverbial saying goes, and finding 'fruits' to partake of and enjoy is quite simple. Other times, however, life can seem 'frozen', unsympathetic and bleak, and the 'fruits' one yearns for seem distant and remote. Tu B'shvat instructs us to perceive that even in 'winter like' times of life we must explore and discover 'fruits' to relish and enjoy. Maybe treasuring something small, tucked away in the present, perhaps something enjoyable from the past. Tu B'Shvat beckons us to appreciate that we can always find pleasure in life, no matter when, no matter where. Good Yom Tov!



Our New Home

We are thrilled to announce that we've signed a lease on office space. Our new home will enable us at LifeSpark to begin the process of opening our long awaited LifeSpark Center. Our Center will include space for physical therapy (one on one, as well as group therapy), voice therapy and occupational therapy. It will serve as a home wherein we can feel comfortable to discover opportunities, find support, encouragement, and continue to build our wonderful LifeSpark community.

Rabbi Tzwiki Fener

The Skinny on Skin and Bone Health

This article is based on a Parkinson's Foundation Expert Briefing webinar exploring these connections presented by Nicki Niemann, MD, Muhammad Ali Parkinson Center at Barrow Neurological Institute, and Kenneth W. Lyles, MD, Duke University Medical Center. Barrow and Duke are Parkinson's Foundation Centers of Excellence.

Parkinson's disease (PD), **skin** and **bone health** are closely intertwined. Researchers are exploring how they are connected to uncover information that could improve lives. Higher bone fracture risk, flaky or dry skin and too much or too little sweating can be common in Parkinson's. Simple tips can help you tackle these and other related changes.

Parkinson's and Skin Health

Research shows an overlap in skin health and PD. Overall cancer risk is reduced in Parkinson's disease, but **skin cancer** risk — especially melanoma — increases.

In Parkinson's, misformed **alpha-synuclein** protein builds up and clumps in the brain. Skin cancer biopsies of people with PD also show increased alpha-synuclein in the skin, compared to the general population. Additionally, people diagnosed with **rosacea** – facial flushing, redness and sometimes, bumps – are nearly two times as likely to be diagnosed with Parkinson's.

PD and other neurological disorders also increase the risk for bullous pemphigoid (a skin condition causing itching, redness and large, fluid-filled blisters that can break and cause blood-borne infection).

Connections such as these have scientists exploring skin health as a possible biomarker (a measurable sign, such as heart rate, that can clue doctors in on your health) to help detect Parkinson's sooner. Skin biopsy holds promise as a potential future Parkinson's disease diagnostic tool. Earlier diagnosis can improve outcomes for people living with PD.

Skin Cancer Safeguards

Despite past misconception, **levodopa**, the most commonly prescribed PD medicine, does not increase risk of melanoma. However, though the association is not yet clear, some of the same shared risk factors for PD can also increase melanoma risk. These include being male, Caucasian, having **red hair**, fair skin and previous pesticide exposure.

Protect yourself by reducing direct sun exposure, wearing sunblock and visiting the dermatologist annually.

When it comes to spotting melanoma, the **American Academy of Dermatology** recommends watching for these signs:

Asymmetry -the shape of a spot or mole is unequal

Border - an irregular or scalloped edge

Color – blues, reds, browns or black; suspect spots can vary in hue **D**iameter differs, too; melanomas can be the size of a pencil eraser, larger or smaller

 $\ensuremath{\mathsf{E}}\xspace$ volution in spot color, shape or size should also be shared with your doctor

Skin Health Strategies

Studies estimate between 20 to 60% of people with Parkinson's may also live with seborrheic dermatitis, compared to just three to four percent of people without PD. Symptoms can include itching, scaling, oiliness, redness and burning — mainly on the scalp, but for some people, the face, chest or back, too.

Over-the-counter medicated shampoos containing salicylic acid, zinc, selenium, tar or ketoconazole can help. A dermatologist can recommend treatment for severe symptoms, such as prescriptionstrength shampoos, steroids or other immune suppressants.

Excessive **drooling** can also be common in Parkinson's. It can cause perioral dermatitis – redness and irritation around the mouth. **Anticholinergic medications** and botulinum toxin A (BOTOX*) can be used to decrease drooling.

Sweating Changes

Sweating too much – whether on the head, neck or trunk – is more common in Parkinson's than not sweating enough. Excess sweating can also happen on the foot soles, palms or at night. It's often experienced even prior to a Parkinson's diagnosis.

Sometimes changes in the autonomic nervous system, an area controlling automatic body functions such as rate of breathing, are responsible. Carbidopa-levodopa-related **motor fluctuations**, or "wearing off," can increase sweating, as can other medications unrelated to PD, such as certain antidepressants. Infections, sleep apnea, endocrine conditions and cancer can intensify sweating, too. Though not as common, decreased sweating can also pose problems for some people with Parkinson's. This is often related to anticholinergics, including **amantadine** and trihexyphenidyl. Review your medication list with your doctor who can adjust prescriptions, identify other causes or offer treatments, such as:

• topical medications, including prescription antiperspirant aluminum chloride hexahydrate

- oral propranolol (Inderal®)
- anticholinergic drugs, such as glycopyrrolate
- BOTOX [®] injections for localized sweating
- electric current iontophoresis therapy

These at-home tips can help with sweating:

- Wear breathable cotton clothes and socks, & non-synthetic shoes
- Take lukewarm or cold showers
- Increase fluid intake
- Drink cold liquids
- Use antiperspirant

Skin Changes

Sometimes, PD treatments can cause skin issues. While there are few reports of true levodopa/carbidopa allergy, the 25/100 formulation can cause a rash for some people, possibly due to a yellow dye. If this side effect occurs, your doctor might switch you to formulation without yellow dye, including 10/100, 25/250, Parcopa, Stalevo or Sinemet CR.

Some Parkinson's medications can also cause leg edema (swelling due to trapped fluid). These include amantadine and **dopamine agonists**, such as ropinirole, pramipexole, rotigotine and apomorphine. Talk to your doctor if leg swelling occurs within a few months of starting a medication.

People using Duopa therapy, levodopa/carbidopa intestinal gel delivered by pump through a small, surgically placed hole in the

stomach, can also experience skin issues, including redness, leakage around the opening or abscess. Proper pump tube care and increased healthcare provider access is essential.

Deep brain stimulation (DBS) uses surgically placed electrodes in the brain and with an implantable pulse generator to block abnormal nerve signals in the brain that cause motor symptoms. Though skinrelated complications are uncommon, a small percentage of users might experience hardware-site infection, or skin erosion near components.



Parkinson's and Bone Health

Caring for bone health when living with Parkinson's is critical. Exercise, regular bone mineral density screenings are key.

It's estimated that about 45 million Americans have low bone mass, putting them at risk of joining the more than 12 million people in the U.S. who live with osteoporosis (a condition where bones become thin, fragile and prone to fracture). Such skeletal problems are often associated with aging.

People with PD are at higher skeletal fracture risk than others, experiencing fractures two to three times more frequently. Hip fractures occur four times as frequently. At best, less than five percent of people with Parkinson's who experience fractures are treated. However, addressing and treating fractures is crucial: **It can take someone who lives with PD longer to recover from a fall injury or fracture**, and they may experience worsening symptoms, loss of independence and cognitive decline.

Fortunately, there are many ways to reduce fracture rates in people with PD and current research is exploring further ways to minimize bone risks.

Who's at a high risk of osteoporosis?

- People living with Parkinson's
- Women
- Older people
- Those with low body weight
- Those with a family history of osteoporosis
- Those with a history of fractures or low-impact fractures
- Smoking and excessive alcohol intake increase risk

Glucocorticoid therapy, medicine used to reduce inflammation, can increase bone loss and fracture risk. Other medications can too — including proton pump inhibitor therapy, anticonvulsants, aromatase inhibitors, tamoxifen, Depo-Provera and steroids. Conditions that are associated with bone loss include gastrointestinal and autoimmune diseases, genetic issues, diabetes and others.

Boosting Bone Health

What's good for your body is also good for your bones:

- Stop smoking
- Limit alcohol
- Avoid sedating medications

Exercise can keep bones strong and strengthen muscles and in Parkinson's, it can also improve many disease-related symptoms. Find something that makes you want to move and stay active. **Physical therapy** can help, too.

Maintaining **optimal levels** of calcium and vitamin D3 benefits bones and overall health. Because calcium in dairy foods can inhibit levodopa absorption, people with PD can find it hard to get the recommended 1200 mg daily for women over 50 and 1000 mg daily for men over 70. Calcium-fortified foods, such as juices, rice and breakfast cereals, can boost calcium levels. Chewable calcium citrate tablets can be taken without food and are easily absorbed. Doctors recommend limiting single doses to no more than 600 mg elemental calcium, splitting the dose if needed.

The body also needs adequate vitamin D to take in enough calcium. Research shows depressed vitamin D levels in people living with Parkinson's. Vitamin D is easy to absorb if you live in a sunny place — wear sunscreen. If this isn't possible, a **nutritious diet**, including fatty fish, such as salmon, liver, eggs and fortified milk or cereals, can help. Your doctor might also recommend vitamin D3 supplements.

Osteoporosis Medications

Medicines are also available to treat bone density loss. Hormonal medications include estrogen therapy and raloxifene, a selective estrogen receptor modulator, or SERM.

Prescription therapies that stop bone breakdown, called antiresorptives, include bisphosphonates such as alendronate (Fosamax*), risedronate sodium (Actonel*), ibandronate sodium (Boniva*) and zoledronic acid (Reclast *). Anabolic medications boost bone building, and include teriparatide, abaloparitide and romosozumab.

On The Horizon

The TOPAZ trial is currently enrolling people to test if a medicine called zoledronate can prevent fractures in people with PD. You can join without leaving your home. If you are eligible, a registered, Certified Mobile Research Nurse (CMRN) will come to your home to give you a short exam.

Learn more about this Parkinson's study here or call the Parkinson's Foundation Helpline at 1-800-4PD-INFO (1-800-473-4636).

(Please speak to your GP or Neuro\Movement Disorder Specialist prior to joining any trial)

Edited for Print. Reprinted with permission from Parkinson.org

Interview with Mrs. C.F.



Describe your reaction to your mothers' diagnoses with Parkinson's Disease?

My mother was actually diagnosed a year before she let me in on the diagnoses. At that point she looked well. I was not aware of how Parkinson's would affect her. I honestly did not even know what Parkinson's is all about.

How did you hear about LifeSpark?

As I mentioned earlier, my mother looked well and really functioned quite well the first number of years after being diagnosed. Over the last year and half, the progression of the disease has been much more visible and has taken a toll. I was scrambling to find a way to help her One day, I was talking to a friend and lamenting the fact that I have nowhere to turn to get direction in helping my mother She suggested that I contact BINA, an organization that helps brain injury victims. I reached out to them and they told me about LifeSpark!

At this point what do you find the most challenging part of Parkinson's and what do you think is most challenging for your mother?

I would say that we both find similar challenges being the most difficult. For me it is watching my feisty mother lose her ability to be mobile. For my mother it's not being able to be as productive as she is had been. Obviously, I can never really understand the challenge that it is for her, but just from knowing how industrious she had been I can only imagine the difficulty she is going through.

What was your experience with the consultation with Rabbi Gruskin?

The consultation proved to be invaluable and empowering. Whereas until now we were lost and directionless, after the conclusion of the consultation we were armed with information with which to move forward! For my mother it was comforting to hear someone who is "walking in her shoes" validate what she is experiencing. For my family the path to follow was now mapped out for us. "We could have gone on for another hour". And that was after an hour and a half.

In what way can we help now, and what can LifeSpark offer you in the future?

It is very important to us to deal with doctors who understand that my mother is more than a package of symptoms. We have gone from one top tier doctor to another, and as is their practice, they keep giving us more and more medication. If they were to see my mother as a whole person, with all the experiences that make her unique, they would be better able to treat her. I wish doctors would have told us early on what are other helpful things that can help her improve and maintain her quality of life in conjunction with the medication that treats her symptoms.

I also find that the ability to reach the doctor to answer our questions is very limited. So often we need an answer fairly quickly and the response time can be a couple of days. And that is through email. Talking to a doctor directly does not have the same effectiveness as does an email.

All in all, I would say that a team of doctors and therapists that provide a holistic approach would help the quality of life for patients with Parkinson's immeasurably!

Thank you so much for your time. Please know that we are constantly looking to improve the services that we provide and will take your suggestions into account earnestly.

Website Updates

Our newly designed LifeSpark website is almost ready to be launched. The site is chock-full of useful information,

including general info on PD and access to past LifeSpark educational events (audio and visual), postings of upcoming events, as well as an 'ask the doctor' forum enabling answers to inquiries and timely questions. The design is tasteful and truly beautiful, inviting one to immerse, enjoy and benefit from this newest LifeSpark endeavor.

Making a difference...One at a time

A friend of ours was walking down a deserted beach at sunset. As he walked along, he began to see another man in the distance. As he grew nearer he noticed that the local native kept leaning down, picking something up and throwing in out into the water. Time and again, he kept hurling things out into the ocean. As our friend approached even closer, he noticed that the man was picking up starfish that had been washed up to the beach and, one at a time, he was throwing them back into the water. Our friend was puzzled. He approached the mand and said, "Good evening, friend. I was wondering what you are doing"? "I'm throwing these

starfish back into the ocean. You see, its low tide right now and all of these starfish have been washed up onto the shore. If I don't throw them back into the sea, they'll die up here from lack of oxygen." "I understand", my friend replied, "but there must be thousands of starfish on this beach. You can't possibly get to all of them. There are simply too many. And don't you realize this is probably happening on hundreds of beaches all up and down this coast? Can't you see that you can't possible make a difference?" The local native smiled, bent down and picked up yet another starfish, and as he threw it back into the sea, he replied, "Made a difference to that one!"

Season of Enjoyment

The Mishna in the beginning of Maseches Rosh Hashanah lists four ראשי השנה, beginning with the the ראש השנה למלבים, regarding the dating of legal documents, and ending with the ראש השנה לאילן, the one we celebrate on גע"ו.



It is interesting to note, that aside from ע"ו בשבט, we do not celebrate¹ any other of these ראשי השנה. They are merely times of halachik implication, and therefore do not warrant recitation of special prayers or the like.

However, in regard to times of judgment, the Mishna does go on to list ימים טובים wherein we say special prayers and even bring קרבנות. It tells us² that on Pesach we are judged on the harvest, and we therefore bring the העומר in order to be judged favorably. So too, at the time of שבועות when we are judged upon the, שירות האילן, the שירות האילן etc.

This all begs the question, why then do we celebrate on ע"ע בשבט, as it is merely a day of legal implication?

The answer can be found in the Talmud Yerushalmi, at the conclusion of Maseches Kiddushin³: "Rav Chizkiya taught in the name of Rav, a person will give a final accounting (in heaven) for anything he saw, was able to eat and enjoy⁴, and did not. R' Lazar (a prime disciple of Rav) was careful to fulfill this dictate of Rav, and would therefore gather coin by coin (throughout the year) and once yearly would enjoy from all delicious fruits".

This judgement concerns our perception of the very essence of creation. Hashem made this world in order to shower us with goodness⁵. He wants us to truly understand this. To perceive reality for what it is – for us to appreciate His world and enjoy it.

ט"ו בשבט is the yearly junction designated for the fulfillment of Rav's ruling, wherein we stand before Hashem in judgment; have we taken the time to focus, to be mindful in appreciating His world? To sense the current and ultimate pleasure that He has in store for us?

This is the essence of the celebration and prayers on ט"ו בשבט. While א"ט" is counted in the original list of ראשי השנה, the character of ט"ו בשבט does not end there. Tu B'shevat contains another dimension. It has the characteristics of a יום טוב as well. Similar to those days when we stand in judgment, on ע"ו בשבט we stand in the "Judgment of Rav"; have we achieved a healthy perception of reality? Do we take the time to notice His goodness, to enjoy it, to thank Him for it all? It is this dimension of יום הדין that engenders the extra ברכות and added תפילות by the by the take the time to notice His goodness.

May we know Hashem's goodness, always and forever. גוט יום טוב! Rabbi Tzviki Feuer

וּכמבו' בשו"ע, או"ח סי' קל"א, דאין אומרים תחנון בט"ו בשבט ואף במנחה שלפניו. ואף דשאר ר"ה נופלים בר"ח וממילא א"א בהם תחנון, אבל הרי ז"ב דלא מצינו להם שום זכר כיו"ט, או אף מנהגא לחגוג בהם שום דבר. ²ועי"ש בברייתא שם (טז,א). ∛פרק ד' הלכה י"ב. ⁴ראה ס' מסילת ישרים פי"ג.

פכל" האריז"ל בס' עץ חיים: כשעלה ברצונו יתברך שמו לברוא את העולם כדי להיטיב לברואיו. וכל' ריש ס' מסילת ישרים: האדם לא נברא אלא להתענג על ה'.

PUZZLE TIME (P)

Pig Jig Crossword Puzzle

A dance for hogs could be called a PIG JIG. (See Clue 37 Down). A mystery about a violin could be called a FIDDLE RIDDLE.

Do you have the idea now?

Find a rhyming pair of words for each of these 45 definitions. When you enter your answers in the crossword, do not leave spaces between words.

If you get stuck on an answer, move on to another clue. You'll supply letters that will help you find other answers.

Clues:

Across

- 1. The route for an equine race
- 8. A tall tale about a farm building
- 9. Slime inhabited by web-footed birds
- 11. Final actors
- 13. Opening in a male pig's pen
- 14. The perfect stature
- 17. An animal doctor
- 18. Shrewd detective
- 22. Twisted penny
- 26. A pulpy adventure
- 27. An extra seat
- 30. Carriage for certain insects
- 32. An angry boy
- 33. A simple locomotive
- 34. Footwear adhesive
- 38. Best harvest of grain
- 39. A cozy carpet
- 40. Favorite visitor
- 41. A tidy avenue
- 42. A spicy place
- 43. A skinny smile

Down

- 2. A wise beginning
- 3. 24 hours of fun time
- 4. Short sorrow
- 5. A silent piccolo
- 6. A 50% giggle
- 7. Wisecrack about a hen's egg
- 10. A nice number
- 12. Chief of police
- 13. A meat burglar
- 15. Carnival for grizzlies
- 16. Pale wallcovering
- 19. A solar joke
- 20. A colorful mattress
- 21. Metal sleigh
- 22. A huge truck
- 23. An angry employer
- 24. Agricultural enchantment
- 25. An evening airplane trip
- 28. A flaw in a safe
- 29. A plastic pond
- 31. Insect embrace
- 35. Scalding kettle
- 36. An airplane collection
- 37. Hog dance

Are You Clever?

Unscramble the letters in the BLACK boxes to spell one more "pig jig."

Clue: An inmate convicted of stealing a certain kind of fruit

Answer:





Brand Out Stay Grounded Go Out On A Limb **Reach For The Sky Adapt To Change Stand Tall And Be Proud Bend Before Your Break**

Remember Your Roots Drink Plenty Of Water Get Rid Of Dead Wood Be Confident Never Stop Turn Over A New Leaf

EVENT ROUNDUP

Our Taking Charge of your Parkinson's Zoom Event, held on Sunday; January 9 th, 2022 had a message of both courage and hope for those of us suffering from the disease.

Erika Adelman, LMSW started off the event with a full-blown account on the emotions of early diagnosis of Parkinson's. Her address was both informative and all inclusive, as she advised on initial patient reactions of diagnosis, continual ways to keep a patient upbeat and symptoms of emotional fatigue in PD.

Dr. Phil Schneider gave us a strong message of inspiration, courage and hope, as he told of his PD diagnosis, subsequent denial and final decision to take his future into his own hands. His focus on constant therapy and diet, as well as some medication as needed, has helped him improve his life substantially. In Dr. Schneider's words 'I'm in better physical condition now. I spend more time doing things I've always enjoyed but put off, like having fun being physical. I now have an excuse for that!'

Alex Tressor gave an enjoyable mini dance-therapy session, along with his trusted partner 2 year old Mila, and his broomstick. As a professional Broadway dancer, as well as a current ballet instructor, Alex showed us how to do dance moves in everyday activities, and to keep the music going. His story, just as inspiring as Dr. Schneider's, gave us a glimpse into how much a PD patient can better his/her life with a focus on both diet and therapy.

For questions, info and/or a copy of the recording of the event, please email us at info@lifesparkpd.com, or call our office at 732-534-6388.



107 7th street Lakewood, NJ 08701 732.534.6388 info@lifesparkpd.com

INSIDE:

BONE HEALTH PUZZLE TIME INTERVIEW UPDATES D'VAR TORAH SHORT STORY

