

IFESPARK, NEWSLETTER

THE JOY OF MASKS

Purim is a יום שמחה. It requires us to set aside feelings of sorrow and to celebrate in joy and good cheer. There are many מנהגים designed to help us fulfill this obligation. One מנהגים adopted by Klal Yisroel to generate joy is the custom of wearing a mask on Purim. A source brought for this custom is the words of Rebbi Shimon Bar



Yochai (Megillah 12A) regarding Klal Yisroel's Purim salvation. He said that although the Jewish people deserved to be destroyed, as they had all bowed before the idol of גבוכדנצד, nonetheless, Hashem miraculously saved them.

When his students asked him why they deserved such a miracle if they had indeed sinned, he answered:

"הם לא עשו אלא לפנים, אף הקדוש ברוך הוא לא עשה עמהן אלא לפנים".

"The Jewish people only worshiped the idol for appearance (inside their hearts, however, they had no intention to serve), so too, Hashem was only angry for appearance (pretending He meant to destroy them)."

In other words, our initial sin of bowing to פסל נבוכדנצר was merely an act, a 'mask' we donned to appease a wicked king, while inside we remained faithful to Hashem. Hashem's anger, as well, was only a mask to initiate us to do Teshuva.

One of the valuable lessons of Purim's long, painful, and ultimately miraculous saga is the 'lesson of the mask.' We realize that although, at times, we may act unbecoming, those actions are not who we truly are; they are

merely a transient 'mask' that we've applied to appease an overwhelming Yetzer Harah. We learn to embrace our identity, essence, and Neshama, which has always stayed faithful to its mission and creator.

Keeping this lesson in mind serves as a wellspring of joy on Purim and even all year long. The source of all sadness and misery is our misguided identity with all the negativity and sin that we have done. Sadness can be devastating if we believe that our transgression and deficiency are who we truly are. However, when we absorb the 'lesson of the mask', learning that just beneath the 'mask' of our actions rests a pure, pristine Neshama, we can rejoice in who we are, who we always were, and in our glorious future that lies ahead.



Rabbi Tyviki Fener



1 כדכת' על כן היהודים וכו' עושים וכו' שמחה ומשתה יו"ט וכו' (אסתר ט, יט), ועי' רש"י מגילה ה.ב ד"ה נטיעה של שמחה, רמב"ם הל' מגילה פ"ב הי"ד, ובפי' אב"ע עה"כ וביום שמחתכם (במדבר י, י), ובמשנת יעב"ץ או"ח סימן מ"ה.

המנהג מוזכר ברמ"א (תרצ"ו, ח) משו"ת מהר"י מינץ, דאף אין איסור בזה לגבר ללבוש כלי אשה וכו', ועי"ש במשנ"ב מד' הב"ח יו"ד סי' קפ"ב, 2 ושא"ס. ורמז לדבר בשבת סו,ב: פרמי – טלמוסא הנקשרת על הפרצוף להבעית הבנים (רש"י), די"א דלשון 'פרמי' מרמז ל'פורים'. ולהא דלהלן י"ל דמותר משום דבפורים מגלים עצם נקודת צורת האדם שהיא למעלה מפרצופי איש ואשה, ויל"ע. ועוד טעמים ניתנו למנהג, כגון זכר לאליהו שהתחפש לחרבונה, או זכר לרבים מעמי הארץ המתייהדים שהתחפשו ללבוש כיהודים כי נפל פחדם עליהם, ועוד כהנה.

3 אף שהם לא עשו אלא לפנים, בכ"ז נתחייבו בתשובה כיון שמעיקר הדין הי' להם למסור נפשם שלא לעבוד ע"ז.

THE MASKS WE WEAR

אסתר מן התורה מנין, שנאמר, ואנכי הסתר אסתיר פני ביום ההוא.

[חולין קלט,ב, דברים לא, יח]

"Where does the Torah allude to [Queen] Esther? [In the Posuk] that says: 'I will surely have concealed My face on that day [because of all the evil that Klal Yisroel did...']."

The underlying story of Purim is that Hashem's face was in 'hiding'; He was right there with us, watching, protecting, and guiding us along our journey, while

His face was merely 'concealed.' Hashem had donned a 'mask,' and at just the right moment, He removed it, showing us how His devotion was constant and His love never waned. As masks are the narrative of our Yom Tov, we've chosen to present an article regarding masks and their connection to Parkinson's disease.

PARKINSON'S MASK

Parkinson's can impact the use of facial muscles. This is often referred to as having a 'Parkinson's mask,' 'facial masking,' or hypomimia.

Facial expressions are complex signals that last only a few minutes and are important for communicating intention, motivation, and emotional states. In humans, various neurological and psychiatric conditions alter the tendency to use facial signals. One of the main symptoms of Parkinson's Disease (PD) is diminished facial expressivity or "masked facies," which refers to the expressionless appearance of individuals with the disorder. When the muscles of the face are stiff or take longer to move, it can be hard to smile, raise your eyebrows, or otherwise express your feelings using your face, which is an important part of how we communicate.

Although when we think of muscles that can be affected by stiffness and slowness, the muscles you work out in the gym are probably the first to come to mind: legs, arms, and maybe even abdominals. However, the same stiffness and slowness that can impact your walking and other activities can have more subtle impacts, as well. One of these is reduced facial expression or facial masking.

Combined with Parkinson's speech changes, such as low voice volume, facial masking can make it hard for others to interpret your mood and intentions. People might assume you're upset or depressed all the time, which can be frustrating if they constantly ask, "What's wrong?" when you are feeling fine. On the other hand, if you are experiencing symptoms of depression, talk to your doctor. Mood changes are common in Parkinson's and treatable.

MANAGING FACIAL MASKING

Medications to treat movement symptoms should help with facial masking, as they alleviate rigidity.

It is also a good idea to ask your doctor for a referral to a speech-language pathologist. He or she can teach you facial exercises that may help with masking, as well as other issues you may be having, including speech and swallowing problems.

Finally, if you have more frequent cases of people misinterpreting your mood or not believing you when you say how you are doing, try explaining the difficulty with muscle control and expression. This may help people to understand better how you are feeling and increase their awareness of Parkinson's. If you have Parkinson's, a lack of dopamine in the brain can stop your facial muscles working as well as they used to. This can limit the number of facial expressions you have.

When this happens, it can sometimes look like you have a blank expression, even if you're actually experiencing a strong emotion.

The medical term is hypomimia, but it's often referred to as a Parkinson's mask or facial masking.

Having a Parkinson's mask is a common symptom.



If someone can't use their facial muscles to express themselves as easily anymore, it doesn't mean they are low or depressed.

Some people with Parkinson's have apathy and problems with motivation. This means they may not respond to emotions like they used to. It may seem like there's a link in some cases, but it may be 2 common aspects of Parkinson's happening at the same time.









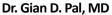


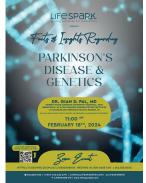
LECTURE SUMMARY OF PARKINSON'S DISEASE & GENETICS

This month's Monthly Educational ZOOM event occurred on Sunday, Feb. 18th, and was titled PARKINSON'S DISEASE & GENETICS. It

featured Dr. Gian D. Pal, who delivered a fascinating presentation on this topic. Dr. Pal is a neurologist specializing in psychiatry, neurology & movement disorders. His expertise includes treating Parkinson's disease, non-Alzheimer's dementia, Essential Tremor, Secondary Parkinson-ism, and Deep Brain Stimulation, among other conditions.







Dr. Pal's talk was extensive and filled with valuable information. Our synopsis will suffice to mention only a few points he discussed. We highly encourage watching the event video on the LifeSpark website (under the 'education' tab) for the rest of the valued material.

GENETICS

Parkinson's genetics is a highly prevalent topic these days. Genetics research studies how individual genes or groups of genes are involved in health and disease. Understanding genetic factors and disorders is essential in learning more about promoting health and preventing disease. Genetics also examines how disorders run in families and are passed down to further generations.

GENETIC TESTING

There are three main reasons why someone with PD would be interested in going for genetic testing. We'll call them the three pros of genetic testing:

- **1. To qualify for a clinical trial.** In the PD world, there are trials for different genetic abnormalities. The research hopes to better understand the workings of PD by identifying the genetic abnormalities that may cause them. This is one reason a PD patient will go for testing: they cannot qualify for these trials without comprehensive genetic testing.
- **2. Curiosity.** People often ask themselves "Why did I develop PD?" If you test and identify the genetic abnormality, you can 'put your finger' on what may have caused it or at least increased the risk of it manifesting. Perhaps it is not the whole story, but sometimes people feel better knowing even part of it.

3. Being treated with DBS [Deep Brain Stimulation]. Different genetic mutations react differently to DBS. Parkinson's is varied, but we can see commonalities in reactions of different genetic subtype mutations. Knowing your genetic variation can help you when discussing with your doctor to figure out together what your life may look like after getting DBS based on what happened to previous patients with the same genetic components.

THE CON OF GENETIC TESTING

The critical reason not to go for genetic testing is that no proven treatment is based on any genetic mutation status. The testing is purely to gain more information. No evidence-based findings are saying the testing can bring actionable information.



FROM Q & A SESSION WITH DR. PAL FOLLOWING THE LECTURE:

VARIATION OF TRIALS

Q: If one decides to join a clinical trial, how do they go about it?

Q: There are many trials - how do you choose which to go with?

A: First, you need to decide which trial type you want. There are observational and interventional trials.

Observation – learn about you and your disease, but no trial for drug treatment.

Intervention – includes some treatment trial – you will receive a placebo or investigational drug.

After you decide which type of trial you would like to be part of, there are many subcategories within each.

There are also many restrictions about each trial – age, other drug restrictions, etc.

After that, when you narrow down all your choices – you reach out to the trial committees, messaging them to send you the informed consent form. It will describe the benefits and risks in layperson's terms, which you can discuss with your family and doctor.

During Dr. Pal's talk, he discussed a clinical trial he is conducting. The trial concerns the identification of the contributing genes to Parkinson's disease. We sent out an email to the LifeSpark community with the trial information for all those interested in joining. Anyone else interested please contact the LifeSpark office.



Dear LifeSpark Team,

Wow! Thank you for hosting Linda K. Olsen. That was absolutely amazing and so inspirational! The C Family

To Lifespark,

Thank you for your recommendation for Dr. Kim Badiola. She is kind, understanding and extremely knowledgeable!

-S.L. from NJ

I am interested in the new small DBS monitors I heard about in an online seminar, do you have any research that you can share?

We are including that information in this issue's Medical Movement section.

Hi Paulette.

Thanks so much for all your help with this. We already have seen Dr. Gupta and the speech therapist you recommended. They both have been great resources. Meeting with Dr. Gupta even once has been invaluable!

- T.R.

Thank you for sending me the email with the registration information for the APDA 2-day seminar. It was super informative & it was great connecting to others in the same boat as us!

MOUNT SINAI SLEEP STUDY-LIGHT THERAPY

Mount Sinai Hospital recently requested our own Rabbi (Moshe Y.) Gruskin to join in their experimental sleep study, using light therapy as a therapeutic tool to heal sleep issues in those suffering from Parkinson's Disease.

The theory is that a person's sleep issues can be triggered by the fact that their internal 'timer' is 'off schedule.' By projecting light onto the body, the body is made to believe that it is daytime and can then recalibrate its internal day/night timer. The short article below will delve into the fundamental theories and therapies regarding light therapy. In an upcoming article, we hope to share more research findings and specific PD symptoms that have been found to be helped with light therapy.

RABBI GRUSKIN'S REACTION

First, we'll quote Rabbi Gruskin's perspective and his reaction to the therapy: "In the beginning, when I kept the desired schedule of the lighting therapy, I found that I achieved a better-quality sleep. However, as I was not as consistent in keeping my morning light therapy schedule, I, therefore, found that my sleep was not as good as it was at the beginning of the light therapy – when I was keeping a schedule. However, my overall sleep is still better than it was ini-



tially before I began the therapy. It took approximately three weeks of treatment for me to see improvement in my sleep. My sleep became deeper, and I generally feel more relaxed."

MRS. GRUSKIN'S REACTION

My husband's sleep is better than before he began light therapy. But not as good as at the beginning of the treatment, when he was staying by the lights for a more prolonged period.

FUNDAMENTALS OF LIGHT THERAPY

And now for the fundamentals of light therapy. Here's what we know about this treatment so far. Laser light therapy is already used as a complementary therapy to treat pain, reduce inflammation, and increase tissue repair. It shows promise as a non-invasive and non-drug-based treatment for Parkinson's symptoms, which could be given at home without the need for any specialist training.

HOW DOES IT WORK?

Light therapy uses specific wavelengths of light that can harmlessly penetrate the skin and tissues. Light therapy primarily focuses on treatment via the gut or abdomen. There's ongoing research into a potential link between the gut and the brain, especially when it comes to the start and progression of Parkinson's [see previous LifeSpark newsletter – Issue #18, for a report on the LifeSpark Monthly Zoom Event with Dr. El-Nachef on Dec. 17, 2023]. While the link hasn't been fully proven yet, we do know that some people report digestive problems or constipation many years before a Parkinson's diagnosis.

It is thought that light therapy to the gut could decrease inflammation, allowing it to function more normally. The small-scale clinical trials currently being reported indicate light therapy could improve mitochondrial function; the power stations of your cells, improving energy levels and decreasing fatigue. Treatment was also associated with reduced pain in people with Parkinson's using the device.

A DOCTOR'S VIEW

Professor David Dexter, Associate Director of Research at Parkinson's UK, said: "Using light therapy for Parkinson's is not a new idea but certainly an interesting one. Over 20 years ago, researchers were able to show how abdominal light therapy improved gait and balance and reduced tremor using mouse models of Parkinson's. What we're starting to see now is the results of trials in people with Parkinson's. These early, small-scale trials are showing promise, suggesting that the benefits of a short course of treatment could last for a long time and improve both motor and non-motor symptoms like tremors, mobility, and sleep."

MORE ON THE THEORIES ABOUT WHY LIGHT THERAPY MIGHT WORK FOR PD.

1] Light acts directly to reset the body's master clock. The system of circadian rhythms controls the aspects of human physiology that cycle as a function of the time of day – the chief of which is sleep and wakefulness. Light, sensed by the eyes, is the key (but not only) regulator of this system. The suprachiasmatic nucleus, which is a brain structure that is located behind the eyes, is the body's master clock. Abnormalities of the circadian system are becoming an increasingly well-established non-motor symptom of PD. External light can potentially regulate the master clock that is not working correctly.

2] Light may enhance dopamine transmission. Multiple lines of research in animal models suggest that light can have a direct effect on the dopamine system, and this may be the mechanism of action by which light improves PD symptoms.

3] Near-infrared light is absorbed by cytochrome C-oxidase in the mitochondria, the energy-man-ufacturing component of the cell. This absorption is thought to have various effects, including increasing energy production and regulating cell signaling. Mitochondrial dysfunction is well-established to play a role in the development of PD, and near-infrared light may, therefore, be able to undo some of this dysfunction.

(Based on an article on the ADPA website)

DUICK FACTS REGARDING THE STUDY FROM THE STUDY MANAGERS

Sleep and Parkinson's: We are on the cusp of understanding the role of sleep and the body's natural daily (circadian) rhythm in Parkinson's disease. Night-time sleep affects daytime alertness, memory, mood, and actions. Further, there is even some suggestion that the body clears toxic compounds during sleep, making sleep even more important. The NIH has extended our Parkinson's genetics study so that we can learn more about the different elements of sleep and fatigue in Parkinson's and their effect on thinking, memory, and mood.

[The following is a very concise version of the study. The intention is to give a glimpse into what one can expect from the study. For detailed information on the study see contact info. below]

THE STUDY

In the first part of the study, we collect information about sleep using questionnaires, wrist monitors to measure motion and sleep (called an **Actigraph**, similar to a FitBit), and light monitors to measure light exposure (called a **Daysimeter**). The 2nd part of the study is the LIGHT THERAPY, when the Actigraph and Daysimeter should be worn daily for one week prior

to us installing lighting in your home and then again beginning one week before the lights are picked up. Prior to both time points, the devices will be shipped

to you. You will also be asked to collect a urine sample at nighttime, which you can leave for pickup. (This sample is to check your nighttime melatonin levels). During this first week, we will come to install the lights in your home. For the next four weeks, we ask that you spend at least two hours each day sitting in proximity to the lights. Once the four-week trial is complete, we will come collect the lights and follow up over Zoom to complete a few questionnaires.



The Principal Investigator for this study is Dr. Rachel Saunders-Pullman.

If you would like to join the study, please reach out to Amy Astefanous, phone: 212.844.6947 amy.astefanous@mountsinai.org.



SOME WEAR THEIR MASK ON PURIM, MINE'S A COSTUME ALL YEAR LONG, IT HIDES ME FROM MYSELF,

CUZ' I FEEL I DON'T BELONG

MASKING ME

I'M SURE I NEED TO DISAPPEAR,
I'M NOT WORTH VERY MUCH,
THE SHAME, THE PAIN, I'VE GOT TO RUN,
NEVER TO BE TOUCHED

ALL I DO, THINK, OR SAY,
IS TO PROTECT THE FRAGILE ME,
AS IF I CAN'T STAND ON MY OWN,
AND LIFE'S A TRAGEDY

PURIM IS WHEN I LEARN THE TRUTH,
OF WHOM I AM, FOR REAL,
MY MASK, IT MELTS AND DISAPPEARS,
I KNOW MY SELF, I FEEL

PURIM'S VEIL HELPS ME SHED,
MY FACADE OF ALL YEAR LONG,
NO MORE LIES AND SELF-DECEPTION,
I'M HERE TO SING MY SONG

TODAY, MY 'FACES' PEEL AWAY,
IT'S MY TIME OF LIBERTY,
IN MY DRUNKEN COURAGE,
I FIND THE FREEDOM TO BE ME



SO, HERE'S MY JOY ON PURIM,
I KNOW WHAT I LIVE FOR,
MY SOUL REVEALED, FOR ME, FOR ALL,
I FOOL MYSELF NO MORE

MY SENSE OF WHO I AM IS CLEAR, I CAST AWAY DISGUISE, FROM DARK CLOUDS, I SEE A RAY, JUST LOOK INTO MY EYES

MY SMILEY FACE OF YESTERYEAR, THAT HID MY HURT INSIDE, IS NO MORE; MY LOOK IS REAL, I'VE FOUND MY HEALTHY PRIDE

YOU MAY WONDER HOW THIS WORKS,
I'LL TELL YOU, MY DEAR FRIEND,
IT'S A PROCESS OF HARD WORK,
WELL WORTH IT IN THE END

AND LIKE THE TALE OF OUR PURIM, IN CONCLUSION, WE SHALL SEE, HASHEM WAS WITH US ALL ALONG, AND THAT'S THE GREATEST JOY, THAT CAN EVER BE.

Ah Freilichen (transparent) Purim! Hatzofe, 84

MEDICAL MOVEME DOUBLE 40 4A

PRODUODOPA - NEW TO THE MARKET!

Based on a press release of the AbbVie Company News Center [NORTH CHICAGO, Ill., Jan. 9, 2024]:

PRESENTLY THIS MEDICATION IS ONLY AVAILABLE IN THE EU (European Union).

AbbVie has launched PRODUODOPA® for People Living with Advanced Parkinson's Dis-

ease. PRODUODOPA® is the first and only subcutaneous [I.e., under the skin] 24-hour infusion of levodopa-based therapy for the treatment of advanced Parkinson's disease with severe motor fluctuations and hyperkinesia (excessive movement) or dyskinesia (involuntary movement), and when available combinations of Parkinson's medicinal products have not given satisfactory results. It demonstrated sustained improvements in "Off" time (when symptoms return between medication doses), "On" time (when symptoms are controlled), without dyskinesia (involuntary movement), and morning akinesia ("Off" time upon waking).

"People living with Parkinson's disease experience daily challenges and uncertainty, especially as their disease progresses and symptoms are no longer adequately controlled," said Roopal Thakkar, Senior Vice President, CMO, AbbVie. "This approval is an example of our unwavering commitment to this community by developing new, transformative therapeutic options for people experiencing advanced Parkinson's disease, their families, and care partners".

The launch was supported by three studies: an open-label study that evaluated the long-term safety, tolerability, and efficacy of continuous subcutaneous infusion of PRODUODOPA, a study that compared the efficacy and safety of PRODUODOPA to oral levodopa/carbidopa, and a pharmacokinetic [i.e., how the body interacts with the medicine while exposed to it] comparability study.

Findings from the safety and tolerability study showed a favorable benefit/risk profile and demonstrated sustained improvements in "Off" time and "On" time without dyskinesia, and morning akinesia. Most adverse events were nonserious and mild or moderate in severity. The most frequent adverse events (greater than or equal to 10 percent) were infusion site events (infusion site pain, reaction, infection, etc.), hallucination, falls, and anxiety.

"This approval represents a significant advancement for those with Parkinson's disease who have historically had limited treatment options for advanced stages," said Angelo Antonini, MD, University of Padua, Italy. "When oral treatment no longer sufficiently helps with improvement in motor fluctuations, patients need alternative options. PRODUODOPA's around-the-clock infusion allows for continuous delivery of levodopa, the gold standard of treatment."

"As Parkinson's progresses, it can take a significant physical and emotional toll not only on the person but also on their family and care partners, who often play a critical role in their daily lives," said Josefa Domingos, President of Parkinson's Europe. "It is vital that the Parkinson's community have more options that can help them manage their symptoms."

MEDICAL MOVEMENT

LATEST TECHNOLOGY IN DBS THERAPY

DEEP BRAIN STIMULATION (DBS)

DBS is the most performed surgical treatment for Parkinson's. DBS therapy consists of a small pacemaker-like device implanted under the skin of the chest or abdomen that delivers electrical stimulations through leads to a targeted area in the brain.



While transformative for some, DBS is not for everyone. This treatment is approved for people who have had Parkinson's disease for at least four years and who get a benefit from medication but have motor complications, such as significant "off" time (periods when symptoms return because the medication isn't working well) and/or dyskinesia (uncontrolled, involuntary movements).

DBS typically works best to lessen motor symptoms of stiffness, slowness, and tremor. It doesn't work as well for imbalance, freezing of gait (sudden inability to move when walking), or non-motor symptoms. As DBS may worsen thinking or memory problems, it's not recommended for people with dementia.

THE LIBERTA RC DBS SYSTEM FROM ABBOT

The Abbot company recently launched the world's smallest rechargeable DBS system with remote programming capabilities to treat movement disorders. The Liberta RC^{TM} DBS system was recently approved by the

U.S. FDA and features NeuroSphere™ Virtual Clinic, which allows for remote programming of the system. The system also offers the longest time between charges of any DBS technology on the market, allowing people with movement disorders to recharge the device only 10 times a year.

NeuroSphere™ Virtual Clinic enables communication between people and their doctors, which is critical to ensuring exceptional care, especially for those who suffer from chronic conditions, such as Parkinson's disease and essential tremor. The system allows people to communicate with their doctors to ensure proper settings and functionality and receive new treatment settings remotely as needed without stepping foot in a doctor's office. Abbott developed Neuro-Sphere Virtual Clinic after research showed that the average Abbott DBS user in the U.S. must travel more than 150 miles to access a movement disorder specialist.



"When our patients choose a rechargeable DBS system, it is often based on the smaller size of the device, but the tradeoff has always been how recharge frequency affects their lifestyle," said Dr. Paul Larson, professor of neurosurgery at the University of Arizona. "The Liberta RC DBS system excels in both areas, as a compact rechargeable device with the lowest recharge requirement of any FDA-approved DBS system. This achievement, coupled with the integration of remote programming capabilities, is a significant advancement for patients."

At approximately the height and width of a smartwatch face, the Liberta RC DBS system is about 31% smaller than other commonly used implantable, rechargeable DBS devices currently available in the U.S. When used under standard settings, Abbott's Liberta RC DBS system needs to be recharged as few as every 37 days – or 10 times a year – using a wireless charger that is placed over the device.

To see if you qualify and may benefit from a DBS device, please talk with your movement specialist.











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DID YOU KNOW THAT FACIAL MASKING CAN MAKE IT HARD FOR OTHERS TO INTERPRET YOUR MOOD AND INTENTIONS?

CLIP & SAVE

COMING EVENTS!



