



PARKINSON News

PUBLISHED BY THE PARKINSON ASSOCIATION OF GREATER DAYTONA BEACH (PAGDB)

WE'RE BACK IN THE SADDLE!!!

As previously noted, the PAGDB is pleased to announce that "Sole Support for Parkinson's" Fun Walk is returning and is **scheduled for Saturday November 13th 2021 from 10am-2pm at the City of Port Orange Lakeside Community Center & Amphitheater**. As difficult as the past two years have been, there is an optimistic sense that life is beginning to shift towards "Getting back to normal", and we can't think of a better opportunity than the "Sole Support for Parkinson's" Fun Walk to again rejoin in a beautiful outdoor setting and enjoy fun, exercise, food, prizes, entertainment, and most importantly - each other! We hope you will join us as we celebrate the return of our annual outdoor festival.

In this Newsletter you will find a printable registration form, or see page 2 to register online. You can also register and pay online at: www.parkinsondaytona.org
We can't wait to see you there...

"Moving ON with RYTARY - A Community-Based Conversation"

Tuesday, July 27, 2021 • 2:00 PM

Join us for an interactive conversation between a Stories in Parkinson's (SPARK) Ambassador and a healthcare provider! Together, they will share insights about living well with Parkinson's, managing symptoms, and how RYTARY might be able to help. Attendees will hear firsthand from a SPARK Ambassador about their experience with Parkinson's and where they find inspiration. Explore an exciting Parkinson's treatment option and resources for talking to your healthcare provider, connect with others in the Parkinson's community, and find answers to your questions.



Dr. Ramon Rodriguez

Dr. Ramon Rodriguez held the position of Director of Clinical Services for the University of Florida Center for Movement Disorders and Neurorestoration and Director of the Clinical Research Center for Neurological Disorders, where he supervised over 50 clinical research studies encompassing areas such as Parkinson's disease. Afterwards, Dr. Rodriguez had the role of Chief of the Neurology Service at the Orlando VA Medical Center. During his tenure, he established the Parkinson's Disease Consortia Site, a Center of Excellence for PD. He now runs his own clinic of Neuroscience and Brain Wellness dedicated to the health and well-being of patients and caregivers with complicated neurological disorders.

This event will take place via Zoom. Online registration for this webinar is required. To register click the button below or visit: www.parkinsondaytona.org/you-me-pd

Register for Webinar

DRINKING WATER IMPLICATED IN CAUSING PD IN CERTAIN VETERANS

Environmental exposures and their relationship to Parkinson's disease have been a hot topic for some time. Recently the wife of a former PAGDB member who served in the USMC (recently deceased), made me aware of a variety of veterans benefits available to people that had served in the US Military at Camp Lejeune NC, and while there exposed to chemical tainted drinking water and later diagnosed with Parkinson's disease. The VA will not limit entitlement to active-duty military, but will also presume exposure for reserve and National Guard members who served at Camp Lejeune for at least 30 days (cumulative) between August 1, 1953 and December 31, 1987. These benefits can be extremely helpful to individuals/families that qualify. To find out more about these benefits please click on the below links. *PLEASE NOTE there has been additional changes in legislation since many the articles featured in the below links were drafted, and there may very well be other Military Camps/Bases in the Carolinas that have been discovered with the same drinking water issues resulting in subsequent diagnoses of Parkinson's disease. Please be sure to check the following links:

<https://www.va.gov/disability/eligibility/hazardous-materials-exposure/camp-lejeune-water-contamination/>
<https://www.pbs.org/newshour/nation/u-s-pay-billions-marines-affected-contaminated-drinking-water>
<https://www.publichealth.va.gov/exposures/publications/gulf-war/gulf-war-winter-2017/camp-lejeune.asp>
<https://www.calvet.ca.gov/VetServices/Documents/USDVA%20Camp%20Lejeune%20Presumptive%20Factsheet.pdf>

In addition to the above links, or for additional info you can also call Volusia County Veterans Services Division at: 386-254-4646.

RECENT GIFTS & GRANTS

- ♥ Anonymous – Gift to Dance for PD Online Program by way of PAGDB
- ♥ Ellen Lauturner – Gift to PAGDB in Memory of Reginald Lyon-Mercado
- ♥ Jennifer Bryant - Gift to PAGDB in Memory of Reginald Lyon-Mercado
- ♥ F.O.E. Auxiliary 3800 – Gift to the PAGDB
- ♥ Magali Roman by way of Safelite Auto Glass – Gift to the PAGDB
 - ♥ The Families of Powers, Henderson, Beck, Kelley, O'Reilly, & Hersey – Gift to the PAGDB in memory of Dorothy Hand

A huge debt of gratitude to all those that donate to our cause. Your gifts and grants go a long way in enabling us to carry on. Thank You!

To make a gift in honor or memory of a friend or loved one, to provide a grant, or to simply **donate to the PAGDB cause: By mail**, please make checks payable to Parkinson Association of Daytona, P.O. Box 4193 Ormond Beach, FL 32175. **To donate online**, please visit our website at: www.parkinsondaytona.org and click on the Donate link.

[Donate](#)

FUN RIDDLES

1. I am big on Saturday and Sunday. I am small on Tuesday, Wednesday, and Thursday. I am not on Monday and Friday. What am I?
2. What can travel around the world while staying in a corner?

ANSWERS

1. The letter 'S'
2. A STAMP

MARK YOUR CALENDAR!

Tuesday, September 21, 2021

Mark your calendars for our Tuesday September 21st You, Me & PD Zoom Webinar Program as we will be hosting Neurologist and Movement Disorder Specialist Dr. Sheila Baez-Torres who'll be discussing dyskinesia and off episodes in PD, and will present an overview of the Parkinson medication Gocovri.



Sheila Baez-Torres, MD

REMINDER: There will be no meeting in August.

This event will take place via Zoom. Online registration for this webinar is required. To register click the button below or visit:

www.parkinsondaytona.org/you-me-pd

[Register for Webinar](#)

FUNNY SIDE UP - FUN FACTS!

1. You can't see your ears without a mirror
2. You can't count your hair
3. You can't breathe through your nose with your tongue out
4. You just tried number 3
6. When you did number 3 you realized that it is possible, only you looked like a dog
7. You are smiling right now because you were fooled
8. You skipped number 5
9. You just checked to see if there is a number 5
10. Share this with your friends so they can have some fun too

HAVE A NICE DAY!

[Fun Walk Online Registration](#)

NOTE: The information in this newsletter and the information provided by our speakers is not intended as medical advice. Please consult your physician before trying anything new or different.



Parkinson's & Constipation Nutrition Study

If you have been diagnosed with Parkinson's and suffer from slight constipation symptoms, you may be eligible to participate in a research study.

The effect of a Mediterranean diet intervention to improve gut health in Parkinson's disease.

The UF Food Science and Human Nutrition (FSHN) Department is conducting a 10-week study to determine if the Mediterranean diet impacts gastrointestinal function of people diagnosed with Parkinson's disease who experience at least slight constipation symptoms.

You will be randomly assigned to follow a Mediterranean diet or receive standard of care for the intervention period.

During the study, you will complete daily and weekly questionnaires to assess bowel function, stress, quality of life, and dietary intake.

You will be asked to attend three (3), study visits after an overnight fast and provide stool samples at designated time points.

Participants will receive:

- Compensation upon completion of study procedures
- Light breakfast at study visits
- Diet education by a dietitian (RDN) followed by weekly phone calls

Location

- In-person appointments 3 times over 10-weeks at the UF FSHN Building in Gainesville, FL. Other study procedures will be conducted virtually and/or by phone

Are you eligible?

- 40-85 years old
- Diagnosed with Parkinson's disease
- Hoehn & Yahr Stage \leq 2.5
- Experience at least slight constipation symptoms
- BMI \geq 18.5
- No history of deep brain stimulation (DBS) or gastrointestinal condition
- Additional criteria will apply

If you're unsure if you meet the requirements, call, or email a member of the study team:

- Carley Rusch, MS, RDN, LDN
- Lead Research Dietitian
- nutrition-study@ufl.edu
- (352) 340-7321

If interested, please go to: <https://tinyurl.com/MPDStudy> or call (352) 340-7321



College of Agricultural and Life Sciences

Click anywhere on this flyer to be taken to the webpage to learn more.

SUMMER WORD SEARCH



E U C E B R A B F U T S I A P F
R P A Y S U N G L A S S E S C L
A R U L P F E E E R T M L A P I
X P W O N M A E R C E C I N U P
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T L E A T S W I M M I N G C A L
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G E B N I V I M L O N A U T E S
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A Y H U T S N O W C O N E A R P
L E K R O N S P A R A D I S E C
F I R E F L I E S N L U S R U T

SUNNY
PARADISE
POPSICLE
FLAMINGO
FLIP FLOPS
VACATION

SNOWCONE
WATERMELON
SUNGLASSES
BEACH
SNORKEL
PICNIC

BARBECUE
OCEAN
PALM TREE
SAND
SUNBLOCK
POOL

TOWEL
ICE CREAM
STRAWBERRY
LIFEGUARD
FIREFLIES
SWIMMING

ANSWERS ON PAGE 8

NON-MOTOR SYMPTOMS TREATMENT

Article Reprinted FR: WPC BLOG – Clinical Science – March 1, 2021

Ask anyone about Parkinson disease and they will immediately think shaking and perhaps, a shuffling gait. Rarely, will anyone think of the non-motor symptoms that frequently precede the onset of motor signs. Yet, these nonmotor symptoms increase in the number of symptoms and severity throughout the course of PD. In the past, neurologists also focused on the motor features of PD. We now know that nonmotor features become increasingly bothersome to our patients and have significant impact on quality of life.

The non-motor symptoms of PD reflect the global involvement of the nervous system. While past efforts to treat PD revolved around the substantia nigra and dopamine, scientists now realize that PD encompasses many brain functions and neurotransmitters.

One of the earliest symptoms of PD can be REM sleep behavior disorder (RBD). This is characterized by vivid dreams and sleep enactment. During REM sleep, we should be paralyzed and unable to act out our dreams. In some PWP, sleep paralysis does not occur and so, the dreams are acted out. Bed partners often describe, "he was shouting at his old business partner" or "she was running away from something frightening". This can result in injury to the bedpartner or PWP. Treatments include ensuring that medications that can worsen RBD are stopped or minimized, other existing sleep disorders like sleep apnea are treated and safety measures.

On the opposite side of RBD, is daytime sleepiness. This can affect up to 55% of PWP. In its mildest form, it can be annoying but in severe forms, can make operating a car or machinery dangerous. Daytime sleepiness can also cause social withdrawal. Ensuring that sleep is adequate at night, that medications that worsen daytime sleepiness (dopamine agonist more than levodopa) or cause sedation (pain medications and some antidepressants) are optimized.

Apathy is described as lack of motivation resulting in decreased goal-directed behavior and characterized by reduced interests or emotions. Apathy is frequently mistaken for depression by families or alternatively, contrariness on the part of the PWP. It is a great source of conflict between spouses and PWP. Apathy is a common feature of the changes in personality for PWP based on changes in how the brain functions. We are learning more about apathy through special radiology tests. Apathy is often associated with cognitive decline both clinically and in special radiology tests. Treatment can be behavioral (making routines) and recently, medications that improve thinking and memory have improved apathy although this is an early stage of research.

Many non-motor symptoms are due to involvement of the autonomic nervous system. This part of the nervous system controls "automatic" function such as heart rate, blood pressure, bowel function and bladder function. Problems with blood pressure result in early supine hypertension (high blood pressure) and standing hypotension (low blood pressure). This can result in feeling faint, actually fainting or fatigue and fluctuation in the clarity of thinking. Measuring blood pressure first thing in the morning both lying down and then after standing 3 minutes is important. If the blood pressure falls more than 20 mmHg or the standing blood pressure is less than 90 mmHg systolic, treatment will need to occur. Simple treatments can work such as drinking enough water, checking blood pressure pills and timing. Other measures such as wearing pressure stockings or stomping your feet before standing can help increase blood pressure. If these non-pill methods don't work, using specific medications to raise blood pressure may be necessary.

Swallowing is often affected for PWP. If we wait until someone is choking on water or food, we will miss opportunities to make drinking and eating safer.

Bedside tests can be helpful such as swallowing tablespoons of water to check for swallowing effort or coughing. The gold standard for swallowing remains a special x ray where the speech language pathologist will give various consistencies of liquids and solids for you to swallow. The x-ray allows the radiologist and speech language pathologist to assess how your swallowing works and make recommendations to improve safety. Another possible test is endoscopy where a probe that has a camera is inserted in your throat, again with the goal of watching how you swallow.

Simple treatments for swallowing include reducing distractions during eating (we are all guilty of watching TV during dinner sometimes or having a lively debate while trying to swallow), avoiding foods like dry, crusty bread or nuts and instead using nut butters, taking a few sips of water after swallowing each bit to lubricate your mouth and help the food go down, cutting food in small pieces and chewing thoroughly before swallowing.

Finally, constipation is a nearly universal problem for PWP. Daily bowel movements are possible for PWP and the sooner you start to address it, the better. There are a number of dietary changes that you can make to improve your bowel routine: Drink lots of water, eat high fiber foods and more legume and beans (high in digestible fiber). By contrast, using psyllium may worsen constipation as psyllium relies on normal bowel function in order to work. PWP have slower moving bowels and therefore, for psyllium to work, you would have to drink a ton of water! Exercise also improves bowel function. As an added benefit, exercise is great for PWP so get moving! If these are not successful, try PEG 3350 once up to 4 times/day. If necessary, Senokot, a laxative, can be helpful. For those with more severe constipation (no bowel movement for 3 days), they may want to discuss with their clinician trying Dulcolax.

This is just a snapshot of some of the non-motor symptoms that can impact the daily life of someone living with Parkinson's. Not all of them require a new medication and making changes in daily routines, sometimes just small changes, can improve quality of life.

Janis M. Miyasaki, MD, MEd, FRCPC, Director, Parkinson and Movement Disorders Program and Co-Director, Neuropalliative Care. Dr. Miyasaki has spoken at past World Parkinson Congresses, and spoke on Palliative Care and Parkinson's in May at the WPC Virtual Congress.

Ideas and opinions expressed in this post reflect that of the author(s) solely. They do not necessarily reflect the opinions of the World Parkinson Coalition®

Puzzle Answers

Check your answers against the answer key below. Did you get any answers right or solve the brain game/puzzle exercise in the May/June Newsletter?

Recent studies suggest that by adopting an "active cognitive lifestyle," individuals may be able to slow cognitive decline. Add to that studies performed by game theorists and anecdotal evidence, tasks such as puzzles, brain games, and trivia may boost mood and contribute to a more optimistic outlook.

SOLUTIONS

1. Red in the face	2. Green Eggs and Ham
3. Backrub	4. All thumbs
5. Two left feet	6. Black sheep of the family
7. Big fish in a little pond	8. Tennis shoes
9. Long time, no see	10. All in a day's work

"Happiness is not by chance, but by choice."

13th ANNUAL "SOLE SUPPORT" FOR PARKINSON'S FUN WALK
Port Orange Lakeside Community Ctr. - Saturday November 13, 2021 - 10:00am-2pm
****Registration Begins at 9:00am**

-REGISTRATION FORM-

IMPORTANT: This registration form must be filled out in its entirety, signed, and **mailed with your \$25.00 check made payable to the Parkinson Association of Daytona to P.O. Box 4193 Ormond Beach, FL 32175 and be postmarked no later than October 21, 2021.** Registration forms received after 10/21/21 cannot be guaranteed an event T-shirt/goody bag. **For children 12 & under the registration fee is \$15.00. For all registrants less than 18 years of age, a parent or responsible adult must designate as a minor child by checking here: _____ and fill out this form in the minor's name and sign on behalf of the minor child.**

PLEASE PRINT CLEARLY:

Last Name: _____ First Name: _____

Address/City/State/Zip: _____

Phone: (_____) _____ Email Address: _____

Age (if U-18): _____ T-Shirt Size: (circle one) S M L XL XXL

****All registrants – MUST CHECK IN AT THE REGISTRATION TABLE PRIOR TO THE WALK – at check in you will receive a ticket for door prize drawings.**

Participation Release (PR)

By registering to participate in the Parkinson Fun Walk 2021 (event); I understand and agree, that participating in this event may involve risk of personal injury which may result from not only my own actions, inactions, or negligence, but also from the actions, inactions, or negligence of others, the condition of the facilities, equipment, or areas where the event is taking place, and or the parameters associated with the event itself. Being in full knowledge to the foregoing, I hereby release, indemnify, and hold harmless the City of Port Orange and the Parkinson Association of Greater Daytona Beach (PAGDB), and all individuals, agents, employees, volunteers, representatives, officers, directors, and insurance companies associated with the PAGDB of and from any and all liability, claims, demands or causes of action whatsoever arising out of or related to any loss, damage, injury (up to and including death) that may be sustained by me or any property of mine while participating in this event. I further agree, that by participating in this event, that if I suffer any injury or illness, I authorize the event facilitators to use their discretion to have me transported to a medical facility for treatment, and I assume full responsibility for this action. By signing below, I attest that I have read, understand, and agree to the entire content of this PR, that I am in good physical condition and have no medical condition that would be detrimental to my health or wellbeing by participating in this event. Further, I hereby grant full permission to the PAGDB, to use photos, videos, and any other record of me during this event for any purpose, and for which I agree to receive no compensation whatsoever in return. This PR shall be binding upon me, my heirs, my executors, my legal representatives, and my assigns. This PR is construed to the laws of the state of Florida. **I agree that I am participating at my own risk.**

Signature of Registrant or Parent/Responsible Adult

Date

_____ **X here if you cannot participate** in the Parkinson's Fun Walk 2021 **but would like to help support our cause;** all donations are gratefully accepted and much appreciated! Please make checks payable to the Parkinson Association of Daytona and mail to P.O. Box 4193 Ormond Beach, FL 32175. **Thank You!**

The Fun Walk Will Take Place Rain or Shine!

THE WELLNESS CORNER

Exercise Rx: What About Apathy and Fatigue?

Recently, the Parkinson's Foundation partnered with the American College of Sports Medicine to provide new exercise recommendations for people with Parkinson's and certified exercise professionals. The goals of this collaboration are admirable and long overdue. They seek to:

Ensure standards of care for exercise professionals working with people who have Parkinson's
Ensure exercises are safe and effective at improving the quality of life for people with Parkinson's
Develop competencies for exercise professionals who work with people who have Parkinson's

As someone who lived an exercise lifestyle before my Parkinson's diagnosis, I agree that the exercise guidelines documented as an outcome of this partnership will help improve the quality of life for people with Parkinson's. The detailed intensities, duration, and frequencies across the four domains of exercise — aerobic, strength, flexibility, and balance — specific to people with Parkinson's are well-defined.

However, I feel there may be elephants in the room that should be acknowledged.

My background

I am sharing this information because I feel it is important for the reader to understand that I am no stranger to daily exercise.

In 2015, I was diagnosed with Parkinson's at age 62. For most of my adult life, I have lived an exercise lifestyle.

In the years leading up to my diagnosis, I had a fairly aggressive exercise schedule. I danced up to three hours per week, cycled up to 80 miles per week, race walked up to 12 miles per week, weight trained three times per week, and taught several weekly spinning classes.

Now, mainly due to my Parkinson's symptoms of extreme fatigue and apathy, I can't adhere to the exercise guidelines as described by this partnership.



If I couldn't go on autopilot to get my butt out the door to exercise (a skill I developed through years of training), I would find it impossible to exercise.

My quality of life is deteriorating, especially since I can't exercise with intensity anymore. Plus, in addition to feeling terrible, I am exhausted after I work out.

Exercise becomes even more daunting when a person with Parkinson's has never previously exercised regularly.

What are the elephants?

"Apathy can be a major non-motor symptom of Parkinson's disease. Combine it with fatigue, another major non-motor symptom, and it's no wonder we Parkies can be seen as lazy, disinterested or uncaring by friends, family and even strangers." — Bev Ribaudo

Apathy and fatigue can discourage a person with Parkinson's from starting an exercise program. Apathy is defined as a lack of interest or motivation. It interferes with the effective management of Parkinson's symptoms since apathetic people are less inclined to do things like exercise.

Parkinson's-related fatigue can make someone feel like it is impossible to move, as if they had no energy at all.

Ironically, exercise is recommended for alleviating fatigue and apathy. What a conundrum!

Another overlooked elephant "Walking a mile in someone else's shoes isn't as much about the walk or the shoes; it's to be able to think like they think, feel what they feel, and understand why they are who and where they are. Every step is about empathy." — Toni Sorenson

Unless a person has Parkinson's, there is no way they can comprehend how we feel. I once prided myself on my discipline and commitment to exercise. Now that I have Parkinson's, I am overwhelmed with all the time I must put in to fight this disease.

When the following are added to an intense exercise program as described in the exercise guidelines, battling Parkinson's becomes an all-consuming, full-time job:

- Psychotherapy sessions
- Support group attendance
- Speech and swallow therapy
- Occupational therapy
- Smell training
- Handwriting practice

What still needs to be addressed? For this undertaking to be successful, I believe the potential barriers that lead to inactivity must be addressed.

THE WELLNESS CORNER CONT'D...

In the published exercise guidelines, I did not see any acknowledgment of the exercise inhibitors for people with Parkinson's. I believe the exercise professionals must be trained to understand how symptoms of the disease can hinder a patient's success.

Trainers and healthcare professionals must be cognizant of the fact that some of the disease symptoms (such as apathy and fatigue) may truly challenge a person with Parkinson's and negatively affect their ability to follow through on a regular exercise program. Their mind may be willing, but their body cannot follow through.

Additionally, due to all of the therapies that are required for the different symptoms of the disease, a person with Parkinson's may feel inundated when attempting to start a regular exercise program. They may feel disheartened. This can potentially create undue stress, which can further exacerbate symptoms.

As my Parkinson's progresses, I am becoming more challenged and inundated — and this is coming from someone who has never shied away from exercise in the past.



EXERCISES YOU CAN DO AT HOME

Chair Squat

Squat to strengthen your legs and core, which will make everyday movements easier. Starting with a chair underneath you will help you master proper form.

Directions:

Stand in front of the chair with your feet shoulder-width apart, toes pointed slightly out.

Hinging at your hips and bending your knees, lower back and down until your bottom touches the chair, allowing your arms to extend out in front of you.

Push up through your heels and return to the starting position.

* Modify as needed, if you need to hold onto something make sure you have a stable item that is heavy enough to assist you. Or ask a neighbor, partner, friend or friend to help assist you.

<https://parkinsonsnewstoday.com/2021/07/06/exercise-rx-what-about-apaty-fatigue/>

ONLINE BRAIN & BODY TRAINING

Online Brain and Body Training for Alzheimer's, Parkinson's and Adults 50+

Total HealthWorks – an evidence-based virtual fitness platform created by the founders of Delay the Disease, the #1 Parkinson's group-exercise program in the country, is offering their Brain and Body Class **every Wednesday at 12:00 PM Noon EST via Zoom for FREE!**

Fill out the form on their website and receive a link in your email to join the online Brain and Body exercise class with Jackie Russell and David Zid. **Click the button to be taken to their registration page or visit their website to learn more:** <https://totalhealthworks.com/free-online-class/>

Don't worry, if you can't join the class at the scheduled time, **you will receive a link in your email to watch the class whenever you'd like!**

Register

DANCE *for* PD®

CLASSES | TRAINING | RESOURCES

For those that wish to continue to participate in a regular Dance for PD program with local Dance for PD instructor Gabriela Trotta – these classes are now **offered online every Monday at 1:30pm** – it's easy to register and participate and it's **FREE** to all PAGDB Members!

To find out how to connect with our live online Dance for PD program please contact **Gabriela at 386-405-6905 or email her at: gabriela59@aol.com or Nicole at nmante86@gmail.com.**

Gabriela & Nicole will be happy to help you get started.

SO GET OUT AND DANCE!



****Other than provide financial support for its members that wish to participate in this Dance for PD program, the PAGDB has no ownership stake nor controls any of the program content. PAGDB members that wish to participate do so at their own risk. Always consult with your doctor before you engage in any type of exercise program.**

WEBINAR VIDEOS

All of our previous webinars in our You, Me & PD series are available on Youtube and our website! To visit our YouTube channel you can search for it by visiting www.youtube.com. In the search box search for: Parkinson Daytona. You will find our 'channel' and all of our uploads. You can subscribe to follow us and be shown future uploads. We also have all the webinar videos on our website under the 'Events' tab. Visit our website www.parkinsondaytona.org or [click here to visit our YouTube channel](#).

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