

A MONTHLY PUBLICATION OF

PARKINSON'S RESOURCE ORGANIZATION

Working so no one is isolated because of Parkinson's

MESSAGE

P R E S I D E N T ' S

April is a very spiritual month again this year, as I have acknowledged at the bottom of this message, but it also happens to be **PARKINSON'S AWARENESS MONTH!** I've been aware of this disease every moment of every day of every year for the past 29+ years. People with Parkinson's, their caregivers and families are aware of Parkinson's every minute of every day. Parkinson's Resource Organization is too.

Being aware is one thing, outwardly demonstrating your interest and support for those dealing with Parkinson's gives all of us hope and energy. Supporting our efforts to ease the pain, the struggles and unbelievable heartbreak felt by so many is the fuel that keeps us going and fills our hearts with overwhelming gratitude. We applaud you and appreciate you as you join a walk, a run, a bike ride or whatever activity is in your neighborhood and know we are right there with you raising awareness of a world of dear people hanging on by a thread, seeking hope and help from us at PRO and you, our supporters. It begins with **AWARENESS** and continues with **ACTION**... Thank you, thank you for raising your voice and stepping up.

This month, for our outward awareness program, we celebrated our **3rd Annual Mitch's Pitches PRO** on April 7th. We are sharing with you some of the pictures on pages 6 and 7, together with an article from the Press. Please go to the PRO website—as well as our Facebook page; [Facebook.com/Parkinsonsresourceorganization/](https://www.facebook.com/Parkinsonsresourceorganization/)—and see the excitement we had at and surrounding the event. Palm Springs even named April 7th **JO ROSEN DAY!** Can you imagine?

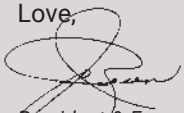
To give you hope, enlightenment and helpful information to use in your quest for "Ultimate Quality of Life" enjoy the PROvocate **UPDATE ON THE ROAD TO THE CURE** on this page.

Our other PROvocate and informative news is **HOW WEARABLE DEVICES HELP SENIORS STAY SAFE AT HOME** on page 2, and **DEVELOPING TREMOR-SUPPRESSION TECHNOLOGY TO HELP PEOPLE WITH PARKINSON'S** on page 3.

Join us in making a difference in your life, or the life of a loved one this MONTH by donating. Supporting us is simple: Make monthly donations through our safe PayPal donation page at [Parkinsonsresource.org/#modal-donate](https://www.Parkinsonsresource.org/#modal-donate) or mail your donation to our office in Palm Desert, California.

Until next month, REMEMBER April Fool's Day on the 1st, Palm Sunday is on the 14th, file your TAXES on the 15th, Good Friday on the 19th, Passover beginning on the 19th, Easter Sunday on the 21st, Earth Day on the 22nd, Arbor Day on the 26th, with Passover ending on the 27th. The flowers are Daisy and Sweet Pea and the Birthstones are Diamond and Crystal. You might also take note that April is National Poetry Month. We would love to receive your favorite poem. ALWAYS remember to CELEBRATE YOU and PRAY FOR OUR TROOPS!

Love,



President & Founder

ICBI UPDATE ON THE ROAD TO THE CURE

A REAL-TIME SCIENCE REPORT MORE HOPE FOR PARKINSON'S CURE

Recently, Stanford researchers were able to improve the cognitive function of older mice after blocking a protein's activity on brain cells known as microglia. These scientists have hunted down a single gene that encodes a protein responsible for age-related cognitive losses, targeted it with special blocking antibodies, and shown in mice that these antibodies can rejuvenate old brains to work as well as young ones.

Microglia is a class of brain cells responsible for immune responses and routine cleanup. Among many other functions, microglia spends their time gobbling up bits of protein deposits and cellular debris that result from normal brain activity, and it's long been known that their garbage-collecting performance deteriorates with age. The decline in microglial cleanup performance is believed to be linked to the kinds of cognitive declines we see with aging. Both Alzheimer's and Parkinson's diseases, for example, are diseases with abnormal accumulation of proteins that are associated with the decline of microglia cleanup activity.

Through analysis of thousands of microglia-related proteins, the scientists found that one protein, CD22, was as much as three times as prevalent on the surface of old mice's microglia as on those of young mice. Thus, CD22 protein was suspected of being the culprit for slowing down clean-up activity of microglia. CD22 protein is found in both mice and humans.

Blocking the effects of CD22: With a possible culprit identified, the team decided to block CD22 protein using specially designed CD22-antibodies. Since antibodies, in general, do not cross the blood-brain barrier (BBB) to enter into the CNS, the scientists injected these antibodies into one side of the mice's hippocampus, and for a control, they injected a different antibody that couldn't bind with CD22 into the other side of the hippocampus. Sure enough, 48 hours post-injection, there were far less of alpha-synuclein protein debris left on the side with the CD22-blocking antibodies.

Turning back the clock: After a month of continuous CD22 antibody injections, the

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Our Wellness Villagers

ACUPUNCTURE

- Dr. David Shirazi

ANIMAL-ASSISTED THERAPY

- Canine Companions


AROMA THERAPY

- Renee Gauthier

ASSISTIVE TECHNOLOGY

- California Phones

BEAUTY

- Younger By Tonight 

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- Rock Steady Boxing  Coachella Valley

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- Atria Hacienda
- A&A Home Care Services
- Caleo Bay

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- Dr. Curtis Buddingh

CLINICAL TRIALS


- Parexel International

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- Dr. Michel Lévesque

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HOW WEARABLE DEVICES HELP SENIORS STAY SAFE AT HOME

Sharon Roth Maguire, MS, RN, GNP-BC,
Chief Clinical Quality Officer, BrightStar Care

Popularity of wearable devices, such as Fitbits and Apple Watches, has increased significantly in recent years, and that trend shows no sign of slowing. According to International Data Corporation, an industry analysis group, the wearables market is expected to nearly double in size by 2021.

Today's wearable devices do so much more than count the number of steps a person takes. They're more like mini-computers that can provide a wealth of valuable data for your healthcare team. Some wearables even offer another layer of security for your loved one when they're home alone.

How Wearable Devices Support Healthcare Goals: Most of us barely scratch the surface of what wearable technology can tell us about

ourselves. The range of wellness information many wearables track can help caregivers find opportunities to protect and improve their loved one's health. Many wearables can track:

- Calories burned**
- Floors climbed**
- Hours slept**
- Distance traveled**
- Heart rate achieved**
- Time spent exercising**

You and your loved one can use this information to adjust their daily routine. For example, studies have found that healthy seniors should get 7,000 to 10,000 steps per day. If your loved one isn't hitting this mark, you could discuss building in more time for exercise, such as short walks around the neighborhood or visiting a nearby walking trail or shopping center.

The information gathered from wearable

DEVELOPING TREMOR-SUPPRESSION TECHNOLOGY TO HELP PEOPLE WITH PARKINSON'S

BoNhia Lee

Mechanical engineering professor Dr. Thê "Leo" Nguyen crouches down toward the floor of his testing facility trying to get a good look at the trembling hand of Winston Field, a 78-year-old man with Parkinson's who is part of a trial study for the professor's new invention.

Nguyen rests his chin between his thumb and index finger, eyes fixated on his subject's hand and the intricacies of each involuntary movement shaking right to left, going up and down, faster, then slower.

The Lyles College of Engineering professor at Fresno State is collecting observational data that he and a graduate student will take back to the lab and use to refine the tremor-suppression device he's created. They follow this process week after week with patient after patient, and will do so until they get it just right.

After years of work in machine design and dynamics, Nguyen decided it was time to use his skills to help people. He spent some time in medical engineering, working to improve the design of leg prosthetics to reduce the cost so people without insurance can afford it.

Now, in between teaching classes, he's working on the research and development of hand and arm devices with graduate student Sreekanth Rudraraju.

"With my expertise, I said, 'OK, why not do this?' I already work on vibrating machines and structures," Nguyen says. "Human arms would be much more complex, but let's give it a try."

The devices use the principle of energy absorption—normally found to steady planes, bridges and tall buildings—to counteract the shaking in hands. The prototypes have a patent pending and are still in the research and testing phase, but early results show that they are working to reduce tremors and improve fine motor skills for some of the patients in the trials.

New California Ventures LLC, a wholly-owned subsidiary of the Fresno State Foundation, provided early seed money and a significant capital investment to Nguyen to conduct research and develop a prototype device through Five Microns, a medical-device company he started. This allowed Nguyen to complete the patent application process, conduct further research and develop and test his prototypes.

Fresno State is the only campus in the California State University system with a for-profit entity that can retain a percentage ownership in such start-up companies. Once a patented product or service is licensed and commercialized, Fresno State will receive a portion of the licensing fees that can be reinvested into scholarly research.

The Desire To Help People - Nguyen's interest in hand tremors started in Vung Tau, Vietnam, where he grew up watching soldiers battle Parkinson's years after exposure to Agent Orange, a blend of herbicides used by the U.S. military to kill leaves, other foliage, and crops during the war. Studies have shown that exposure to Agent Orange increases the risk of developing Parkinson's.

In 2012, Nguyen came to the San Joaquin Valley to teach at Fresno State, where he continued to see and meet people with Parkinson's. The Valley is known to have one of the highest rates of Parkinson's disease in the nation.

"This is affecting people's lives, their independence," Nguyen says. "They're not really ill. They can still lift weight, it's just that they cannot do fine movement anymore. That's my goal, to help that."

Nguyen collaborated with colleagues in the Physical Therapy Department at Fresno State who work with Parkinson's patients. He brainstormed design possibilities with students and made it a class project. In 2016, Nguyen used a basic mechanical engineering concept to create the first prototype.

The Tremelo is a sleeve with two to four vibration absorption panels fitted around a patient's wrist. Inside each panel is a mass-spring-damper system that swishes back and forth against the arm, absorbing the energy created by the shaking which helps stabilize the arm. The device does not run on batteries, and it does not deliver electric shocks.

In recent months, the Five Microns team created two more devices, using the

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WEARABLE DEVICES – cont. from page 2

technology can also be of great value to your loved one's care team. For example, if their device shows they're not getting enough sleep, their doctor might consider testing for sleep apnea or other sleep disorders. You can share the information with their Care Nurse or Commercial Caregiver, print reports from the device and bring them to appointments, or email the information to their doctor's office.

There's even a growing market for wearable technology geared specifically toward diabetes care. Special diabetic socks can track temperature changes on the bottoms of your loved one's feet, which can indicate the presence of a foot injury or ulcer. In addition, a company named PKvitality is developing a smartwatch that can track blood sugar levels without the need for a blood test. It is exciting to think of the difference innovations like these could make to help seniors avoid serious diabetes complications and help you feel more confident about your loved one's health and safety.

How Devices Keep Seniors Safe at Home: Falls are a major concern for seniors, particularly those who live alone. As the Centers for Disease Control and Prevention (CDC) reports, more than 25 percent of older adults fall each year. Falls account for more than 800,000 hospitalizations per year. They're the most common cause of traumatic brain injuries, and they cause 95 percent of all hip fractures.

Related reading: *7 Ways You Can Help Your Loved One After a Fall.* Seniors who fall while they're alone may not be able to reach a phone to call for help. Many wearable devices, worn on a necklace or bracelet, include buttons seniors can press to summon emergency aid. Others feature accelerometers that can detect a fall so the device can call for help automatically. These devices don't replace 24-hour care or other in-home care options, but they can add an extra layer of security and make it possible for more older adults to live at home for longer. Many home-based medical alert services offer discounts on their monthly fees to members of AARP or other organizations for seniors.

Of course, falls aren't the only risk aging adults can face when they live at home. Seniors also can use wearable devices to call for help in other medical emergencies, such as a heart attack. In addition, Life Alert offers home-intrusion protection and can monitor smoke and carbon monoxide levels in your loved one's home. These systems often include cellular connections and GPS monitoring as available options, so seniors don't need to be home to call for help, and so first responders can locate them wherever they might have an emergency.

When you sign your loved one up for a medical alert service, you'll designate a list of emergency contacts.

It's natural for older adults to want to live at home and maintain their independence. When you incorporate wearable devices into their fitness routines and daily life, both you and your loved one can gain much-needed peace of mind.

Ask John Mason about their policies for being listed as your loved one's first or second contact in non-emergency situations. This especially can be helpful if you live in a different city or state, since his providers will be able to respond much faster than you could to check in.

John Mason, a Brightstar Care affiliate is a member of the Wellness Village since September 2018. His agency is located in Van Nuys, CA. PRO has received only high marks for the services of him and his caregivers.

TREMOR SUPPRESSION – cont. from page 3

same vibration control concept, to address the range of tremors that exist — some swing back and forth, some go up and down and others happen only while resting.

Rudraraju, who is from India, says this is one of the most intricate designs he's ever worked on. The mechanical engineering major, who will earn his master's degree in mechanical engineering at the end of the fall semester, has worked on the tremor project with Nguyen for two years. Before that, he worked in the mechanical engineering industry in India for nine years.

"Every time you see a patient, you're trying to understand their behavior," Rudraraju says. "Then it's understanding the mechanical mistakes and how to influence the design, how to modify the design. That is really most challenging."

cont. on next page

TREMOR SUPPRESSION – cont. from previous page

Promising results – Winston Field, the man participating in trial studies, is upbeat and eager as he walks slowly into the Water, Energy and Technology Center, a business incubator at Fresno State, to test Nguyen's hand-tremor devices as he's done several times before as part of the trial.

An avid motorcyclist for 35 years, Field first noticed his arms shaking in 2008 while gripping the handlebars of his bike. He was diagnosed a year later with Parkinson's. His father had it, too.

The disease has slowly taken away Field's ability to use his right hand for tasks like drawing a straight line and using a spoon. He takes two pills five times a day to suppress the shaking. But on this day, Field skips his mid-morning dose because he needs the severity of his hand tremors to show.

There aren't many options for treating Parkinson's, just loads of medication or brain stimulation surgery when the meds don't work. Exercise can also help.

Field, a former psychiatric nurse, once participated in balance assessments through the College of Health and Human Services at Fresno State.

Dr. Monica Rivera, assistant professor of physical therapy at Fresno State, introduced Field to the Five Microns team two years ago, and he has become their most loyal community participant. He walks the treadmill four times a week and participates in balance classes twice a week. He doesn't want brain surgery and wants to reduce his dependence on drugs.

There are other hand-tremor devices in the research and testing stages, but none that use the energy absorption concept that makes the Tremelo family of devices unique, Nguyen says. Dr. Bhupinder Singh, assistant professor of physical therapy at Fresno State who helped Nguyen submit grants for the device, agrees the product is one-of-a-kind. Nguyen has collaborated with physical therapists who know how this will work on patients and he is actually testing the device in different ways, Singh says. Singh specializes in the study of gait and biomechanics and also runs the Gait Analysis Movement Evaluation lab, which works with Parkinson's patients in the Valley.

"Everyone else is focused on what they call aggressive exercises to help improve the ability to do a task," Singh says. "Dr. Nguyen is trying to address the problem first hand."

Nguyen and Rudraraju are working hard to finalize designs for the devices. "We are doing our best to get the device to the users as soon as possible," Nguyen says. "It will potentially help thousands of patients with severe tremors regain many activities of daily living to improve their quality of life. That's the ultimate goal of this work."

To demonstrate, Field holds a black marker in his hand and attempts to trace a straight line on a whiteboard. His right-hand shakes back and forth picking up speed creating long waves weaving through the straight line like a seismograph that has just picked up strong vibrations in the earth.

The tremors get faster when he's excited by an activity. Then, Rudraraju slips the Tremelo on Field's arm. He goes back to the board and traces the line with more ease and smaller, less frequent waves.

"The devices work. They do work. And they've gotten to be more effective in my opinion," Field says.

In August, Nguyen and his team brought pizza to Field's Fresno home to celebrate his birthday — and used it as another opportunity to test their research. Field wraps his hand around the handle of Nguyen's newest model, holds a cup with water and raises it to his mouth with no shaking. Without the device, the water slops over the sides of the cup.

"One of these days, there will be a cure for Parkinson's," Field says. "Dr. Nguyen was very real about this and said it wasn't going to solve things next year or the year after that. But I think there are real possibilities."

BoNhia Lee is a writer in University Communications at Fresno State.

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3rd Annual MITCH'S PITCHES PRO

CELEBRATING THE 29TH YEAR OF PARKINSON'S RESOURCE ORGANIZATION

Parkinson's Resource Organization Celebrates 29 Years of "Working So No One Is Isolated Because Of Parkinson's"

April 7, 2019 - Palm Desert, Calif - On the patio at Mitch's on El Paseo under a beautiful sunset, 175 people gathered for dinner to celebrate Jo Rosen and her 29 years of service to the Coachella Valley and beyond. Since 1990, Parkinson's Resource Organization (PRO) has served countless people caring for and living with Parkinson's disease, a disorder of the central nervous system which affects movement, often including tremors.

Two PRO board members, Michael Rudder and Michael Lu, who both suffer from Parkinson's disease, were honored.

Michael Rudder, a successful businessman who has also survived brain cancer, a stroke, and a heart dissection was honored with PRO's "Nine Lives" Award.

Michael Lu is a young man, only 30 years old, who works with and helps reintegrate individuals from a variety of socioeconomic backgrounds who suffer from medical, mental and physical disabilities. Lu was honored for his tireless positive attitude and given PRO's "Winning At Life" Award.

Mitch Epstein said a few words about how Parkinson's affected his life as his favorite uncle lived with and died from Parkinson's. When Mitch's favorite aunt found love again, married her new husband, and was later diagnosed with Parkinson's, it illustrated the pandemic that the disease has become.

Jo Rosen was presented with Proclamations from Rancho Mirage, Cathedral City, Indian Wells, Indio and the City of Palm Springs, which declared April 7, 2019, as "Jo Rosen Day" in recognition of her work and the impact she is making globally for people caring for and living with Parkinson's disease.

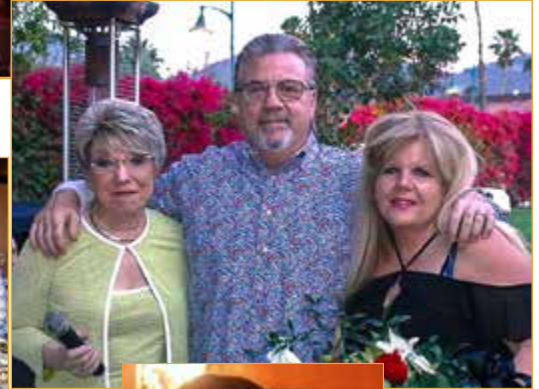
Curtis Cannon spoke about his benefits from PRO as a caregiver. Dr. Samantha Peters and Laura Meeks both spoke about the benefits of PRO's online Wellness Village, which is a virtual, vetted Resource Directory and one of the main sources of revenue for Parkinson's Resource Organization. Actor Marc McClure, famous for his roles in Superman and Back to the Future, spoke about his relationship with Michael J Fox, and international singer, songwriter, and actor, Trini Lopez, an honorary member of PRO, spoke of his admiration of Jo Rosen and his pride in being involved with such a great cause.

After a silent auction with several one-of-a-kind trips and a Chinese auction with several themed packages, the Grand Prize Drawing was the last surprise of the evening, donated by Robert & Sharon Keith, which included a one-week stay at their home on Coronado Island.

Founder Jo Rosen was the adult child of a person living with Parkinson's and later a spouse of a person with Parkinson's. She was inspired to create an organization that would advocate for, educate and provide emotional support for families affected by Parkinson's. Now they are known worldwide with an online Wellness Village providing resources for Legal, Insurance, Financial Planning, Caregiving and Care Management, Medical Professionals, Hospice and Science as well as support meetings throughout Southern California. They are "working so no one is isolated because of Parkinson's" and working to find choices in creating the ultimate quality of life.

Save the date for next year's gala, which is February 15, 2020.





UPDATE ROAD TO THE CURE – cont. from page 1

mice improved their performance on two different learning and memory tests to the point that they significantly outperformed control mice of the same age.

How Can ICBI Turn These Results into a Parkinson's Cure? – ICBI plans to develop a CD22-SMART Molecule. SMART Molecules (SMs) have unique characteristics to cross the BBB into the CNS. Instead of drilling holes in the skull to inject CD22-antibodies as these Stanford scientists did, ICBI CD22-SM will be injected in the arm. ICBI is confident that it can develop such an SM.

WOULD YOU LIKE TO HELP get their drugs to market faster? The joy of being a part of this historical event can be had by helping ICBI find the funds to bring these trials to fruition through your investing, and by finding others with the financial ability and humanitarian mindset to accomplish the - until now - impossible. Please contact Jo Rosen at 760-773-5628 or joosen@Parkinsonsresource.org or by contacting ICBI directly through their website <http://icbii.com/> or by phone 858-455-9880.

IMAGINE the world without Parkinson's, MSA or Alzheimer's disease. **JUST IMAGINE.**

PRO CALENDAR FOR APRIL 2019

The current support group meeting locations are listed below.

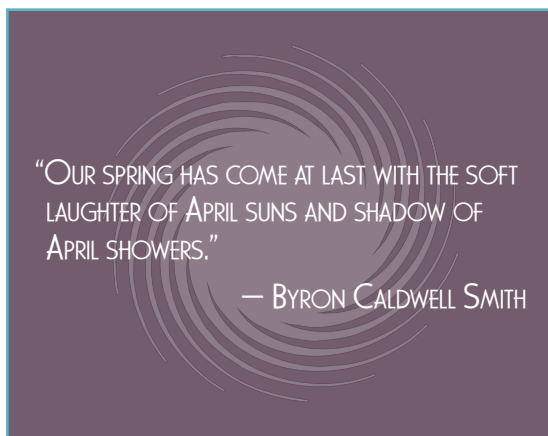
For any information regarding any of these meetings, please contact the PRO Office at 877-775-4111.

	APRIL FOOL'S DAY 1 PALM DESERT Caregiver Only 10:00 AM PRO Office 74-090 El Paseo Suite 104	2	LONG BEACH 3 Round Table For Everyone 6:30 PM Cambrian Home Care "Training Center" 5199 Pacific Coast Hwy	4	5	6
7	8 PALM DESERT Round Table For Everyone 6:30 PM Atria Hacienda 44-600 Monterey Ave	9	10 GLENDDORA Caregiver ONLY 6:30 PM La Fetra Senior Center 333 E Foothill Blvd	NEWPORT BEACH 11 Round Table For Everyone 6:30 PM Oasis Senior Center 801 Narcissus Corona Del Mar	12	13
14 PALM SUNDAY	TAX DAY 15 PALM DESERT Caregiver Only 10:00 AM PRO Office 74-090 El Paseo Suite 104	16	17 ENCINO Round Table For Everyone 7:00 PM Rehab Specialists 5359 Balboa Blvd	SANTA MONICA 18 Round Table For Everyone 7:00 PM Rehab Specialists 2730 Wilshire Blvd Ste 533	19 GOOD FRIDAY PASSOVER BEGINS	20
21 EASTER	22 PALM DESERT Speaker Meeting 6:30 PM Atria Hacienda 44-600 Monterey Ave	MANHATTAN BEACH 23 Round Table For Everyone 6:30 PM American Martyrs Welcome Cntr 700 15th Street	24	25 SHERMAN OAKS Educational Meeting 1:00 PM Sherman Oaks East Valley Adult Center 5056 Van Nuys Blvd	26 ARBOR DAY	27 PASSOVER ENDS
28	29	30	<p>And remember, April is...</p> <h2 style="color: orange;">PARKINSON'S AWARENESS MONTH!</h2>			

CAREGIVER MEETING: (For caregivers only) Come share the ups and downs of living with someone with Parkinson's. Together there are ways of finding solutions that, when alone, might never be considered. No need to continue with your frustrations because you are not alone. Give yourself a break.

SPEAKER MEETING: We invite the community, especially the Person with Parkinson's and their family or friends, to attend. Speaker Meetings usually feature guest speakers who are professionals servicing the Parkinson's Community. Speaker Meetings are packed with a wealth of amazing information so bring your pencil and notepad!

"ROSEN ROUND TABLE" MEETING: Join a loving circle of like-minded individuals including local professionals. Learn what works for others, share what works for you. Find out what doesn't work for certain individuals. Share emotional trials and tribulations. Realize that you are not alone and that others can relate to and learn from your story.



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PARKINSON'S RESOURCE ORGANIZATION
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