

PARKINSON'S RESOURCE ORGANIZATION

Working so no one is isolated because of Parkinson's

MESSAGE

PRESIDENT'S

Whoever coined the phrase "The Lazy Days of Summer" did NOT know Parkinson's Resource Organization. As the annual "season" in the Coachella Valley comes to a close, the team at PRO is gearing UP for a summer of planning exciting events, making BIG changes on our website and welcoming a variety of NEW members into our Wellness Village. ALL in the interest of serving our community better.

The management and creative team at PRO is growing and bursting with inspiration, energy and boundless talent. It is our pleasure to formally welcome and personally introduce you to: Brittany Disston, joining us as my Executive Assistant, Graison Stemper as our Wellness Village Director, and of course Dan Ball, our Director of Development who joined us earlier this year.

In the planning stages is our symposium: the "Road to the Cure" an event everyone touched by Parkinson's simply MUST attend. Stay tuned as we roll out the details in the coming months.

After almost 8 years it's time to step up our online conversation, retire our current website and present our image and resources in a fresh new look. Reaching everyone throughout the world dealing with Parkinson's, our NEW website, due to launch in September, promises to be easily found, easier to navigate and a resource everyone will want to share. Filled with more resources, information, and inspiration our goal is to make access to the vital resources and information we have amassed over more than 25 years easy and straight forward.

Did you know you can communicate with us through Facebook at [facebook.com/ParkinsonsResourceOrganization/](https://www.facebook.com/ParkinsonsResourceOrganization/) or on Twitter at [@ParkinsonsPRO](https://twitter.com/ParkinsonsPRO), on LinkedIn at [Linkedin.com/in/jrosenpro/](https://www.linkedin.com/in/jrosenpro/) and now on Instagram at [ParkinsonsResourceOrganization](https://www.instagram.com/ParkinsonsResourceOrganization). There's no reason not to stay in touch with us now.

Continuing #YearOfTheCure, this month's Update on **ROAD TO THE CURE** on this page is quite exciting. The scientists are making tremendous strides in bringing the Road To The Cure to fruition.

We proudly bring you articles of interest and effective use, like: Our newest Wellness Villager Gloria Landau's article on **ROCK STEADY BOXING- DESERT CITIES** on page 2; **TRUMP CALLS FOR A MASSIVE CUT IN MEDICAID** on page 3; **ARE YOU DEFICIENT IN MAGNESIUM?** on page 4; **BOWEL TRAINING FOR CONSTIPATION RELIEF** on page 5; and **LSVT BIG® AND HOW YOU CAN BENEFIT FROM IT**, also on page 5. Plus, we've added in our Inspirational

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UPDATE ON PARKINSON'S "ROAD TO THE CURE" PROJECT

John looked out the window, remembering better days. He could smell the scent of freshly baked banana nut bread and hear the laughter of his children when they ran out of the kitchen with their mother's apron over their heads. He could see her smile as she walked into the room, handing him the first piece of bread, just out of the oven. He remembered the long walks they used to take and the time they spent talking about... anything at all. The thing is - John now has to take those walks alone. Unfortunately, his wife, Lilly, who suffers from Parkinson's, can no longer walk, her speech is inaudible and her memory appears to be failing.

Does this story sound familiar? Or does it connect with you, your purpose, and passion in life to help others who may be going through something similar?

The bad news is that to date, central nervous system diseases such as Parkinson's (PD) and Alzheimer's (AD) have affected the lives of some 55M individuals worldwide... with no cure and no hope in sight.

The good news is that scientists with ICB International, Inc. (ICBI) are on the verge of changing this... forever! Could you imagine a world where diseases such as Parkinson's (PD) and Alzheimer's (AD) are no longer heard of? What would it feel like to mention these words to someone and have them ask you, "What is that?" If you are like many, you may think this is just a goal scientists have and that any hope of a cure is too far-fetched. If billions of dollars have already been spent with no result, why think it's possible now? We want to share the answer to that question with you and include you in this life-changing movement. Here's the update...

ICBI, was founded with the sole mission and purpose of helping to alleviate human pain and suffering due to diseases such as Parkinson's and Alzheimer's. Their dedicated scientists have been working tirelessly to do so and are just now ready to be the first to succeed in this area. To date, one of the main reasons for the lack of progress in resolving brain disease is due to the physical barrier, known as the blood-brain barrier (BBB), which prevents most of the pharmaceuticals from entering the brain. Drugs such as Levodopa, that do cross the BBB, only treat symptoms for a short-while without halting the disease progression.

ICBI SOLUTION

To overcome this centuries old problem of breaking through the BBB, ICBI has developed a technology referred to as SMART Molecules (SMs) technology. This technology has been proven to work in live animals to:

- i. Detect pathology of Parkinson's disease
- ii. Halt the progression of Parkinson's

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OUR WELLNESS VILLAGERS:

ACUPUNCTURE

- Dr. David Shirazi

ADAPTIVE CLOTHING

- Health Aides Made Easy

AROMA THERAPY

- Renee Gauthier

ASSISTIVE TECHNOLOGY

- California Phones

BRAIN OPTIMIZATION

- Brain Optimizers

CARE FACILITIES

- Atria Hacienda

CHIROPRACTIC

- Dr. Curtis Buddingh

CLINICAL TRIALS

- Parexel International

CRANIOSACRAL THERAPISTS

- Center for Physical Health

DEEP BRAIN STIMULATION

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- Betty Anna Gidlof

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CMD/TMJ DENTISTS

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- (CA) Dr. Maryam Bakhtiyari
- (CA) Dr. Dwight Jennings
- (CA) Dr. Steven Olmos
- (CA) Dr. David Shirazi
- (CT) Dr. Patricia A. Richard
- (IL) Drs. Ed and Lynn Lipskis
- (KY) Dr. William H. Funk
- (PA) Dr. Stephen D. Smith
- (TX) Dr. Risto Hurme
- (VA) Dr. Brendan C. Stack
- (VA) Jeffrey L. Brown

SLEEP MEDICINE DENTISTS

- (CA) Dr. Maryam Bakhtiyari
- (CA) Dr. Steven Olmos

SLEEP MEDICINE DENTISTS (CONT.)

- (CA) Dr. David Shirazi
- (IL) Drs. Ed and Lynn Lipskis
- (PA) Dr. Stephen D. Smith
- (TX) Dr. Risto Hurme
- (VA) Dr. Brendan C. Stack
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- Wild Blue-Green Algae
- Nerium Age Defying Formula

HOSPICE CARE

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- Gentiva Hospice (regional)
- Vitas Healthcare (Nationwide)

INCONTINENCE SUPPLIES

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IN HOME CARE PROFESSIONALS

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- Cambrian Homecare
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LSVT BIG PROGRAM

- New Beginning Physical Therapy
- Rosi Physiotherapy

MASSAGE & BODYWORK

- Mot'us Floatation & Wellness Center

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- In & Out Mobility

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- Gloria Landau, Head Coach

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ROCK STEADY BOXING- DESERT CITIES

Gloria Landau, Head Coach

As we all know, there are several medications that can temporarily relieve the symptoms of Parkinson's, but **exercise** is the only treatment that has actually been medically proven to slow the progression of Parkinson's. So, why boxing? Several medical studies on exercise and Parkinson's have concluded that **forced intense exercise** can slow the progression of Parkinson's. In other words, when exercise is done at a volunteer rate, there is less benefit than when exercise is done that pushes or forces someone out of their comfort zone. If **forced, intense** exercise is the proven form of exercise for people with Parkinson's, then boxing is a good fit!

Boxers train to improve balance, hand-eye coordination, speed of movement, agility, muscle power and mental focus. All of these things happen to be issues for people with Parkinson's. So instead of focusing on the specific symptoms of Parkinson's, people can learn a new skill that is fun and a good stress reliever while addressing many of the symptoms of Parkinson's. Plus, it's more fun to tell your friends, children and grandchildren that you're going to boxing class rather than physical therapy!!

Rock Steady Boxing (RSB)- Desert Cities in Palm Desert, California understands that there are many different levels

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TRUMP CALLS FOR A MASSIVE CUT IN MEDICAID

New budget proposal also would slash health research funding

David Frank, AARP, May 23, 2017

PRO Publisher's Note: With the cost of caring for an advanced stage person with Parkinson's at an average of \$8,515 per month or \$102,180 per year, the following article may bring concern to you. Very often persons with Parkinson's and their families must resort to Medicaid (Medi-Cal in California) for financial support of their care.

The Trump administration today released a federal budget proposal that would cut more than a trillion dollars over 10 years from Medicaid, the nation's largest source of health care coverage, which provides a lifeline for children and adults with disabilities and low-income seniors. Under the president's proposal, Medicaid would face a \$600 billion decrease. That's in addition to the more than \$800 billion cut in the American Health Care Act (AHCA) passed this month by the House of Representatives.

The budget, released while President Trump was in the Middle East on his first foreign trip as president, also would shrink funding for the National Institutes of Health (NIH), the Centers for Disease Control and Prevention (CDC), the Children's Health Insurance Program (CHIP), Social Security disability, environmental protection, and housing and transportation assistance.

At the urging of the president's daughter, Ivanka Trump, the budget proposes spending \$25 billion over the next 10 years on paid parental leave, a new initiative.

Members of both parties in the House and the Senate have strongly opposed trimming Medicaid in the past.

Many of the other cuts also face strong bipartisan opposition on Capitol Hill. For example, Rep. Tom Cole (R-Okla.), chairman of the House Appropriations Subcommittee on Labor, Health and Human Services, Education and Related Agencies, has sharply criticized the cuts earmarked for the NIH and CDC.

White House Budget Director Mick Mulvaney reiterated the administration's view that the AHCA does not go far enough on Medicaid. "We go another half a step further and ratchet down some of the growth rates that are assumed into AHCA," he said in a call with reporters on Monday.

During today's press briefing, Mulvaney said that "we're no longer going to measure compassion by the number of programs or the number of people on those programs, but by the number of people we help get off of those programs."

AARP staked out a strong position against the president's budget.

AARP "opposes the budget proposed today because it explicitly harms the very people we are counting on the President to protect," said AARP Executive Vice President Nancy LeaMond in a statement. "Today's budget proposes to cut Social Security benefits, as well as funding for critical health, hunger, housing and transportation assistance to low and middle-income seniors. The budget sends a powerful message to older Americans and their families that their health and financial security is at risk."

AARP sounded a positive note on the administration's parental leave initiative. "We do want to acknowledge the Administration's paid leave proposal," LeaMond said. "Although it must be improved so that it addresses the workplace needs of family caregivers, we hope that it leads to a national conversation about ways to support family caregivers in the workplace."

The budget assumes economic growth reaching 3 percent a year by 2021, a figure widely seen as unrealistic.

The budget also includes a dramatic decrease in the Supplemental Nutrition Assistance Program (SNAP), also known as food stamps. "If you are on food stamps, we need you to go to work," said Mulvaney. "If you are on disability and should not be, we need you to go back to work."

The president's budget is the first step in a lengthy process. Congress

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ARE YOU DEFICIENT IN MAGNESIUM?

A Care2.com favorite

Michelle Schoffro Cook

Magnesium is the partner mineral to calcium. Typically, wherever calcium is needed in the body, magnesium is also required. Magnesium is Nature's relaxation and anti-stress mineral, since it plays an important role in helping our bodies combat stress. It is necessary for healthy artery, blood, bone, heart, muscle and nerve function, yet experts estimate that approximately 80 percent of the population in North America may be deficient in this important mineral.

Magnesium is vitally important to our health and wellbeing. It is involved in the production of energy for most of our bodily processes and even the structuring of our basic genetic material is dependent on adequate amounts of magnesium. Your body also requires adequate supplies of magnesium to manufacture the approximately 500 enzymes needed for basic life and metabolic functions.

FOOD SOURCES OF MAGNESIUM

almonds	dark, leafy greens
sesame seeds	celery
sunflower seeds	alfalfa sprouts
pumpkin seeds	brown rice
figs	spinach
lemons	avocados
apples	

SYMPTOMS OF A MAGNESIUM DEFICIENCY

Back pain
Carpal tunnel syndrome
Chronic fatigue
Confusion
Cravings for chocolate
Depression
Dizziness
Epilepsy or convulsions
Excessive body odor
Heart palpitations or irregular heartbeat
High blood pressure
Hyperactive or restlessness
Inability to control bladder
Insomnia
Irritability or anxiety
Muscle cramps or muscle tension
Nervous tics or twitches, or muscles that twitch or spasm
Pain in knees or hips
Painful and cold feet or hands
Restless legs, especially at night
Seizures, convulsions, or tremors
Sensitive or loose teeth
PMS or painful periods

Of course, many symptoms overlap with other conditions, so just because you have some of the symptoms above doesn't necessarily mean you are deficient in magnesium. If you have any health conditions, you should consult a qualified physician. If you suspect a magnesium deficiency, consult a qualified nutritionist for testing.

A typical dose of magnesium is 800 mg. daily and is usually taken with calcium supplements. Supplementing with calcium and not taking magnesium can cause a depletion of the body's reserves of magnesium.

BOWEL TRAINING FOR CONSTIPATION RELIEF

<http://www.everydayhealth.com/>

By Diana Rodriguez

Medically Reviewed By Lindsey Marcellin, MD, MPH

If you're having trouble with your bowels and are plagued by constipation, a bowel training program can help.

Bowel problems may be a digestive health issue you want to keep to yourself, and you may try to deal with any discomfort or embarrassment on your own. But a more effective way to find relief from constipation is by seeing your doctor for an examination and following his recommendations, which might include bowel training.

Bowel training is a technique you can use to control bowel movements, and it can be beneficial for either fecal incontinence (the involuntary passage of stool) or constipation.

Bowel training programs can be formal, with techniques followed under a doctor's supervision, or more informal, says Francisco Marrero, MD, a gastroenterologist with the Cleveland Clinic in Ohio. The most appropriate type of bowel training really depends on the individual patient and the particular problem, says Dr. Marrero.

Whether working with a doctor for formal bowel training or trying an informal bowel training program yourself, you can learn to have bowel movements regularly with a few tips and a consistent schedule.

What Is Bowel Training?

Bowel training often involves creating a schedule for trying to have a bowel movement. For instance, says Marrero, some people with a weakened anal sphincter (the muscle around the anus) or those with certain nerve problems may not recognize the sensation that their rectum is filling and they need to have a bowel movement. Bowel training in this situation involves sitting down on the toilet, even if you don't feel like you have to go, Marrero explains.

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LSVT BIG® AND HOW YOU CAN BENEFIT FROM IT

By Dr. Samantha Peters, PT, DPT, ATC

LSVT stands for Lee Silverman Voice Treatment. It was at the Lee Silverman Center for Parkinson's Disease in Scottsdale AZ in 1987 that the speech therapy LSVT LOUD® program was first invented. LSVT LOUD® has been extensively studied and has tons of research to support its effectiveness on patients with Parkinson's Disease. It was from this proven continuous success that LSVT BIG® was created.

LSVT BIG® is an intensive amplitude-based exercise program for the body. Research has documented improvements in balance, trunk rotation, activities of daily living, faster walking and bigger steps on individuals with Parkinson's Disease that have completed the LSVT BIG® program.

The LSVT BIG® protocol consists of 16 treatment sessions provided 4 consecutive days a week over a 4-week time frame. Each session must be delivered by a Certified LSVT BIG® occupational or physical therapist. All 16 treatments last 60 minutes. Patients are also required to complete daily homework and exercises outside of the therapy sessions. The program is not easy to complete, it requires a lot of commitment and dedication.

Certain aspects of the treatment sessions are customized specifically to each patient in order to address personal difficulties or concerns. Exercises can be performed standing, sitting or lying down so it is safe for all stages of the disease process. The certified LSVT BIG® therapist can also make modifications to accommodate for any preexisting conditions such as low back pain, shoulder pain or balance issues.

Dr. Samantha Peters PT, DPT, ATC of Rosi Physiotherapy was a member of a research group in Ohio that studied the retention of gains made by individuals that had completed LSVT BIG®. Her study determined that participants

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THE PRO NEWSLETTER
AS LEGAL OR MEDICAL ADVICE
NOR TO ENDORSE ANY
PRODUCT OR SERVICE.
WE INTEND IT TO SERVE AS
AN INFORMATION GUIDE.



ROAD TO THE CURE – cont. from page 1

This is huge! Think of what this could mean for our loved ones. This means that ICBI has successfully found the solution. They just now need to find a way to begin human trials.

What Needs to be Done for Human Testing?

For human testing, ICBI needs to scale up the production of its drug using a process known as cloning. By cloning, we do not mean that we will be cloning people or animals, rather cloning is a known and well established hands-on technique that is very involved. It's a way to reproduce the effective elements of the drug. This allows ICBI to be able to produce the drug for human trials in quantities that will really make a difference.

That said, ICBI needs to hire a group of scientists to start the cloning experiments, which may take anywhere between 9 to 15 months. An additional 4-5 months are needed for large scale production, purification, and validation of the cloned drug by replicating some of the previous experiments.

Following the cloning procedures, ICBI will submit an IND application with the USFDA for studying the drug in humans. At this point, it will be available for human trials and eventually, will be available for anyone who currently suffers from Parkinson's and Alzheimer's... and eventually other similar neurological diseases.

SUMMARY

- ◇ *ICBI technology solves the BBB issue... it works!*
- ◇ *Technology is validated by third parties (i.e., not just enthusiastic claims)*
- ◇ *Diagnostic and therapeutic efficacy demonstrated in animals (i.e., all are ethical and monitored studies)*
- ◇ *Need to scale up the production for human use (involving the cloning process and hiring more scientists)*
- ◇ *This technology has the potential to end human suffering caused by neurological diseases such as Parkinson's and Alzheimer's... not just treat the symptoms.*

HOW YOU CAN HELP

The joy of being a part to this historical event can be had by helping ICBI find the funds to bring these trials to fruition through your personal, including your IRA investment, and/or by finding others with the financial ability and humanitarian mindset to accomplish the, until now, impossible. Please contact Jo Rosen at Parkinson's Resource Organization 760-773-5628, or by eMail, JoRosen@Parkinsonsresource.org, or by contacting ICBI directly through their website ICBI.com, or by phone at 858-455-9880.

IMAGINE a world without Parkinson's or Alzheimer's disease. *Just Imagine.*

LSVT – cont. from page 5

had continued improvements in mobility, lower body strength, balance and endurance for up to 27 months after completion of the LSVT BIG® program. Don't hesitate to start this completely safe and research proven effective therapy treatment. To find a certified LSVT BIG clinician please refer to the LSVT BIG Program section of the Wellness Village or go to lsvtgolbal.com.

Doctors Samantha Peters, PT, DPT, ATC and Branden Rosi, PT, DPT, CSCS are brand new members of the Wellness Village under the category of LSVT BIG. They are traveling physical therapists, meaning, they will come to your home if you are in the Coachella Valley.

BOXING – cont. from page 2

of Parkinson's and many levels of fitness. RSB coaches are trained to modify exercises so that anyone can benefit. There is a FIGHT in all of us. Rock Steady Boxing can be done at any level of Parkinson's disease through the tough love of the coaches and their understanding of the disease. RSB is a hybrid of many different training regimens that are good for Parkinson's. With boxing at the foundation, we bring different elements to the mix during the workouts, which keeps the curriculum fresh and challenging. An assessment is done on each participant before they join the program so the coach can learn about the client and place them in the proper level class for their needs.

We encourage you to visit a class before you join to see if Rick Steady Boxing is for you.

Rock Steady Boxing – Desert Cities has been a member of the Wellness Village since August of 2016 and you can reach head coach, Gloria Landau to set an appointment and discuss your individual needs at <http://www.parkinsonsresource.org/spotlight/rock-steady-boxing/>

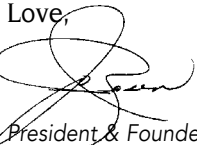


PRESIDENT'S MESSAGE – cont. from page 1

Corner, **FROM AUDREY HEPBURN** on page 7.

Thank you for your tax-deductible donations giving us the opportunity to help MORE – to help MORE people, MORE often, MORE timely, with MORE information in a MORE compassionate way. We know we are providing valuable information and support in the Parkinson's community, we continue to appreciate your monthly or general donations through our safe PayPal donation page at [ParkinsonsResource.org/contribute-2/](https://www.parkinsonsresource.org/contribute-2/), or by mail to our office in Palm Desert, California.

Until next month, REMEMBER Flag Day on the 14th, Father's Day on the 18th, Summer Solstice on the 21st. The flowers are the Rose & Honeysuckle and the Birthstones are the Pearl, the Moonstone, and the Alexandrite, which all symbolize health and longevity. ALWAYS remember to CELEBRATE YOU and PRAY FOR OUR TROOPS!

Love,

 President & Founder

INSPIRATIONAL CORNER**Audrey Hepburn**

For attractive lips, speak words of kindness.

For lovely eyes, seek out the good in people.

For a slim figure, share your food with the hungry.

For poise, walk with the knowledge that you never walk alone. People, even more than things, must be restored, renewed, revived, reclaimed, and redeemed; never throw out anyone.

Remember, if you ever need a helping hand, you will find one at the end of each of your arms. As you grow older, you will discover that you have two hands; one for helping yourself, and the other for helping others.

TRUMP – cont. from page 3

will set its own priorities as it develops its own budget resolution.

AARP can be reached at their website, [AARP.org/](https://www.aarp.org/)

BOWEL TRAINING – cont. from page 5

Another technique involves strengthening the anal sphincter, which is a muscle. Kegel exercises — squeezing and holding the muscles in the pelvic area — can strengthen the muscle and help it to work better, Marrero says.

Biofeedback, a training technique that teaches you how to recognize and control bodily functions, is one formal approach. With biofeedback you learn how to regulate certain muscles that can be used to help control a bowel movement and manage constipation.

Bowel Training for Constipation

People with constipation can train their bodies to get things moving by taking certain steps after eating.

"The colon tends to be most active after a meal," says Marrero. This is because of the gastrocolic reflex, which senses food in the stomach and sends the lower gastrointestinal tract the message that it is time to function. If you're constipated, sitting on the toilet for 20 to 30 minutes following a meal, even if you don't feel the urge to have a bowel movement, can encourage your bowels to move.

Marrero also stresses what he calls good "bowel hygiene" — how you go about your process of having a bowel movement," he explains. For instance, your body's position during a bowel movement can help. Instead of sitting on the toilet with your feet flat on the floor, it's easier to have a bowel movement if you put your feet up on a stool at about a 90-degree angle. "That can actually help people quite a bit," Marrero says.

It's also important to train yourself on the right intensity with which to push. "Don't push too hard when you're trying to have a bowel movement. Sometimes when people are straining and pushing too hard, they're squeezing their anal sphincter muscle and trying to evacuate against a closed sphincter," Marrero says. On a scale of 1 to 10, with 1 being straining very hard, he suggests staying between five and seven.

Of course, though these methods can be very helpful, you can't force your body to do what it's not ready to do. "If it doesn't work, give up and come back to the bathroom later and try again," he suggests.

Marrero says that several techniques can be used to train the bowels and relieve constipation. If you can't find relief and are frequently constipated, work with your doctor for the best ways to manage your discomfort.

PRO CALENDAR FOR JUNE 2017

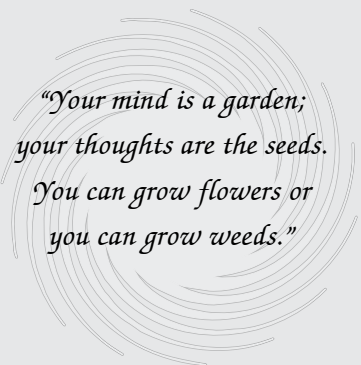
The current support group meeting locations are listed below.
For any information regarding any of these meetings, please contact the PRO Office at 877-775-4111.

				1	2	3
4	5	6	LONG BEACH 7 Speaker Meeting for Everyone 6:30 pm Bixby Knolls Tower 3737 Atlantic Ave	8	9	10
11	12	13	14	15	16	17
18	19	20	21	22	23	24
25	26	27	28	29	30	

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.

EDUCATIONAL MEETING: We invite the community, especially the Person with Parkinson's and their family or friends, to attend. Educational meetings usually feature guest speakers who are professionals servicing the Parkinson's Community. Educational 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.



NEWSWORTHY NOTES

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PARKINSON'S RESOURCE ORGANIZATION

Working so no one is isolated because of Parkinson's

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