

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

As Charles Dickens said about March, "It was one of those days when the sun shines hot and the wind blows cold: when it is summer in the light, and winter in the shade." March encompasses lots of beginnings and endings just as we regularly experience in the PRO office.

Next time you call, please introduce yourself to **Paul Hietter**, our new Director of Development. We worked with Paul on an extraordinary fundraising event in 2008, "**An Evening of Elegance**" when he was with a different company. He brings with him an expertise in non-profit work, fundraising, and project management. We are pleased to have him with us.

Join us at our **2nd Annual MITCH'S PITCHES PRO** fundraising event observing Parkinson's Awareness Month on April 8th. Information can be found on page 7. If you cannot attend you can still support us with a donation.

For your reading edification this month we're proud to present to you: **ICBII Update On The Road To The Cure: THE FDA SEEMS TO BE LOOSENING RESTRICTIONS ON APPROVING DRUGS FOR ALZHEIMER'S DISEASE** on this page; **AVOID OPIOIDS! PHYSIOTHERAPY IS PAIN MANAGEMENT** on page 2; **WHAT IS MULTIPLE SYSTEM ATROPHY? A PARKINSON(ISM)** on page 3; **ALL ABOUT MAGNESIUM: Could It Help With Constipation?** on page 4; and **APHASIA DEFINITIONS** on page 5.

Again, Thank You all for your tax-deductible donations giving us the opportunity to support MORE people in a timely fashion. We are providing valuable information and support to the Parkinson's community. Keep giving. We appreciate your donations through our safe PayPal donation page at **ParkinsonsResource.org/contribute-2/** or by mail to our office in Palm Desert, California.

Where to connect with PRO on social media:

Facebook: [facebook.com/Parkinsonsresourceorganization/](https://www.facebook.com/Parkinsonsresourceorganization/);

Twitter: [@ParkinsonsPRO](https://twitter.com/ParkinsonsPRO);

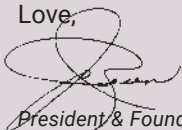
LinkedIn: [linkedin.com/in/jorosenpro/](https://www.linkedin.com/in/jorosenpro/);

Instagram: [Instagram.com/parkinsonsresourceorg/](https://www.instagram.com/parkinsonsresourceorg/).

"Like" us and connect so we can stay in touch with you.

Until next month, REMEMBER the Academy Awards on the 4th, International Women's Day on the 8th, Daylight Saving begins on the 11th, Spring begins on the 20th—that's also International Day of Happiness—Palm Sunday on the 25th, and Passover starts on the 31st. The flower is the Daffodil, and the birthstone is the Aquamarine, Bloodstone & Jade. ALWAYS remember to CELEBRATE YOU and PRAY FOR OUR TROOPS!

Love,



President & Founder

### ICBII UPDATE ON THE ROAD TO THE CURE

**THE FDA SEEMS TO BE LOOSENING RESTRICTIONS ON APPROVING DRUGS FOR ALZHEIMER'S DISEASE**  
*Could Parkinson's Be Next?*

With the population living longer, neurodegenerative diseases such as Alzheimer's (AD) and Parkinson's (PD) diseases have become an increasing economic threat to the welfare of the world community, not to speak of the emotional toll it has taken on the patients and loved ones. According to some estimates, Alzheimer's has more than 55 million individuals afflicted with the disease. US alone has 5.1 million Alzheimer's patients, which does not take account for the millions that are yet to be diagnosed and those that are misdiagnosed. **AD is the sixth-leading cause of death in the United States. It is the fifth-leading cause of death among those ages 65 and older and a leading cause of disability and poor health.** With no cure on the horizon, the FDA has begun to rethink its strategy for the approval of new drugs for treating early stage (stage 1) Alzheimer's disease. The following paragraph from the FDA is being distributed for comments purposes only, not for implementation.

#### **Endpoints for Early AD Trials in Stage 1 Patients**

- "Because it is highly desirable to intervene as early as possible in AD, it follows that patients with characteristic pathophysiologic changes of AD but no subjective complaint, functional impairment, or detectable abnormalities on sensitive neuropsychological measures (Stage 1 patients) are an important target for clinical trials. A clinically meaningful benefit cannot be measured in these patients because there is no clinical impairment to assess (assuming that the duration of a trial is not sufficient to observe and assess the development of clinical impairment during the conduct of the trial). In Stage 1 patients, an effect on the characteristic pathophysiologic changes of AD, as demonstrated by an effect on various biomarkers, may be measured. Such an effect, analyzed as a primary efficacy measure, may, in principle, serve as the basis for an accelerated approval (i.e., the biomarker effects would be found to be reasonably likely to predict clinical benefit, with a post-approval requirement for a study to confirm the predicted clinical benefit). As with the use of neuropsychological tests, a pattern of treatment effects seen across multiple individual biomarker measures would increase the persuasiveness of the putative effect."

[Source: *Early Alzheimer's Disease: Developing Drugs for Treatment Guidance for Industry*, February 2018]

**In essence: The End Point simply means how to determine if the drug is working. In the case of**

cont. on page 6

# Our Wellness Villagers

## ACUPUNCTURE

- Dr. David Shirazi

## AROMA THERAPY

- Renee Gauthier

## ASSISTIVE TECHNOLOGY

- California Phones

## BRAIN OPTIMIZATION

- Brain Optimizers

## CARE FACILITIES

- Atria Hacienda

## CHIROPRACTIC

- Dr. Curtis Buddingh

## CLINICAL TRIALS

- Parexel International
- Asclepes

## DEEP BRAIN STIMULATION

- Dr. Michel Lévesque

## DENTAL HYGIENISTS-MOBILE

- Betty Anna Gidlof

## DENTISTS

### CMD/TMJ DENTISTS

- (CA) Dr. George Altuzarra
- (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
- (CA) Dr. David Shirazi
- (IL) Drs. Ed and Lynn Lipskis
- (TX) Dr. Risto Hurme
- (VA) Dr. Brendan C. Stack
- (VA) Jeffrey L. Brown

## ELDER LAW ATTORNEYS

- (CA) Zoran K. Basich
- (CA) William R. Remery
- (NY) Ronald A. Fatoullah

## ESTATE PLANNING- LEGAL

- (CA) William R. Remery
- (NY) Ronald A. Fatoullah

## ESTATE PLANNING – FINANCIAL PLANNING

- Cypress Wealth Services

## FELDENKRAIS METHOD® PRACTITIONERS

- LeAnn Brightwell, CM

## FINANCIAL ASSISTANCE

- The Assistance Fund, Inc

## HEALTHY PRODUCTS

- Healthy Chocolate
- Wild Blue-Green Algae
- Nerium Age Defying Formula
- Protandim Nrf2

## HOSPICE CARE

- Family Hospice (local)
- Gentiva Hospice (regional)
- Vitas Healthcare (nationwide)

## INCONTINENCE SUPPLIES

- Geewhiz

## IN HOME CARE PROFESSIONALS

- Cambrian Homecare
- Senior Helpers of the Desert
- A&A Homecare

## LEGAL-ATTORNEY-LAWYERS

- (CA) Zoran K. Basich
- (CA) William R. Remery, Esq.
- (NY) Ronald A. Fatoullah

## LSVT LOUD PROGRAM

- Easy Speech Communication Center

## LSVT BIG PROGRAM

- New Beginning Physical Therapy
- Rosi Physiotherapy

## MASSAGE & BODYWORK

- Mot'us Floatation & Wellness Center



## MEDICAL MARIJUANA

- PSA Organica

## MEDICAL SUPPLIES

- Access Medical, Inc, dba In & Out Mobility
- In & Out Mobility

## MEDICINE

- US World Meds

## NEUROSCIENCE

- Desert Psychology & Neuroscience Center

## NURSING HOME ATTORNEYS

- (CA) Zoran K. Basich

## NUTRITION- WELLNESS CONSULTANTS

- Wayne Myers



## PHARMACIES

- Cornerstone



## PHYSICAL THERAPISTS- TRAINING SPECIALISTS

- Arroyo Physical Health
- New Beginning Physical Therapy
- Innergy Therapy Systems
- Rosi Physiotherapy
- Rehab Specialists



## PHYSICIANS AND SURGEONS

- Dr. Michel Lévesque

## RESIDENTIAL CARE FACILITIES

- A & A Home Care

## SENIOR HOUSING

- Atria Hacienda

## SPEECH THERAPY

- Easy Speech Communication Center

## TRANSPORTATION

- LA Car Service

## VISION

- Riverside Institute of Vision Rehabilitation
- Drs. Kohtz & Spurling

## WATSU

- Kim L. Hartz, LMT, WABA

## AVOID OPIOIDS! PHYSIOTHERAPY IS PAIN MANAGEMENT

Dr. Samantha Peters, DPT

In the last twenty years the sale and use of opioids have more than **QUADRUPLED** in the US, according to the Centers for Disease Control and Prevention (CDC). We are currently in the period known as the "Opioid Crisis". This is a public health epidemic. Physicians over prescribe medications that are highly addictive and are only intended to mask pain. In an effort to reduce opioid use, in March 2016 the CDC updated its opioid prescription guidelines for prescribing these dangerous medications. There are certain conditions, such as cancer treatments, end of life care and palliative care, in which opioids may be appropriate. However, the CDC has found many cases where opioids should not have been used.

The CDC recommends physical therapy, a non-opioid intervention, to treat pain prior to the use of opioids. Why physical therapy you ask? Well, let me tell you... physiotherapy is more effective at eliminating pain!

Physical therapy time and time again is proven to be more effective in eliminating chronic pain. Osteoarthritis, back pain and fibromyalgia have the significantly better results from physiotherapy when compared to opioids. Opioids are made to block pain receptors from reaching the brain. This is a way of masking your brain from interpreting the pain. Opioids will not fix any problem that causes pain. That is a fact. Physiotherapy is the restoration of function caused by injury, disease or disability. Physical therapists treat and eliminate pain by determining the source of dysfunction and correcting it.

## WHAT IS MULTIPLE SYSTEM ATROPHY? A PARKINSON(ISM)

### National Institutes of Neurological Disorders and Stroke

Multiple System Atrophy (MSA) is a progressive neurodegenerative disorder characterized by a combination of symptoms that affect both the autonomic nervous system (the part of the nervous system that controls involuntary action such as blood pressure or digestion) and movement. The symptoms reflect the progressive loss of function and death of different types of nerve cells in the brain and spinal cord.

Symptoms of autonomic failure that may be seen in MSA include fainting spells and problems with heart rate, erectile dysfunction, and bladder control. Motor impairments (loss of or limited muscle control or movement, or limited mobility) may include tremor, rigidity, and/or loss of muscle coordination as well as difficulties with speech and gait (the way a person walks). Some of these features are similar to those seen in Parkinson's disease, and early in the disease course it often may be difficult to distinguish these disorders.

MSA is a rare disease, affecting potentially 15,000 to 50,000 Americans, including men and women and all racial groups. Symptoms tend to appear in a person's 50s and advance rapidly over the course of 5 to 10 years, with progressive loss of motor function and eventual confinement to bed. People with MSA often develop pneumonia in the later stages of the disease and may suddenly die from cardiac or respiratory issues.

While some of the symptoms of MSA can be treated with medications, currently there are no drugs that are able to slow disease progression and there is no cure.

MSA includes disorders that historically had been referred to as Shy-Drager syndrome, olivopontocerebellar atrophy, and striatonigral degeneration.

What are the common signs or symptoms? The initial symptoms of MSA are often difficult to distinguish from the initial symptoms of Parkinson's disease and include:

- *slowness of movement, tremor, or rigidity (stiffness);*
- *clumsiness or incoordination;*
- *impaired speech, a croaky, quivering voice;*
- *fainting or lightheadedness due to orthostatic hypotension, a condition in which blood pressure drops when rising from a seated or lying down position, and;*
- *bladder control problems, such as a sudden urge to urinate or difficulty emptying the bladder.*

Doctors divide MSA into two different types, depending on the most prominent symptoms at the time an individual is evaluated:

- *the parkinsonian type (MSA-P), with primary characteristics similar to Parkinson's disease (such as moving slowly, stiffness, and tremor) along with problems of balance, coordination, and autonomic nervous system dysfunction, and;*
- *the cerebellar type (MSA-C), with primary symptoms featuring ataxia (problems with balance and coordination), difficulty swallowing, speech abnormalities or a quivering voice, and abnormal eye movements ("cerebellar" reflects a part of the brain involved with coordination)*

MSA tends to progress more rapidly than Parkinson's disease, and most people with MSA will require an aid for walking, such as a cane or walker, within a few years after symptoms begin.

Additional symptoms of MSA include:

- *contractures (chronic shortening of muscles or tendons around joints, which prevents the joints from moving freely) in the hands or limbs;*
- *Pisa syndrome, an abnormal posture in which the body appears to be leaning to one side like the Leaning Tower of Pisa;*
- *antecollis, in which the neck bends forward and the head drops down*
- *involuntary, uncontrollable sighing or gasping;*
- *sleep disorders, including a tendency to act out dreams (called REM/ (Rapid Eye Movement sleep behavior disorder), and;*
- *Some people with MSA may experience feelings of anxiety or depression.*

What causes MSA? The cause of MSA is unknown. The vast majority of cases are sporadic, meaning they occur at random. A distinguishing feature of MSA is the accumulation of the protein alpha-synuclein in glia, the cells that support nerve cells in the brain. These deposits of alpha-synuclein particularly occur in

cont. on page 6

## BOARD OF DIRECTORS

### GOVERNING BOARD

**JO ROSEN**

*President & Founder*

**WILLIAM R. REMERY, ESQ.**

*ELDER LAW, PRO Secretary/Treasurer*

**KAYA KOUVONEN**

*Transportation*

### ADVISORY BOARD

**JACOB CHODAKIEWITZ, MD**

**PATRICIA DUNAY**

**DAVID M. SWOPE, MD**

**DR. ANA LORENZ**

**CLAUDE VALENTI, OD, FCOVD**

**DANA BERNSTEIN**

*Advertising Director*

**SUE DUBRIN**

### HONORARY BOARD MEMBERS

**GREG A. GERHARDT, PHD**

**MICHEL LÉVESQUE, MD**

**STEPHEN MACHT**

*Actor/Director*

**TRINI LOPEZ**

*Int'l Singer/Songwriter*

### EMERITUS

**MARIA ELIAS**

**DEBBIE STEIN**

**ROGER RIGNACK, MBA**

### GONE, BUT NOT FORGOTTEN

**ALAN ROSEN, FAIA**

**ELINA OSTERN**

**JERRY BERNSTEIN**

**JACK HISS, MD**

**PHILIP GUSTLIN, ESQ.**

**DR S. JEROME TAMKIN**

**KENNETH SLADE**

**SHIRLEY KREIMAN**

**LEONARD RUDOLPH**

**CAROLE ROBERTS-WILSON, MS-SLP**

### FOUNDING MEMBERS

**JO ROSEN, Founder**

**ARNIE KRONENBERGER (deceased)**

**CATHERINE BUCKINGHAM**

**JENNIFER REINKE**

**DARLENE FOGEL**

**CHUCK KOCH**

**ALAN ROSEN, FAIA (deceased)**

**WAYNE FRIEDLANDER**

**PAUL ROSEN**

**ELAINE VACCA**



## Special Thanks

...TO OUR "SPECIAL" BOOSTERS:

LYNN HAWKS, ONLINE MEDIA PROS

GARY LOPEZ ~ G~ARIES VISIONS

THE DESERT COMPUTER DOCTOR,

ROBIN BROWN

SUE DUBRIN

FRANK & MARY BUYTKUS

IRENE MOTTA

WALT & PAT BENSON

JON & MARTHA HANSON

RON BUCKLES

JOHN & JUDITH GUNDERSEN

EVA MYERS

JOHN PERL

RICHARD CORDES, CPA, JD, LLM

MASSI ABADI, MFT

IRENE SOMERS

MICHELLE WALDNER

DAVID ALLAUN

BRENDA WALLACE

JEREMY SIMON

LYNN JOHNSON

ELYSE DELFRANCIA

BILL LEWIS

PAUL HIETTER

## ALL ABOUT MAGNESIUM

### Could It Help With Constipation?

**What Is It?** – Magnesium is a mineral your body needs to work right. It helps with hundreds of important body processes, including those that control how your muscles and nerves work. It helps to keep your bones strong, heart healthy, and blood sugar normal. It also plays a role in your energy level. You can get magnesium in many foods and drinks. But if your doctor thinks you need more, s/he may suggest that you add supplements.

**How Much Do You Need?** – An adult woman needs about 310 milligrams of magnesium a day, and 320 milligrams after age 30. Pregnant women need an extra 40 milligrams. Adult men under 31 need 400 milligrams and 420 milligrams if they're older. Kids need anywhere from 30 to 410 milligrams, depending on their age and gender. Talk with your pediatrician about how much magnesium your child needs.

**Are You Getting Enough?** – Almost half of Americans don't get enough magnesium from their diet. Over time, low levels of the mineral may set the stage for a variety of health issues, including type 2 diabetes, high blood pressure, and migraines. Older adults, alcoholics, and those with type 2 diabetes or digestive issues are more likely to lack it, either because their bodies get rid of too much magnesium or they don't take in enough in the first place.

**Can You Get Too Much?** – If you're healthy, your kidneys flush out the extra magnesium you get from foods. Still, too much of it can bring on cramps or nausea. If you use magnesium supplements, don't take more than 350 milligrams a day. The same is true if you use laxatives or antacids that have magnesium. At really high doses, the mineral can make you very sick.

**Benefit: Strengthens Bones** – Your body uses magnesium to build new bone cells. Research suggests that it may also protect against bone loss, broken bones, and the bone disease osteoporosis. Studies show that women with osteoporosis tend to have lower levels of magnesium than those who don't.

**Benefit: Fights Inflammation** – Inflammation is your immune system's reaction to potential harm. In the short term, it helps your body fight off viruses and heal wounds. But if you have inflammation all the time, it can lead to health problems such as heart disease, arthritis, and diabetes. Magnesium can help keep that from happening.

**Benefit: Protects the Heart** – Magnesium helps your heart pump blood. Right levels of the mineral can lower your chances of an irregular heartbeat, heart disease, or a heart attack. Magnesium relaxes the walls of your blood vessels, and that can help keep your blood pressure down. It also may help boost your HDL, or "good," cholesterol levels.

**Benefit: Prevents Migraines** – Experts think magnesium helps to block or lower pain chemicals in your brain and keeps your blood vessels from tightening. You're more likely to get migraines if you don't get enough. A 400- to 500-milligram supplement may help keep these headaches away.

**Benefit: Lowers Odds of Diabetes** – Magnesium helps a hormone called insulin work right. Insulin helps keep your blood sugar levels steady. In one study, people who got the most magnesium in their diet were less likely to get the disease than those who got the least.

**Source: Nuts and Seeds** – Snack on an ounce of almonds or cashews, and you'll get about 80 milligrams of magnesium. Other good choices include pumpkin seeds, pecans, sunflower seeds, peanuts, and flax. Sprinkle them on a salad or toss them into a trail mix. You'll also get heart-healthy fats, fiber, and antioxidants.

**Source: Whole Grains** – When it comes to nutrition, whole grains beat out white bread and other highly processed foods. Not only do they have lots of fiber, but they're also high in magnesium. Two slices of whole wheat bread pack 45 milligrams of the mineral, a half-cup of brown rice has about 40 milligrams, and a half-cup of cooked oatmeal gives you 30 milligrams.

**Source: Avocado** – Any way you slice, dice, or mash it, this is a great source of magnesium. One cup of the diced fruit holds 44 milligrams. It also serves up heart-healthy fats, fiber, and folate. Try adding avocado to your sandwich, salad, or taco.

**Source: Dark Leafy Greens** – Here's yet another reason to eat your veggies. You'll get about 150 milligrams from a cup of cooked spinach or Swiss chard. Besides those two standouts, other good magnesium sources are dark leafy greens such as collard greens and kale. Bonus: They're also loaded with calcium, potassium, iron, and vitamins A, C, and K. The vegetables don't all have to be leafy. Okra, for example, is magnesium-rich.

**Source: Soy Products** – Soy is a staple among vegetarians for its plant-based protein. But it's no slouch in the magnesium department, either. A cup of soy milk rings up 60 milligrams, while a half-cup of firm tofu packs about 50 milligrams. Also check out tempeh, made with fermented

cont. on page 7

"LIKE" US ON FACEBOOK  
AND FOLLOW US ON TWITTER!



Facebook.com/  
ParkinsonsResourceOrganization



twitter.com/ParkinsonsPro

## APHASIA DEFINITIONS

Aphasia is an impairment of language, affecting the production or comprehension of speech and the ability to read or write. Aphasia is always due to injury to the brain—most commonly from a stroke, particularly in older individuals. But brain injuries resulting in aphasia may also arise from head trauma, from brain tumors, or from infections or be an adjunct to Parkinson's.

Aphasia can be so severe as to make communication with the patient almost impossible, or it can be very mild. It may affect mainly a single aspect of language use, such as the ability to retrieve the names of objects, or the ability to put words together into sentences, or the ability to read. More commonly, however, multiple aspects of communication are impaired, while some channels remain accessible for a limited exchange of information.

It is the job of the professional to determine the amount of function available in each of the channels for the comprehension of language, and to assess the possibility that treatment might enhance the use of the channels that are available.

Below you can find more information on the different types of aphasia such as Global, Broca's, Wernicke's, Primary Progressive, Anomic, and Mixed Non-fluent aphasia.

### *Varieties and special features of aphasia*

Over a century of experience with the study of aphasia has taught us that particular components of language may be particularly damaged in some individuals. We have also learned to recognize different types or patterns of aphasia that correspond to the location of the brain injury in the individual case. Some of the common varieties of aphasia are:

**Aphasia** – This is the most severe form of aphasia and is applied to patients who can produce few recognizable words and understand little or no spoken language. Persons with Global Aphasia can neither read nor write. Global aphasia may often be seen immediately after the patient has suffered a stroke and it may rapidly improve if the damage has not been too extensive. However, with greater brain damage, severe and lasting disability may result.

**Broca's Aphasia** – ('non-fluent aphasia') In this form of aphasia, speech output is severely reduced and is limited mainly to short utterances of less than four words. Vocabulary access is limited and the formation of sounds by persons with Broca's aphasia is often laborious and clumsy. The person may understand speech relatively well and be able to read but be limited in writing. Broca's aphasia is often referred to as a 'non-fluent aphasia' because of the halting and effortful quality of speech.

**Mixed Non-Fluent Aphasia** – This term is applied to patients who have sparse and effortful speech, resembling severe Broca's aphasia. However, unlike persons with Broca's aphasia, they remain limited in their comprehension of speech and do not read or write beyond an elementary level.

**Wernicke's Aphasia** – ('fluent aphasia') In this form of aphasia the ability to grasp the meaning of spoken words is chiefly impaired, while the ease of producing connected speech is not much affected. Therefore, Wernicke's aphasia is referred to as a 'fluent aphasia.' However, speech is far from normal. Sentences do not hang together and irrelevant words intrude-sometimes to the point of jargon, in severe cases. Reading and writing are often severely impaired.

**Anomic Aphasia** – This term is applied to persons who are left with a persistent inability to supply the words for the very things they want to talk about—particularly the significant nouns and verbs. As a result, their speech, while fluent in grammatical form and output is full of vague circumlocutions and expressions of frustration. They understand speech well, and in most cases, read adequately. Difficulty finding words is as evident in writing as in speech.

**Primary Progressive Aphasia (Ppa)** – is a neurological syndrome in which language capabilities become slowly and progressively impaired. Unlike other forms of aphasia that result from stroke or brain injury, PPA is caused by neurodegenerative diseases, such as Alzheimer's Disease or Frontotemporal Lobar Degeneration. PPA results from deterioration of brain tissue important for speech and language. Although the first symptoms are problems with speech and language, other problems associated with the underlying disease, such as memory loss, often occur later.

cont. on page 6

## PARKINSON'S RESOURCE ORGANIZATION

### VOLUNTEERS

**LYNN HAWKS**

*Web Design & Marketing*

**GARY LOPEZ**

*Graphic Artist*

### AMBASSADORS

**SOPHIE BESHOFF**

**CHERYL EPSTEIN**

**CHARLENE & BOB SINGER**

### GROUP FACILITATORS

**PEGGY SEXTON**

**BARBARA ENGLISH**

**SUE DUBRIN**

**KAY GRAY**

**MARTHA HANSON**

**JOHN MASON**

### VOLUNTEERS/OFFICE SUPPORT

**EVA MYERS**

**JOHN PERL**

**IRENE SOMERS**

**GAY BAYLESS**

**MICHELE WALDNER**

**JEREMY SIMON**

**DAVID ALLAN**

**PAUL HIETTER**

**BILL LEWIS**

WE DO NOT INTEND  
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

***Alzheimer's, clearance or reduction of the amyloid-plaque, a biomarker, would be an indication that the drug is working.***

Because clinically meaning benefit cannot be measured in early stage AD patients, the FDA seems to suggest that if a drug can bring “functional” change in the biomarkers of the disease the drug may serve as the basis for accelerated approval. This is an encouraging news for Companies like ICB International (ICBII) as it can potentially accelerate market penetration of its SMART Molecules for Alzheimer's as these drugs have already shown significant reduction of amyloid-plaque (biomarker) in Alzheimer's mouse models. The same may be true for Parkinson's disease down the road, which will facilitate market entrance of ICBII's drug,  $\alpha$ -Syn-SM.

**MULTIPLE SYSTEM ATROPHY** – cont. from page 3

oligodendroglia, a type of cell that makes myelin (a coating on nerve cells that lets them conduct electrical signals rapidly). This protein also accumulates in Parkinson's disease, but in nerve cells. Because they both have a buildup of alpha-synuclein in cells, MSA and Parkinson's disease are sometimes referred to as synucleinopathies. A possible risk factor for the disease is variations in the synuclein gene SCNA, which provides instructions for the production of alpha-synuclein.

How is MSA diagnosed? Making a diagnosis of MSA can be difficult, particularly in the early stages, in part because many of the features are similar to those observed in Parkinson's disease.

After taking a clinical history and performing a brief neurological examination, a doctor may order a number of tests to help make the diagnosis. These tests might include autonomic testing (such as blood pressure control, heart rate control), assessment of bladder function, and/or neuroimaging such as an MRI (magnetic resonance imaging) or PET scan. An MRI of the brain may identify changes which might suggest MSA or rule out other causes of the observed symptoms.

A PET scan (positron emission tomography, which allows doctors to see how organs and tissues are functioning) is sometimes used to see if metabolic function is reduced in specific parts of the brain. DaTscan can assess the dopamine transporter in a part of the brain called the striatum and can help physicians determine if the condition is caused by a dopamine system disorder; however this test cannot differentiate between MSA and Parkinson's disease. Individuals with MSA typically do not have sustained improvement in their symptoms with levodopa (a drug used to treat Parkinson's disease), a finding that often supports the diagnosis of MSA.

How is it treated? Currently, there are no treatments to delay the progressive neurodegeneration of MSA, and there is no cure. There are treatments to help people cope with the symptoms of MSA.

In some individuals, levodopa may improve motor function; however, the benefit may not continue as the disease progresses.

The fainting and lightheadedness from orthostatic hypotension may be treated with simple interventions such as wearing compression stockings, adding extra salt and/or water to the diet, and avoiding heavy meals. The drugs fludrocortisone and midodrine sometimes are prescribed. In 2014, the U.S. Food and Drug Administration approved the medication droxidopa for the treatment of orthostatic hypotension seen in MSA. Dihydroxyphenylserine helps to replace chemical signals called neurotransmitters which are decreased in the autonomic nervous system in MSA. Some medications used to treat

orthostatic hypotension can be associated with high blood pressure when lying down, so affected individuals may be advised to sleep with the head of the bed tilted up.

Bladder control problems are treated according to the nature of the problem. Anticholinergic drugs, such as oxybutynin or tolteridine, may help reduce the sudden urge to urinate.

Fixed abnormal muscle postures (dystonia) may be controlled with injections of botulinum toxin.

Sleep problems such as REM sleep behavior disorder can be treated with medicines including clonazepam, melatonin, or some antidepressants.

Some individuals with MSA may have significant difficulties with swallowing and may need a feeding tube or nutritional support. Speech therapy may be helpful in identifying strategies to address swallowing difficulties.

Physical therapy helps maintain mobility, reduce contractures (chronic shortening of muscles or tendons around joints, which prevents the joints from moving freely), and decrease muscle spasms and abnormal posture.

Individuals may eventually need assistive devices such as walkers and wheelchairs. Occupational therapists help with home safety and learning new ways to address activities of daily living such as dressing and eating.

Researchers hope to learn why the protein alpha-synuclein accumulates in glial cells in MSA and neuronal (nerve) cells in Parkinson's disease. Recent studies have demonstrated that the alpha-synuclein taken from brain tissue of patients with MSA is a potent inducer of alpha-synuclein clumping when injected into the brain of experimental animals. One exciting area of ongoing research is aimed at blocking the spread of this protein clumping problem throughout the brain.

**APHASIA** – cont. from page 5

***Other Varieties*** – In addition to the foregoing syndromes that are seen repeatedly by speech clinicians, there are many other possible combinations of deficits that do not exactly fit into these categories. Some of the components of a complex aphasia syndrome may also occur in isolation. This may be the case for disorders of reading (alexia) or disorders affecting both reading and writing (alexia and agraphia), following a stroke. Severe impairments of calculation often accompany aphasia, yet in some instances patients retain excellent calculation in spite of the loss of language.

For more information about Aphasia go to National Aphasia Association. [naa@aphasia.org](http://naa@aphasia.org)



MAGNESIUM – cont. from page 4

soy, edamame, and soy yogurt.

Source: Beans – On a given day, only 8% of Americans eat a serving of beans. That means most people are missing out on a healthy magnesium source. A half-cup of black beans has 60 milligrams and kidney beans has 35 milligrams. Other magnesium-rich legumes include chickpeas, white beans, and lentils. From stews to salads, you can add beans to nearly any dish. You'll get an extra dose of fiber, protein, iron, and zinc.

Interactions With Medicines – Talk to your doctor before you take a magnesium supplement. And make sure s/ he knows everything else you take. Some drugs can make it harder for your body to absorb magnesium. And magnesium supplements can make some antibiotics and osteoporosis meds not work as well as they should.

OPIOIDS – cont. from page 2

The CDC considers all non-opioid interventions “much lower risks”. There are very few, to no risks associated with Physiotherapy. Opioids are highly addictive substances that are very difficult to stop using once you start. The long-term effects that these medications have on the body are still uncertain.

If you are already on an opioid, the CDC still recommends that you couple this with a non-opioid intervention, such as physical therapy. If you have not been prescribed an opioid but are experiencing pain, TRY PHYSIOTHERAPY FIRST! Don't risk addiction!

For more information on PHYSIOTHERAPY FIRST, visit Rosi Physiotherapy where they do not use experimental treatments. Their doctors practice safe and effective interventions to heal pain. Find them under Physical Therapy in the Wellness Village. Member since June 16, 2017.



2<sup>nd</sup> Annual  
**MITCH'S  
PITCHES  
PRO**  
APRIL 8, 2018  
6:30 PM  
HOSTED BY  
*Mitch's*  
ON EL PASEO  
PRIME SEAFOOD

Tickets are now available for Parkinson's Resource Organization's 2<sup>nd</sup> Annual MITCH'S PITCHES PRO event April 8th, 2018 hosted by Mitch's on El Paseo Prime Seafood, 73-951 El Paseo, Palm Desert, CA 92260. Beginning at 6:30 pm, the event kicks off with cocktails and Specialty Auction, at 7:00 pm, we're seated for a wine-paired, gourmet, three-course dinner with live music and an up-and-coming songstress, Hanna Johnson.

Help us complete our goals plus accentuate a robust launch of the WELLNESS VILLAGE, our virtual online, vetted, video-driven, resource directory which will help hundreds of thousands of families affected by Parkinson's.

Please RSVP by March 31, 2018. All proceeds benefit Parkinson's Resource Organization, a 501(c)(3) tax-exempt charity.

Yes, I/we will attend, please reserve!  
Quantity \_\_\_ at \$125.00 ..... \$ \_\_\_\_\_  
Additional tax deductible donation ..... \$ \_\_\_\_\_  
Total ..... \$ \_\_\_\_\_

I/we are sorry we cannot attend, but please accept my/our tax-deductible donation of ..... \$ \_\_\_\_\_

I/we would like to become a sponsor:  
**GOLD PACKAGE** (VIP Leader Sponsor): .....\$5,000  
• Your business name and/or logo listed on all email blasts  
• Your business name and/or logo listed in the Program Book.  
• Table of 8  
• Bottle of Dom Perignon Champagne at your table  
• Acknowledgement from the podium and the opportunity to speak

**SILVER PACKAGE** (Entertainment Sponsor): ..... \$ 2,500  
• Your business name and/or logo listed on all email blasts  
• Your business name and/or logo listed in the Program Book  
• Table of 8

**BRONZE PACKAGE** (Wine sponsorship): .....\$ 1,500  
• Your business name and/or logo listed in the Program Book  
• Reservations for 4 in a prominent location

**INDIVIDUAL PACKAGE** (a la carte): .....\$750  
• Your business name and/or logo listed in the Program Book  
• Reservations for 2

**PROGRAM UNDERWRITER** .....\$250  
• Name Listed in Program as a PRO Sponsor & Supporter

Check (enclosed)     Visa     MasterCard

American Express     Discover Card

Card # \_\_\_\_\_

Exp \_\_\_ / \_\_\_    CVA \_\_\_\_\_

Name on card \_\_\_\_\_

# PRO CALENDAR FOR MARCH 2018

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 PALM DESERT Caregiver Only 10:00 am PRO Office 74-090 El Paseo Suite 104	6	7 LONG BEACH Support Meeting 6:30 pm Cambrian Home Care "Training Center" 5199 Pacific Coast Hwy	8 NEWPORT BEACH Caregiver Only 6:30 pm Oasis Senior Center 801 Narcissus Corona Del Mar	9	10
11	12 PALM DESERT Round Table For Everyone 6:30 pm Atria Hacienda 44-600 Monterey Ave	13	14 GLENDDORA Speaker Meeting 6:30 pm Kindred Rehab at Foothill 401 W Ada Ave	15 SANTA MONICA Speaker Meeting 6:30 pm Rehab Specialists 2730 Wilshire Blvd Ste 533	16	17
18	19 PALM DESERT Caregiver Only 10:00 am PRO Office 74-090 El Paseo Suite 104	20	21 ENCINO Caregiver Only 7:00 pm Rehab Specialists 5359 Balboa Blvd	22 SHERMAN OAKS Support Group Meeting 1:00pm East Valley Adult Center 5060 Van Nuys Blvd	23	24
25	26 PALM DESERT Speaker Meeting 6:30 pm Atria Hacienda 44-600 Monterey Ave	27 MANHATTAN BEACH Speaker Meeting 6:30 pm American Martyrs Parish House 659 15th Street	28	29	30	31

**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

March 2018 / Issue No. 304 / Published Monthly

### PARKINSON'S RESOURCE ORGANIZATION

Working so no one is isolated because of Parkinson's

74-478 Highway 111, No 102 • Palm Desert, CA 92260-4112

760-773-5628 • 310-476-7030 • 877-775-4111 • 760-773-9803

eMail: [info@ParkinsonsResource.org](mailto:info@ParkinsonsResource.org) • web: [ParkinsonsResource.org](http://ParkinsonsResource.org)

501(C)(3)#95-4304276

We do not intend the PRO Newsletter as legal or medical advice, nor to endorse any product or service; we intend it to serve as an information guide.

"THE ONLY PERSON YOU SHOULD TRY TO BE BETTER THAN IS THE PERSON YOU WERE YESTERDAY."

— ANONYMOUS