Issue No. 309

#### August 2018

PARKINSON'S RESOURCE ORGANIZATION

Н

Working so no one is isolated because of Parkinson's

## MESSAGE

ugust already... where has the Summer gone? As we enjoy our HOT desert summer temperatures, we hope your "Lazy Days" are filled with time to relax and reflect, a good book or two and treasured time with family and friends. Fall is just a few months away, so we encourage you to sit back and enjoy every moment of the "vacation" season.

If you want something PROvocative and engaging to read, this month's *Newsworthy Notes* has lots to pique your interest.

By no means lackadaisical, the articles this month include ICBII UPDATE ON THE ROAD TO THE CURE on this page (as many of you know, my mother lived with PSP, although diagnosed with Parkinson's disease); FORMER INVESTMENT BANKER JOINS LOCAL CHARITY BOARD also on this page and we are so pleased with Michael coming on board; WHAT IS ALIEN HAND SYNDROME? on page 3; FIRST OF ITS KIND RESOURCE DIRECTORY FOR PEOPLE AFFECTED BY PARKINSON'S: The Wellness Village is on page 2; VITAMIN D AND **DEPRESSION** on page 4, and especially during these summer months, 6 UNUSUAL SIGNS OF DEHYDRATION YOU SHOULD KNOW ABOUT on page 5.

Join us in making a difference in your life or the life of a loved one this MONTH by donating. Without YOU, we could never do all that we do. Supporting us is simple: Make monthly donations through our safe PayPal donation page at **ParkinsonsResource.org/contribute-2/** or mail your donation to our office in Palm Desert, CA.

Until next month, REMEMBER Nat'l. Girlfriend Day on the 1st, Friendship, and Nat'l. Sister Day on the 5th, Int'l. Left-Handers Day on the 13th, and National Dog Day on the 26th. The flowers are the Poppy & Gladiolus, and your Birthstone is Peridot. ALWAYS remember to CELEBRATE YOU and PRAY FOR OUR TROOPS!



# ICBII UPDATE ON THE ROAD TO THE CURE

What is progressive supranuclear palsy? Progressive supranuclear palsy (PSP) is a rare brain disorder that affects movement, control of balance, speech, swallowing, vision, mood and behavior, and thinking. The most common first symptom of PSP is a loss of balance while walking. Individuals may have unexplained falls or stiffness and awkwardness in gait. As the disease progresses, most people will begin to develop a blurring of vision and problems controlling eye movement. In fact, eye problems, in particular slowness of eye movements, usually offer the first definitive clue that PSP is the proper diagnosis. Individuals affected by PSP especially have trouble voluntarily shifting their gaze vertically (i.e., downward and upward) and also can have trouble controlling their eyelids, leading to a need to move the head to look in different directions, involuntary closing of the eyes, prolonged or infrequent blinking, or difficulty in opening the eyes. Another common visual problem is an inability to maintain eye contact during a conversation which can give the mistaken impression that the person is hostile or uninterested.

Estimates vary, but only about three to six in every 100,000 people worldwide, or approximately 20,000 Americans, have PSP, making it much less common than Parkinson's disease (a movement disorder estimated to have 55,000 Americans diagnosed each year). Symptoms of PSP begin

cont. on page 6

## FORMER INVESTMENT BANKER JOINS LOCAL CHARITY BOARD

PALM DESERT – Parkinson's Resource Organization (PRO) proudly announces that Michael Rudder, formerly with TJ Bettes Company, and the current President and CEO of Thermaltech Development, Inc. (TDI) a business development consulting firm providing governance and strategic direction and planning, has joined the PRO Board of Directors. Michael Rudder is an eleven-year veteran of Parkinson's, diagnosed in 2008.

Mr. Rudder has been helping emerging entities recognize their full potential in fulfilling their mission and finding their financial sustainability. His humanitarianism, board memberships and personal philanthropy include Chairman and Business Plan Developer for Project Open Hand (San Francisco) replicated as Project Angel Food (Los Angeles) and God's Love We Deliver (New York); A founding Board Member of Ford Foundation's National AIDS Fund, D. C.; California Pacific Medical Center Executive and Finance committee member for their five-campus hospital in San Francisco; and the Kinsey Institute, Indiana University; Board of Directors' member and IU Executive Committee.

"I've spent much of the last 40 years in the world of non-profits and particularly with those who fill the gaps where the community, and the industry, don't have the answers but the ORGANIZATION does." Says Rudder, "I think this is what PRO has done and I am delighted to be a part of that."

According to Jo Rosen, President and Founder of PRO, "What Mr. Rudder thinks is exciting about PRO is that the Parkinson's community has many of the answers within itself and PRO has made it possible for others to know that. He thinks that PRO's mission is much more powerful than any medication. Isn't that neat?" Rosen further says, "Watch us grow, helping millions of people affected by Parkinson's. It's a 28-year dream-come-true after helping one-person-at-a-time."

## **Newsworthy Notes**

#### ACUPUNCTURE

Dr. David Shirazi

#### ANIMAL-ASSISTED THERAPY

Canine Companions

#### **AROMA THERAPY**

Renee Gauthier

#### **ASSISTIVE TECHNOLOGY**

California Phones

- **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
- (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

them, or that they even existed.

(VA) Jeffrey L. Brown

The Wellness Village

#### **ELDER LAW ATTORNEYS**

Iness

(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

PALM DESERT - PRO (ParkinsonsResource.org) holds a unique, first of its kind, vetted, virtual, video-driven Resource Directory for people throughout the world affected by Parkinson's disease. Set to aggressively initiate a global outreach this September, The Wellness Village, on the PRO website, will provide connections to professionals and relevant products to aid the Parkinson's

Believed to be the first Resource Program of its kind in the world, along with education of their need or usage, The Wellness Village introduces professionals and products to a desperate-for-information community that may not know where to get

"When a person is diagnosed with Parkinson's disease or a Parkinsonism, their medical doctor rarely, if at all, lets them know what to expect with their diagnosis," says Jo Rosen, President & Founder of Parkinson's Resource Organization. "The patient,

"We look for professionals and products that PWPs (People with Parkinson's) told us worked for them, or that the professional or product distributor informed us works for this community," Rosen continues. "When we find them we vet them to the best of our ability to make certain they are legitimate, licensed, responsible and reflective of our very high standards. Only after this

#### **LSVT BIG PROGRAM**

New Beginning Physical Therapy •

FIRST OF ITS KIND RESOURCE DIRECTORY FOR PEOPLE AFFECTED BY PARKINSON'S

world with the greatest quality of life possible as they go through the progressive journey of Parkinson's disease.

or their family member(s) start looking for resources, and that's where Parkinson's Resource Organization comes in."

process are they published in the Wellness Village on the PRO website. ParkinsonsResource.org/the-wellness-village

Rosi Physiotherapy

#### **MASSAGE & BODYWORK**

Mot'us Floatation & Wellness Center

#### **MEDICAL MARIJUANA**

PSA Organica

#### **MOBILITY PRODUCTS**

 In & Out Mobility LiftUp, Inc

#### **MEDICINE**

My

wist

Maw

**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

**PHYSICIANS AND SURGEONS** 

**RESIDENTIAL CARE FACILITIES** 

Easy Speech Communication Center

Riverside Institute of Vision Rehabilitation

Rehab Specialists

Dr. Michel Lévesque

A & A Home Care

**SENIOR HOUSING** 

Atria Hacienda

**SPEECH THERAPY** 

Drs. Kohtz & Spurling

VISION

## WHAT IS ALIEN HAND SYNDROME?

**PRO Staff Writer** 

When we see or hear of a condition, or symptom, more than once we begin to think there may be many more in the Parkinson's world experiencing the same. They may not know what it is either, so we bring the information to you. Here at PRO, we have seen or heard of this symptom twice in the last couple of months.

We've taken excerpts from several online sources to provide this information to you... Healthline.com, NCBI PubMed.gov and About-Brains.com.

Alien Hand Syndrome (AHS) is a rare neurological condition that causes one hand to act on its own free will. Sometimes one leg is affected, though this isn't as common.

With AHS, the hand isn't under the control of the mind and moves as though it has its own mind. The affected hand feels foreign to its owner during these episodes and seems to move deliberately to carry out tasks that are unintentional.

While it can affect children, usually alien hand occurs in adults. It's sometimes referred to as Dr. Strangelove syndrome, Strangelovian hand, or anarchic hand. You may remember watching Dr. Strangelove, the movie, some years back, finding Dr. Strangelove's ordeal extremely funny, never suspecting that this remarkable affliction could exist in the real world.

It occurs in some cases after brain surgery, stroke, infection, tumor, aneurysm, migraine and specific neurodegenerative brain diseases such as Alzheimer's disease and Creutzfeldt-Jakob disease (*March 2017 Newsworthy Notes issue*). Other areas of the brain that are associated with AHS are the frontal, occipital, and parietal lobes.

Alien Hand Syndrome is linked to brain surgeries that separate the two hemispheres of the brain. The corpus callosum divides the brain hemispheres and allows for communication between the two sides. Surgeries to treat epilepsy sometimes affect the brain in this way. Lesions may also be in the anterior cingulate cortex, posterior parietal cortex, and supplementary motor cortex areas of the brain.

Brain scans show that people with AHS have isolated activities in the primary motor cortex area. This is thought to be due to lesions or damage in the parietal lobe which integrates sensory information among various modalities, including spatial sense and navigation [proprioception], the main sensory receptive area for the sense of touch. This affects intentional planning systems and can cause spontaneous movements.

The most prominent symptom of Alien Hand Syndrome is the inability to control the hand as it acts independently. The affected hand may move involuntarily and perform goal-directed tasks and actions. The hand is said to move without cognitive control or awareness. It's as though it's being controlled by someone else or has a mind of its own.

The hand may touch your face, button a shirt, or pick up an object, sometimes repeatedly or compulsively. The alien hand may also levitate on its own. The hand may also engage in self-oppositional actions such as closing a drawer that the other hand just opened or unbuttoning a shirt that you just buttoned. The alien hand is uncooperative and may perform incorrect actions or fail to follow commands.

People with Alien Hand Syndrome may sense that the hand or limb is foreign or doesn't belong to them. However, they don't deny limb ownership, which can happen in other disorders. Diagnosing Alien Hand Syndrome is complicated because it's a neurological disorder that lacks a psychiatric component. This makes it more difficult to diagnose because behavioral issues are more common than Alien Hand Syndrome. Symptoms can sometimes be attributed to a psychiatric disorder, which may be frustrating to the person affected.

The condition is treated or managed using muscle control therapies such as botulinum toxin (*Botox*) and neuromuscular blocking agents. Benzodiazepines have been successful in some cases, but behavioral techniques seem to be more beneficial.

Mirror box therapy, cognitive therapy techniques, and learning task behavioral



**BOARD OF** 

3

President & Founder WILLIAM R. REMERY, ESO. ELDER LAW, PRO Secretary/Treasurer MICHAEL RUDDER Director at Large 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



SKY LUNDY

**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** 

**IRENE SOMERS** 

MICHELLE WALDNER

DAVID ALLAUN

**JEREMY SIMON** 

**ADAN OLIVAS** 

**ESTEBAN LAGOS** 

KANAMI OKABE

MICHAEL LU

TERRY STRALSER

MICHAEL RUDDER

**RISA LUMLEY** 

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



Facebook.com/ ParkinsonsResourceOrganization



twitter.com/ParkinsonsPro

## VITAMIN D AND DEPRESSION

## EverydayHealth.com

Many studies have linked Vitamin D deficiency with depression. In a cross-sectional study of 12,594 patients in a database at the Mayo Clinic, researchers found that low Vitamin D levels were associated with depressive symptoms, especially in persons with a history of depression. In another study published in the American Journal of Clinical Nutrition, researchers evaluated 81,189 women ages 50 to 79 and found that the women with higher Vitamin D levels (who had higher intakes of Vitamin D from food sources) had less depressive symptoms. Vitamin D can affect the function of two important neurotransmitters, dopamine and norepinephrine.

Symptoms of Vitamin D Deficiency. How do you know if you're Vitamin D deficient? The best way is a simple blood test. Your primary care physician can help you with that. But here are some other tell-tale signs:

- 1. Broken Bones and Stress Fractures One of the critical roles of Vitamin D is to help the intestines absorb calcium into the bloodstream. Without enough Vitamin D, our body will break down bones to get the calcium it needs. In fact, in one study, 50 percent of women treated for bone loss had inadequate Vitamin D levels. Research indicates that adequate Vitamin D intake can prevent osteoporosis, which reduces bone density and increases the risk of broken bones. One study published in the Journal of the American Geriatrics Society found that nursing home residents who took 800 IU daily of Vitamin D fell less and had a lower incidence rate of falls over five months than those taking lower doses of the vitamin. Since we tend to stop building bone mass around age 30, Vitamin D supplementation is important to keep our bones in good condition.
- 2. Chronic Pain and Muscle Weakness A Vitamin D deficiency can also cause your joints and muscles to ache. Research has associated the link between deficiency of Vitamin D and all kinds of musculoskeletal pain. For example, in one study 276 patients with nonspecific pain at different regions (leg pain, widespread pain, rib pain, back pain, fibromyalgia) were compared with 202 other people. In patients with skeletal pain, Vitamin D levels were significantly lower than the control group. Another study found Vitamin D deficiency may also exacerbate ageing of skeletal muscles. However, the good news is that muscle weakness is reversible with Vitamin D supplementation. A study published in the Western Journal of Medicine says that, "Improvement in muscle strength has been observed as early as after a week, but usually within one to two months."
- 3. *Hair Loss* In a study published in Skin Pharmacology and Physiology, researchers evaluated 80 females ages 18 to 45 years old with hair loss, either chronic telogen effluvium (TE) or female pattern hair loss (FPHL), and 40 females without hair loss. Vitamin D deficiencies were associated with hair loss in females with TE and FPHL. Although we don't know as much about Vitamin D's role in hair growth as we do in, say, bone health, Rania Mounir Abdel Hay, MD, a dermatologist at Cairo University suspects it could be that Vitamin D helps regulate the expression of genes that fosters normal hair follicle growth.
- 4. **Drowsiness** In a 2012 study published in the Journal of Clinical Sleep Medicine, researchers determined that there is a significant correlation between daytime sleepiness and low levels of Vitamin D. The study involved 81 patients who complained of sleep problems and nonspecific pain. Vitamin D levels were measured by blood sampling. The authors previous and current research suggest that low levels of Vitamin D may cause or contribute to excessive sleepiness either directly or by means of chronic pain.
- 5. *High Blood Pressure* A large-scale genetic study involving over 155,000 people demonstrated the link between hypertension and Vitamin D deficiency. Those with high concentrations of 25-hydroxyVitamin D had reduced blood pressure and therefore a reduced risk of hypertension. "Our study strongly suggests that some cases of cardiovascular disease could be prevented through Vitamin D supplements or food fortification," said Dr. Vimal Karani from the University of Reading in the UK. "Our new data provide further support for the important non-skeletal effects of Vitamin D."
- 6. *Excessive Sweating* Michael Holick, M.D., a Vitamin D expert at Boston University Medical Center says that one of the first signs of Vitamin D deficiency is a sweaty

## 6 UNUSUAL SIGNS OF DEHYDRATION YOU SHOULD KNOW ABOUT Nancie George

Medically Reviewed by Kelly Kennedy, RD

Dry or flushed skin could be a sign that you're dehydrated. Dehydration occurs when the body has insufficient water to function properly. While mild dehydration may be just uncomfortable, more severe dehydration can lead to blood clots, seizures, and other potentially fatal complications.

Clearly, severe dehydration must be treated promptly, but even mild dehydration can have adverse effects on mood and energy. It's important to catch any degree of dehydration early, but the signs of dehydration aren't always obvious ones like thirst and fatigue.

Here are six surprising signs and symptoms of dehydration.

- Bad Breath Saliva has antibacterial properties, but dehydration can prevent your body from making enough saliva. "If you're not producing enough saliva, you can get bacteria overgrowth in the mouth, and one of the side effects of that is bad breath," says John Higgins, MD, an associate professor of cardiovascular medicine at the University of Texas in Houston and the chief of cardiology at Lyndon B. Johnson General Hospital in Houston.
- Dry Skin "A lot of people think that people who get dehydrated are really sweaty, but in fact, as you go through various stages of dehydration, you get very dry skin," Dr. Higgins says, adding that skin may appear flushed as well.

When pinched, the skin of a dehydrated person may remain "tented" and take some time to return to its normal, flat appearance.

3. *Muscle Cramps* – Dehydration is only one potential cause of muscle cramps, but it's one worth considering if you get cramps while exercising, particularly in hot weather.

"The hotter you get, the more likely you are to get muscle cramps, and that's from a pure heat effect on the muscles. As the muscles work harder and harder, they can seize up from the heat itself. Changes in the electrolytes, such as sodium and potassium, can lead to muscle cramping as well," says Higgins.

Even in cooler weather, dehydration is possible if you don't drink enough fluids while working out. According to Higgins, symptoms may be milder or come on slower, but dehydration carries the same risks, regardless of the outside temperature.

4. *Fever and Chills* – If your body is severely dehydrated you may experience fever and chills. Fever, in turn, can worsen dehydration, and the higher the fever, the more dehydrated you may become.

In infants, so-called dehydration fever may develop if there is inadequate fluid intake, diarrhea, or vomiting. Any fever in an infant or toddler is cause for concern. Ask your pediatrician for guidelines on when to call for help.

Adults with fever should seek medical help if their temperature reaches 103°F.

5. Food Cravings, Especially for Sweets - "When you're dehydrated, it can be difficult for organs like the liver, which uses water, to release glycogen [stored glucose] and other components of your energy stores, so you can actually get cravings for food," Higgins says.

While you can crave anything from chocolate to a salty snack, cravings for sweets are more common because your body may be experiencing difficulty breaking down glycogen to release glucose into the bloodstream to use as fuel, he says.

It's also not uncommon for the body to confuse the feeling of thirst with hunger, meaning that you may feel hungry when all you really need is water.

6. *Headaches* – Even mild dehydration can cause a dehydration headache

## VOLUNTEERS

**Sky Lundy** Web Design

**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 Michele Waldner Jeremy Simon Paki Horton Susan Moller Jan Seiden Terry Stralser Risa Lumley Dyan White Adan Olivas Risa Lumley Kanami Okabe Esteban Lagos

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.

#### Issue No. 309

## **ROAD TO THE CURE** - cont. from page 1

on average after age 60 but may occur earlier. Men are affected more often than women. First described as a distinct disorder in 1964 three scientists published a paper that distinguished the condition from Parkinson's disease. It was sometimes referred to as Steele-Richardson-Olszewski syndrome, reflecting the combined names of the scientists who defined the disorder.

PSP results from damage to nerve cells in the brain. The disorder's long name indicates that the disease worsens (*progressive*) and causes weakness (*palsy*) by damaging certain parts of the brain above nerve cell clusters called nuclei (*supranuclear*). These nuclei particularly control eye movements. One of the classic signs of the disease is an inability to aim and move the eyes properly, which individuals may experience as blurring of vision.

How is PSP different from Parkinson's disease? Both PSP and Parkinson's disease cause stiffness, movement difficulties, and clumsiness, but PSP is more rapidly progressive as compared to Parkinson's disease. People with PSP usually stand exceptionally straight or occasionally even tilt their heads backward (and tend to fall backward), termed "axial rigidity." Those with Parkinson's disease usually bend forward. Problems with speech and swallowing are much more common and severe in PSP than in Parkinson's disease and tend to show up earlier in the course of the disease. Eve movements are abnormal in PSP but close to normal in Parkinson's disease. Both diseases share other features: onset in late middle age, bradykinesia (slow movement), and rigidity of muscles. Tremor, very common in individuals with Parkinson's disease, is rare in PSP. Parkinson's patients benefit markedly from the drug levodopa, while PSP patients respond minimally and only briefly to this drug.

Clinically, PSP results from the accumulation of the protein *tau* in affected brain cells, while Parkinson's disease results from the accumulation of a protein called *alpha-synuclein*.

**What causes PSP?** The exact cause of PSP is unknown. The hallmark of the disease is the accumulation of abnormal deposits of the protein *tau* in nerve cells in the brain so that the cells do not work properly and die. The protein *tau* is associated with microtubules – structures that support a nerve cell's long processes, or axons, that transmit information to other nerve cells. The accumulation of *tau* puts PSP in the group of disorders called the *tauopathies*, which also includes other disorders such as Alzheimer's disease, corticobasal degeneration, and some forms of frontotemporal degeneration.

PSP is caused by a gradual deterioration of brain cells in a few specific areas of the brain, mainly in the region called the brain stem. One of these areas, the substantia nigra, is also affected in Parkinson's disease, and damage to this region of the brain accounts in part for the motor symptoms that PSP and Parkinson's have in common. PSP is usually sporadic, meaning that it occurs infrequently and without known cause; in very few cases the disease results from mutations in the *MAPT* gene, which then provides faulty instructions for making tau to the nerve cell. Genetic factors have not been implicated in most individuals.

There are several theories about PSP's cause. A central hypothesis in many neurodegenerative diseases is that once the abnormal aggregates of proteins like *tau* form in a cell, they can affect a connected cell to also form the protein clumps. In this way the toxic protein aggregates spreads through the nervous system. How this process is triggered remains unknown. Some theories are: 1) That an unconventional infectious agent takes years or decades to start producing visible effects (as is seen in disorders like Creutzfeldt-Jakob Disease); 2) That random genetic mutations happen to occur in particular cells or certain genes in just the right combination to injure these cells; 3) That there is exposure to some unknown chemical in the food, air, or water which slowly damages certain vulnerable areas of the brain. This theory stems from a clue found on the Pacific island of Guam, where a common neurological disease occurring only there and on a few neighboring islands shares some of the characteristics of PSP, Alzheimer's disease, Parkinson's disease, and amyotrophic lateral sclerosis. Its cause is thought to be a dietary factor or toxic substance found only in that area; 4) Another possible cause of PSP is cellular damage caused by free radicals, which are reactive molecules produced continuously by all cells during normal metabolism. Although the body has built-in mechanisms for clearing free radicals from the system, scientists suspect that, under certain circumstances, free radicals can react with and damage other molecules. A great deal of research is directed at understanding the role of free radical damage in human diseases.

What is the prognosis? The disease gets progressively worse, with people becoming severely disabled within three to five years of onset. Affected individuals are predisposed to serious complications such as pneumonia, choking, head injury, and fractures. The most common cause of death is pneumonia. With good attention to medical and nutritional needs, it is possible for individuals with PSP to live a decade or more after the first symptoms of the disease

*Is there any treatment?* There is currently no curative treatment for PSP. One of the main reasons for lack of curative therapies for PSP and other neurodegenerative diseases is that most of the potentially disease altering drugs do not reach the CNS due to the presence of a physical barrier in the brain known as the blood-brain barrier (BBB). The good news is that ICB International has demonstrated that its SMART Molecules overcome the challenges of the BBB. The Company is now working on developing a BBB permeable SMART Molecule for pathogenic *tau* protein.

*How you can help*? The satisfaction of being a part of this historical event can be accomplished by investing in, or finding investors for, ICBII to bring these trials to fruition. Neurodegenerative diseases are on the rise. The good news is that ICBII has developed technology that can potentially halt the disease progression and ameliorate the sufferings of patients afflicted with brain diseases, which was impossible until now. We urge you to join PRO in this humanitarian mission to fight the epidemics of neurodegeneration. Feel free to contact Jo Rosen at Parkinson's Resource Organization, 760-773-5628 or *jorosen@Parkinsonsresource.org*.

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

## VITAMIN D – cont. from page 4

head. You sweat when your body temperature rises above 98.6. Most of the time, this is not a problem. Sweating is actually good for your health, as it releases toxins buried in the fat cells underneath the skin. However, excessive sweating may indicate a deficiency in Vitamin D.

- 7. Low Immunity Vitamin D has an important role for the immune system, as well. Before antibiotics were available, Vitamin D was used to treat infections like tuberculosis. There have been multiple studies associating lower levels of Vitamin D with increased infection. For example, in one study, people with lower Vitamin D levels were more likely to report a respiratory tract infection than those with adequate levels. Other studies indicate that Vitamin D deficiency predisposes children to respiratory infections and can play a role in protecting a person from contracting the flu. Some studies are evaluating the associations between Vitamin D deficiencies and HIV disease progression.
- 8. Irritability and Depression As mentioned above, there is a strong correlation between Vitamin D deficiency and depression. In addition to the studies already included, a study published in Nutrition Journal found that adults who received high doses of Vitamin D had improved depressive symptoms after two months.

## ALIEN HAND - cont. from page 3

therapies can help manage symptoms. Visuospatial coaching techniques may also help. Sometimes the individual will try to restrain their alien hand by holding it under or between their legs or sitting on it. Some people may find that it's helpful to hold an object in the alien hand to prevent it from performing tasks.

It may help the individual with Alien Hand Syndrome or another person to give verbal commands to stop the actions. However, this method may not provide long-lasting results. A doctor may recommend physical and occupational therapies.

First recorded in 1909, Alien Hand Syndrome usually affects the left or nondominant hand.

### **DEHYDRATION** - cont. from page 5

and even trigger a migraine headache. Since it's often not clear what is causing a headache, drinking a full glass of water and continuing to sip more fluids during the day is an easy way to ease your pain if, in fact, dehydration is contributing to it.

## How to Tell if You're Dehydrated

If you're thirsty, you're already dehydrated. But lack of thirst doesn't necessarily mean you're well hydrated. Here are two other ways to check whether your body is dehydrated:

Try this skin test. Use two fingers to pinch up some skin on the back of your hand, then let the skin go. The skin should spring back to its normal position in less than a couple of seconds. Higgins says that if the skin returns to normal more slowly, you might be dehydrated.

Check your urine. If you're well-hydrated, your urine will be mostly clear with a tinge of yellow (*the color of light lemonade before it hits the bowl*). Darker yellow or orange are the "warning" colors to watch for. If you see those colors, start drinking fluids.

## Tips for Staying Hydrated

When it comes to daily water intake, the Institute of Medicine recommends that most women get about 2.7 liters of water a day (or about 12 cups), and most men get about 3.7 liters a day (or about 15 cups). Those totals include water gained from foods and beverages like tea, milk, and fruit juice.

Here are some tips for getting all the fluids you need and avoiding dehydration:

*Keep your water bottle handy* – "If it's right next to you, you'll likely get into the habit of sipping it without even realizing it," says the nutrition expert and Everyday Health columnist Johannah Sakimura.

**Spice up plain water** - "If you don't love plain water, jazz it up by adding a splash of fruit juice or chunks of fresh or frozen fruit," says Sakimura. "Or try naturally flavored, calorie-free seltzers — their fizz and fruit flavor makes them more appealing than plain, flat water."

*Try different teas* – Sakimura recommends drinking unsweetened teas, which are available in lots of different flavors. "Sip fruity iced teas during the day (with lots of ice if it's hot out), or cozy up with a mug of hot peppermint or chamomile tea at night — they all count toward your daily fluid goal."

*Make over your snacks* – "Swap dry snacks like chips, pretzels, and crackers which have a very low water content—with refreshing munchies like fresh or frozen fruit, yogurt, healthy smoothies, celery with peanut butter, and cut veggies with hummus," recommends Sakimura. *Pile on the produce* – "Aim to make half your plate produce at meals. All

**Pile on the produce** – "Aim to make half your plate produce at meals. All those vegetable and fruit servings will supply water as well as a hearty dose of vitamins, minerals, and fiber," says Sakimura.

"In fact, some fruits and vegetables are more than 90 percent water, including cantaloupe, strawberries, watermelon (*of course*), cucumber, celery, lettuce and leafy greens, zucchini, tomatoes, and bell peppers," Sakimura says.

*Sip more during meals* – "Sipping water with meals will help you eat more slowly, pace your eating, and, of course, stay hydrated," Sakimura says.

**Dehydration in the elderly** – Elderly people may be at higher risk for dehydration for a number of reasons.

Some elderly people become chronically dehydrated if they take certain medications such as diuretics, have a diminished sense of thirst, are not able to get themselves a glass of water easily, or forget to drink because of dementia. Chronic dehydration in an elderly person may lead to confusion, low blood pressure, dizziness, and constipation.

If you have an elderly relative with mobility limitations or cognitive problems, be sure to monitor them for signs of dehydration or ask their caregivers to do so.



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.

For any mornation regarding any of these meetings, please contact the rice of other at or 7 776 4111.						
			1	2	3	4
5	6 PALM DESERT Caregiver Only 10:00 am PRO Office 74-090 El Paseo Suite 104	7	8	9	10	11
12	13	14	15	16	17	18
19	20 PALM DESERT Caregiver Only 10:00 am PRO Office 74-090 El Paseo Suite 104	21	22	23	24	25
26	27	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.



August 2018 / Issue No. 309 / 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 • web: 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.