

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

My September Birthday was simply wonderful and I thank each one of you that sent greetings and messages. I celebrated by taking a whirlwind trip to Boston where I participated in a Parkinson's Summit orchestrated by Sunovion, a pharmaceutical company with two Parkinson's drugs in their pipeline, one for off episodes and the other for psychosis. It was a very uplifting meeting and I met some very wonderful people. We hope to see some of them at our October 28th symposium.

"A GUIDED JOURNEY ON THE ROAD TO THE CURE" A Day And Night Devoted To Families Affected By Neurological Disorders symposium being held October 28th is percolating wonderfully. Check out our website and stay tuned to our social media for updates and breaking news. Also see page 6 for the invitation and pricing.

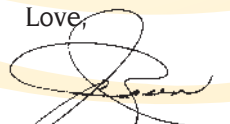
The **SUPPORT GROUPS** are now in full session in all locations. Included in this Newsletter are: **UPDATE ON THE ROAD TO THE CURE** on this page; **DEMENTIA CARE: A HUGE FINANCIAL BURDEN FOR U.S. FAMILIES** on page 2; an article reprinted from March 2011, **TREATMENT OFFERS HOPE**, on page 3; **CAREGIVING NEEDS DOUBLE AS END OF LIFE NEARS** on page 4; **PHARMACISTS ARE AN ESSENTIAL RESOURCE FOR PARKINSON'S DISEASE PATIENTS** on page 5; **INVITATION TO SYMPOSIUM** on page 6; and our **INSPIRATIONAL "PUPPIES FOR SALE"** on page 7.

Thank You all, who participated, 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. Keep giving, we continue to appreciate your monthly or general donations through our safe PayPal donation page online at [ParkinsonsResource.org/contribute-2/](https://www.ParkinsonsResource.org/contribute-2/) or by mail to our office in Palm Desert, California.

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 Linked-In at [Linkedin.com/in/jorosenpro/](https://www.linkedin.com/in/jorosenpro/) and now on Instagram at [Instagram.com/parkinsonsresourceorg/](https://www.instagram.com/parkinsonsresourceorg/) There's no reason not to stay in touch with us now. We would love to receive your social media handles so we can be more easily in touch with you as well.

Until next month, REMEMBER Columbus Day on the 9th, Bosses Day on the 16th, National Chocolate Day and **A Guided Journey On The Road To The Cure** on the 28th, and Halloween on the 31st. The flower is the Calendula, and the Birthstones are Opal and Tourmaline. ALWAYS remember to CELEBRATE YOU and PRAY FOR OUR TROOPS!

Love,



President & Founder

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

Ram Bhatt, PhD

Potential of Second Pharma Collaboration

SPOTLIGHT ON ICBI FROM BIG PHARMA! ICBI scientists met with another US pharmaceutical company in September. The meeting was followed by an enquiry from this pharmaceutical company on whether ICBI would be interested in discussing collaboration scenarios. Although our drugs are not yet ready for human use, several companies around the globe have shown a great deal of interest in learning more about ICBI's technology. Imagine what the pharmaceutical world's response will be when we actually have drugs that are ready for human use.

Due Diligence Documents Requested by European Pharma

INTEREST IN ICBI FINDINGS! Our September conference call with a European pharmaceutical company also triggered a request by the company to create an online data room where all due diligence scientific and business documents can be loaded.

ICBI Expresses Sincere Thanks to Jo Rosen

SUPPORT JO ROSEN AND THE PARKINSON'S COMMUNITY – JOIN US! We wholeheartedly thank Jo Rosen's unrelenting efforts to help ICBI develop disease altering therapy for Parkinson's disease. Giving ICBI an opportunity to present its technology at the October Symposium is one of Jo's ways to gather support for ICBI's Parkinson's programs so that the science developed so far can be expeditiously taken from the lab bench to the patients. Jo is indeed a dedicated champion to fight the battle against the debilitation of Parkinson's disease.

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

JUST IMAGINE.

Make your reservations and join us at the Parkinson's Resource Organization's symposium, **"A GUIDED JOURNEY ON THE ROAD TO THE CURE"**: A Day and Night Devoted to People Affected By Neurological Diseases, October 28th in Rancho Mirage, California.

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DEMENTIA CARE: A HUGE FINANCIAL BURDEN FOR U.S. FAMILIES

Annual costs may top \$320,000, study estimates

Alan Mozes

TUESDAY, Aug. 22, 2017 (HealthDay News) — Caring for a family member with a neurological disorder such as dementia is vastly more expensive than caring for a senior who is dementia-free, a new study finds.

The average yearly cost of caring for a dementia-free senior is roughly \$137,000. But the price tag rises to \$321,000 for care of those struggling with dementia.

And about 70 percent of that yearly cost ultimately falls on the shoulders of the family members rather than insurance, the researchers said. The rest of the cost typically splits evenly between Medicare and Medicaid.

"A lot of people, I think, believe that Medicare will pay for their long-term care," said lead author Eric Jutkowitz, an assistant professor at Brown University's School of Public Health.

"That's not the case. Private long-term care insurance may help, but benefits can be exhausted and few families have policies. For a disease like dementia, the burden and cost falls on the individual and the family," he explained in a school news release.

About 5 million Americans currently have Alzheimer's or another form of dementia, the researchers said. *cont. on page 7*

TREATMENT OFFERS HOPE

Risto E. Hurme, DDS - San Antonio, TX

Could Parkinson's disease be an advanced stage of TMD (Temporomandibular Disorder)? Last month's "ULTIMATE QUALITY OF LIFE SYMPOSIUM" in Indian Wells, California, addressed that question. It was an amazing conference, bringing together members of the medical and dental professions, and patients, to share information that perhaps these two disorders are related. My hope is that the symposium will spur on more research, and whet the appetites of patients to learn more. The symposium covered the Parkinson's/TMD connection extremely well, and all of the speakers were excellent! Dr. Brendan Stack presented case histories of patients with movement disorders whose symptoms greatly improved after treatment for TMD. I strongly suggest that anyone interested should buy the DVD set and study these lectures.

The questions I didn't hear, however, were "Why is our 'Quality of Life' deteriorating?" and "What causes Parkinson's Disease?" That subject is addressed in the books below, which are classics, written by doctors, geniuses all, who were way ahead of their time. Maybe the public is ready for them now. They may have been written quite a while ago, but they are favorites of mine and still relevant today and excellent sources of information:

Nutrition and Physical Degeneration, 1939 by Dr. Weston A. Price;

The Dental Physician, 1977, by Aelred C. Fonder, D.D.S.;

Killing Pain Without Prescription, 1980, by Harold Gelb, DMD.

For his book, **Nutrition and Physical Degeneration**, Dr. Weston A. Price spent nine years traveling 150,000 miles, studying isolated/primitive peoples and their diets, then documented their deterioration after adopting our modern diet. What he originally found were healthy, well-built people with no health problems, as long as natural laws were followed, anywhere in the world. Dr. Price found no one with degenerative diseases like TMD or Parkinson's, or cancer, or even muscle tightness in the neck and shoulders. They had all 32 teeth, and their teeth were straight. They had wide orthodontic arches, wide noses, and no cavities. Their condition changed rapidly, in just one generation, after trading posts introduced them to white flour, sugar, and processed foods. Children were born with severe malocclusions and cranial distortions, and ill health followed.

Offering a modern update on Dr. Price's important work, Dr. Dwight Jennings brought up these facts in his presentation:

1. *Our brains are getting smaller due to vertical growth patterns, resulting in long and narrow faces. The native peoples had horizontal growth and wide faces.*
2. *Our upper jaws have moved back over the last 100,000 years by approximately 1 centimeter, deteriorating our airway.*
3. *Our mouths are getting smaller and more over-closed, thus not providing adequate space for our tongues, compromising our airways and exacerbating neck and shoulder tightness and tension.*

The above changes are very detrimental to our airway, also the skeleton is negatively affected, and the pelvis narrows, resulting in more cranial distortions through birth trauma.

In his book, **The Dental Physician**, Dr. A.C. Fonder described the effects of malocclusion, what he referred to as 'the bad bite', as it relates to general health. He called it "The Dental Distress Syndrome" and showed how it affected the entire body and all its systems. With occlusal (*relating to the biting surface of a molar or premolar tooth*) correction, he could eliminate 80%–100% of all symptoms of Parkinson's, epilepsy, CNS problems, headache, sinusitis/respiratory problems, bad posture, GI and gynecological problems. His results were presented at several international congresses—over thirty years ago.

The last of these geniuses, and the only one still living, lecturing, and

cont. on page 7

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CAREGIVING NEEDS DOUBLE AS END OF LIFE NEARS

Most rely on family members to provide that support, researchers say

TUESDAY, Aug. 22, 2017 (HealthDay News) -- Reliance on caregivers doubles as people near death, and half of those caregivers -- typically unpaid family members -- report having no time for themselves, a new study indicates.

The research used a nationally representative sample of about 2,400 older adults in the United States. The study authors found that caregivers provided nearly twice the number of hours of help each week to dying individuals than to those not at the end of life.

"We were certainly aware when dealing with end-of-life care that families are mostly involved, but we couldn't quantify that prior to this [research]," said study author Dr. Katherine Ornstein. She's an assistant professor of geriatrics and palliative medicine at the Icahn School of Medicine at Mount Sinai in New York City.

More than 34 million Americans provided unpaid care to an adult aged 50 or older in the past 12 months, according to 2015 figures from the National Alliance for Caregiving and AARP. Most caregivers are female.

Ornstein and her team drew from two nationally representative surveys in which caregivers in the United States reported their experiences caring for dying adults over age 65. The researchers contrasted this data with that of other caregivers providing ongoing care.

Older adults were classified as being at the end of life if they died within 12 months of the surveys' completion.

The study found that dying adults had an average of 2.5 caregivers assisting them. Those near the end of life received 61 hours of help per week compared to 35 hours of help per week for older adults who weren't at the end of life.

More than one-third of the end-of-life caregivers reported physical difficulty related to their duties. Just over half reported having no time for themselves. These figures were 21 percent and 40 percent, respectively, for other caregivers.

Nearly nine in 10 caregivers are unpaid, according to the study. For end-of-life caregivers who were spouses, nearly two-thirds reported receiving no help from family or friends.

"What we see now is, on average, there are 2.5 people helping someone at the end of life. You can imagine if they don't have that, it's much more difficult," Ornstein said. "When spouses are serving as caregivers, the majority are reporting doing it alone and have the [most challenging] consequences."

Barbara Coombs Lee is president of Compassion & Choices, a Washington, D.C.-based advocacy organization for patients' rights and end-of-life issues. She pointed out that the caregivers surveyed in the new study didn't necessarily know ahead of time that the person they were caring for was at the end of life.

This lack of awareness may have increased caregivers' stress levels, she said.

"This told me the caregivers were probably struggling, not knowing this was an end-of-life situation. Our [organization's] research indicates that uncertainty about decision-making is an inherent and extremely powerful source of stress," Lee said.

"I would guess that many of these people didn't know they were dying ... so they pursued heroic, torturous, futile treatment," she added. "Often the default decision [to continue treatment] increases the caregiver burden."

Ornstein said she hopes greater awareness of the family burden of caregiving, especially at the end of life, comes from her research.

"We need to think about expanding access to palliative care services, which can help facilitate the delivery of supportive services to families earlier," she added. "And we can see how we need to provide more paid family leave so families can provide the support we're pretty much expecting them to provide."

cont. on page 7

PHARMACISTS ARE AN ESSENTIAL RESOURCE FOR PARKINSON'S DISEASE PATIENTS

The Pharmaceutical Journal 28 Sep 2017

Pharmacists are well placed to manage the complex medication regimens of patients with Parkinson's disease by not only addressing a raft of motor and non-motor symptoms but also managing other co-morbidities, such as diabetes or hypertension.

Two centuries have passed since the term 'Parkinson's disease' (PD) was first coined; however, we do not yet have any treatments that can cure, slow, stop or reverse progression of the condition, and scientists are still unsure as to why people get PD in the first place.

As a result, managing the symptoms of PD is a crucial element of the care that healthcare professionals can provide to these patients, and this often involves medicines.

Levodopa — a drug discovered in the 1970s that compensates for the loss of dopamine-producing neurons — remains the most successful drug to be developed for the condition despite the fact that it becomes less effective over time.

However, each patient's experience of PD is different, so they may need to try a number of different drugs, doses and therapies to find out which works best for them. This is where pharmacists can make a real difference.

Undoubtedly, pharmacists are well placed to manage the complex medication regimens of PD patients by not only addressing a raft of motor and non-motor symptoms but also managing other co-morbidities, such as diabetes or hypertension.

In a letter to *Clinical Pharmacist*, Stephanie Bancroft from the London North West Local Practice Forum described the outcome of a PD-specific medicines use review pilot across eight pharmacies in the area[1]. Patients were said to welcome the opportunity to provide feedback and be able to talk to a pharmacist about their concerns and problems, in particular regarding problems with non-motor symptoms and a lack of understanding around their medicines and how they work.

Managing the symptoms of PD while limiting the incidence of unpleasant side effects presents a challenge to healthcare professionals. In its guidance for pharmacists, Parkinson's UK emphasizes that if not enough attention is paid to Parkinson's medication, symptoms can become poorly controlled and the patient's condition can, very quickly, deteriorate.

The importance of medicines management in PD means that pharmacists are an essential resource that should not be undervalued.

Pharmacists in community and hospital settings can support patients to adhere to their prescribed medicines, help them to understand possible side effects, make sure other medicines do not exacerbate PD, support people with hospital admissions and, most importantly, help people take control of their condition, particularly if they have been in hospital.

In July 2017, the National Institute for Health and Care Excellence (NICE) released new guidance on PD, the first update since 2006. One key change was to recommend the use of levodopa as a first-line treatment for patients whose motor symptoms start to interfere with their quality of life.

All pharmacists should find out more about PD and equip themselves as best as possible to support patients with this condition while scientists inch closer to a cure.

References: [1]Stephanie Bancroft. Parkinson's disease-specific medicines use review. *Clinical Pharmacist* 2017;9(1):11

Citation: *The Pharmaceutical Journal*, Vol 299, 7905, online | DOI: 10.1211/PJ.2017.20203618

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The Journey Begins...

FRIDAY, OCTOBER 27

VIP Reception
7:00 pm – 9:00 pm

Meet the Speakers

SATURDAY, OCTOBER 28

Dress comfortably. Bring a jacket or sweater.

Program

- 7:30 am – 8:30 am** Registration & Continental Breakfast
- 8:30 am – 4:30 pm** Lectures, Boxed Lunch & Exercise
- 6:00 pm – 9:00 pm** Dinner & Entertainment

EXHIBITS

Educational, informational and commercial exhibits will be available for viewing and inquiries before, during and after the symposium. Questions: All day Saturday from 7:30 am – 6:00 pm.

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- * Life at the End of Life
- * On The Road to the Cure – The Science That Is Here

Inspirational Corner

PUPPIES FOR SALE (Understanding)

A shop owner placed a sign above his door that said: "Puppies For Sale."

Signs like this always have a way of attracting young children, and to no surprise, a boy saw the sign and approached the owner; "How much are you going to sell the puppies for?" he asked.

The store owner replied, "Anywhere from \$30 to \$50."

The little boy pulled out some change from his pocket. "I have \$2.37," he said. "Can I please look at them?"

The shop owner smiled and whistled. Out of the kennel came Lady, who ran down the aisle of his shop followed by five teeny, tiny balls of fur. One puppy was lagging considerably behind. Immediately the little boy singled out the lagging, limping puppy and said, "What's wrong with that little dog?"

The shop owner explained that the veterinarian had examined the little puppy and had discovered it didn't have a hip socket. It would always limp. It would always be lame.

The little boy became excited. "That is the puppy that I want to buy."

The shop owner said, "No, you don't want to buy that little dog. If you really want him, I'll just give him to you."

The little boy got quite upset. He looked straight into the store owner's eyes, pointing his finger, and said; "I don't want you to give him to me. That little dog is worth every bit as much as all the other dogs and I'll pay full price. In fact, I'll give you \$2.37 now, and 50 cents a month until I have him paid for."

The shop owner countered, "You really don't want to buy this little dog. He is never going to be able to run and jump and play with you like the other puppies."

To his surprise, the little boy reached down and rolled up his pant leg to reveal a badly twisted, crippled left leg supported by a big metal brace. He looked up at the shop owner and softly replied, "Well, I don't run so well myself, and the little puppy will need someone who understands!"

DEMENTIA – cont. from page 2

That number is expected to grow considerably because more than 61 million baby boomers will be 65 or older by 2029.

The current finding stems from a computer analysis that modeled expenses incurred caring for about 16,000 hypothetical seniors. Data was drawn from Medicare records as well as national studies. The average age of dementia used in the model was 83.

The study was published Aug. 22 in the Journal of the American Geriatrics Society. SOURCE: Brown University, news release, Aug. 17, 2017 HealthDay Copyright (c) 2017 HealthDay. All rights reserved.

TREATMENT – cont. from page 3

treating patients for over 50 years, is Dr. Harold Gelb. His phrase, "If your jaw joint is off, you can kiss your body goodbye!" is well known, for good reason. In his book, **Killing Pain Without Prescription**, he clearly explains step by step what happens to people with misaligned jaws. He states that birth trauma is the #1 cause of malocclusion and the resulting TMD. "You can see it in their faces!" One eye is higher than the other, one eye is smaller, there is a higher ear, higher shoulder, higher pelvis on the same side of the body. Dr. Gelb is also the author of two textbooks, **Head, Neck and TMJ Pain and Dysfunction**, 1977 and **New Concepts in Craniomandibular and Chronic Pain Management**, 1994. All the above-mentioned books should be required reading for anyone in the healthcare field!

If your car was in an accident and its frame was bent, wouldn't you straighten out that frame? If there were a flood that eroded part of your home's foundation, wouldn't you have that fixed to support the structure? If your child was born with severe cranial distortions resulting in severe malocclusion (*due to our modern diet and lifestyle—a poor foundation!*), wouldn't you want to correct your child's foundation?

Both TMD and Parkinson's disease are treatable to a certain degree. Prevention is preferable for both and that starts even before birth with the parents' health! For more information, see **PPNF.org** and **Westonaprice.org**. Thanks to Jo Rosen for organizing this wonderful conference, and helping to bring this information to more people.

If you think you have TMJ reach out to anyone listed in the Wellness Village at ParkinsonsResource.org/tmj-dentist/ and call for an evaluation.

CAREGIVING DOUBLES – cont. from page 4

Lee agreed with the need for expanded access to hospice and palliative care.

"One of the big barriers to access to hospice is [an] information gap," Lee said. "People don't understand that hospice is appropriate to them in their journey in their illness. Palliative care utilization would go up if people had more candid conversations and were privy to information that physicians have but aren't sharing."

The study was published recently in the journal *Health Affairs*.

SOURCES: Katherine Ornstein, Ph.D., M.P.H., assistant professor, geriatrics and palliative medicine, Icahn School of Medicine at Mount Sinai, New York City; Barbara Coombs Lee, president, Compassion & Choices, Washington, D.C.; July 2017, *Health Affairs*
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PRO CALENDAR FOR OCTOBER 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 PALM DESERT Caregivers Only 10:00 am PRO Office 74-090 El Paseo Suite 104 | 3 | 4 LONG BEACH NEW LOCATION 6:30 pm Cambrian Homecare "Training Center" 5199 Pacific Coast Hwy | 5 | 6 | 7 |
| 8 | 9 PALM DESERT Round Table for Everyone 6:30 pm Atria Hacienda 44-600 Monterey Ave | 10 | 11 GLENORA Emotional & Educational Speaker 6:30 pm Kindred Rehab at Foothill 401 W Ada Ave | 12 NEWPORT BEACH Caregiver Only 6:30 pm Oasis Senior Center 801 Narcissus Corona Del Mar | 13 | 14 |
| 15 | 16 PALM DESERT Caregivers Only 10:00 am PRO Office 74-090 El Paseo Suite 104 | 17 | 18 ENCINO Emotional & Educational Speaker 7:00 pm Providence Tarzana Outpatient Therapy Cntr 5359 Balboa Blvd | 19 WEST LA Emotional & Educational Speaker for Everyone 6:30 pm NEW LOCATION 2730 Wilshire Blvd, #533 Santa Monica | 20 | 21 |
| 22 | 23 PALM DESERT Emotional & Educational Speaker for Everyone 6:30 pm Atria Hacienda 44-600 Monterey Ave | 24 MANHATTAN BEACH Emotional & Educational Speaker for Everyone 6:30 pm 659 15th Street | 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.

"OUR GREATEST WEAKNESS LIES IN GIVING UP.
THE MOST CERTAIN WAY TO SUCCEED IS ALWAYS
TO TRY JUST ONE MORE TIME."

— THOMAS A. EDISON

NEWSWORTHY NOTES

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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

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