

PARKINSON'S RESOURCE ORGANIZATION

Working so no one is isolated because of Parkinson's

MESSAGE

PRESIDENT'S

Happy Valentine's Day and month. Love abounds at this time of year. Savor the precious moments of each day.

This is such an exciting time with such a tremendous amount of activity going on. In the Parkinson's world I find it extremely exciting because after 22 years of eating, breathing, sleeping and living Parkinson's through my mother, my husband, my friends and PRO I actually believe that the end is near. With that said, we present the sequel to last month's front page article **REVERSING PARKINSON'S? Treating Neurodegenerative Parkinson's Disease**; and I might add, this may be the "patient driven" answer we've been looking for.

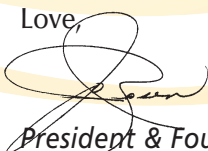
We discuss **TEN TIPS FOR COMMUNICATING WITH A PERSON WITH DEMENTIA** on page 3. You may find this interesting; **HOMICIDE NO LONGER #1 CAUSE OF DEATH**, on page 4; and then **WELLNESS TIPS FOR PARKINSON'S** is on page 5; while on page 6 you can find a **SPECIAL VALENTINE DESSERT** by Diane Tompkins, one of our Glendora group members. We know this cake is good; we had it at the last meeting.

On behalf of everyone who benefits from our efforts, thank you, ALL OF YOU, who made donations during 2011 and the beginning of 2012. We urge you to continue. You may make them on line through our secure website, ParkinsonsResource.org/contribute.

Check the website often because we are continually adding articles and valuable information such as the **Five Stages** of Parkinson's which you'll currently find on the HOME page.

Until next month, REMEMBER Groundhog Day on the 2nd, Super Bowl Sunday on the 5th, Abe Lincoln's Birthday on the 12th*, Valentine's Day on the 14th, and George Washington's Birthday on the 22nd*. Remember to CELEBRATE YOU and PRAY FOR OUR TROOPS!

Love,



President & Founder

*celebrated on the 20th

REVERSING PARKINSON'S?

TREATING NEURODEGENERATIVE PARKINSON'S DISEASE

Last month's article, entitled **PARKINSON'S DISEASE: A COLLABORATIVE**, focused on identifying the key issues, which have been in the way of developing curative treatment for neurodegenerative diseases. The main issues were: 1) Limited understanding of the disease etiology; 2) The inability of most drugs to go across the blood-brain barrier (BBB) into the central nervous system (CNS). Continued efforts to understand etiology have lead to the identification and characterization of the key pathogenic proteins involved in causing PD. Although more research is needed to fully understand the PD etiology, most neuroscientists believe that therapeutic intervention to regulate the function of some of the already identified pathogenic proteins will alleviate, halt, and/or reverse the disease process. This article focuses on the types of therapeutic molecules that can be used for treating PD, keeping in mind the key requisite that such therapeutic drug has to be able to cross the BBB.

Pharmaceuticals can be classified into two types of molecules: small molecules and macromolecules. Most small molecules such as Aspirin, Motrin, and Levodopa are BBB permeable. For decades the process of drug discovery has been centered on designing, developing and selecting small molecules with activity at a particular site or receptor in the brain with scant regard for non-specific targeting and organ distribution, which lead to undesirable side effects. In addition, small molecule drugs have low therapeutic indices and develop drug resistance shortly after initial treatment. A handful of FDA approved small molecule drugs that slow down the disease symptoms in some patients stop working after some period, leaving the patient helpless. Daily we see our friends and relatives inflicted by PD frequently changing medications, trying to adjust dose and consulting different physicians in search of a better drug, which so far, sadly, does not exist. Thus, in spite of remarkable BBB permeability, the small molecule based drugs have been plagued with lack of specificity, development of drug resistance, low therapeutic indices and frequent administration, in addition, being inept to cure the disease.

Macromolecules are large molecule modern drugs such as engineered proteins (eg: nerve growth factors), antibodies, genes, vectors, micro-RNA, Si-RNA, and ribozymes, which are otherwise effective in ex-vivo studies, have been discarded during their development for clinical use due to a failure to deliver them in sufficient quantity to the CNS. Antibodies are molecules of unsurpassed specificity but conventional antibodies do not cross the BBB. Similarly, micro-RNA, Si-RNA, and ribozymes are highly specific molecules but cannot cross the BBB. Although neurodegenerative diseases



ALL MEETINGS BEGIN AT 7:00 PM. EXCEPT AS NOTED.

The current support group meeting locations are listed below. Contact the PRO Office.

PRO CALENDAR FOR FEBRUARY 2012

~ **Long Beach • Educational** • Meets Feb 1 ~ 1st Wednesday of the month ~ at Bixby Knolls Towers, 3737 Atlantic Avenue, Long Beach.

~ **West Los Angeles/Brentwood • Caregiver only/ Person with Parkinson's only (two in one)** Meets Feb 2nd ~ 1st Thursday of the month ~ at OPICA Adult Day Care Center, 11759 Missouri Avenue, West Los Angeles.

~ **Glendora • Caregiver Only • (meetings alternate)** Meets Feb 8th ~ 2nd Wednesday of the month ~ at Foothill Nursing Center, 401 W. Ada Avenue, Glendora.

~ **Newport Beach • Educational • (meetings alternate)** Meets Feb 9th ~ **Oasis Senior Center** • 2nd Thursday of month ~ at 801 Narcissus, Corona Del Mar.

~ **Manhattan Beach • Caregiver Only** • Meets Feb 9th ~ 2nd Thursday of the month ~ at the Keller Williams offices, 1601 Pacific Coast Highway, Suite 265, Hermosa Beach.

~ **Palm Desert • Open Meeting, Emotional Support** • Meets Feb 13th ~ 2nd Monday of the month 6:30 PM ~ at Portola Community Center, 45-480 Portola Avenue, Palm Desert

~ **Encino • Caregiver Only** • Meets Feb 15th ~ 3rd Wednesday of the month ~ at the Providence Tarzana Outpatient Therapy Center, 5359 Balboa Blvd, Encino.

~ **West Los Angeles/Brentwood • Educational Only** • Meets Feb 16th ~ 3rd Thursday of the month ~ at OPICA Adult Day Care Center, 11759 Missouri Avenue, West Los Angeles

~ **Palm Desert • Educational Only** • Meets Feb 27th ~ 4th Monday of the month 6:30 PM ~ at Portola Community Center, 45-480 Portola Avenue, Palm Desert

~ **Manhattan Beach • Educational Only** • Meets Feb 28th ~ 4th Tuesday of the month ~ at the Keller Williams offices, 1601 Pacific Coast Highway, Suite 265, Hermosa Beach

CAREGIVER MEETINGS (For Caregivers Only. No PWP's please) – Come share the ups and downs of living with Parkinson's. Together there are ways of finding solutions that, when alone, you might never consider. No need to continue with your frustrations because you are not alone. Give yourself a break. This is a confidential forum for sharing and caring.

EDUCATIONAL MEETING – We invite the community, especially the Person with Parkinson's and their family or friends, to attend. Please call contacts listed in each meeting description to make reservations so the coordinator knows how to set up the room. It's the proper and respectful thing to do.

PARKINSON'S MEETINGS "For People with Parkinson's only" – These meetings are for People with Parkinson's or Parkinsonisms ONLY. Come share the ups and downs of living 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. This is a fabulous forum for sharing and caring.



- To show you care about someone with *Parkinson's disease or any other brain disease or disability.*
- To help break the barriers to treatment and support.
- To help eliminate the stigma against those who suffer.
- To show you believe there's hope through education & research.



If you would like to make a donation, please make checks payable to Parkinson's Resource Organization or via the website, ParkinsonsResource.org

Toll Free: 877-775-4111

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TEN TIPS FOR COMMUNICATING WITH A PERSON WITH DEMENTIA

We were not born knowing how to communicate with a person with dementia; however, we can learn. Improving communication skills will help make caregiving less stressful and will likely improve the quality of your relationship with your loved one. It may help to remember that your loved one is ill and therefore cannot help his or her actions and reactions. Yet good communication skills will also enhance your ability to handle the difficult behaviors you may encounter as you care for a person with a dementing illness.

- 1. Before interacting, set a positive mood.** Your attitude and body language communicate your feelings and thoughts stronger than your words. Set a positive mood by speaking to your loved one in a pleasant and respectful manner. Use facial expressions, tone of voice and physical touch to help convey your message and show your feelings of affection.
- 2. Get the person's attention.** Limit distractions and noise—turn off the radio or TV, close the curtains or shut the door, or move to quieter surroundings. Before speaking, make sure you have his/her attention; address him/her by name, identify yourself by name and relation, and use nonverbal cues and touch to help keep him/her focused. If s/he is seated, get down to his/her level and maintain eye contact.
- 3. Clearly state your message.** Use simple words and sentences. Speak slowly, distinctly and in a reassuring tone. Refrain from raising your voice higher or louder; instead, pitch your voice lower. If s/he doesn't understand the first time, use the same wording to repeat your message or question. If s/he still doesn't understand, wait a few minutes and rephrase the question. Use the names of people and places instead of pronouns or abbreviations.
- 4. Ask simple, answerable questions.** Ask one question at a time; those with yes or no answers work best. Refrain from asking open-ended questions or giving too many choices. For example, ask, "Would you like to wear your white shirt or your blue shirt?" Better still, show him/her the choices—visual prompts and cues also help clarify your question and can guide his/her response.
- 5. Listen with your ears, eyes and heart.** Be patient in waiting for your loved one's reply. If s/he is struggling for an answer, it's okay to suggest words. Watch for nonverbal cues and body language, and respond appropriately. *Always strive to listen for the meaning and feelings that underlie the words.*
- 6. Break down activities into a series of steps.** This makes many tasks much more manageable. You can encourage your loved one to do what s/he can, gently remind him/her of steps s/he tends to forget, and assist with steps s/he's no longer able to accomplish on his/her own. Using visual cues, such as showing him/her with your hand where to place the dinner plate, can be very helpful.
- 7. When the going gets tough, distract and redirect.** When your loved one becomes upset, try changing the subject or the environment. For example, ask him/her for help or suggest going for a walk. *It is important to connect with the person on a feeling level, before you redirect.* You might say, "I see you're feeling sad—I'm sorry you're upset. Let's go get something to eat."
- 8. Respond with affection and reassurance.** People with dementia often feel confused, anxious and unsure of themselves. Further, they often get reality confused and may recall things that never really occurred. *Avoid trying to convince them they are wrong.* Stay focused on the feelings they are demonstrating (which are real) and respond with verbal and physical expressions of comfort, support and reassurance. Sometimes holding hands, touching, hugging and praise will get the person to respond when all else fails.

cont. on page 7

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INTEGRATED WEALTH MANAGEMENT

HOMICIDE NO LONGER #1 CAUSE OF DEATH

By Shari Roan, Los Angeles Times / For the Booster Shots blog January 11, 2012

Homicide was not one of the nation's top 15 causes of death in 2010, according to new government statistics. That's the first time since 1965 that homicide has not ranked as a major killer of American citizens.

The top 15 list, released Wednesday by the Centers for Disease Control and Prevention, analyzes data from death certificates. The report is preliminary; a more detailed analysis will be released later.

The death rate fell the most from 2009 to 2010 for non-Latino black males with a nearly 2% decline in deaths. The death rate for non-Latino black females decreased 1.5%.

The preliminary homicide rate for 2010 was 5.2 deaths per 100,000 people.

Overall, life expectancy inched upward, from 78.6 in 2009 to 78.7 in 2010. Heart disease and cancer still account for about half of all deaths. HIV death rates fell 13.3% from 2009 to 2010. But the disease "remains a public health concern, especially for those between the ages of 15-64," the authors wrote.

THE LEADING CAUSES OF DEATH ARE:

Heart disease

Cancer

Lower respiratory diseases

Stroke and related cerebrovascular diseases

Accidents (unintentional injuries)

Alzheimer's disease

Diabetes

Kidney diseases

Influenza and pneumonia

Suicide

Septicemia

Chronic liver disease and cirrhosis

Hypertension and related renal disease

Parkinson's disease

Pneumonitis due to solids and liquids

Number 15 on the list—pneumonitis—refers to inflammation of the lungs caused by medications or other exposures, such as breathing something harmful over time. Death rates increased in 2010 for five conditions: Alzheimer's, kidney disease, chronic liver disease and cirrhosis, Parkinson's and pneumonitis.

The infant mortality dropped 3.9% from 2009 to 2010.

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please make checks payable to:*

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WELLNESS TIPS FOR PARKINSON'S

If you've been diagnosed with Parkinson's, you can help keep yourself in safe and healthy ways by taking certain precautions.

- ⊙ Physical therapy is almost always beneficial.
- ⊙ Group wellness programs, group exercise, yoga, tai-chi, and support groups which include the involvement with others can help with the isolation and depression some people with Parkinson's feel.
- ⊙ Exercise can ease symptoms. Research shows that patients with Parkinson's disease who exercise regularly do better than those who don't. Any degree of exercise helps!

Exercise tips:

- ⊙ Check with your doctor before starting an exercise regime.
- ⊙ Practice physical and occupational therapies from certified therapists.
- ⊙ Exercise your face, jaw and eyes whenever possible.
- ⊙ Perform bending, stretching, and breathing exercises often and regularly.
- ⊙ Exercising in bed may be easier than on the floor.
- ⊙ Even if that means having to hold onto something, build your walking skills.
- ⊙ Exercising in the water is easier on the joints. Many fitness centers, hospitals, colleges, and YMCAs or YWCAs have water exercise programs.

Safety tips:

- ⊙ Ask your doctor for a prescription/referral for a home safety evaluation by an occupational therapist.
- ⊙ Install grab bars in the tub and shower.
- ⊙ Use a bath chair or stool in the shower.
- ⊙ Keep floors smooth but not slippery.
- ⊙ Stockpile supplies in easy to reach cabinets.
- ⊙ Make sure stairwells are lit.
- ⊙ Get nightlights for bathrooms and hallways.
- ⊙ Keep walking areas free of clutter.
- ⊙ Wear low heeled, comfortable shoes. Avoid walking in slippery socks and slippers.
- ⊙ Make sure carpets are fully tacked to the ground, and avoid throw rugs.

Diet and eating tips:

- ⊙ To avoid choking and encourage digestion cut foods into smaller portions.
- ⊙ Remain upright for 30 minutes after eating.
- ⊙ For upset stomachs linked to medication, try eating a small amount of non-protein based food before taking medication.
- ⊙ If protein blocks your body's ability to absorb levodopa (Sinemet), you may need to avoid taking this medication within 30 minutes before to 1 hour after eating meat or other high-protein foods.

Parkinson's and dementia

Dementia is a less common feature of Parkinson's disease. Approximately 20% of people with Parkinson's disease will develop Parkinson's disease Dementia (PDD). A person with Parkinson's who experiences hallucinations and more severe motor control problems are at risk for dementia. For those people with Parkinson's who go on to develop dementia, there is usually at least a 10 to 15 year lag time between their diagnosis and the onset of dementia.

Signs of dementia would include:

- ⊙ memory problems
- ⊙ distractibility
- ⊙ slowed thinking

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Special Valentine Dessert

By Diane Tompkins

Ingredients:

- 1 box of Pillsbury Strawberry Moist Supreme Premium Cake Mix
- 1 ¼ C water
- 1/3 C vegetable oil
- 4 egg whites

Frosting:

- 1-8 oz. pkg. Philadelphia Cream Cheese
- 1-3/4oz. pkg. Jell-O Sugar Free Instant Cheesecake flavor pudding mix
- 1-envelope (1.3 oz.) Dream Whip
- 2/3 C low fat milk
- 1-pkg. frozen raspberries thawed or, use fresh raspberries

Procedure:

1. Prepare 13 x 9 pan by lightly coating the bottom of the pan with Crisco (or cooking spray) Then dust lightly with flour.
2. Blend the cake mix, water, oil and egg whites in a large mixing bowl, until moistened. Beat with mixer on medium speed for 2 minutes or whisk by hand for 2 minutes. Pour mixture into prepared pan.
3. Bake at 350 degrees for 32 to 36 minutes. The cake is done when a toothpick inserted in the center comes out clean. Place pan on rack and cool completely.

Frosting:

1. Rinse and drain the raspberries. Blot dry with a paper towel. Set aside.
2. Soften the cream cheese by setting it out of the fridge earlier, or by using 1/2 power in the microwave oven. Just soften it! Don't cook it! Mix with an electric mixer, until the cheese is smooth.
3. In a separate bowl, mix the Dream Whip with 2/3 cup milk, until the mixture is thick and stands in peaks.
4. Slowly, spoon the cream cheese into the Dream Whip, mixing well.
5. Next, spoon in the powdered pudding mix. Mix until well blended and thick.
6. Spread this frosting onto the cooled cake. Spread VERY slowly and carefully, doing a small area at a time.
7. Scatter the raspberries on top of the frosting.

At the end of the occasion, refrigerate any remaining cake.

Enjoy!

WELLNESS TIPS – cont. from page 5

- ⊙ disorientation
- ⊙ confusion
- ⊙ moodiness
- ⊙ lack of motivation
- ⊙ hallucinations

Parkinson's disease Dementia (PDD) is different from a similar disorder, known as Dementia with Lewy Bodies (DLB). DLB is characterized by fluctuations in alertness and attention, recurrent visual hallucinations, and Parkinsonian motor symptoms like rigidity and the loss of spontaneous movement. In this disorder, the cognitive problems, such as hallucinations, tend to occur much earlier in the course of the disease and often precede the difficulties with walking and motor control.

Is the dementia caused by Parkinson's disease or something else?

Indications that dementia may be caused by something other than Parkinson's include agitation, delusions (strongly held false beliefs), language difficulties, and early onset of memory symptoms. If these factors are present, your physician can test for other possible causes of dementia, such as a Vitamin B-12 deficiency or an underactive thyroid gland. Depression is also common in people with Parkinson's and can mimic dementia by causing similar symptoms.

Additionally, Alzheimer's and Parkinson's are both common in the elderly, especially in those over 85. Therefore, people with Parkinson's who develop dementia may develop Alzheimer's dementia as well. If a person with established Parkinson's develops signs of Alzheimer's dementia, he or she will probably benefit from medications for Alzheimer's dementia as well. The similarities in symptoms between Parkinson's, Diffuse Lewy Body, and Alzheimer's disease, can make it difficult to determine the cause of the symptoms. Therefore, obtaining a thorough consultation with a neurologist is recommended to make a definitive diagnosis and establish an appropriate plan of care.

There are other, much less common disorders with features similar to Parkinson's with dementia such as Multiple System Atrophy (MSA), Normal Pressure Hydrocephalus (NPH), Corticobasal degeneration (CBD) and Progressive Supranuclear Palsy (PSP) to name a few. If people do not respond to treatments for Parkinson's disease or if they have unusual features, referral to a neurologist who specializes in Movement Disorders is often helpful.

The bottom line

Parkinson's is a disorder of muscle and movement control that should be quite manageable and controllable for a lengthy period of time. About 20% of patients develop dementia, including loss of memory and other cognitive functions. If patients with Parkinson's develop behavioral or memory problems; a physician can help determine the cause of the problems and develop a treatment plan.

REVERSING PARKINSON'S – cont. from page 1

have been known for many decades and despite enormous research efforts both by private sectors and government institutes, there are no diagnostics and curative treatments for Alzheimer's and Parkinson's diseases. With more than 50 million people afflicted worldwide by neurodegenerative diseases, this epidemic summons an immediate response from local, national and international communities to develop early diagnosis and treatment. With aging population living longer, the number of people suffering from neurodegenerative diseases will continue to escalate unless highly specific curative drugs (minimally toxic) are developed today. Disease curative drug is the one that, in addition to treating the symptoms, modifies the disease by halting its progression.

Realizing the urgent medical need, a small La Jolla based Biotech Company, has taken upon it the challenge of developing diagnostics and therapeutics for the world's most debilitating neurodegenerative Alzheimer's and Parkinson's diseases. Funded by a grant from the US Government, this company first focused upon tackling one of the biggest challenges of medicine, which was to overcome the hurdles of BBB impermeability. After two years extensive research efforts, the company's scientists developed a proprietary technology which breached the hitherto impermeable BBB in a mouse model. The validation of its technology was done by a world renowned UCSD neuroscientist. To demonstrate BBB permeability, the scientists developed an Alzheimer's disease specific pharmaceutical macromolecule, which when injected in the tail vein of a mouse traveled across the BBB into the CNS where it specifically bound with the amyloid-plaque found in the brain of Alzheimer's transgenic mouse. Having demonstrated BBB permeability, the company is now trying to scale up the production of its drug to establish therapeutic efficacy against Alzheimer's disease.

Having been encouraged by the BBB study of its Alzheimer's drug, the company has launched a program to develop BBB permeable therapeutic molecules for Parkinson's disease. It has developed a drug to neutralize and/or modulate the function of one of the pathogenic proteins, alpha-synuclein, implicated in the pathogenesis of

cont. next column

PD. The company is now in the process of gathering resources to advance this potential pharmaceutical to preclinical and clinical trials.

As the founder and moving force behind PRO, Jo Rosen has, for the past 22 years, fostered and promoted a better quality of life for Parkinsonians and their caregivers through emotional support and education. While continuing in her role as president of PRO, and continuing the emotional and educational support mission of PRO to make sure that no one is isolated because of Parkinson's disease, Jo has taken on a personal mission to raise funds for this exciting new research, in hopes of achieving human clinical trials for a possible cure within 12 to 18 months.

If you are, or know someone, who is an experienced, sophisticated, investor with the ability to underwrite (\$100,000 or more) this expensive research, I invite you to contact Jo Rosen personally at 760-895-5161 to further discuss the details of this project, answer your questions and, hopefully inspire you to join her in funding this scientific research. The company doing the research is a for-profit company founded and run by scientific entrepreneurs.

TEN TIPS – cont. from page 3

9. **Remember the good old days.** Remembering the past is often a soothing and affirming activity. Many people with dementia may not remember what happened 45 minutes ago, but they can clearly recall their lives 45 years earlier. Therefore, *avoid asking questions that rely on short-term memory*, such as asking the person what they had for lunch. Instead, try asking general questions about the person's distant past—this information is more likely to be retained.
10. **Maintain your sense of humor.** Use *humor whenever possible, though not at the person's expense*. People with dementia tend to retain their social skills and are usually delighted to laugh along with you.

For video tips and information
go to our website at:
[ParkinsonsResource.org/patient-information/
ten-tips-for-communicating-with-a-person-with-
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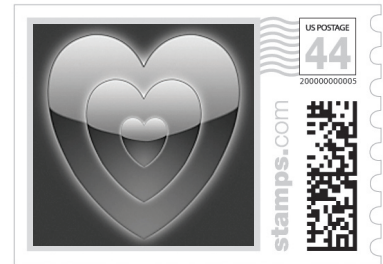
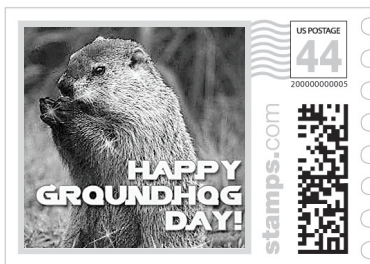
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"Love is the best music in the score of all life. Without it, one would forever be out of time in the immense choir of humanity."

— Roque Schneider

NEWSWORTHY NOTES

February 2012, Issue No. 234, published monthly

PARKINSON'S RESOURCE ORGANIZATION

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