Issue No. 316

March 2019

PARKINSON'S RESOURCE ORGANIZATION

6

Working so no one is isolated because of Parkinson's

MESSAGE

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.

We hope to see you at our MITCH'S PITCHES PRO Fundraising event on April 7th. Early Bird pricing remains until March 21st.

Each article this month was designed to give you hope, enlightenment and helpful information to use in your quest for "Ultimate Quality of Life."

Enjoy the PROvocative UPDATE ON THE ROAD TO THE CURE; CLINICAL TRIALS IN ALZHEIMER'S AND PARKINSON'S DISEASES ARE FAILING: WHAT CAN BE DONE? on this page; our other PROvocative and informative news is ARE WE FACING A PARKINSON'S PANDEMIC? on page 3; I NEED TO RELOCATE FOR MY HEALTH & SAFETY: WHERE DO I **BEGIN** is on page 4; we have been working with two PWPs in the last month with apraxia of lid opening-inability to open or keep the eyelids open-and so we bring some information on this in WHAT IS APRAXIA OF EYELID OPENING AND HOW DO YOU TREAT IT? on page 5; and TEN TIPS FOR COMMUNICATING WITH A PERSON WITH DEMENTIA can be found on page 7.

Join us in making a difference in your life, or the life of a loved one this *month* by donating. Supporting us is simple: Make monthly donations through our safe PayPal donation page at *ParkinsonsResource.org/#modaldonate* or mail your donation to our office in Palm Desert, California.

Until next month, REMEMBER Daylight Savings Time begins on the 10th, St. Patrick's Day is on the 17th, Spring begins on the 20th, and National Puppy Day on the 23rd. The flower is the Daffodil, and the Birthstones are the Aquamarine, Bloodstone & Jade. You might also take note that March is National Nutrition Month. ALWAYS remember to CELEBRATE YOU and PRAY FOR OUR TROOPS!

Love President/& Founder

ICBI UPDATE ON THE ROAD TO THE CURE A Real-Time Science Report

CLINICAL TRIALS IN ALZHEIMER'S AND PARKINSON'S DISEASES ARE FAILING: WHAT CAN BE DONE?

With no drugs that can stop the progression of the disease and hundreds of clinical trials failing, where is the hope for people with Alzheimer's and Parkinson's?

As the global population is living longer, diseases of the central nervous system (CNS) such as Alzheimer's and Parkinson's have become the biggest diseases of the 21st century. But despite the efforts of science, as of today, no drug is available that can stop the progression of the disease. This is definitely not for a lack of trying. Over several hundred clinical trials were run between 2002 and 2014 but without success with any of the tested drugs to stop or slow down the disease. The situation has not improved much since then. In the last few years, Merck, Pfizer, J&J, Eli Lilly and Roche have all failed large Phase 3 trials in Alzheimer's disease.

One of the most common explanations given to the failures seen in clinical trials has been that it might be already too late to treat patients when they already have advanced symptoms of the disease, and that trials should be run in people with milder, earlier symptoms. Another common explanation given in the case of failure of Alzheimer's clinical trials has been the blame on "amyloid hypothesis', which may not be the disease-causing hypothesis.

But there might be something else behind these failures. These trials were conducted using mouse monoclonal antibodies which are large molecule biologics. Below is what is known about large molecules:

"Biologics are large molecule drugs that do not cross the bloodbrain barrier (BBB), and past central nervous system biologic drug development programs were pursued in the absence of BBB drug delivery technology. Few biologics have been FDA approved for brain diseases, and these approved drugs do not cross the BBB", William Pardridge, Bio Drugs, 31, 503 (2017). If drugs do not reach the CNS, expecting a cure for brain diseases has been not only irrational but also a fool's paradise. Consequently, perhaps several hundred billion dollars have gone down the drain casting a gloom over the entire CNS Research and Development Program all over the world.

Where Do We Go From Here? Thankfully, a small biotech company ICB International, Inc., ("ICBII"), in La Jolla, CA has developed technology to deliver drugs across the BBB. Their unique approach has been verified by third parties. The table below shows what ICBII scientists have done to address the key issues which led to the failure of past clinical trials conducted by big pharmaceutical companies during the last decade.

Good News: The BBB permeable technology and its successful applications in animal models to stop and reverse Alzheimer's and Parkinson's diseases positions ICBII in a unique situation to take its drugs from laboratory to patients in a way no one has done so far. The Company has accomplished all this with \$5.5M, which others haven't accomplished even spending \$Billions. With as little as

Newsworthy Notes

ACUPUNCTURE

Dr. David Shirazi

ANIMAL-ASSISTED THERAPY

Canine Companions

AROMA THERAPY

Renee Gauthier

ASSISTIVE TECHNOLOGY

California Phones

BEAUTY

NW Younger By Tonight

NA4

BOXING/EXERCISE

Rock Steady Boxing NAW Coachella Vallev

CARE FACILITIES

- Atria Hacienda
- A&A Home Care Services
- Caleo Bav

CHIROPRACTIC

Dr. Curtis Buddingh

CLINICAL TRIALS

Parexel International

DEEP BRAIN STIMULATION

Dr. Michel Lévesque

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
- (TX) Dr. Risto Hurme
- (VA) Dr. Brendan C. Stack .
- (VA) Dr Jeffrey L. Brown .
- (CA) Dr Alice Sun <

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

858-455-9880.

(VA) Dr. Brendan C. Stack

clinical trials on its Parkinson's drug.

Alzheimer's disease. JUST IMAGINE.

UPDATE ROAD TO THE CURE - cont. from page 1

an additional \$7M to \$10M, ICBII plans to conduct Phase-1

Would you like to help get their drugs to market faster?

The joy of being a part of this historical event can be had by

helping ICBI find the funds to bring these trials to fruition

through your investing, and by finding others with the

financial ability and humanitarian mindset to accomplish the,

until now, impossible. Please contact Jo Rosen at 760-773-5628 or JoRosen@ParkinsonsResource.org or by contacting

ICBI directly through their website ICBII.com, or by phone at

IMAGINE the world without Parkinson's, MSA or

- (VA) Jeffrey L. Brown
- . (CA) Dr. George Altuzarra
- (CA) Dr. Dwight Jennings

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

GRAPHIC DESIGN / PHOTOGRAPHY G-Aries Visions

- **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

LAN

IN HOME CARE PROFESSIONALS

- Cambrian Homecare
- Senior Helpers of the Desert
- A&A Home Care Services
- Brightstar Care .
- AccentCare, Inc

LEGAL-ATTORNEY-LAWYERS

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

LSVT LOUD PROGRAM

- Easy Speech Therapy Center .
- Bolden Communication, Inc

LSVT BIG PROGRAM

- New Beginning Physical Therapy
- . Rosi Physiotherapy

MASSAGE & BODYWORK

- Mot'us Floatation & Wellness Center
- Rehab Specialists
- **MEDICAL MARIJUANA**

PSA Organica

- **MEDI-CAL CONSULTING**
- Medi-Cal Consulting Services, LLC

MOBILITY PRODUCTS

- In & Out Mobility
- LiftUp, Inc

PHARMACIES

.

.

MEDICINE

US World Meds

NURSING HOME ATTORNEYS

Easy Speech Therapy Cente

PHYSICAL THERAPISTS- TRAINING SPECIALISTS

Lamann Z

Advantages

Improved brain penetration

penetration

Improved intracellular space

· Enhanced understanding of the

disease process and pathways allow

us to target disease specific

biomarkers.

· Both the radiolabeled and the

targets in brain.

It allows direct visualization of

therapeutic SMs bind to the same

disease progress, modulation, and treatment results.

(CA) Zoran K. Basich

OCCUPATIONAL THERAPY

Cornerstone Pharmacy

Arroyo Physical Health

Reneé Gauthier

Rosi Physiotherapy

Dr. Michel Lévesque

A & A Home Care

SENIOR HOUSING

Atria Hacienda

SPEECH THERAPY

VISION

RISK

Low CNS penetration:

the blood-brain barrier (BBB)

into the CNS

Lack of understanding of

disease process

Lack of tools to diagnose and

monitor CNS diseases: No

diagnostic test for early

diagnosis and/or track

treatment progress

Low penetration of drug acro

REAL ESTATE

Rehab Specialists

New Beginning Physical Therapy

Easy Speech Therapy Center

John Sloan Real Estate Group

RESIDENTIAL CARE FACILITIES

Easy Speech Therapy Center

Drs. Kohtz & Spurling

ICBII Approach for De-Risking

ICBII has developed SMART Molecules

(SMs), which are engineered heavy-chain

antibody mimics, that cross 8BB

efficiently

Low dose SMs labelled with radioisotope

can be used as companion diagnostic tool

to track disease status when used in

conjunction with brain PET imaging

Disease Biology

Genetic Pathways

Glial (Immune) Pathways Lysosomal Pathways

2

Riverside Institute of Vision Rehabilitation

Bolden Communications

PHYSICIANS AND SURGEONS

ARE WE FACING A PARKINSON'S PANDEMIC?

Published Sunday 3 February 2019 by Tim Newman. Fact checked by Jasmin Collier MedicalNewsToday

According to one new study paper, evidence is emerging that Parkinson's disease is becoming a pandemic. The authors discuss their concerns and the challenges ahead. Parkinson's is on the rise, but can we slow its march? Parkinson's disease is a neurodegenerative condition. Primarily affecting the motor regions of the central nervous system, symptoms tend to develop slowly.

Over time, even simple movements become difficult; and, as the disease progresses, dementia is common.

Historically, Parkinson's was rare. In 1855, for instance, just 22 people living in the United Kingdom died with Parkinson's disease.

Today, in the United States, the National Institutes of Health (NIH) estimate that about half a million people are living with the disease.

Recently, a group of experts from the field of movement disorders published an article in the Journal of Parkinson's Disease. Titled "The emerging evidence of the Parkinson's pandemic," the authors outline their growing concerns and what might be done.

A pandemic?

Globally, neurological disorders are the leading cause of disability. Of these, Parkinson's disease is the fastest-growing. In 1990-2015, the number of people living with Parkinson's doubled to more than 6.2 million. By 2040, experts predict that that number will reach 12 million.

The term "pandemic" is normally associated with diseases that can spread from person to person. Of course, this does not apply to Parkinson's. However, according to the study authors, the condition's spread does share some of the characteristics of a pandemic.

For instance, it is a global concern that is present in every region of the planet. It is also becoming more prevalent in all regions that scientists have assessed. Additionally, pandemics tend to move geographically. In the case of Parkinson's disease, it seems to be moving from West to East as demographics slowly change.

Some researchers also believe that although people cannot "catch" noncommunicable conditions such as diabetes through contact with pathogens, they may still be pandemics. They explain that these conditions are still communicable via new types of vectors — namely, social, political, and economic trends.

In the case of diabetes, for instance, one author argues that we are transmitting risk factors across the world. Such factors include "ultra-processed food and drink, alcohol, tobacco products, and wider social and environmental changes that limit physical activity."

Increasing risk

Because Parkinson's primarily affects people as they grow older, the steady increase in humanity's average age means an inevitable increase in the prevalence of Parkinson's. This slow lift in our average age is not the only factor playing into the hands of a potential epidemic.

Some studies show that, even when analysis accounts for increasing age, Parkinson's disease still seems to be becoming more prevalent.

This means that the average older adult today has an increased risk of developing Parkinson's disease.

Tobacco's surprising influence

Globally, the number of people who smoke tobacco has dropped significantly over recent decades. People roundly and rightly consider this to be a huge benefit to public health.

The study authors outline some of the factors that appear to be increasing the risk of Parkinson's disease today.

However, smoking tobacco appears to reduce the risk of Parkinson's disease. Some studies have shown that smoking can reduce risk by more than 40 percent.

Reducing tobacco consumption may, therefore, be raising the overall prevalence of Parkinson's disease.



3

Governing Board Jo Rosen President & Founder William R. Remery, Eso. Elder Law, PRO Secretary/Treasurer Michael Rudder Director at Large Michael Lu

Director at Large Kaya Kouvonen

Transportation

-- ADVISORY GROUP --

JACOB CHODAKIEWITZ, MD PATRICIA DUNAY DAVID M. SWOPE, MD DR. ANA LORENZ CLAUDE VALENTI, OD, FCOVD DANA BERNSTEIN Advertising Director SUE DUBRIN

- Honorary 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

JON & MARTHA HANSON

RON BUCKLES

JOHN GUNDERSEN

EVA MYERS

JOHN PERL

RICHARD CORDES, CPA, JD, LLM

IRENE SOMERS

MICHELLE WALDNER

JEREMY SIMON

ADAN OLIVAS

ESTEBAN LAGOS

KANAMI OKABE

MICHAEL LU

TERRY STRALSER

MICHAEL RUDDER

RISA LUMLEY

LINDA BORLAUG

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



Facebook.com/ ParkinsonsResourceOrganization



twitter.com/ParkinsonsPro

I NEED TO RELOCATE FOR MY HEALTH & SAFETY: WHERE DO I BEGIN?

Leann Dale, owner

Senior Living Options of the Desert

Last year June got the news that her dad needed to move to a Board and Care or an Assisted Living Community because he needed a higher level of care. The independent living community he had been living in for years was no longer able to care for his needs. He needed a memory care community, and he needed to move quickly. Because of the deterioration in his health, he needed assistance getting in and out of bed.

June wanted to make sure that the transition went smoothly for her dad. He had a caregiver that he loved, and June wanted to make sure this new move would include her. And, her dad had a cat that he would not part with. So, any old assisted living community would not do.

But, June knew nothing about Board and Care Homes or Assisted Living Communities in her area. She found herself suddenly needing to tour many of them to find out which ones would work best for her dad. On top of that, how would she have the time to research cost, care options, how other residents feel about the facility, their activities, what kind of food is served, and if the facility has a history of violations. Needless to say, June was overwhelmed.

What Is A Board & Care Home or An Assisted Living Community Referral Service? Board & Care Home or Assisted Living Referral Services are organizations that help families identify which assisted living community is best for their loved one. Choosing the right residence is a difficult process, especially for those unfamiliar with assisted living and who are currently caring for an elderly person. Board & Care Home or Assisted living referral services are also helpful for people who live far from their loved ones that require care. Referral services provide significant assistance in narrowing down the choices, and they provide their services to families FREE of charge.

Services They Provide When matching an individual to a specific Board & Care or Assisted Living Community, there are many factors to consider, such as location, cost, current and future care requirements, and amenities. Referral services can provide all of this, as well as more community-specific information in minutes. If you were to try to gather this information from each of the many assisted living communities in your geographic area, it would take you days of phone calls and meetings. It would also subject you to countless sales pitches in which it would still be difficult to obtain the information you need.

In addition to the obvious information you would want, referral services also have access to information about which a family might not necessarily think to inquire, like information about pricing variables, occupancy rates, number of residents, resident to staff ratios, proximity to hospitals, family reviews, and resident complaints. Furthermore, referral services can save you money by helping you understand how to negotiate with the Board & Care or Assisted Living residence and making sure you get signed up for the correct level of care.

Prior to deciding on a community, most families will take a tour of the residence. Tours are necessary but vastly time-consuming, difficult, and emotionally challenging. Working with a referral service might decrease the number of tours that are needed from 5 or 6 to just 1 or 2. In addition, they provide scheduling assistance in arranging tours and will accompany you to make sure all the right questions are being asked.

The Benefits Of Using an Assisted Living Referral Service The benefits of using an assisted living referral service are:

- It is most often a free service;
- They have a comprehensive list of residences in your area;
- It can save you and your family time and money;
- They have access to information that you and your family do not have;
- Reduces the number of tours you and your family will have to take;
- Provide free tools to help you with your search.

How To Best Use a Referral Service While assisted living referral services help you figure out which is the best assisted living community for your loved one, it is helpful to give some thought prior to contacting them. At a minimum, you should know the location in which you are seeking an assisted living residence.

WHAT IS APRAXIA OF EYELID OPENING AND HOW DO YOU TREAT IT?

Richard L. Anderson, M.D., F.A.C.S Medical Director, Center for Facial Appearances Salt Lake City, Utah

Apraxia of lid opening is a condition in which patients who have otherwise normal eyelids have difficulty opening the eyelids. This is a problem in the circuitry for opening the eyelids, much like blepharospasm is a problem in the circuitry causing squeezing of the eyelids. Pure apraxia of lid opening (which is not associated with blepharospasm) is very rare. However, apraxia of lid opening is commonly associated with blepharospasm. The specific cause or control center for these disorders is poorly understood but must be somehow intertwined. A blepharospasm patient with associated apraxia of lid opening will typically have spasms closing the eyelids and then for seconds after the spasm stops, the patient is still unable to open the eyelids. The eyelids may open almost normally for a time period and then, without warning, either droop shut or are closed by spasm. Apraxia of lid opening patients typically elevate their brows in an attempt to open their eyelids until the eyelids eventually open. Patients may use a finger to help open the eyelids and have difficulty maintaining open eyelids.

To adequately treat apraxia of lid opening, all blepharospasm or squeezing in the upper eyelids must be relieved. In some apraxia of lid opening patients, it has been shown by EMG that simultaneous impulses to the squeezing muscles and opening muscles occur. Under normal conditions, antagonistic muscle groups cannot contract at the same time. Patients cannot voluntarily squeeze the eyelids closed and open the eyelids simultaneously, and if upper eyelids have even minimal spasm, opening cannot occur in some cases. Botulinum toxin, myectomy, or a combination thereof is required to completely relieve upper eyelid orbicularis muscle spasm and allow the levator muscle to contract and elevate the eyelid. Unfortunately, the orbicularis muscle in the central upper eyelid cannot be fully weakened with Botox without inducing a ptosis or droopy eyelid in many patients.

In botulinum toxin failures it is important to differentiate whether the patient has failed treatment because of the inability of botulinum toxin to relieve squeezing, or whether opening the eyelids is the problem. This can be determined by having the patient vigorously squeeze the eyelids closed while the examiner's fingers attempt to pry the eyelids open. If the patient has markedly weakened eyelid squeezing, then botulinum toxin is working. We have shown that in blepharospasm patients who appear to be botulinum toxin failures, the incidence of apraxia of lid opening approximates 50%. It is important for physicians and patients to diagnose and understand apraxia of lid opening, as it is the most common cause of failure or inadequate response with botulinum toxin therapy. Increasing the dose of botulinum toxin beyond what is necessary to relieve spasm frequently makes ptosis (droopy eyelids). After apraxia of lid opening the next most common cause of inability to adequately open the eyelids is ptosis, brow ptosis, and dermatochalasis. This is simply droopy eyelids and brows or excess baggage and skin in the eyelids. Ptosis (droopy eyelids) can easily be corrected by tightening the tendon of the muscle that raises the eyelids. Dermatochalasis (baggy eyelids) can be corrected by removing the excess baggage and skin in the evelids. These operations are referred to as a ptosis repair and blepharoplasty. Removing excess tissues in the brow or elevating the forehead corrects brow ptosis. In blepharospasm sufferers we frequently combine these surgeries with removal of the squeezing muscles in the upper eyelids, a procedure called an upper myectomy. Following myectomy, both the function and cosmesis of the eyelids is usually greatly improved. The amount of botulinum toxin required is decreased, and the effect and duration of botulinum toxin are increased. Blepharospasm

Parkinson's Resource Organization

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 Chris Rubio Adan Olivas Risa Lumley Linda Borlaug Michael Whishaw

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.

cont. on page 6

PANDEMIC - cont. from page 3

The growth of the industry

Also, industrialization might be playing a part in the steady rise in Parkinson's risk. As the authors write:

"Numerous byproducts of the Industrial Revolution, including specific pesticides, solvents, and heavy metals, have been linked to Parkinson disease."

For instance, China — a country that has witnessed rapid industrial growth — has had the swiftest increase in Parkinson's disease.

Scientists are still debating the role that pesticides play in Parkinson's. However, one in particular, paraquat, is strongly linked to the condition and is now banned in 32 countries.

Despite this, the study authors say that in the U.S., people are using it "in ever greater quantities." The U.K. is 1 of 32 countries to have banned paraquat usage. Regardless, they continue to manufacture it and sell it to countries including the U.S., Taiwan, and South Africa.

"Parkinson's disease is increasing and may be a creation of our times," write the authors. "As opposed to most diseases whose burden decreases with improving socioeconomic level, the burden of Parkinson's disease does the opposite."

Increasing rates of Parkinson's disease are concerning for obvious reasons, but what can we do? Can we turn the tide?

The study authors believe that the key to transforming this seemingly inevitable rise in Parkinson's disease is activism.

Conditions such as HIV and breast cancer have benefited widely from this approach. For example, many focus on raising awareness, amassing funds, improving treatments, and changing policy.

Stopping the production and use of certain chemicals that may increase the risk of Parkinson's is essential. As the authors write:

"We have the means to prevent potentially millions from ever experiencing the debilitating effects of Parkinson disease."

Also crucial, as ever, is financial backing. More research is needed to understand why the condition appears and how it progresses, and this type of scientific investigation is never cheap.

In particular, scientists need to develop better medications. Currently, the most effective therapy is levodopa, which is 50 years old and not without its issues, including both psychological and physical side effects.

While this recent analysis is worrying, the authors leave the reader with some positivity, concluding that "the Parkinson pandemic is preventable, not inevitable."

According to the USFDA, Sinemet (Carbidopa/Levodopa) was approved by the FDA 05/02/1975 (44 years ago) It was given an orphan drug status and approval by the FDA. It was given a "High Priority" status.

APRAXIA – cont. from page 5

sufferers who have the combined advantages of myectomy and are benefited by botulinum toxin are the most satisfied patients in our practice. They have improvement in function and cosmesis from both the myectomy and the Botulinum toxin only. A few patients are true failures of botulinum toxin (botulinum toxin provides no weakness when injected in muscles). These patients require both upper and lower myectomy.

Blepharospasm patients with apraxia of lid opening are treated by an upper myectomy associated with tightening of the levator tendon that raises the eyelids (aponeurotic ptosis repair). By tightening the tendon of the muscle that raises the eyelids, patients can more effectively open their eyelids. By excising the squeezing muscles in the upper eyelids via a myectomy, residual squeezing that is not completely relieved by botulinum toxin is eliminated. Most patients with apraxia of lid opening are markedly improved with a combination of myectomy and ptosis repair. In patients with apraxia of lid opening, nearly every fiber of orbicularis muscle in the central portion of the eyelid must be removed. Orbicularis muscle is meticulously removed overlying the eyelash follicles at the lid margin. Care must be taken not to damage the eyelash follicles and brow hair follicles. If residual muscle is left in the upper eyelid, apraxia of lid opening patients cannot open the eyelids. BOTOX is still used in the lower eyelids after an upper myectomy. If BOTOX provides no weakness in these muscles, then a lower myectomy is performed approximately 6 months after the upper myectomy. Even after myectomy surgery and BOTOX, there remains a small group of patients with apraxia of lid opening who are unable to adequately function. In this group, frontalis suspension (frontalis sling) is performed at a second operation. In a frontalis sling, the forehead muscle is used to raise the eyelids by running a permanent suture material from this muscle into the eyelids. We recommend a O-Gore-Tex suture for frontalis suspensions. This suture is readily obtainable and allows vascular ingrowth. The myectomy operation should be performed before a frontalis sling, which is the last resort for apraxia of lid opening. Unfortunately, drugs have provided little or no improvement in apraxia of lid opening.

In summary, apraxia of lid opening is the most difficult problem associated with blepharospasm. Pure blepharospasm responds remarkably well to botulinum toxin and/or myectomy. The "failures" of botulinum toxin have a high incidence of apraxia of lid opening. It is important for physicians and patients to understand, diagnose, and treat apraxia of lid opening appropriately. The specific causes of blepharospasm and apraxia of lid opening are unknown, but these two conditions frequently co-exist and make this multifactoral and multifaceted disease that we call blepharospasm more difficult to treat.

Here at PRO, we have found that very few neurologists understand Apraxia of the eyelids. It might be very different for Parkinson's than for Blepharospasm. Some patients have to use Botulinum Toxin B. It is also believed that Apraxia can come from complications at the 7th cranial nerve.

6

TEN TIPS FOR COMMUNICATING WITH A PERSON WITH DEMENTIA

We aren't born knowing how to communicate with a person with dementia—but we can learn. Improving your communication skills will help make caregiving less stressful and will likely improve the quality of your relationship with your loved one. Good communication skills will also enhance your ability to handle the difficult behavior you may encounter as you care for a person with a dementing illness.

1. Set a positive mood for interaction. 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, the 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 her attention; address her by name, identify yourself by name and relation, and use nonverbal cues and touch to help keep her focused. If she is seated, get down to her level and maintain eye contact.

3. State your message clearly. 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 she doesn't understand the first time, use the same wording to repeat your message or question. If she 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 her the choices—visual prompts and cues also help clarify your question and can guide her response.

5. Listen with your ears, eyes, and heart. Be patient in waiting for your loved one's reply. If she 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 he can, gently remind him of steps he tends to forget, and assist with steps he's no longer able to accomplish on his own. Using visual cues, such as showing him 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 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.

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.

RELOCATE – cont. from page 4

You should also know the approximate type of care your loved one needs, specifically do they require assistance because of Parkinson's, Alzheimer's / dementia or simply assistance with the activities of daily living.

Finally, you should also know if you are seeking the most affordable facility in the area, a mid-range or highend residence. Once you contact the referral service, ask them specifically what other factors you should be taking into consideration when choosing an assisted living residence. Keep a list of the factors and request that the referral service research those factors for all the potential communities in your area.

When you've narrowed the decision down to several options, ask your Family Advisor about negotiating with the communities. They should be able to discuss "occupancy rates" and know which fees are negotiable and which are not. A good assisted living referral service will be informative and unbiased about the residences. If they do not know an answer to a question you have, they should volunteer to find that information out. They should not put that responsibility on you. They should also be responsive. Expect answers to your questions (which they cannot answer immediately) within a day or two. If they don't respond within that time frame, expect them to follow up and say when they will be able to respond.

Finally, if you do not like the service you are receiving, do not hesitate to find another service. You are under no obligation to continue working with anyone just because you initially started working with that agency.

About: Senior Living Options of the Desert is Southern California's leader in senior living referral. They've been helping families find compassionate care for their loved ones since 2004 and have been members of the Wellness Village ParkinsonsResource.org/the-wellness-village/directory/senior-living-options/ since October 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.

For any mormation regarding any of these meetings, please contact the FKO Office at 677-775-4111.						
					1	2
3	4 PALM DESERT Caregiver Only 10:00 AM PRO Office 74-090 El Paseo Suite 104	5	LONG BEACH 6 Round Table For Everyone 6:30 PM Cambrian Home Care "Training Center" 5199 Pacific Coast Hwy	7	8	9
10 DAYLIGHT SAVINGS TIME BEGINS	11 PALM DESERT Round Table For Everyone 6:30 PM Atria Hacienda 44-600 Monterey Ave	12	13 GLENDORA Round Table 6:30 PM La Fetra Senior Center 333 E Foothill Blvd	14 NEWPORT BEACH Caregiver Only 6:30 PM Oasis Senior Center 801 Narcissus Corona Del Mar	15	16
17 St patrick's Day	18 PALM DESERT Caregiver Only 10:00 AM PRO Office 74-090 El Paseo Suite 104	19	FIRST DAY OF SPRING 20 ENCINO Caregiver Only 7:00 PM Rehab Specialists 5359 Balboa Blvd	21 SANTA MONICA Round Table 7:00 PM Rehab Specialists 2730 Wilshire Blvd Ste 533	22	23 NATIONAL PUPPY DAY
24	25 PALM DESERT Speaker Meeting 6:30 PM Atria Hacienda 44-600 Monterey Ave	MANHATTAN 26 BEACH 26 Round Table For Everyone 6:30 PM American Martyrs Welcome Cntr 700 15th Street	27	28 SHERMAN OAKS Speaker Meeting 1:00 PM Sherman Oaks East Valley Adult Center 5056 Van Nuys Blvd		

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.

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

May the sun shine all day long, Everything goes right and nothing wrong. May those you love bring love back to you, And may all the wishes you wish come true.

- IRISH BLESSING

NIAWAWORTHY NOTES

March 2019 / Issue No. 316 / 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 • *fax*: 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.