

A MONTHLY PUBLICATION OF
PARKINSON'S RESOURCE ORGANIZATION
 Working so no one is isolated because of Parkinson's

MESSAGE

PRESIDENT'S

It seemed that through the COVID-19 pandemic, time went at a snail's pace; all of a sudden, we are more than halfway through this year. Amazing Grace!

Our new offices are extraordinary. In retrospect we cannot imagine how we got so much done in such little space as we had on the old office. If you are in the area, please come by to see us. If you can help us furnish it, we would love your participation, we'll even put your name on the furniture or room you would like to sponsor.

July is National Awareness Month, and even more fun is that it is National Wheelchair Beautification Month. We would love to see your pictures of this.

Summer, of course, is a perfect time for traveling now, and we've addressed that and other important topics.

The **UPDATE ON THE ROAD TO THE CURE** on this page addresses sensitive topics about our medicine approval system.

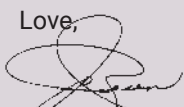
Additionally, we PROudly present other PROactive, PROvocative articles and informative news items: **WELLNESS VILLAGE SPOTLIGHT** on page 2; **PREPARING FOR UTILITY BLACKOUTS** on page 3; **WHAT HAPPENS WHEN THE CAREGIVER DIES BEFORE THE PATIENT?** on page 4; **WHAT IS GRIEF?** about our first group meeting is also on page 4; **TRAVELING THIS SUMMER?** on page 5; **MOVING WITH PETS** on page 6; Our **BITS AND PIECES: TELL ME WHY MY FACE LOOKS SO BLANK** is on page 7, and; **announcing PRO's newest specialty group** which is for PWP's and partners in care, **EXERCISE: USE IT OR LOSE IT** is also on page 7.

In addition to donating, join us in becoming a key part of our advocacy efforts. Contact us to "Get Involved." Make monthly donations through our secure donations page at ParkinsonsResource.org/donate, or mail your donation to our office in Palm Desert, CA.

Until next month, REMEMBER Canada Day on the 1st, Independence Day on the 4th, (celebrated on the 5th), World Chocolate Day on the 7th, Bastille Day on the 14th, National Hot Dog Day on the 22nd, National Vanilla Ice Cream Day on the 23rd, and International Day of Friendship on the 30th. The flowers are the Larkspur & Water Lily and the Birthstones: Ruby and Onyx.

ALWAYS remember to CELEBRATE YOU and PRAY FOR OUR TROOPS!

Love,



President & Founder

ICBII UPDATE ON THE ROAD TO THE CURE A REAL-TIME SCIENCE REPORT

Ram S. Bhatt, PhD., Chief Science Officer

The FDA's Approval Of Biogen's Alzheimer's Drug, Aduhelm - A Cruel and Dangerous Decision

On June 8, 2021, the US Food and Drug Administration (FDA) approved Biogen's Aduhelm for treating Alzheimer's disease despite the committee's overwhelming rejection of the drug after reviewing clinical trial data that did not support its therapeutic efficacy. None of the eleven FDA's advisors saw a reason to approve the drug. Thus, Aduhelm has little data indicating it is effective in treating Alzheimer's and it **comes with a hefty risk of painful and potentially dangerous brain swelling and bleeding**. In fact, Aduhelm initially flunked out of two randomized, double-blind, placebo-controlled Phase III clinical trials in 2019. An early analysis dubbed the drug "futile" and Biogen ended the trials early.

In a powerful statement of disagreement with the FDA's approval of Biogen's controversial Alzheimer's drug, three high profile scientific advisors have resigned from the independent committee that advised the agency on the treatment. Dr. Aaron Kesselheim, who resigned from an FDA advisory committee soon after the FDA announced its decision said, "This might be the worst approval decision that the F.D.A. has made that I can remember". Aaron Kesselheim, a professor of medicine at Harvard Medical School and Brigham and Women's Hospital, submitted his resignation after six years on the committee. Two other members of the committee resigned the same week, expressing dismay at the approval of the drug against the committee's approval.

Dangerous and Cruel Decision – The FDA's decision to approve Aduhelm, that has not demonstrated any therapeutic efficacy, is only disgraceful but also a dangerous and a cruel sham. The decision is dangerous because of the potential serious side effects such as brain inflammation and bleeding. By setting the approval bar as low as seen with Aduhelm, the FDA has set up a dangerous precedent for the approval of a future CNS drug - the drugs with no benefit to the patients. **The decision is cruel because the hopeful patients and loved ones will likely find after 12 to 18 months' treatment that their great expectations are dashed to ground as the treatment would not either slow down the disease progression or improve cognition.**

The main question is why the FDA would approve a drug against the recommendations of its advisors? The answer may appall everyone. **What most of us don't know is that the "Biopharmaceutical Industry Provides 75% of The FDA's Drug Review Budget. Is This A Problem?"** [Forbes, June 28, 2018].

Caroline Chen of **Pro Publica** has written a provocative article challenging the objectivity of the FDA in its approval of new drugs. Entitled: "FDA Repays Industry by Rushing Risky Drugs to Market", Chen contends that the agency

Our Wellness Villagers

ANIMAL-ASSISTED THERAPY

- Canine Companions

AROMATHERAPY

- Renee Gauthier

ASSISTIVE TECHNOLOGY

- California Phones

BALANCE

- SeeOurSocksInAction

BEAUTY

- Younger By Tonight

CHIROPRACTIC

- Dr. Curtis Buddingh

CLINICAL TRIALS/RESEARCH

- Parexel International
- University of OULU

DEEP BRAIN STIMULATION

- Abbott
- Boston Scientific

DENTISTS

CMD/TMJ DENTISTS

- (CA) Dr. George Altuzarra
- (CA) Dr. Maryam Bakhtiyari
- (CA) Dr. Dwight Jennings
- (CA) Dr. Steven Olmos
- (CA) Dr. David Shirazi
- (IL) Drs. Ed and Lynn Lipskis
- (TX) Dr. Risto Hurme
- (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
- (CA) Dr. George Altuzarra
- (CA) Dr. Dwight Jennings

ELDER LAW ATTORNEYS

- (CA) Zoran K. Basich
- (CA) William R. Remery

END OF LIFE DOULA

- Glendon Muir Geikie, MSW INEDLA

ESTATE PLANNING- LEGAL

- (CA) William R. Remery

ESTATE PLANNING – FINANCIAL PLANNING

- Cypress Wealth Services

FINANCIAL ASSISTANCE

- The Assistance Fund, Inc

GRAPHIC DESIGN / PHOTOGRAPHY

- G-Aries Visions

HOSPICE CARE

- Family Hospice Care

HYPNOTHERAPY

- Palm Desert Hypnosis

INCONTINENCE SUPPLIES

- Dependable Daughter

IN HOME CARE PROFESSIONALS

- Cambrian Homecare
- Senior Helpers of the Desert
- Brightstar Care
- Caregivers-To-Go, LLC
- Helping Hands Senior Resources
- Comfort Paradise Home Care

INSURANCE - LTC & DISABILITY

- Jim Lawless, MBA

LEGAL-ATTORNEY-LAWYERS

- (CA) Zoran K. Basich
- (CA) William R. Remery, Esq.

LIFE COACHING

- Lynda Reid, EdD, RPCC, PCC

LSVT LOUD PROGRAM

- Easy Speech Therapy Center

LSVT BIG PROGRAM

- Rosi Physiotherapy

MASSAGE & BODYWORK

- Rehab Specialists

MEDICAL DEVICE – DUOPA

- AbbVie Inc

MEDICAL MARIJUANA

- The Leaf El Paseo

MEDI-CAL CONSULTING

- Medi-Cal Consulting Services, LLC

MOBILITY PRODUCTS

- At Home Medical
- LiftUp, Inc

MEDICINE

- Supernus / US World Meds
- Acorda Therapeutics
- Sunovion Pharmaceutical Company
- Amneal Pharmaceuticals
- AbbVie Inc

NURSING HOME ATTORNEYS

- (CA) Zoran K. Basich

OCCUPATIONAL THERAPY

- Easy Speech Therapy Center
- VIBRA Rehabilitation Hospital

PATIENT ADVOCACY

- Cindy Johnson, BCPA, CSA®
- LA Patient Advocates

PHARMACIES

- Cornerstone Pharmacy

PHYSICAL THERAPISTS - TRAINING SPECIALISTS

- Renee Gauthier
- Rosi Physiotherapy
- VIBRA Rehabilitation Hospital

REAL ESTATE

- John Sloan Real Estate Group

REHABILITATION HOSPITALS

- VIBRA Rehabilitation Hospital

RELOCATION SERVICES

- Senior Living Options of the Desert
- Caring Transitions Desert Cities
- Helping Hands Senior Foundation

SOCKS

- SeeOurSocksInAction

SPEECH THERAPY

- Easy Speech Therapy Center
- VIBRA Rehabilitation Hospital

VIATICAL

- Rehburg Life Settlements

VISION

- Optometric Vision Care, Dr Eric Ikeda

WELLNESS VILLAGE SPOTLIGHT

Cambrian Homecare

Rhiannon Acree, Founder and CEO

Rhiannon is delighted to offer continuing support to the amazing Parkinson's Resource Organization (PRO) community. Her company, *Cambrian Homecare*, joined the Wellness Village years ago when it was first introduced because she felt personally inspired to help those dealing with the condition. Rhiannon knew her small town upbringing, earlier nursing education and passion to help people maintain their independence would be core strengths in her ability to support those living with chronic diseases such as Parkinson's. She realizes there are challenges beyond the obvious physical symptoms and sincerely hopes that the efforts of PRO's Wellness Village and PRO can fundamentally change society's stigma of this disease. Nothing is more upsetting than witnessing a person being made fun of because of their physical differences or limitations. Her dedication to progress is deeply personal now that her husband faces symptoms similar to Parkinson's.

Entrepreneurial in spirit, generous of time and talent, one of Rhiannon's favorite quotes is "The best way to predict the future is to create it! Better to try and fail than fail to try." She knows the power of positive thinking and understands that all families need help at some point. Cambrian Homecare was designed to deliver the right amount of care to enable the highest quality of life for those diagnosed with Parkinson's and their primary caregivers - the families. Without exception, Rhiannon and her caring and capable team at Cambrian strive every day to make life's journey a little easier.

Visit Cambrian Homecare in the Wellness Village at ParkinsonsResource.org/the-wellness-village/directory/cambrian-homecare/ where they have been members since August 2012. Cambrian Homecare also sponsored our monthly, pre-COVID, Long Beach, CA Support Group meetings.

PREPARING FOR UTILITY BLACKOUTS

Eileen Lynch

Fire and heat season is upon us, and like clock-work the Southwest USA, in particular, is experiencing rolling power outages. But you need not live in the Southwest to experience power outages. Unexpected loss of power can cause serious interruptions for those managing Parkinson's care, but the good news is you can do a lot right now to make an emergency plan in advance to ensure you and your loved ones' safety.

It is important to note no utility company can guarantee that your electricity will never be cut or slowed down during fire, storm, and high heat emergencies. That does not mean your provider won't help you with your special circumstances. In Southern California, for instance, you can reach out to Southern California Edison, online, and get some Incredible tips. Here are a few things you can do right now to protect yourself.

- **Know what's coming:** familiarize yourself with your provider's outage alert system. SoCal Edison's comprehensive [Outage Center](#) includes a way to sign up for email, text, and phone alerts, as well as tips and resources.
- **Know local resources:** SoCal Edison's website directs users towards local cooling centers and can even find hotel discounts for you, should you need to relocate. **You can also register your medical devices through the site to get your bill lowered.**
- **Know what you have:** Preparing your emergency supply kit is relatively easy. Here are some tips for building your **Outage Supply Kit:**
- **First Aid Kit:** In addition to the standard first aid kit, prepare a medicine supply buffer of up to a month in advance of service shutdowns. Update your medicine kit frequently and check for expired medications.
- **Potable Water:** Experts recommend at least one gallon per day per person
- **Flashlights & batteries:** People with Parkinson's should take extra care to have backup batteries and generators ready. Make sure you have an external rechargeable battery pack, and do not forget to keep it charged! Store them where you can easily find them - even when it is dark.
- **Perishable Items:** Stock up on nonperishable staples for you and your family. With canned food, make sure you have a can opener! Prepare a few large coolers to fill with ice in the event of an outage to store temperature-dependent medicine and perishable food. Choose items that do not require cooking or heating.
- **Manual can opener**
- **Coolers or ice chests:** Have a few to store ice in case of a lengthy outage.
- **Special-needs items:** This includes items for infants, the elderly, or the disabled.
- **Battery-operated radio:** To access news reports
- **Fresh batteries:** For all battery-powered equipment
- **External rechargeable battery pack:** To charge cell phones and other electronic devices. For those affected by Parkinson's, extra care must be taken to preserve battery power and build a strong medical first aid kit.
- **Non-cordless phone:** To plug in during power outages.
- **Elder/Disabled/Infant/Pet Care:** Make a care plan for everyone in your family, including your pets. Stock up on sensitive care items such as diapers, soft foods, kitty litter, etc.

✓ Do you know where you will take the people in your care in the event of dislocation?

As a dress-rehearsal of sorts, take some time to familiarize yourself with your utility box, write down important phone numbers and addresses for your refrigerator, and place flashlights (with batteries!) strategically throughout the house. Most importantly, **never use a gas generator inside the house.** Identify a place outside the house, on a clean, level surface, for safe use.

Heat like we have experienced in the last few weeks is nothing to underestimate. Stay indoors. Stay hydrated. Stay cool. We are rooting for all of you, and we are sending love and luck to everyone living in a fire zone, of which we are included!

Eileen Lynch is joining the PRO team on August 1st as our Director of Operations. She is relocating from Vermont. They have power outages in Vermont as well, but perhaps not like we have in California.

BOARD OF DIRECTORS

--- GOVERNING BOARD ---

JO ROSEN

President & Founder

WILLIAM R. REMERY, ESQ.

Elder Law, PRO Secretary/Treasurer

MICHAEL LU

Director at Large

MATTHEW LU

Director at Large

KAYA KOUVONEN

Director at Large

--- ADVISORY GROUP ---

JACOB CHODAKIEWITZ, MD

PATRICIA DUNAY

DAVID M. SWOPE, MD

DR. ANA LORENZ

CLAUDE VALENTI, OD, FCOVD

DANA BERNSTEIN

SUE DUBRIN

--- HONORARY MEMBERS ---

GREG A. GERHARDT, PHD

STEPHEN MACHT

--- 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

TRINI LOPEZ

--- FOUNDING MEMBERS ---

JO ROSEN, Founder

ARNIE KRONENBERGER (deceased)

CATHERINE BUCKINGHAM

JENNIFER REINKE

DARLENE FOGEL

CHUCK KOCH

ALAN ROSEN, FAIA (deceased)

WAYNE FRIEDLANDER

PAUL ROSEN

ELAINE VACCA

Special Thanks

...TO OUR "SPECIAL" BOOSTERS:

SKY LUNDY

GARY LOPEZ / G-ARIES VISIONS

SUE DUBRIN

FRANK & MARY BUYTKUS

MARTHA HANSON

JOHN GUNDERSEN

EVA MYERS

JOHN PERL

RICHARD CORDES, CPA, JD, LLM

JEREMY SIMON

ADAN OLIVAS

MICHAEL LU

LINDA BORLAUG

CHERYL EWOLDT

CAROLYN RINDONE

MATTHEW LU

DONNA STURGEON

SUE LAMPARTER

SANDRA RODLEY

KYLE WALKENHORST

TYLER HAYCOX

WAYNE TSAI

THINGS TO THINK ABOUT RIGHT NOW

WHAT HAPPENS WHEN THE CAREGIVER DIES BEFORE THE PATIENT?

When a person with Parkinson's dies, their family caregiver faces a period of adjustment as their caregiving responsibilities come to an end. They grieve, of course, but they also adapt and carry on with the business of living. When the situation is reversed, however, and a family caregiver dies before their cared-for, things are instantly much more complex... especially for those with cognitive issues and motor skill disorders.

Imagine the grief one goes through upon a loved one's passing, and then try to imagine going through this as a person with Parkinson's, with or without cognition issues but with motor skills disorder. To put it simply, it is near impossible.

If something were to happen to the caregiver, the cared for must immediately rely on someone else.

Things To Think About Right Now — If you are the caregiver, who would be able to take your place? How quickly would your replacement be on site to assume your caregiving responsibilities? Would that person even be "willing" and able to accept this role? For how long? People with Parkinson's—especially those with cognitive issues and motor skill disorders—who require high levels of care, rely heavily on their spouses, children, and others to do so much for them. When a primary caregiver experiences a temporary medical setback of their own, or dies, it is utterly devastating in multiple ways.

For instance, consider financial obligations. A person with Parkinson's—especially those with cognitive issues and motor skill disorders—may not have a clue who they owe, how much they owe, where the accounts are or how to access them. They may not know when the water, cable or electricity bills are due, or even more, they may not remember to make the payments. If they would not remember that, how can they remember how to get things to file the taxes, balance the checkbook, ensure that insurance policies are current or manage the other financial assets?

Managing the finances is not the only item of concern, but the bills do keep coming.

How about managing the doctor appointments, the other health care needs, the socialization? How about getting to and from places... the transportation? How about bathing, dressing and the other activities of daily living?

In most cases, these are impossible tasks for a person with Parkinson's, with or without cognition issues but with motor skills disorder, especially while grieving. Pretty unimaginable, don't you think?

All caregivers should have back-up plans (*yes, more than one back-up plan*) to ensure the person with Parkinson's care continues as seamlessly as possible if the person with Parkinson's normal routine is disrupted.

Here are some questions to ask yourself. What would my cared-for do if I were unexpectedly hospitalized? What would happen to my cared-for if I suffered a fatal heart attack or died suddenly?

This may seem morbid, but is not far-fetched. Rough statistics show that 63%

cont. on page 7

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



Facebook.com/
ParkinsonsResourceOrganization



twitter.com/ParkinsonsPro

WHAT IS GRIEF?

Experiencing Losses

What an impactful meeting PRO's first new "GRIEF" GROUP was. Attended by People with Parkinson's, Partners in Care, and former Partners in Care, facilitated by Glendon Geikie, MSW, IELDA, CGCS and Jo Rosen, President of PRO. We were so inspired and moved by the participants, because grief, as you know, is so much more than "The End of Life". Grief for a person with Parkinson's may happen as they start grieving their losses of movement, grief for a Partner in Care may start as they start losing the partner relationship they once knew; and grief for a child may start as they witness what appears to be "losing their hero."

Next Meeting: July 8

Continues - 2nd & 4th Thursday
of each month

Time - 10:00am PST

Anticipatory Grief

Loss of Movement Grief

Loss of Relationship Grief

Eternal loss, forever Loss

Thank you Glendon, for this wonderful collaboration.

TRAVELING THIS SUMMER?

Work with a Travel Specialist
Sandy Rodley, PRO Advocate

Parkinson's should not stop anyone from visiting the wonders of the world or the wonderful world we live in if you can practice some simple tips. Working with travel specialists is recommended, because they know about available resources and the "ins and outs" when planning a trip with someone who has "specific requirements".

Whether you are considering an awe-inspiring trip to Mount Rushmore in Keystone, South Dakota, a weekend getaway to the beach, or you have what is commonly referred to as the "Bucket List", do not ever feel that because you have a "disability", your world must shrink.

If you will be traveling this summer by airplane and use a wheelchair, scooter or walker, here is some important information you need to be aware of ahead of time. Protocols generally don't differ between US airlines, but can vary with international carriers. Working with a travel advisor ensures that your trip abroad will go smoothly when traveling with someone who is disabled.

Always, *always* when traveling with someone who needs wheelchair/mobility assistance, make sure to inquire ahead of time about caregiver and wheelchair policies.

Whether you are booking directly with an airline on their website, over the phone, or working with a travel advisor, alerting them to your specific needs can make the difference in your travel experience.

Should you be on a US airline website and you have made your reservation—most but not all—once a ticket is issued you can indicate a special request such as wheelchair assistance (see below), if you won't be traveling with yours. If you are on the phone with them, of course you can mention this to them as well. Should you forget, and to ensure that they receive and notify the airport staff in a timely fashion, you should make your request at least 48 hours prior. Anything less could result in miscommunication along the way.

In most cases you can travel/fly with your wheelchair, scooter, or walker. Some wheelchairs might be too bulky or heavy, in which case you might want to rent a traveling one, also referred to as a transfer wheelchair. There are many different versions of wheelchairs depending on your needs, so plan ahead to determine if your chair will be appropriate to travel with you. You can check your wheelchair or walker as luggage, or you can use it all the way to the gate, and if you are mobile and can walk the aisle they will check it below at that point. But you can fly with your electric or battery-powered wheelchairs, carts or scooters. The airline or travel advisor will advise you as to what their protocol and restrictions are for traveling with these devices.

Four designations determine the type of airline wheelchair policies:

1. Passengers who can walk onto a plane but need help getting from the terminal to the aircraft;
2. Passengers who cannot navigate stairs, but who can walk on board a plane but who need a wheelchair to move between an aircraft and a terminal;
3. Passengers with a disability of their lower limbs who can take care of themselves, but who need help boarding and departing from a plane, and;
4. Passengers who are completely immobile and need help from the time they get to the airport through to the time they need to board the aircraft.

Airports in the past would have skycaps available to assist you at curbside. Making that wheelchair request in advance alerts the airport that you will need a wheelchair so that upon arrival you can confirm your request for one.

Some airports are so large that they utilize "go carts" to transport folks who have mobility issues between gates and terminals, but this feature is *not* offered in all airports. And unfortunately, going forward, what methods were available previously might not be available any longer due to COVID-19.

When you make your request for assistance and you are taking multiple flights (connecting), your request will automatically notify all involved airports. If you have booked multiple different airlines, i.e., American to Delta, you will need to notify each airline of your needs. In this scenario your request will *not* be passed on to the other. If you are working with a travel advisor, they will know this, and can automatically take care of all notifications in making these arrangements for you.

cont. on page 7

PARKINSON'S RESOURCE ORGANIZATION

PRO STAFF

KYLE WALKENHORST
Wellness Village Director

TYLER HAYCOX
IT/Communications Assistant

DONNA STURGEON
Wellness Village Coordinator

JEREMY SIMON
IT/Communications Director

VOLUNTEERS

SKY LUNDY
Web Design

GARY LOPEZ
Graphic Artist

AMBASSADORS

SOPHIE BESHOFF
CHERYL EPSTEIN
CHARLENE SINGER

OFFICE SUPPORT

EVA MYERS
JOHN PERL
SUSAN MOLLER
ADAN OLIVAS
LINDA BORLAUG
CHERYL EWOLDT
CAROLYN RINDONE
SUE LAMPARTER
SANDRA RODLEY
WAYNE TSAI

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.

MOVING WITH PETS

John Sloan

Let's be real; moving can be quite stressful. And if it's this stressful for us, how do you think it is for our furry friends? Moving to a new location, going for a long drive, new rooms, new yard - it's a lot for a pet. So, if you're making a move this summer, I wanted to share a few tips to make it easier for you and your pets. Check out four tips to make moving with pets a little easier.

Prepare a Moving Kit — Create an overnight bag for your pet. Add food, toys, a bed, and litter so that everything they need is easily accessible while you are busy unpacking boxes.

Keep Your Pet Away from the Hustle — Your moving day will come with a lot of commotion. All of the moving can create anxiety for your pet. Try to keep them away from the hustle. Ask a friend to watch your pet on moving day or take them to a kennel for the day. If that is not possible, let them stay in a quiet room.

Let Them Ride with You — When everything is loaded and it's time to make a move to your new home, make sure that your pet rides with you. If your pet is really nervous, put them in their crate and cover it with a blanket so that they can't see the changing scenery.

Ease Your Pet into Your New Home — If it's possible, set up as much as you can in your new home before moving your pet. If not, keep your pet secluded in a calm area of the house with things they recognize, like toys or a bed, until things look normal for them. Easing them into their new space will make it more comfortable. Do not let your pet outside unattended until they've adjusted to their new neighborhood.

I hope these tips help you and your pet have a safe and calm move. If you are thinking about a move this summer, I'd be happy to help you find the perfect home for you and your furry friends.

John Sloan has been in the Wellness Village since September of 2018. Mention PRO, and he'll give us 10% of his commission.

ParkinsonsResource.org/johnsloan

ROAD TO THE CURE – cont. from page 1

is beholden to the biopharmaceutical industry which pays three quarters of the FDA's budget used for the drug review process. This is an astounding number. Is any other federal agency supported to this extent by the industry it regulates? Given this level of support, one might assume that the FDA would bend over backwards to meet the needs of its financial backers".

Likewise, last year, FDA approved Gilead's Remdesivir for COVID-19 despite WHO found that the drug does not provide benefits to the patients. It turns out Gilead is a big donor to the FDA. Thus, the confidence of the scientific community in the FDA has eroded as the drug approval is being made using data that does not support effectiveness of the drug.

About Aduhelm — Aduhelm is a mouse monoclonal antibody raised for human brain plaque made of amyloid-beta.

Unfortunately, mouse monoclonal antibodies are notorious for extremely low brain uptake that has been documented to be no more than 0.1%. With such a poor brain uptake it is impossible to achieve therapeutically effective brain concentrations of any drug, which may be one of the reasons why the FDA advisors failed to observe clinical effectiveness in the data obtained from the patients treated with Aduhelm. Besides, by the time amyloid plaque appears in the brain most of the neurons have already been compromised as the disease process started long (10-20 years) before the appearance of the plaque. So, clearing the plaque is not likely to improve cognition.

Biogen's Aduhelm vs ICBI Amyloid-beta-SMART Molecule — Treatment with Aduhelm has to be administered for about 18 months at a high dose to see some decrease in the levels of amyloid-plaque in the brain of patients, though the FDA advisors were not convinced. Assuming Biogen's claim to be true, 18 months is too long of a treatment with a drug that has dangerous side effects such as brain inflammation and bleeding.

ICB International, Inc., "ICBII", has developed its own amyloid-beta antibody, referred to as amyloid-beta-SMART Molecule (A β -SM). In animal studies A β -SM has obtained 60% reduction of amyloid-plaque with as few as one weekly low dose (2 mg/Kg) for twelve weeks, thereby demonstrating superior therapeutic performance to available mouse monoclonal antibodies such as Aduhelm that target brain amyloid-plaque. **ICBII, however, does not believe that attenuation of amyloid-plaque alone will improve cognition without rejuvenating processes and mechanisms that became dysfunctional 10-20 years earlier before the clumps of aggregated amyloid-beta appeared in the brain.** Thankfully, ICBII scientists have devised a solution to potentially repair such faulty processes that lead to the death of neurons in the brain of debilitating neurodegenerative Alzheimer's, Parkinson's, and other central nervous system disease patients.

WOULD YOU LIKE TO HELP get ICBII's 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 ICBI directly through their website **ICBII.com** or by phone 858-455-9880, or contact Jo Rosen at PRO for a personal introduction to the scientists.

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

JUST IMAGINE.

BITS AND PIECES

**TELL ME WHY
MY FACE LOOKS SO BLANK****David Verdery, PRO advocate***Parkinson's Sign #8:**Loss of Facial Expression (Hypomimia)*

*Its beginning was very subtle.
In fact, I was unaware
That today I'd look at a mirror
And see nothing, but a stare.*

*My work is setting deadlines.
They're hard to meet in a bank.
It must be that, because what else
Could make my face so blank.*

*I saw my doctor on Friday.
I was nervous going in.
She said my kind of blank face
was Parkinsonian.*

*She asked, "Do you know how to whistle?"
I replied my dad had taught a tune
He learned when he was a little boy.
"Would you like me to whistle it too?"*

*She agreed, so I started to whistle,
But only air was coming forth.
"I want to get you in touch with
ParkinsonsResource.org*

*It's Jo Rosen you'll want to see.
Her team of PROs will turn
Your fears to years of life with PD
A better life for all concerned.*

TRAVELING – cont. from page 5

International airlines and airports have different procedures and protocols, and some airports may offer a concierge service or offer a paid-for assistance. Some airports have way stations or holding areas for handicap passengers where the sky cap will take you to wait for your flight in comfort, but could forget to come and retrieve you and get you to your gate on time. So being your own advocate and speaking out can be helpful in this case.

Also, most airlines do board based on zones, but some will offer pre-boarding for those who need additional time. Make sure to let the gate agent know that having extra time would be appreciated and less stressful.

Flying in the post-pandemic world will see a lot of changes. For the most part procedures will still be in place, TSA will still do security, but there could be longer lines due to lack of airport staff, TSA staff and increased safety protocols. So have contingency plans if you get delayed by these procedures, or your flight is delayed and be prepared for all scenarios in regard to your meals and medication rituals. There is no meal service being offered on flights within the US at this time and some airlines are offering limited snacks where payment can only be by credit card. And many airports, even though they are operating their food courts and shops, might not be. So be prepared. As time goes on, the airports and airlines will return to "normal". It is very important that you are comfortable with the entire process from the moment you leave your home until you reach your final destination.

If you get to the airport, are waiting at your gate and you start to panic because there are people with masks and no masks, or not doing social distancing, and you are getting concerned about your level of comfort, and wondering if the flight will be crowded with someone sitting next to you, do a self-check prior to traveling and ask yourself, "Am I good with this?". You are going on vacation, and no one should be stressed out. Vacations are supposed to be stress-free.

And speaking of stress-free, should you not want to travel with your wheelchair or scooter, you can rent one for your destination. It can be delivered to your hotel or cruise ship.

Soon you can visit Sandy Rodley in the Wellness Village under Travel. She is a Manager/Travel Consultant at Via Verde Travel (A Division of Plaza Travel) and a PRO Advocate.

WHAT HAPPENS WHEN – cont. from page 4

of caregivers **die before those they are caring for**, especially if the cared-for is a person with Parkinson's with cognitive issues and motor skill disorders. Illness that does not lead to death is rampant, as well... depression and auto-immune diseases are high on the list. Families need to think about things like this and create alternate care plans for these scenarios.

For more information about insurance needs, especially Long Term Care or any health, disability, or other insurance that might be needed for Parkinson's, a Parkinsonism, or the Partner in Care, contact Jim Lawless, MBA, a member of the Wellness Village since August 2019, ParkinsonsResource.org/the-wellness-village/directory/lawless-mba/

EXERCISE: USE IT OR LOSE IT**For PWP's & Partners in Care**

PRO's newest *Specialty Group* is launching this month and is facilitated by Brandon Rosi, DPT, CSCS, Cert MSKUS.

A time for discovery. Exercise... How do we start? Where do we start? What do we need? Can we work together? Should we work together? How do we get the most out of exercise? What am I looking for from exercise? How do I exercise if I can barely, or cannot, walk? When should I start? What time of the day should I exercise? What should I wear? Are my shoes important? Do I need shoes? Bring your questions and let's talk with Dr. Rosi.

START: July 13th / **CONTINUES:** 2nd Tuesday of each month

TIME: 10:00 am PST

Exercise for Beginners

Exercise for People with Parkinson's

Exercise for the young

Exercise for buffs

Exercise for Partners in Care

Exercise for the mature

Improve your muscle strength and boost your endurance.

Thank you, Dr. Brandon Rosi, for the wonderful collaboration.

ParkinsonsResource.org/rosiphysio

PRO CALENDAR FOR JULY 2021

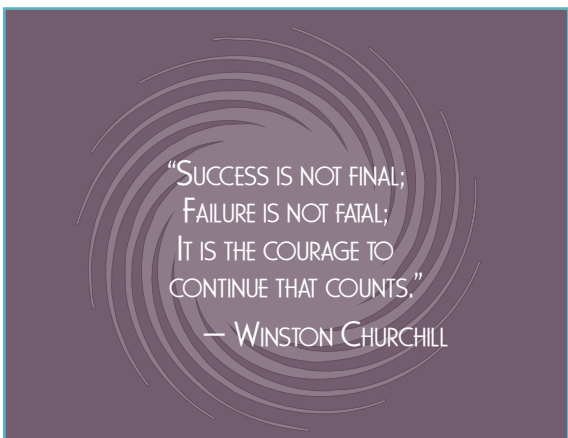
The current, **VIRTUAL ONLY**, support group meetings are listed below. **ALL MEETINGS CLOSE 15 MINUTES AFTER START TIME!**
For any information regarding any of these meetings, please contact the PRO Office at 877-775-4111.

				1 CANADA DAY	2	3
4 INDEPENDENCE DAY	5 INDEPENDENCE DAY OBSERVED	6	7 WORLD CHOCOLATE DAY Round Table 6:00 PM PDT 8:00 PM CDT 9:00 PM EDT 3:00 PM HST 7:00 PM MT	8 Grief Group 10:00 AM PDT 12:00 PM CDT 1:00 PM EDT 7:00 AM HST 11:00 AM MT	9	10
11	12 Round Table 6:00 PM PDT 8:00 PM CDT 9:00 PM EDT 3:00 PM HST 7:00 PM MT	13 Use It or Lose It Exercise 10:00 AM PDT 12:00 PM CDT 1:00 PM EDT 7:00 AM HST 11:00 AM MT	14 BASTILLE DAY Village Meeting 4:00 PM PDT 6:00 PM CDT 7:00 PM EDT 1:00 PM HST 5:00 PM MT	15	16	17
18	19 Partner in Care 10:00 AM PDT 12:00 PM CDT 1:00 PM EDT 7:00 AM HST 11:00 AM MT	20 Grief Group 10:00 AM PDT 12:00 PM CDT 1:00 PM EDT 7:00 AM HST 11:00 AM MT	21 Partner in Care 6:00 PM PDT 8:00 PM CDT 9:00 PM EDT 3:00 PM HST 7:00 PM MT	22 Round Table 1:00 PM PDT 3:00 PM CDT 4:00 PM EDT 10:00 AM HST 2:00 PM MT	23	24
25	26 Village Meeting 6:00 PM PDT 8:00 PM CDT 9:00 PM EDT 3:00 PM HST 7:00 PM MT	27	28	29 INTERNATIONAL DAY OF FRIENDSHIP	30	31

PARTNER IN CARE MEETING: (Formerly "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.

VILLAGE 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. Village Meetings are packed with a wealth of amazing information so bring your pencil and notepad!

"ROSEN ROUND TABLE" MEETING: Join a loving circle of like-minded individuals including local professionals. Learn what works for others, share what works for you. Find out what doesn't work for certain individuals. Share emotional trials and tribulations. Realize that you are not alone and that others can relate to and learn from your story.



NEWSWORTHY NOTES

July 2021 / Issue No. 344 / Published Monthly

PARKINSON'S RESOURCE ORGANIZATION

Working so no one is isolated because of Parkinson's
74785 Highway 111, Suite 208 • Indian Wells, CA 92210

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.