

PARKINSON'S RESOURCE ORGANIZATION

Working so no one is isolated because of Parkinson's

MESSAGE

PRESIDENT'S

December: the end of another amazing year all wrapped up in Holiday celebrations, merriment, good cheer, New Year's resolutions, and reflections. Many people take stock, and mark the year as one to: remember, forget, celebrate, regret. Each summary is as unique, personal, and individual as we are, but in the end, one year ends, and a new one begins.

How will *you* remember the year? At PRO, blessed by your appreciation and gratitude, our choice is to reflect on the good we have done, the difference we have made and the change in attitude and circumstance we help bring about with the resources, counseling, support groups, and education we deliver to those needing our help.

The road seems never ending, every step takes so much effort, yet as we move forward we must always reflect on our PROGRESS: a desperate cry for help, answered; a resource shared with someone in need; answers to a million questions asked by a new attendee at a support group. Miracles and magic, one and all, each giving US the power and inspiration to greet the new year with enthusiasm and excitement.

We all have much to be grateful for. PRO is grateful for YOU, your thoughts, your encouragement and your constant support. Together let's move forward with the strength of our progress and the inspiration of all that is possible in the months and years to come.

The **ROAD TO THE CURE** on this page continues with the UPDATE *"Our plans are to take our drug to the patients... before starting clinical..."*.

Enjoy other PROVOCATIVE and informative news such as: **MITCH'S PITCHES PRO** results on page 2; **WHAT IS LSVT BIG?** by Lucy Sanchez, M.S. CCC-SLP on page 3, **THE GIFT-OF-HOPE" DONOR PROGRAM**, Reprinted by Popular Request on page 4, **NON-DRUG TIPS FOR COPING WITH CHALLENGING BEHAVIORS** by Esther Heerema, MSW, on page 5, and **PIANO LESSONS** on Page 7.

We know we are providing valuable information and support in the Parkinson's community, we continue to appreciate your monthly or general donations through our safe PayPal donation page at ParkinsonsResource.org/contribute-2/ or by mail to our office in Palm Desert, California.

Until next month, REMEMBER Pearl Harbor Remembrance Day on the 7th, Winter Solstice

cont. on page 7

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

Ram S. Bhatt, CSO, CEO

"Our plans are to take our drug to the patients... before starting clinical..."

ICBI-Pharma Collaboration

We have a Material Transfer Agreement (MTA) with a large pharmaceutical company to affirm our efforts and findings in their laboratory. This process was agreed upon prior to their making a possible offer to ICBI. ICBI scientists shipped mice to this US pharma in July for eight weeks' acclimatization in a facility nearby. The experiment was supposed to have been performed in September but was delayed due to reorganization at the pharmaceutical company where the Director of their Imaging Program, one of the champions for ICBI/Pharma collaboration was let go September 1st, along with numerous other employees. The new scientist responsible for conducting this study is working to familiarize himself with the SPECT scanner the Pharma has together with other aspects of the experiment. This Pharma has never imaged a mouse brain using a radiolabeled antibody, consequently the new scientist is insisting on using fivefold higher dose, of iodine-125 labeled-syn-SM for imaging a mouse brain, than what was proposed by in the initial Material Transfer Agreement. We are concerned that the capability of the Pharma's scanner and the inexperience of the scientist assigned to our project may create an unsuccessful collaboration. Nevertheless, we are hoping that this Pharma conducts this experiment before the year ends with results that are as good as the one our Canadian partners obtained two years ago.

Therapeutic Efficacy of our Parkinson's Drug

(alpha-Synuclein-SMART Molecule)

We are happy to report that Parkinson's-like mice treated with two and six doses of our alpha-synuclein-SMART Molecule showed significant reduction in the levels of pathogenic (disease causing) protein in their brain. These experiments support the therapeutic utility of our Parkinson's drug. Dr. Angela Cone presented the therapeutic efficacy data at the Therapeutic Conference held by the Michael J. Fox Foundation (MJFF) in New York on October 24th. According to Angela, no one else presented data related to therapeutic effect of drugs on Parkinson's disease at the MJFF conference. ICBI was the only company that demonstrated therapeutic utility of its drug in an animal model.

However, there are some major conceptual differences between ICBI and the advisors of MJFF:

- 1) The Foundation's emphasis is on the development of a diagnostic test for early diagnosis of Parkinson's while ICBI's focus is both diagnosis and therapeutic modification and the halting of Parkinson's progression. Our drug is capable of diagnosing and halting the disease progression in animals.
- 2) The big difference, however, is in defining what forms of pathogenic alpha-synuclein should be targeted for diagnosis and therapy. Currently, according to Dr. Eliezer Masliah, one

cont. on page 6

OUR WELLNESS VILLAGERS:

ACUPUNCTURE

- Dr. David Shirazi

ADAPTIVE CLOTHING

- Health Aides Made Easy

AROMA THERAPY

- Renee Gauthier

ASSISTIVE TECHNOLOGY

- California Phones

CARE FACILITIES

- Atria Hacienda

CHIROPRACTIC

- Dr. Curtis Budding

CLINICAL TRIALS

- California Clinical Trials

CRANIOSACRAL THERAPISTS

- Center for Physical Health

DEEP BRAIN STIMULATION

- Dr. Michel Lévesque

DENTAL HYGIENISTS-MOBILE

- Betty Anna Gidlof

DENTISTS

CMD/TMJ DENTISTS

- (CA) Dr. George Altuzarra
- (CA) Dr. Maryam Bakhtiyari
- (CA) Dr. Dwight Jennings
- (CA) Dr. Steven Olmos
- (CA) Dr. David Shirazi
- (CO) Dr. Stephen Winber
- (CT) Dr. Patricia A. Richard
- (IL) Drs. Ed and Lynn Lipskis
- (KY) Dr. William H. Funk
- (PA) Dr. Stephen D. Smith
- (TX) Dr. Risto Hurme
- (VA) Dr. Brendan C. Stack
- (VA) Jeffrey L. Brown

SLEEP MEDICINE DENTISTS

- (CA) Dr. Maryam Bakhtiyari
- (CA) Dr. Steven Olmos
- (CA) Dr. David Shirazi
- (IL) Drs. Ed and Lynn Lipskis
- (PA) Dr. Stephen D. Smith
- (TX) Dr. Risto Hurme
- (VA) Dr. Brendan C. Stack
- (VA) Jeffrey L. Brown

ELDER LAW ATTORNEYS

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

ESTATE PLANNING- ACCOUNTING

- (CA) Reesa Manning
- (CA) William R. Remery
- (NY) Ronald A. Fatoullah

FELDENKRAIS METHOD® PRACTITIONERS

- Center for Physical Health
- LeAnn Brightwell, CM

FINANCIAL ASSISTANCE

- The Assistance Fund, INC

HEALTHY PRODUCTS

- Healthy Chocolate
- Wild blue-green algae
- Nerium Age Defying Formula

HOSPICE CARE

- Family Hospice (local)
- Gentiva Hospice (regional)
- Vitas Healthcare (Nationwide)

INCONTINENCE SUPPLIES

- Geewhiz

IN HOME CARE PROFESSIONALS

- Eldercaring
- Cambrian Homecare
- Senior Helpers of the Desert

LEGAL-ATTORNEY-LAWYERS

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

LSVT LOUD PROGRAM

- Easy Speech Communication Center

LSVT BIG PROGRAM

- New Beginning Physical Therapy

MASSAGE & BODYWORK

- Mot'us Floatation & Wellness Center

NEUROSCIENCE

- Desert Psychology & Neuroscience Center

NURSING HOME ATTORNEYS

- (CA) Zoran K. Basich

NUTRITION- WELLNESS CONSULTANTS

- Wayne Myers

PHYSICAL THERAPISTS- TRAINING SPECIALISTS

- Center for Physical Health
- New Beginning Physical Therapy
- Innergy Therapy Systems
- Desert Zen Wellness

PHYSICIANS AND SURGEONS

- Dr. Michel Lévesque

ROCK STEADY BOXING-DESERT CITIES

- Gloria Landau, Head Coach

SENIOR HOUSING

- Atria Hacienda

SPEECH THERAPY

- Easy Speech Communication Center

TRANSPORTATION

- LA Car Service

VISION

- Riverside Institute of Vision Rehabilitation
Drs. Kohtz & Spurling

WATSU

- Kim L. Hartz, LMT, WABA

MITCH'S PITCHES PRO

Wednesday, November 9, 2016, and the beautiful location was Mitch's Prime Seafood Restaurant on El Paseo. It was *exquisite*. Not only was it oversold, it produced sufficient funds for us to purchase our new software and get it implemented. Look for changes to our website and better responses to inquiries in 2017.

We first must thank our financial sponsors, Sharon & Robert Keith and the Auen Foundation.

The Grand Prize winners, Suzanne & David Etheridge, were not in attendance (*it was not a requirement*) however, because they were local, at a later date, we were able to introduce the winners to **Sharon & Robert Keith**, the donors of a one-week stay in their lovely home in Coronado Cays.

The Musicians were made up of our former employees, Douglas VanSant (now leader of the band The Flusters) and Ivan Garcia (now known as Eevann Tré) and their friends... simply wonderful music was chosen.

Our celebrities were **Trini Lopez**, International Songwriter & Singer and on the BOD of PRO, **Tristin Rogers**, of **General Hospital** and **The Young and The Restless** fame, and **Jim Lefebvre**, former MLB second baseman, third baseman, manager and coach, and television actor, and they mingled with everyone. Our Emcee was local radio host, **Dan McGrath** of **Sunny 103.1 FM**. Together he and **Jo Rosen** did a superb job of keeping the program short, yet entertaining and informative.

The major donors to our "Technology Ask" declined being identified, yet they unselfishly donated \$10,000 in memory and honor of Harry Parkhurst. Other local Wellness Villagers were in attendance, and acknowledged.

Two representatives from the Biotech ICBI, Douglas Bennett and Richard Simpson, were there supporting the event.

cont. on next page

WHAT IS LSVT BIG?

Lucy Sanchez, M.S. CCC-SLP

The Lee Silverman Voice Treatment (LSVT) BIG Program is designed to help with the initiation and execution of physical movements. The LSVT BIG program was created according to the principles of the LSVT Voice program, which follows a structured schedule that research has shown to produce positive patient outcomes. Participants in the LSVT BIG program should expect a comprehensive treatment—four sessions per week for four weeks for a total of 16 sessions. The LSVT BIG program is given by a licensed Occupational Therapist or licensed Physical Therapist who undergoes LSVT training and certification program to learn improved strategies for control of upper and lower limbs, balance, walking, and other movements, designed to help an individual with Parkinson's with everyday living movements.

According to LSVT research, greater results are obtained as soon as there is a diagnosis of Parkinson's (LSVT, n.d.). Improved outcomes are seen by patients who undergo the LSVT BIG program. (LSVT, n.d.). (*What is LSVT big? LSVT Global. Retrieved from: lsvtglobal.com/patient-resources/what-is-lsvt-big*)

The BIG Program is demonstrated with **BIG arms, BIG steps, BIG fingers** in the course of a 60-minute workout with the word “big,” before modeling the movement. The therapy emphasizes amplitude—in this case, exaggerated size in movement—in order to restore normal activity.

You can take medications, you can have surgery, but in a disease that makes people feel completely out of control, this is empowering. It gives them control.

There is also some research evidence that it can slow the progression of the disease. The same approach can also help stroke patients, those with multiple sclerosis, cerebral palsy and Down syndrome, according to the LSVT website. The exercises are great for fall and balance issues too.

According to one LSVT BIG client, “Parkinson's is kind of a sneaky disease and the BIG program is the only thing that's kept me mobile.” It was particularly helpful to her after with her balance after experiencing several falls.

By emphasizing amplitude, whether in speech or movement, you get at many different aspects, including improved posture. The big movements also help to counteract slowed movement of the disease.

Part of the therapy's efficacy, according to the organization's website, is its simplicity. By focusing exclusively on one aspect to change, it's easy for clients to comply, follow and practice the recommendations.

The therapy also relies on an initial intensity to promote “activity-dependent neuroplasticity,” in which the brain actually creates new pathways. It is designed to counterbalance the loss of ability by instituting other muscular activities.

The BIG program requires four one-hour sessions weekly for four weeks and is covered by most commercial insurance providers.

LSVT BIG is now being offered at Easy Speech Therapy Center, a fully licensed and certified LSVT provider. Easy Speech Therapy Center is also a participatory Medicare provider, and coverage for LSVT Big is now available via Medicare benefits. Find Easy Speech Therapy Center in the Wellness Village under ParkinsonsResource.org/blog/easy-speech-communication-center/

MITCH'S PITCHES – cont. from previous page

We had wonderful Silent and Chinese auctions. Our volunteers and staff monitored and ran the auctions very smoothly. PRO couldn't have asked for better, more jovial and hospitable help.

Our photographer was our friend Kate Porter. Pictures of the event will be placed on our website under ParkinsonsResource.org/category/special-events/

We continue “Working so no one is isolated because of Parkinson's.”

BOARD OF DIRECTORS

GOVERNING BOARD

JO ROSEN

President & Founder

WILLIAM R. REMERY, ESQ.

ELDER LAW, PRO Secretary/Treasurer

KAYA KOUVONEN

Transportation

ADVISORY BOARD

JACOB CHODAKIEWITZ, MD

PATRICIA DUNAY

DAVID M. SWOPE, MD

DR. ANA LORENZ

CLAUDE VALENTI, OD, FCOVD

DANA BERNSTEIN

Advertising Director

SUE DUBRIN

HONORARY BOARD MEMBERS

GREG A. GERHARDT, PHD

MICHEL LÉVESQUE, MD

STEPHEN MACHT

Actor/Director

TRINI LOPEZ

Int'l Singer/Songwriter

EMERITUS

MARIA ELIAS

DEBBIE STEIN

ROGER RIGNACK, MBA

GONE, BUT NOT FORGOTTEN

ALAN ROSEN, FAIA

ELINA OSTERN

JERRY BERNSTEIN

JACK HISS, MD

PHILIP GUSTLIN, ESQ.

DR S. JEROME TAMKIN

SHIRLEY KREIMAN

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 RECENT "SPECIAL" BOOSTERS:

LYNN HAWKS, ONLINE MEDIA PROS

GARY LOPEZ ~ G~ARIES VISIONS

THE DESERT COMPUTER DOCTOR

ROBIN BROWN

CHARLENE AND FRANK RAU, PH.D.

MARILYN VAN SANT, MFT

SUE DUBRIN

FRANK & MARY BUYTKUS

IRENE MOTTA

LINDA McCANN & BILL SMITH

WALT & PAT BENSON

MARY ETTA HANSBOROUGH

CHARLENE & ROBERT SINGER

JON & MARTHA HANSON

RON BUCKLES

JOHN & JUDITH GUNDERSEN

SHEILA HEFFERNAN

EVA MYERS

JON PEARL

RICHARD CORDES, CPA, JD, LLM

MASSI ABADI, MFT

IRENE SOMERS

CAROLE ROBERTS-WILSON, MS-SLP

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



Facebook.com/
ParkinsonsResourceOrganization



twitter.com/ParkinsonsPro

THE "GIFT-OF-HOPE" DONOR PROGRAM

Reprinted by Popular Request

Frequently Asked Questions About Donation To The "Gift-Of-Hope"
Donor Program For Parkinson's Disease

1. **WHAT IS THE PURPOSE OF A BRAIN DONATION?** Brain donation is a valuable gift. One brain provides a basis for studies by numerous researchers throughout the United States as well as other countries. "Animal models" of human mental illness and many neurologic disorders simply do not exist. Even with improved clinical research methods such as genetic linkage studies or PET and CAT scans, MRI (NMR) and other imaging techniques, our understanding of the biochemistry and pathology of the brain is best achieved through the use of postmortem human brain tissue.

2. **WHO CAN DONATE?** Any legally competent adult can request to donate their brain to be used for research after their death, just as they can request to donate any other organ. Those who maybe incompetent, or otherwise unable to sign, may provisionally donate through their guardian. However, it is the responsibility of the next of kin/guardian to authorize tissue to be removed for research at the time of death.

3. **ARE THERE ANY RESTRICTIONS?** Use of a respirator to aid in breathing maybe allowed but we wish to know this at the time of death. A decision will be made on a case by case basis. As heart, kidney, and liver donors must necessarily be on a respirator at death, we regret that persons wishing to donate those organs cannot donate a brain to our Center. We cannot accept donations from highly contagious or neurological transmissible diseases (i.e. tuberculous, any hepatitis, Creutzfeldt-Jacob [mad cow] disease).

4. **WHAT ABOUT A BODY DONATION VERSUS A DONATION OF BRAIN AND OTHER ORGANS?** Most medical schools do not accept body donations from persons who have donated any type of tissue. One usually must make a choice between donating their organ(s) versus donating one's entire body to a medical school. Please check with your local medical school for their policy. For donors who also wish to donate corneas, skin, bone when donating one's brain to this Center please check with your local hospital's transplant office for their policy.

5. **WHAT HAPPENS WHEN THE DONOR DIES AND WHAT PROCEDURES MUST BE FOLLOWED AT THE TIME OF DEATH?**

- a) At the time of death, the next of kin or a member of the donor's medical care team should call our Donor Coordinator. During office hours at 310-268-3536; 24-hour pager; 310-636-5199. In the unlikely event that you do not receive a response when paging, please call the VA switchboard at 310-478-3711. They will provide additional phone numbers to reach us.
- b) An after death telephonic informed consent from the **next of kin** must be obtained **before** any tissue maybe removed, even if the donor is registered in our Gift of Hope Program.
- c) It is also important to have the tissue removed as quickly as possible, before embalming or other funeral preparations. We prefer to obtain specimens for research within 6-12 hours after death but special circumstances may cause this window of time to be extended. REMINDER: the next of kin must be available immediately after death in order to provide the telephonic consent for removal of tissues for research.
- d) It is important that our Donor Coordinator speaks with the person removing the tissue to ensure that our research protocol is followed. It is also important that the Donor Coordinator speak with the funeral home/ mortuary personnel to coordinate this donation.
- e) We will arrange for the tissue specimen to be sent to our Center.
- f) After the tissue is removed, the body is released to the family for the arranged funeral services.

6. **MUST THE DONOR BE TRANSPORTED TO OUR FACILITY?** No. The tissue is removed at a facility close to the place of the donor's death. Only the brain and other authorized tissue are sent to our Center.

7. **WHO IS RESPONSIBLE FOR ARRANGING FOR TISSUE REMOVAL?** At the time of death the Resource Center's Donor Coordinator will contact a trained person who will remove the tissue for research purposes. Donor/family member may help us prior to

cont. on page 6

NON-DRUG TIPS FOR COPING WITH CHALLENGING BEHAVIORS

Esther Heerema, MSW published in Very Well

One of the more difficult aspects of Parkinson's dementia or Alzheimer's disease is that it changes the way an individual thinks and reacts to every-day situations. Whether you're providing physical care, bringing your loved one to a doctor's appointment or just spending time with them, you may experience a variety of behavioral challenges, including agitation and physical or emotional aggression. Here are eight practical suggestions for coping with these behaviors:

- ❖ Allow extra time. When you're helping your loved one get ready for the day, plan ahead so that you will not have to rush. A slow, calm approach can prevent or minimize a negative reaction.
- ❖ If agitation or aggression increases, take a break. For example, if you are trying to help your husband get dressed and he's becoming more resistive and angry, take a 15 minute break and then come back in the room to try again. Fifteen minutes later may feel like a new day to him, so return with a smile and try again. Don't use this as a threat to him, but rather as a way to allow him a little control over his day. It also provides you with a chance to take a deep breath and refill your patience level.
- ❖ Provide something for your loved one to hold while you give care. Have you ever had the experience of getting slapped or pushed away when you're trying to help someone with Parkinson's dementia or Alzheimer's? Maybe you're helping brush her teeth and it's just not going well. If you're able, try to engage her by asking for her help with brushing the teeth. If this doesn't work, give her something to do or hold with her hands. This serves as a distraction for her and also helps you be able to provide necessary care. I've seen several individuals respond very positively when offered a baby doll, stuffed animal, their wallet, or a book to hold while care is provided.
- ❖ Approach with a smile. It's easy to expect a negative response from your dad if the day before was not a good one. However, individuals with Alzheimer's or other dementias often react to our facial expression and non-verbal signs, so watch what you project. The words you speak may not always make sense to them, but if you're smiling and gentle each time you approach them, this can help calm them and reassure them.
- ❖ Explain before doing. While your daily routine may always be the same as you care for your loved one, don't assume that they know why you're there and what you want them to do. Using simple words and short sentences, explain that it's time to get dressed and that you would like to help them. You can also try using a picture flashcard to visually display what you would like him or her to do.
- ❖ Focus on the feeling behind the behavior. Do you ever feel like it's a battle between opposing teams just to get your spouse ready for the day? Try to validate, or acknowledge, the feelings he has rather than focusing on the behavior he exhibits. For the person with Parkinson's dementia or Alzheimer's, sometimes hearing you put into words what he's feeling can put you both on the same team in his mind. You might identify his frustration or pain, empathize with him, and reassure him that you love him.
- ❖ Depersonalize. It can be very difficult emotionally when loved ones with Parkinson's dementia or Alzheimer's accuse a spouse or adult child of purposely hurting them, hiding things, betraying them or lying to them. To depersonalize this, remember that this is the disease speaking, and not your loved one.

I know of a situation where a wife continually fretted that her husband was going to kick her out of their home and not allow her to call anyone for help. They had been married for 45 years and there was no basis for her fears. Despite reassurance, promises, and declarations that his love for her would always continue, she persisted in this fear and accused him daily of planning for the time when he would make her leave their home. I spoke with him several times and reminded him that this behavior was a result of her confusion, rather than her true feelings for him. This helped him to remain calm and avoid verbally escalating the argument. Eventually she was able to let this delusion go.

Reminding yourself that the disease is a common enemy of both of you can help you

cont. on page 7

PARKINSON'S RESOURCE ORGANIZATION

VOLUNTEERS

LEONARD RUDOLPH

Bookkeeper

LYNN HAWKS

Web Design & Marketing

GARY LOPEZ

Graphic Artist

AMBASSADORS

SOPHIE BESHOFF

CHERYL EPSTEIN

DOLORES LUHRS & KEN LUHRS

CAROLE ROBERTS-WILSON,
MA-CCC/SLP

CHARLENE & BOB SINGER

GROUP FACILITATORS

PEGGY SEXTON

BARBARA ENGLISH

SUE DUBRIN

VOLUNTEERS/OFFICE SUPPORT

SHEILA HEFFERNAN

EVA MYERS

JOHN PERL

IRENE SOMERS

GAY BAYLESS

MICHELE WALDNER

SARA O'SULLIVAN

GISELA GREENAMYER

KATHY SCHRIEFER

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.

ROAD TO THE CURE – cont. from page 1

of the pioneers in the field, and many other scientists, there is no consensus whether a drug should target only oligomeric (oligo-, “a few” + -mer, “parts”) alpha-synuclein or total alpha-synuclein (monomer [a molecule that can be bonded to other identical molecules to form a polymer] and oligomeric forms) but MJFF’s advisors have come to the conclusion, perhaps prematurely, that only oligomeric alpha-synuclein should be targeted. We believe the targeting of oligomeric alpha-synuclein will only help patients with Lewy body disease but not Parkinson’s patients in whom the levels of both monomeric and oligomeric a-synuclein are elevated.

Our drug targets all forms of alpha-synuclein in the brain of animals. It is our belief, supported by several publications, that the levels of both the monomeric and oligomeric alpha-synuclein are elevated in the case of Parkinson’s disease. Our approach is superior to what the MJFF believes in.

Although we have the capability to develop a drug that will only target and clear Lewy bodies, we are not sure if that is going to be good for ICBI’s business, in that we have to individually manufacture and test two different drugs rather than one that can treat most patients.

3) Immediate Plans:

Our plans are to take our drug to the patients. The following needs to happen before starting clinical trials:

- i) Drug needs to be cloned and manufactured (9–12 months)
- ii) Submit an IND application with the USFDA for approval (3 months).
- ii) Conduct Phase-I human trials (6–12 months).

Note from Jo Rosen: I invite you to contact me if you want more information about supporting The Parkinson’s ROAD TO THE CURE. I would be proud to make the important introduction of you to the scientists at ICBI, and we continue to salute these scientists as they forge ahead!

“GIFT OF HOPE” – cont. from page 4

death by contacting local hospitals in their area to obtain names of pathologists for the Donor Coordinator to contact.

8. **AT WHAT LOCATION WILL THE TISSUE BE REMOVED?** In our recent experience the majority of donors are passing away in a home hospice program or a nursing care facility. Therefore, the limited tissue removal will be carried out at the funeral home/mortuary the family has chosen. Even if the donor dies in a hospital, the tissue removal may still take place in the funeral home/mortuary as some of the smaller hospitals do not have autopsy facilities. This situation is dealt with on an individual basis. If the family has chosen a cremation service it is possible that the crematorium may not have the facility to let us remove the tissue. This situation is dealt with on an individual basis.

9. **WHAT DOES THE FUNERAL HOME/MORTUARY HAVE TO KNOW AND DO?** We suggest the issue of donating tissue for research be discussed by the donor/next of kin with the chosen mortuary at the time of the decision to use them. Once we are notified of a mortuary that the family has chosen we will send them a letter to be placed in their files on how to contact us at the time of death so the donation can take place expeditiously.

10. **WHAT HAPPENS TO THE BODY IN THE AUTOPSY SUITE/MORTUARY?** After the brain and other tissue have been removed, the body is released to the funeral director for whatever arrangements the family has made. An open casket or other traditional funeral arrangements is possible. The exact funeral and burial details, however, remain the responsibility of the donor’s survivors or estate.

11. **IS THERE ANY COST?** The Center pays for the tissue removal, transportation of specimen to us and if necessary use of facility where tissue is removed. Funeral arrangements and expenses remain the responsibility of the donor and family.

12. **HOW CAN DONOR’S SURVIVORS DETERMINE WHO IS NEXT-OF-KIN?** The hierarchy of legal relationships is fairly consistent from state to state. Generally, all legal guardianships, powers of attorney, and other court-appointed relationships end at death. The surviving legal next-of-kin is the first to fulfill one of the following requirements:

- a) Spouse (unless divorced or legally separated)
- b) Adult child (if more than one, all must agree)
- c) Parent
- d) Sibling (if more than one, all must agree)
- e) Other relative (niece, nephew, grandchild, etc)
- f) Executor or Administrator (if already appointed)

13. **WHAT NEEDS TO HAPPEN?** When you enroll in our Gift of Hope program we will request you to provide us with your medical history. This helps us maintain comprehensive information for later correlation with research studies conducted by scientists. Next of kin is contacted by the Coordinator after donor’s death to express condolences as well as gratitude for the donation. Even though the next of kin has given a telephonic informed consent to remove tissue after death for research, we are required to obtain and keep on file an original signed informed consent. At this time, we also send authorization for release of donor’s medical records for their signature and return to us. As with all information, these records are kept strictly confidential.

14. **HOW DO I BECOME A DONOR?** Simply let us know of your wish to become one by **completing specific forms and returning them to us**. These forms can be received through Parkinson’s Resource Organization or directly from us. Your consent to donate is only useful if your next of kin knows of your desire to make this donation as they must be willing and available to give telephonic consent at the time of death. Donor should also discuss this with all family members so there is no confusion of the desire to donate.

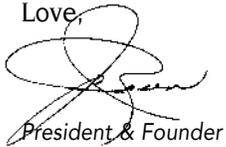
Please feel free to write, call or email us with any other questions you may have.

REMINDER: Even if you are a registered donor in our Gift of Hope Program, your next of kin must be willing and available to give telephonic informed consent at the time of death to make this donation happen.

PRESIDENT'S MESSAGE – cont. from page 1

on the 21st, Start of Hanukkah and Christmas Eve on the 24th, Christmas Day on the 25th and the last day of 2016 or the Eve of 2017 on the 31st. Happy New Year from all of us at PRO!! The flowers are the Narcissus & Holly and the Birthstones are Turquoise & Blue Topaz. ALWAYS remember to CELEBRATE YOU and PRAY FOR OUR TROOPS!

Love,



President & Founder

10 TIPS – cont. from page 6

to decrease your loved one's agitation by allowing you to approach the situation more calmly.

- ❖ Ask for help. Know when to get assistance. As the caregiver, if your own physical, emotional or mental health is declining, seek help. A physician, social worker, other family members and community organizations such as your local Association or Organization can all provide direction for assistance.

Some medications can be helpful in decreasing challenging behaviors. There are also adult day care programs that provide activities during the day time and home health aides that can come in to your home to assist with bathing or other care needs. Sharing the challenge and honor of caring for your loved one with others can lighten the load as well as improve the quality of life for you both.

PIANO LESSONS: A TRUE STORY

At the prodding of my friends I am writing this story. My name is Mildred Honor. I am a former elementary school music teacher from Des Moines, Iowa.

I have always supplemented my income by teaching piano lessons... Something I have done for over 30 years. During those years, I found that children have many levels of musical ability, and even though I have never had the prodigy, I have taught some very talented students. However, I have also had my share of what I call "Musically Challenged" pupils.

One such pupil being Robby. Robby was 11 years old when his mother (a single mom) dropped him off for his first piano lesson.

I prefer that students (especially boys) begin at an earlier age, which I explained to Robby. But Robby said that it had always been his mother's dream to hear him play the piano, so I took him as a student.

At the end of each weekly lesson he would always say "My mom's going to hear me play someday." But to me, it seemed hopeless, he just did not have any inborn ability. I only knew his mother from a distance as she dropped Robby off or waited in her aged car to pick him up. She always waved and smiled, but never dropped in.

Then one day Robby stopped coming for his lessons. I thought about calling him, but assumed that because of his lack of ability he had decided to pursue something else. I was also glad that he had stopped coming. He was a bad advertisement for my teaching!

Several weeks later I mailed a flyer recital to the students' homes. To my surprise, Robby (who had received a flyer) asked if he could be in the recital. I told him that the recital was for current pupils and that because he had dropped out, he really did not qualify.

He told me that his mother had been sick and unable to take him to his piano lessons, but that he had been practicing. "Please Miss Honor, I've just got to play," he insisted. I don't know what led me to allow him to play in the recital—perhaps it was his insistence or maybe something inside of me saying that it would be all right.

The night of the recital came and the high school gymnasium was packed with parents, relatives and friends. I put Robby last in the program, just before I was to come up and thank all the students and play a finishing piece. I thought that any

damage he might do would come at the end of the program and I could always salvage his poor performance through my "Curtain Closer".

Well, the recital went off without a hitch, the students had been practicing and it showed. Then Robby came up on the stage. His clothes were wrinkled and his hair looked as though he had run an egg beater through it. "Why wasn't he dressed up like the other students?" I thought. "Why didn't his mother at least make him comb his hair for this special night?"

Robby pulled out the piano bench, and I was surprised when he announced that he had chosen to play Mozart's Concerto No. 21 in C Major. I was not prepared for what I heard next. His fingers were light on the keys, they even danced nimbly on the ivories. He went from pianissimo to fortissimo, from allegro to virtuoso; his suspended chords that Mozart demands were magnificent! Never had I heard Mozart played so well by anyone his age.

After six and a half minutes, he ended in a grand crescendo, and everyone was on their feet in wild applause! Overcome and in tears, I ran up on stage and put my arms around Robby in joy.

"I have never heard you play like that Robby, how did you do it?" Through the microphone Robby explained, "Well, Miss Honor, remember I told you that my mom was sick? Well, she actually had cancer and passed away this morning. And well... she was born deaf, so tonight was the first time she had ever heard me play, and I wanted to make it special."

There wasn't a dry eye in the house that evening. As people from Social Services led Robby from the stage to be placed into foster care, I noticed that even their eyes were red and puffy. I thought to myself then how much richer my life had been for taking Robby as my pupil.

No, I have never had a prodigy, but that night I became a prodigy... of Robby. He was the teacher and I was the pupil, for he had taught me the meaning of perseverance and love and believing in yourself, and maybe even taking a chance on someone and you didn't know why.

Robby was killed years later in the senseless bombing of the Alfred P. Murrah Federal Building in Oklahoma City in April, 1995.

So many seemingly trivial interactions between two people present us with a choice. Do we act with compassion or do we pass up that opportunity?

PRO CALENDAR FOR DECEMBER 2016

The current support group meeting locations are listed below.
For any information regarding any of these meetings, please contact the PRO Office at 877-775-4111.

				1	2	3
4	5 PALM DESERT Caregivers Only 10:00 am PRO Office 74-090 El Paseo Suite 104	6	7 LONG BEACH Quarterly Round Table Meeting 6:30 pm Bixby Knolls Towers 3737 Atlantic Ave	8	9	10
11	12 PALM DESERT Emotional & Educational Round Table for Caregivers & Public 6:30 pm Atria Hacienda 44-600 Monterey Ave	13	14 GLENDDORA Educational Round Table Meeting 6:30 pm Kindred Rehab @ Foothill 401 W Ada Ave	15 WEST LA Emotional & Educational Support Group for Caregivers 6:30 pm OPICA Adult Day Care Center 11759 Missouri Ave	16	17
18	19 PALM DESERT CANCELLED FOR THE HOLIDAYS	20	21 ENCINO CANCELLED FOR THE HOLIDAYS	22	23	24
25	26 PALM DESERT CANCELLED FOR THE HOLIDAYS	27 MANHATTAN BEACH CANCELLED FOR THE HOLIDAYS	28	29	30	31

CAREGIVER MEETING: (For caregivers only) Come share the ups and downs of living with someone with Parkinson's. Together there are ways of finding solutions that, when alone, might never be considered. No need to continue with your frustrations because you are not alone. Give yourself a break.

EDUCATIONAL MEETING: We invite the community, especially the Person with Parkinson's and their family or friends, to attend. Educational meetings usually feature guest speakers who are professionals servicing the Parkinson's Community. Educational meetings are packed with a wealth of amazing information so bring your pencil and notepad!

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

"FEELING GRATITUDE AND NOT EXPRESSING IT IS
LIKE WRAPPING A PRESENT AND NOT GIVING IT."

— WILLIAM ARTHUR WARD

NEWSWORTHY NOTES

December 2016, Issue No. 289, published monthly

PARKINSON'S RESOURCE ORGANIZATION

Working so no one is isolated because of Parkinson's

74-478 Highway 111, No 102 • Palm Desert, CA 92260-4112

760/773-5628 • 310/476-7030 • 877/775-4111 • 760/773-9803

eMail: info@ParkinsonsResource.org • web: ParkinsonsResource.org

501(C)(3)#95-4304276

We do not intend the PRO Newsletter as legal or medical advice,
nor to endorse any product or service; we intend it to serve as an information guide.