

Parkinson's Patients Support Groups, Inc.

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Donna Kos, the Person Behind the Annual Sunnyvale Parkinson's Walk

By Dean Prescott

Donna Kos is a teacher at Monta Vista High School in Cupertino. With a home in Ohio, she typically drives out to California in the fall and drives back home when school gets out the next summer. In the meantime, when she is not fulfilling her duties as a teacher, she dedicates every extra minute as coordinator of the annual Parkinson's Walk.

The coordinator's job has many facets. First she must pick a date. That sounds easy enough, but it entails picking a date that does not conflict with Mother's Day, the Parkinson's Unity Walk in New York City or half a dozen other concerns. Then she has to go down to the city and reserve the space after the first allowable date and before anybody else takes the spot.

Next is finding sponsors for the event. That means going door-to-door to ask for donations from local businesses. This has not been easy considering the financial climate of these times. Usually it's "Maybe next year." When companies have donated, it is usually with gift certificates that serve as door prizes. Those, of course, are appreciated, but do not help the bottom line as a cash donation does.

Then there is the task of finding people to walk and solicit other people to sponsor them as walkers. This is the real challenge for Donna. How do you find and inspire people to go out and solicit others to sponsor them? Donna does it by going to community events, handing out flyers and talking to hundreds of people about the event, seeking out people who are affected in some way by Parkinson's disease. Maybe it's a relative or a friend who has it.

Once these steps have been exhausted and as the date of the walk draws near, it is time for Donna to turn her attention to the day of the walk. Now she has to make sure there are enough volunteers to man the rest stops, to

register walkers, to pick up donated items such as coffee and ice and snacks that are perishable and can only be picked up on the day of the event.

She should have known it was going to be a tougher than average year when the car she bought to drive out here, blew a head gasket en route, forcing her to complete her journey by airplane and leaving her without a car to help run the endless number of errands that are required for such an event.

Through her persistence, by the day of the walk, enough sponsors had made donations to have a respectable array of prizes. There were enough volunteers to man the registration tables, and the checkpoints. The biggest worry was the weather and though it didn't rain, I have to think that the wind and cold kept some people away. As Parkinson's Walks go, at approximately \$11,000 to \$13,000, this one can be considered an underachiever. After all that effort, this had to be a disappointment.

So what is the difference between this year and others? How can we make the walk better in the future? That is a question we need to grapple with during the off-season. Nobody questions Donna's dedication or her work ethic, however, there are volunteers from respected organizations that may not continue to be associated with an event that seems to be moving in the wrong direction. We have to do better and we have to do it soon.

Does that mean that something good doesn't come out of these events? For me, the amount of money raised is only a part of what the Parkinson's Walk means. It reaffirms the support of my family and friends as I deal with this challenging disorder. For that, I thank Donna Kos for her efforts that make this event possible and I thank my family and friends for their support in dealing with my own issues in fighting Parkinson's disease.

We Have the Power!

By Patricia R. Needle

I was diagnosed with Parkinson's in September 2008. I was pretty freaked. My internal mantra was 'incurable, chronic, progressive neurological disorder.' What lay ahead? What would I look like in a year? Would I be able to continue working as a registered nurse? I told no one but my immediate family, and closest friends. I feared my work would be scrutinized for signs of incipient dementia, or at the least, filtered through the lens of Parkinson's.

I did not imagine that by 2009 I would be dancing! Serendipity arrived in the person of my dental hygienist. She'd asked if I was taking any new medication. I revealed that I had Parkinson's, and had begun to take a dopamine agonist. She offered the phone number of an old friend, also with Parkinson's, who was a founding member of an all volunteer organization: PDActive. The first person I spoke with, Larry Sirott, invited me to a Parkinson's dance performance that evening. I met him, and sat in the audience to watch Claudine Naganuma's original dance, 'Peace about Life.' For the first time since I had been diagnosed with Parkinson's disease, I was in proximity to my new peer group. The dancers with Parkinson's showed incredible strength and grace as they reflected on the impact of Parkinson's in their lives. Larry met with me after the performance and encouraged me to talk about how I was diagnosed. He invited me to join the bimonthly Dance for Parkinson's^R program at Danspace in Rockridge.

Colorful small beach balls are sailing around a sun filled room. The 25 or so people, seated in a circle in folding chairs, are tossing, and kicking them back and forth. Claudine, weaving around the clusters of chairs, carries a bucket filled with long feathers. She invites us to take as many as we'd like. Creativity, and eccentricity are comfortably paired as my fellow dancers with Parkinson's tuck the feathers into their hair, stick them upright alongside their eyeglass stems, or use them to dramatize a gesture. Herb inverts one of the metal folding chairs, and begins to drum. Tim and several women join their voices together to match the beat. Our dance class has begun.

When I entered the Danspace studio for my first lesson I was struck by the spectrum of illness. Some, like myself, took prescription medications, and appeared relatively symptom free. Caregivers and/or partners sat beside wheelchair bound dancers.

The slowed movements and stooped posture of other folks spoke to the physical toll of Parkinson's disease. For the

first time, I looked directly at someone who spoke with a slurred whisper, and had 'mask-like' facial features. I got it. I felt the welcoming spirit of the place support and surround us, equally.

Claudine led the dance class, paired with another Mark Morris Dance Group trained instructor. Her animation, warmth, and clear instruction put me at ease. We sat in chairs and began by announcing our name coupled with a spontaneous gesture. Everyone in the group repeated name and gesture. Laughter punctuated this exercise, as people found more and more outrageous ways to 'gesture.' There was an epidemic of leaps into the air, quickly followed by pratfalls, and log rolls. Don't these people know they're disabled and old?

Claudine, drawing on her own experience, gradually builds up our limited dance vocabulary. She allows us to master some movements, in order to move to more complex interplay, and improvisation. Both instructors, cognizant of the variation in physical abilities, welcome all attempts to follow their lead, while also offering gentler alternatives.

Within a year of joining the bimonthly dance classes I am onstage, performing in a revised "Peace about Life." I'm swaying in time to the atonal music, mirroring the gestures of my peers, and channeling my inner kelp as I move through an underwater garden. Languidly rolling and tumbling sea creatures from age 8 to 80 wash around me. The young dancers assured, supple movements are in sharp contrast to my decades older, hesitant and stiff Parkinson's body. I'm deliriously happy, and obviously out of my depth. Claudine has interviewed me in her soundproof studio (the front seat of her car). Now, I listen to my voice, and the voices of my peers, as they describe their initial response to learning they have Parkinson's. They describe a new puberty: the acceptance of a body transformed by Parkinson's. Our young counterparts, in constant attendance, jump, lift, sway, tremor, and frame our work.

All classes, and even "Peace about Life" end with "The Reverence." We stand in a circle holding hands. When my palm rests against my neighbor's I suddenly become aware that my fellow dancer has a tremor. I turn to my neighbor to make eye contact, and we bow simultaneously. The bow duet is passed along until our circle is complete. It is a silent, and solemn affirmation.

I am awed by the power of the dance to transform, and to alleviate our internal pain. Despite a rainbow of PD side effects, we are all there to dance, to laugh together and to share our best selves. When one of us, barely able to move, does a slow banana twirl into the center of our circle

we give out a collective cheer. We know we have the power.

- Peace about Life was performed at Laney College in Oakland, CA. on June 3, and 4, 2011 at 8:00PM, and on June 5 at 2 :00 PM. Go to www.dNaga.org for more information.
- For more information about programs provided by PDActive in the East Bay including dance, yoga, walking groups and support groups for people with Parkinson's Disease go to www.pdactive.org or call 510-479-6119.
- For more information re: San Francisco Dance for PD: refer to pdsfnetwork@gmail.com or call: 415-285-7377.
- Dance for PD offers dance classes for people with Parkinson's in more than 40 communities around the world. An on-going collaboration between the Mark Morris Dance Group and the Brooklyn Parkinson Group-a chapter of the National Parkinson Foundation-the Dance for PD program also provides teacher training and nurtures relationships among other organizations so that classes based on our model are widely available. For more information contact: www.danceforpd.org

This article was forwarded by Charmaine Eng

Visit our PPSG website: www.ppsg.org for:

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This newsletter was assembled by the Morgan Center in Santa Clara. Thank you!!!

A Note from John Au.....

SUBJECT: New Information at PPSG Web Site

TO: PD Support Group Members

Have you visited the Parkinson's Patients Support Groups' web site, www.ppsg.org, recently? The web site contains volumes of useful information about Parkinson's that is updated regularly. For example, new information packets for patients and caregivers have recently been added. To download the packets, just go to the web site's Home Page; and click on the tabs, **Patients** and/or **Caregivers**, located on the left side of the page.

You will also find tabs for upcoming **Events, Exercise & Therapy, Resources** and Articles of Interest, **Links** to other web sites and the **PPSG Newsletter**. To add yourself to the mailing list for the free newsletters, go to the Home Page and click on **Newsletters**. You will have a choice of receiving the newsletter electronically or through the U.S. Mail. If you use a computer or Mac, PPSG encourages you to sign up for the electronic version because of publication and mailing costs; and you will automatically receive the events calendar electronically whenever it is updated. If you do not have access to a computer, you may request the newsletter via U.S. Mail by writing to the address below or calling (408) 542-5610. Please include your full name, address and telephone number.

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John Au's wife is a member of the Pd Dance class at the Parkinson's Institute.



A Note to Our Readers

This newsletter is for informational purposes only. Readers are advised to consult a trained medical professional before acting on any of the information in this newsletter. The fact that a particular treatment, nutrient, herb, or supplement is discussed in this newsletter in connection with any illness or condition does not necessarily mean that it is safe and appropriate for everyone or that the editor or PPSG recommends its use for that illness or any condition.



Elderly Caregiving: Choices, Challenges, and Resources for the Family

<http://ucsfhr.ucsf.edu/index.php/assist/article/elderly-caregiving-choices-challenges-and-resources-for-the-family/>

By many estimates, the group of American citizens 65 years and older will quadruple in the next three decades. With this expected population growth many of us in the upcoming years will be faced with primary or secondary caregiving for a loved one.

Numerous gerontological research studies report that family members provide nearly 82 percent of the necessary care for an elder family member.

Oftentimes there is one primary caregiver. This person is most frequently the elder's child/children or spouse. There may also be a secondary group of individuals offering support to the elder and the primary caregiver. They could be extended family members, as well as friends.

The Caregivers

The caregivers must often provide care under complex circumstances, often balancing the concerns of their own immediate families, their careers, and their responsibility for elderly caregiving. In fact, caregiving can often be defined as providing unpaid assistance for the physical and emotional needs of another person, ranging from partial assistance to round-the-clock 24-hour care. Caregivers can also be considered *primary* and *secondary*. Several studies report the *primary* is most often a daughter or spouse. The *secondary* caregivers are most often other family and close friends, as well as those who are not relatives. *Secondary* caregivers tend to be less frequently involved in the personal care, although help with support of the elder and respite of the *primary* caregiver.

Feelings and Experience of the Caregiver

Often as the illness or disability condition progresses in aging, the amount of caregiving increases rapidly with little warning. Along this journey of caring also comes a wide range of emotions and circumstances that may be confusing or appear conflictual by the caregiver. For example:

Chronic emotional and physical fatigue.

Internalized guilt.

Issues of death, dying, and other end of life concerns.

Not fully understanding the course or prognosis of the illness.

Anger towards self, the elder, and other caregivers.

Social isolation.

Sadness and grief.

Unexpected and increasing financial burdens.

Complex legal issues.

Stress on one's own immediate family and relationships.

Denial and lack of preparation for the possibility of a difficult course of illness.

Care for the Caregiver

All things considered, one can imagine the incredible importance of the caregivers being attuned to caring for themselves. Many studies report that when there is a strong bond among the caregivers and the elderly that the caregivers feel less stress. However, this may not necessarily be the case at particular points in providing care; therefore, taking care of oneself is important to the entire process. All too frequently caregivers are unwilling, perhaps ashamed to ask for help because they perceive this to be a sign of inadequacy, perhaps even failure. The caregivers cannot be expected to do it all and it is imperative to set limits. To provide effective care, one needs to maintain one's own health. In fact, neglecting your own care may have long-term consequences, not only for you, but also for the person who needs your care. The following items are often neglected by caregivers:

Getting adequate sleep.

Periodic exercise and nutritious meals.

Taking regular short and longer-term breaks from providing care.

Allowing others and/or agencies to take over for you (or collaborate with a co-partner).

A good awareness of knowing and acting upon when you need to rest.

Possible Resources for the Elderly

There are numerous private, community, and government sponsored resources for the elderly and their caregivers. Home delivered meals (often called "Meals on Wheels"), adult day care centers, group living facilities, multicultural centers, religious programs, geriatric social workers, and home health care agencies are examples. The American Association of Retired Persons (AARP), the National Council on Aging (NCOA), the local community senior and cultural centers are also fine examples of

resources. At UCSF there is also the Goldman Institute on Aging at the Mount Zion Medical Center, and the UCSF Auxiliary Services that offers elder care consultation and referral services.

Ten Tips for Family Caregivers

- Caregiving is a job and respite is your earned right. Reward yourself with respite breaks often.*
- Watch out for signs of depression, and don't delay in getting professional help when you need it.*
- When people offer to help, accept the offer, and suggest specific things that they can do.*
- Educate yourself about your loved one's condition and how to communicate effectively with doctors.*
- There's a difference between caring and doing. Be open to technologies and ideas that promote your loved one's independence.*
- Trust your instincts. Most of the time they'll lead you in the right direction.*
- Grieve for your losses, and then allow yourself to dream new dreams.*
- Stand up for your rights as a caregiver and a citizen.*
- Seek support from other caregivers. There is great strength in knowing you are not alone.*
- Caregivers often do a lot of lifting pushing and pulling. Be good to your back.*

As our elderly population increases more rapidly than ever before, and the large numbers of us become caregivers at some point in our life, potentially stressful experiences may await us. However, caring for an elderly individual can be highly rewarding. It may strengthen relationships among family members with numerous opportunities to work together. It is an opportunity to express love and appreciation for the support the elder has given you. Take good care of the elderly, as well as take great pride in yourselves, family, and friends.

This article was forwarded by Robin Riddle.



For current lists on exercise classes, and support group information/activity calendars, please log on to www.ppsg.org.

These lists are maintained by **Steven Russell**.



“You’ve Made a Difference!” Memory Book

By Gail Bauer

Six years ago my husband, a big strong, athletic man of 59, was diagnosed with Progressive Supranuclear Palsy and our lives started to change. One of the most difficult changes has been that he has no longer been able to volunteer and serve others through the church and Rotary. Jay has always been a doer and a giver. He has always been there to help family and friends and the needy. Even though Jay has never complained, I know he misses making a positive difference in the lives of others.

I was at a spouse’s caregiver meeting and I sat beside a man that had just lost his wife to PSP and he said he wished that his wife could have read the wonderful cards and letters that he had received telling happy stories about how she had influenced their lives and made a difference to them.

This made a deep impression on me and I decided Jay needed to hear these positive things now. I sent emails and letters out to all our friends and family asking them to please send pictures and stories of their favorite memories of times with Jay and I put them into a “You’ve Made a Difference! Memory Book”

We had a fantastic response and I showed it to Jay on our 22nd wedding anniversary. We laughed, cried, read and reread the letters. The pictures brought back the images in vivid details. Fortunately, Jay’s mind is still sharp even though he can’t talk, walk, or read. Friends and family are still sending notes and pictures so we are still adding to the book. We will enjoy this book for many years to come. I know it has been a wonderful reminder to Jay of how many ways he has made a positive difference in people’s lives.

I encourage you to do this for your loved one NOW, don’t wait. We all need to know that we have made positive contributions to this world and made a difference.

Blessings to you!

Jay and Gail Bauer are members of the Pd Dance Class at the Parkinson’s Institute. The class meets on Tuesdays, from 10:30 – 12 noon. This article was forwarded by Dr. Melanie Brandabur, Clinic Director at the Parkinson’s Institute.

Neurology Dept. at Stanford University Looking for Study Volunteers -- with PD and Healthy People

The Department of Neurology at Stanford University School of Medicine is looking for volunteers, both male and female, to participate in a brain imaging study of Parkinson's Disease. There are two studies -- one of those with Parkinson's disease and one of healthy volunteers.

Both studies include a functional MRI brain scan, neurological and neuropsychological evaluations, balance and gait testing. The goal for this research is to develop imaging markers to aid in the better understanding of Parkinson's disease. All procedures will be performed at the Stanford University Medical Center.

For more information about either study, contact: **Jennie Lambert-Lynch** at **650-723-0060**, **lambertj@stanford.edu**. Principal Investigator: Kathleen L. Poston, MD, MS, Movement Disorders Center, Department of Neurology, Stanford University Medical Center. For general information about participant rights, contact **866-680-2906**.

Here are specific details of each study:

Volunteers with Parkinson's

When: All procedures will take place in either two or three visits. Most participants are able to complete the study in one full day, and one half day of participation.

Eligibility: Ages 35-75, having a diagnosis of Parkinson's disease, no history of other neurological illness, and able to lay flat for a MRI scan.

What to Expect if you Volunteer for this Study: On the day of your visit, the tests will be carefully explained to you, and any questions will be answered.

- A memory test will be performed
- Two separate two-hour MRI scans will be performed
- Two one-hour balance and coordination test will be performed.

Healthy Volunteers

When: All procedures will take place in either one or two visits. Most participants are able to complete the study in one half day of participation.

Eligibility: Ages 35-75, no history of other neurological

illness, able to lie flat for a MRI scan.

What to Expect if you Volunteer for this Study: On the day of your visit, the tests will be carefully explained to you, and any questions will be answered.

- A two-hour MRI scan will be performed
- A one-hour balance and coordination test will be performed.

To Our Support Groups' Members: By Charmaine Eng, Charman, PPSG

Earlier this year, we, PPSG, printed a descriptive article in our newsletter, (Feb./March 2011 Issue), describing the purpose of a Parkinson's Support Group and the advantages of being part of one. There are many benefits one can receive. A very important aspect is the opportunity to reach out and share among each other, one's concerns and challenges that may be experiencing in his/her daily activities and life; and in return, receive support from the members of the group. Supposedly, all this is done in a **safe** environment. However, it is often taken for granted, the need to be reminded in support groups meetings that **confidentiality** exists, and to be stated openly.

A good example to consider is the "Confidentiality Statement for Petaluma Movers and Shakers," , submitted **Pearl Sorenson, Petaluma SG Leader** , written as follow: "We, the Movers and Shakers, agree to respect one another's privacy by practicing the "golden rule."

For people to feel safe and get what they need from this group, we must remember that what is said to us by others in the group is confidential information. As members gain trust there is more self-disclosure; private information becomes "public": confidentiality is a basic requirement for a successful group. Confidentiality means never discussing, without consent, the circumstances of another member.

This statement has grown out of our 4/15/11 discussion. It can be amended by the group whenever the need arises.

Cognitive Training Can Alter Biochemistry of the Brain

ScienceDaily (Feb. 9, 2009) — Researchers at the Swedish medical university Karolinska Institutet have shown for the first time that the active training of the working memory brings about visible changes in the number of dopamine receptors in the human brain. The study, which is published in the journal *Science*, was conducted with the help of PET scanning and provides deeper insight into the complex interplay between cognition and the brain's biological structure.

"Brain biochemistry doesn't just underpin our mental activity; our mental activity and thinking process can also affect the biochemistry," says Professor Torkel Klingberg, who led the study. "This hasn't been demonstrated in humans before, and opens up a floodgate of fascinating questions."

The neurotransmitter dopamine plays a key part in many of the brain's functions. Disruptions to the dopamine system can impair working memory, making it more difficult to remember information over a short period of time, such as when problem solving. Impaired working memory has, in its turn, proved to be a contributory factor to cognitive impairments in such disorders as ADHD and schizophrenia.

Professor Klingberg and his colleagues have previously shown that the working memory can be improved with a few weeks' intensive training. Through a collaborative project conducted under the Stockholm Brain Institute, the researchers have now taken a step further and monitored the brain using Positron Emission Tomography (PET scans), and have confirmed that intensive brain training leads to a change in the number of dopamine D1 receptors in the cortex.

Their results can be of significance to the development of new treatments for patients with cognitive impairments, such as those related to ADHD, stroke, chronic fatigue syndrome and ageing.

"Changes in the number of dopamine receptors in a person doesn't give us the key to poor memory," says Professor Lars Farde, one of the researchers who took part in the study. "We also have to ask if the differences could have been caused by a lack of memory training or other environmental factors. Maybe we'll be able to find new, more effective treatments that combine medication and cognitive

training, in which case we're in extremely interesting territory."

Positron Emission Tomography is a medical imaging technique based on the decay of radioactive isotopes that is able to produce three-dimensional pictures of the movement of signal substances in the living body. Karolinska Institutet has been able to invest in the world's most powerful PET scanner for brain imaging thanks to a financial contribution by pharmaceutical company AstraZeneca.

In Memory

Donations were recently received in memory of the following individuals:

Lyle Akey, John Chet Banta, Eunice Brown, William Chin, Patrick Forster, MaryAnn Garrido, Gregory A Hively, Mary Kloock (mom), Albert Mauer, Emmett McCourt, Larry McDermott, Robert S Miller, Walter Mitchell, Helen Smith, Paul Smith, Gerald L "Jerry" Swezea, and Ruth R Young.

In Honor

Donations were recently received in honor of the following individuals:

Pierina Fanucchi, Patrick Vivian Forster, And PPPSG Board of Directors.



The positive thinker constantly sends out positive thoughts, together with vital mental images of hope, optimism, and creativity. He therefore activates the world around him positively and strongly tends to draw back to himself positive results.

Excerpted from the writings of Dr. Norman Vincent Peale.



Parkinson's Women's Support Group offers moral support, encouragement and camaraderie for women who are either Parkinson's Disease patients, or caregivers.

In 2008, a group of newly diagnosed and young-onset female Parkinson's Disease patients were introduced to each other by Dr. Melanie Brandabur at the Parkinson's Institute in Sunnyvale, CA. Dr. Brandabur suggested that with our positive desire to help and inspire others we might collectively benefit from each other's company and find a way to reach out to others. The group's focus is on living life as fully as possible despite/with PD.

After meeting once a month socially for couple of years, we decided to bring our good will to a larger audience on Facebook. If you are a woman with Parkinson's you are not alone because we are here with you. Please consider joining us for our next Tuesday lunch (usually the third Tuesday of the month) at Zibbibo's in Palo Alto. More information on reservations for our next lunch are posted on our Facebook site:

<https://www.facebook.com/pages/Parkinsons-Women-Support/121474951248509?sk=wall>



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