



National Parkinson Foundation Orange County Chapter

The Parkinson's Center, 355 Placentia Avenue, #302, Newport Beach, CA 92663 • 949-574-6338

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PAINT A CANVAS OF HOPE

Approximately 8000 of our Orange County neighbors have been stricken by Parkinson's disease, and the Orange County Chapter is once again preparing to do its share to fight back.

On Sunday, October 6 from 2:00-6:00 PM we will hold our fifth annual fund-raising event to generate resources for promising research in Parkinson's disease and for our Patient Services and Outreach Program at Hoag Hospital. **PAINT A CANVAS OF HOPE**, an afternoon of *Art and Ambience*, will be held at the Richard MacDonald Gallery in Laguna Beach.

This year's event will honor the memory of Stanley Scher, the founding president of the Orange County Chapter, which began in 1993. After a twenty-two year battle with Parkinson's disease, Stan passed away in January of this year.

Planning for the day is already underway, but there can never be too many donations...or too many volunteers to help with the effort. We need donations of all kinds...live auction and drawing items...financial contributions...underwriting...and anything else appropriate for a quality event. The program and its sponsors will be widely publicized.

NPFOCC is a 501(c):3 nonprofit corporation. Donations are tax deductible. The success of our efforts will depend on everyone who can contribute funding, gifts, and time. A hard-working committee can only do so much. This is certainly one time when the human resources of all of Orange

County are needed. If you want more information, would like to receive an invitation to the event, or can provide assistance in any way, please call (949) 574-6338. We will be glad to answer your questions or sign you up to lend a hand.

Remember...currently more than one million Americans have been immobilized by Parkinson's disease. While there is still no cure, every research project has the potential to provide the major breakthrough we all hope is imminent. Please join us in this ongoing battle.

❖We re Still Looking❖

The April newsletter sought input and membership for two different local resource groups. If you can help but have not yet contacted us, please do so.

① Our attempts to develop a *resource list* of professionals who have demonstrated an awareness of the unique needs of Parkinson's patients has expanded from the original effort announced in April. Please see the article about PIP that appears on page 2 of this issue.

② We are also seeking participants for a group to exchange information regarding surgical procedures related to Parkinson's. If you have had surgery or are considering it, please contact Ruth Hamilton at the number/address on the bottom of page 2. The first meeting will be on Thursday, July 25 from 10:30-11:30 at our office.

Coordinator's Corner**by Mignone Trenary**

Hi and a warm summer greeting to all of you,

As we enter into the "dog days" of summer, remember to stay cool. Many of you with Parkinson's disease are affected by the hot weather. It seems to sap the energy and strength. Try to avoid being in the sun during the hottest part of the day. Stay inside, turn on the AC, or go to an air conditioned mall or movie. Along with that, pay extra attention to keeping yourself hydrated. While not always easy, it is still recommended that you drink 6-8 glasses of fluid per day. It's important to remember this, as I have known several people in our support groups who have had complications after becoming dehydrated.

Speaking of support groups, most will not meet for the month of July, with two exceptions. The weekly Tuesday Coffee & Chat group will continue. The meeting place is St. Marks Presbyterian Church in Newport Beach from 10-12. The caregiver group will also continue on the second and fourth Mondays at the Irvine Lakeview Senior Center from 3:00-4:30. I hope to see you at one of them.

Thinking beyond summer, there are two events to put in your calendar. On **Sunday, October 6**, NPFOCC will celebrate the Canvas of Hope fundraiser in Laguna Beach. Please see page 1 for details. Some of you may wonder why we need to have such functions. Fundraisers are important for several reasons. When we gather together in a united effort such as this, we not only give each other support, but we also bring our plight to the attention of our neighbors and community. We create a public awareness of our cause, and many, many individuals who may not have known about Parkinson's disease or our fight to find the cure come out to join us. We are doing something that each of you can also join in and be a part of, helping to make this a most special event.

The second date is **Sunday, November 3**. We are honored to have the privilege of Abraham Lieberman, MD as our keynote speaker. Dr. Lieberman is an internationally recognized expert on Parkinson's disease. He is the author of five books on the subject with his most recent *Shaking Up Parkinson Disease – Fighting Like A Tiger, Thinking Like A Fox*. Dr. Lieberman is also the National Medical Director for NPF, as well as the "doctor" at the other end of the website www.parkinson.org "ask the doctor" site. This will be a symposium you won't want to miss.

PIP COMMITTEE FORMED TO PROVIDE RESOURCES AND REFERRALS

A new committee under the leadership of Gary Boelzner has been formed by NPFOCC to provide resources and referrals for Orange County Parkinson's patients. The new committee, Partner's in Parkinson's, is known as PIP for short. The committee's purpose is to compile a countywide list of providers who have demonstrated exceptional care in serving the needs of local Parkinson's patients.

How to reach us...**Mignone Trenary, Coordinator**

The Parkinson's Center
355 Placentia Avenue #302
Newport Beach, CA 92663

Telephone: 949-574-6338

Website: www.npfocc.org

Email: info@npfocc.org

Bob Dallow, Newsletter Editor

Telephone: 949-498-1356

Email: Jobobsocal@aol.com

The list will include neurologists, general practitioners, dentists, physical and occupational therapists, psychiatrists, ophthalmologists, and nutritionists, as well as residential care facilities, and anything else members might suggest.

You can help by providing the names of providers who have demonstrated a special awareness of the needs of Parkinson's patients. Please call Mignone Trenary with the provider's name, address, phone number, and area of specialty.

A tip from Dr. Janet Chance ...her "gait mantra"...First stand straight...think "heel before toe"...swing your arms...feet apart...then walk like John Wayne! This lowers your center of gravity and will decrease the risk of falling.

FROM OUR READERS: Tips, Suggestions, and Ideas

We keep asking...and several of you have answered! A number of people have provided suggestions that might benefit Parkinson's patients and caregivers. We're happy to share them with you, and are hopeful that more of you will share your ideas with us so we can pass them on. Please get them to Bob Dallow or Mignone Trenary at the addresses on page 2.

Roberta and Bill Schmidt of Huntington Beach pass along a tip for the prevention of bladder infections from Dr. Don Udall, a nationally respected urologist.

[1] Drink 5-8 ounces of cranberry juice once or twice a day. Drink only cranberry juice that is unsweetened or sweetened with a natural juice such as grape juice. Avoid the cranberry juice cocktails or blends that have been sweetened with corn syrup or fructose.

[2] Take two time release or extended release 1000 mg Vitamin C capsules a day, one in the morning and one in the evening so that twelve-hour protection is spaced evenly throughout the day.

[3] Drink 6-8 glasses of water throughout the day. Each glass of water should measure eight ounces. The cranberry juice can count as one of the glasses of water.

Nancy and Don Grant of Laguna Beach cite a Reuters report of a British study that concludes the act of chewing gum can have a positive impact on thinking, memory, and other cognitive tasks. The key to the memory improvement is the repetitive chewing motion. Andrew Scholey of the University of Northumbria concludes that improved memory could be attributed to both an increased heart rate and a surge of insulin to the brain as a result of the gum-chewing activity.

Jack Lane of Laguna Woods suggests using a small stool to assist in dressing the lower extremities. Whether it's the initial step in donning slacks or shorts, or putting on shoes or socks, it helps to start with the foot elevated off the floor on a small stool so that the bending distance is minimized.

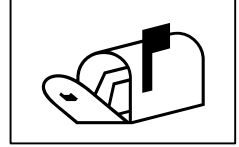
Liz Noriega of Mission Viejo makes us aware of a pen designed for arthritis sufferers, which would also benefit those dealing with micrographia. Called a *ring pen*, it helps by raising the fulcrum of the pen stroke, which automatically will increase the size of writing. This product can often be found in mail order health catalogs.

More from Liz: In addition to the ring pen above, Liz suggests writing can be improved if you use lined paper and write *through*, not *on* the line. She states, "I make it a point to bisect the line with each up and down stroke, and the problem of micrographia or stalling immediately eases. The trick is to cross the line with each letter, above, and then below. I suspect that this is akin to the experience of freezing in which the person cannot step forward until an object, line, or barrier is put in front of the individual."

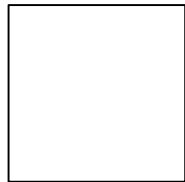
One more time... Finally Liz switches to another communications problem – speaking. She suggests that you can combat the problem of speaking by adding an accent. This is effective whether you wish to initiate a conversation or continue one that was stalled by a sudden loss of speech. "I guess," Liz says, "that since it is the automatic speech pathways from the brain that are impaired by Parkinson's, and an accent is not automatic, the brain sends the message through different pathways, thus detouring the troubled routes." A similar success has been experienced by stutterers and Parkinsonians who are able to sing but can't readily talk to others.

Beyond The World of Orange County

We are all recipients of a large number of Parkinson's mailings from a variety of different organizations and individuals. For that reason, when this newsletter was conceived, we decided that – for the most part – we did not want to repeat articles that you could read in those other sources. That is why we stress tips received from others in our area, our local fund-raiser, and the contributions of those generous individuals who support NPFOCC.



Nevertheless, we also realize that some individuals might not receive the same newspaper, journals, or newsletters as others do. In order to fill that gap, while remaining a local newsletter, we will from time to time offer brief summaries of articles that you may have missed the first time around. This page is devoted to such topics.



We have our own website, and you are urged to periodically check www.npfocc.com for updates. But there is another website that you also should visit on a regular basis. The national organization can be located at www.parkinson.org. In addition to such topics as Events, Reference, and Research Studies, you can ask questions of a doctor, dietitian, or other resource. If you read something elsewhere and want more information, try this website.

And speaking of reading, here are a few articles that you may or may not have seen the first time around...

One of the most well publicized topics recently has been the costs of **drugs** and the issuance of drug discount cards. Congress has been debating the issue. The June issue of the *AARP Bulletin* reported that the organization "last month escalated its campaign to curb prescription drug costs when it joined three lawsuits charging drug makers with acting illegally to keep low-cost generic drugs off the market." What about the drug discount cards? On April 10 the *Los Angeles Times* reported on the availability of the discounts through the Together RX Card, offered free to eligible Medicare enrollees by seven drug companies or through separate discount cards offered by two companies – Pfizer Inc. and Eli Lilly & Co. But a subsequent, follow-up article proclaimed in its subhead that "Firms admit highly publicized offers are a limited, interim remedy for rising prescription costs." This is undoubtedly a story that will not go away, and one that every Parkinson's patient and caregiver should follow diligently to see what impact possible discounts will have on the costs of their medications.

The June issue of the journal *Nature Medicine* reports that "a protein that exists in most of the cells in the brain has been identified as a possible factor in the development of Parkinson's disease," according to an Associated Press report. Thus far the research involves theoretical studies in the laboratory. No trials involving patients have yet been undertaken. This study was conducted at Harvard Medical School. While there is no way to predict whether this study or many others being conducted around the world will be the one that finally leads to the "cure," it is reassuring to continue to read of the many scientists, doctors, and others who have devoted themselves to ending this insidious disease.



Thanks for Your Generosity

We are pleased to be able to recognize the following contributions made during the second quarter of this year. Thanks to all the individuals whose gifts will help to fund the continuing search for a cure for Parkinson's disease. Donations received after June 15 will be included in the next issue.

Continuing Donation

Charles L. Bond**

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HONORARIUMS

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Renee Scher

Birthday-Dennis Lollobrigida

Tom Brown
Mignone Trenary

MEMORIALS

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Gloria Boyle
Bill Cobb
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In Memory: Bob Mc Callum

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In Memory: Stan Scher

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Barbara & James Kahn
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Margaret C. Flahive
Connie & John Melsky

In Memory: Wilfred H Sullivan

Dorothy & Lee Mosley

In Memory: Wm. Widdrington

Barbara A. Baum

**Multiple Donations

DRIVE TIME

There are many more ways to make a contribution to your local Parkinson's foundation than the traditional gifts of cash. You may have one valuable resource taking up space in your garage or driveway. Why not consider donating that car you're no longer driving to benefit our organization? Besides your benefiting the Parkinson's movement, you'll also gain room to store the items you buy at your neighbor's next garage sale.

In order to make arrangements to have your car picked up, call 800-203-2940, and answer a few questions from the representative of the towing company. Once they have made any necessary repairs, they will then sell the vehicle to any of several sources. NPFOCC receives 100% of the net selling price, and you can then deduct 100% of the fair market value from your taxes.

The company handles all the paperwork and repairs, and will even deal with smog certification. Call NPFOCC at 949-574-6338 for more information, and thank you for considering this nontraditional way of contributing to our fund-raising efforts.

3 More Reasons to Call Us

Support Groups: Nine support groups under the auspices of NPFOCC meet regularly every month. If you want to check on specifics for any group, give us a call at 949-574-6338. Locations are as follows:

Anaheim	Laguna Hills
Dana Pt/San Clemente	Laguna Niguel
Huntington Beach	Newport Beach
Irvine	Seal Beach
Irvine Caregivers	

Publications: NPFOCC has published two resource booklets for Parkinson's patients and caregivers. "Dear Friends and Family" is the message of a recently diagnosed Parkinson's patient; it is suggested that you acquire multiple copies for relatives and friends. "We Are There" is a detailed guide covering nine areas for patients and caregivers. Every Parkinson household should have at least two copies.

Volunteers: Do you have a few hours that you can spare, and at the same time benefit your local Parkinson's organization? Volunteers are always needed to help in our office with mailings, telephone calls, and other routine clerical tasks. As our major fund-raiser approaches, your help will be more valuable than ever. Please call.