

Greater Los Angeles Chapter **Update**

Fourth Annual Walk Most Successful Yet

In This Issue:

Research Briefing
Jeff Bronstein

How to get
involved in a clinical
Trial

PD Information and
Referral Centers

Thank you to our
donors

On a beautiful sunny day in Santa Monica, April 27 to be exact, some 300 walkers and dozens of onlookers set out to make a real difference in the fight against Parkinson's disease at APDA's fourth annual Walk-A-Thon. The walk gets bigger and better every year and this year was no exception.

The Lawn at the Santa Monica Civic Center was transformed into the liveliest place you could imagine complete with stilt-walkers, performers, exhibitors displaying the latest innovations assisting those with Parkinson's Disease, and vendors offering up cool drinks and a host of snacks to energize walkers and enthusiastic onlookers. New this year was the opportunity to be a virtual walker. What, you ask, is a virtual walker? Someone raising funds for the walk, but not actually walking the course. Pretty clever!

Did you know that 100% of the net proceeds from the walk goes to fund medical research? Our new and improved website: <http://parkinsonla.org/> was the place to register as a walker, virtual walker, or donate to an individual walker or team. By the way, have you been to our website lately? If not, you're missing out on the latest about chapter events, research updates, and a lot more information that you'll want to know about. Check out the website often, we update it all the time.

The success of this year's Walk-a-Thon belongs to the many walkers, donors, supporters, sponsors, and volunteers whose tireless efforts and determination fill us with admiration and pride. Speaking of volunteers, read the newsletter article on volunteering to see how you can be part of next year's walk. Our sponsors, to whom we owe a huge debt of gratitude include the Fred and Lenore Kayne Foundation, Stan Dashew of the Dashaway Company, Vernalis and Adam Fine of accessible Design and Consulting.

Lots of hard work and countless hours go into organizing a walk of this magnitude. Those participating supported a worthy cause, honored a friend or loved one, and had a gloriously fun time while doing so. As a result of this year's walk, it was our joy and privilege to hand APDA a check in the amount of \$50,000. It was truly a great day.



They Hiked for Mike



The Greater Los Angeles
Chapter of the American
Parkinson Disease Association
Board of Directors

Mark Siegel, President
John McCraw, Vice President
Phil Kass, Treasurer
Madeline Field
Liz Cantz
Linda Behar
Sandy Yaras
Nessa Weinman

Madeline Field
Editor

President's Column

Mark S. Siegel

President, Greater Los Angeles Chapter

It has been a very productive year for the Los Angeles Chapter. We parlayed the success of the holiday-season House of Blues event; we had an even more successful Walk-a-thon. We were proud to send a \$50,000 check to the APDA headquarters in Staten Island New York. The money will be used for research.. These fundraisers are not easy to organize. We owe a debt of gratitude to Janice Feder for her leadership and her commitment. Thank you, Janice.

I also want to thank our walk sponsors who gave us their generous support in underwriting the event so that the money raised by the walkers can go to the fight against Parkinson's disease. They are listed on the 5th page.

I also want to thank the folks who showed up on what seemed like the hottest day of the year to walk the course along Palisades Park in Santa Monica. Despite the oppressive heat, most everyone completed the walk.

The Board of the Los Angeles Chapter of APDA are also deserving of a special

thank you. Board member Nessa Weinman, whose husband Mike suffers from PD, recruited the most walkers. Her team was fittingly called the Hike with Mike. They are blessed to have so many loyal friends who are willing to step up to help fight the disease. Sandy Yaras also deserves a shout out for his managing our website APDALA.org. He worked with a software company, Convio in creating a website that enabled us to accept donations on line. This enabled us for the first time to have "virtual" walkers. Who stayed in their air conditioned home office and still participated in the walk by making a generous contribution. Other board member, Linda Behar, John McCraw, Phil Kass, Madeline Field, Liz Cantz and Judy Yaras also made important contributions to the success of the event.

And a special and warm thank you to the West Coast Office of APDA, Sharin, John and Lisa really come through in a big way.

This summer, APDA Young Onset persons with PD from APDA chapters from the Western United States will retreat for a weekend in July. In November the L.A. chapter will host a wine tasting event that will feature a silent auction fundraiser.

Thank you so much for your support, and I hope to see you in November.

CALIFORNIA CLINICAL TRIALS

IN TOUCH WITH THE PD COMMUNITY

You've probably heard about California Clinical Trials (CCT). Perhaps you've seen their ads, heard their radio spots or attended one of their in-services for PD patients. Founded in 1981, CCT is one of the largest clinical research-focused companies in the United States. Their four investigative sites (Glendale, Culver City, Paramount and San Diego) provide a wide spectrum of services, extensive research expertise and are unique in their dedication to finding answers to help those with PD. CCT has had an enviable reputation for reaching out to the PD community for many years. In addition to advertising efforts, CCT Community Relations experts personally visit hospitals, YMCA's, centers for the aged and other key facilities to make informative presentations to patients and caregivers.

Many people find volunteering for clinical trials, also referred to as medical research studies, to be a very rewarding experience in that they are making an effort to help others and perhaps themselves. To find out if you initially qualify for a study, you will first speak with a Patient Services Representative who will go over a number of questions with you, including your medical history. All of your information is confidential. If you meet the criteria to be screened, you then visit the clinic for a physical examination and other tests as applicable to a specific study. After these procedures, it is determined whether or not you qualify for a particular study. The study (inpatient or outpatient) and what will be expected of you will be explained in detail. If you agree to participate, you sign a consent form and are given instructions regarding your participation.

When you volunteer at CCT, you are well-cared for in a safe and private environment. There is no cost to you for study-related expenses, such as a physical exam and lab tests. If you qualify for the study, there is monetary compensation depending on the level of your involvement. Personalized care is provided by highly experienced, board-certified physicians, clinical pharmacologists, pharmacists, RN's, LVN's and clinical research associates. Each team member is sincerely interested in your well-being and ensuring a positive experience throughout the study.

Individuals interested in participating in a CCT study should call 1-888-CC-TRIAL(1-888-228-7425) for details or visit thier website www.cctstudy.com to fill out a questionnaire.

Where to Go for Help

Have you ever wanted, or needed, more information about a certain aspect of Parkinson's disease, but didn't know where to look -- let alone who to ask? Do you want to join a support group or need a referral to a qualified speech therapist, but you just don't know where to go? We've got the answer. Your local American Parkinson Disease Association I&R Center.

What's an I&R Center?

What, you're probably asking, is an I&R Center? Otherwise known as an Information & Referral Center (thus, I&R Center for short), they are invaluable resources helping people better understand Parkinson's disease and manage daily needs. All services are free of charge.

The I&R Centers are established and funded by the American Parkinson Disease Association in partnership with their host medical institution. They are committed to assisting people diagnosed with Parkinson's disease and their families in order to maintain quality of life. A sample of services offered include:

- Booklets, articles and publications available on all aspects of Parkinson's disease and treatment. Current information on medical and surgical treatment

- Referrals to neurologists who specialize in treating Parkinson's disease (PD).
- Information on support groups in the greater Los Angeles area for people diagnosed with PD and caregivers.
- Referral to community resources and services including exercise classes, physical, speech and occupational therapy, medical equipment, hiring help at home, housing options, educational programs, and counseling services.

Whatever your information needs, your local I&R Center is there to help and is just a phone call away. There's I&R Centers throughout the country, but the great thing about them is that there's one near you -- near work or home, they are an invaluable resource.

Next time you have a question about Parkinson's disease or need a referral to a skilled practitioner, call your local I&R Center Coordinator. You will be amazed at all the information that's out there. To help you find your nearest I&R Center, we've listed some below:

American Parkinson Disease Association Information and Referral Centers

Cedars-Sinai Medical Center

8700 Beverly Blvd., Room 8215
Los Angeles, CA 90048
(310) 423-7933
(877) 223-3277 -- toll free
E-mail: Linda.oconnor@cshs.org
Linda O'Connor, LCSW -- Coordinator

UCLA

710 Westwood Plaza, Suite A 153
Los Angeles, CA 90095
(310) 206-9799
E-mail: hsalazar@mednet.ucla.edu
Henrietta Salazar -- Coordinator
Jeff Bronstein, MD -- Medical Director

Center for Aging, Research and Education (CARE)

18433 Roscoe Blvd., Suite 210
Northridge, CA 91325
(818) 885-8623
(866) 499-2732 -- toll free
E-mail: valleyapda@yahoo.com
Viviane Tondeur -- Coordinator
Ronald Ziman, MD -- Medical Director

Huntington Hospital

100 W. California Blvd.,
La Vida Bldg., Rm 4308D
Pasadena, CA 91109
(626) 397-2684
Patricia "Trish" Low -- Coordinator
Jai-Hyon Rho, MD, Ph.D. -- Medical Director
Jerome Lisk, MD -- Co-Medical Director

Memorial Care Centers (Long Beach, Fountain Valley, Laguna Hills)

9940 Talbert Ave., Suite 204
Fountain Valley, CA 92708
(714) 378-5022
(877) 610-2732 -- toll free
E-mail: dbaires@memorialcare.org
Debbie Baires -- Coordinator
Daniel Truong, MD -- Medical Director



Research Briefing

Jeff Bronstein, MD, PhD PD

Drug Found to be Disease Modifying

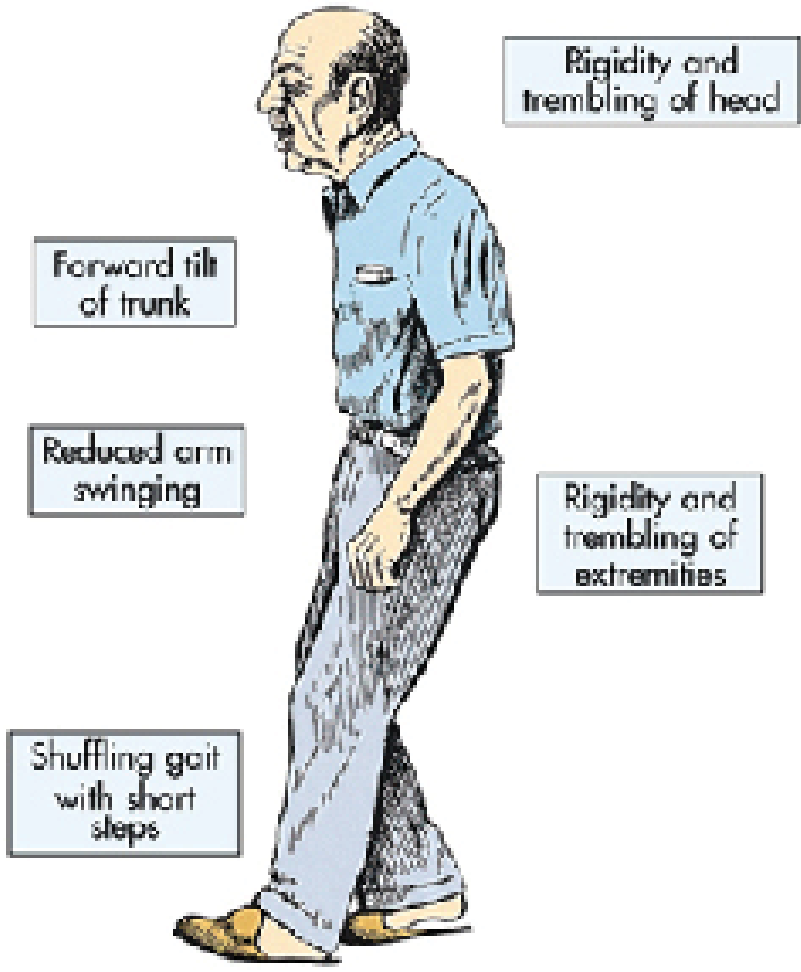
What is the story with the research that shows rasagiline (Azilect) to be disease modifying?



Rasagiline is a relatively new medication that, like selegiline, inhibits an enzyme called monoamine oxidase B (MAO-B). Rasagiline was approved 2 years ago for its symptomatic benefits to newly diagnosed patients and those who suffer from wearing off. There have been hopes since 1993 that MAO-B inhibitors would

slow the progression of Parkinson's disease (PD) but proof has been difficult to achieve.

One confounding problem has been that both selegiline and rasagiline provide some symptomatic benefits making it difficult to distinguish between merely covering up the symptoms or truly slowing the progression of neuronal cell loss. In an attempt to circumvent this confound, researchers used a novel study design called "delayed start" to test rasagiline's ability to slow disease progression (The TEMPO Study). In this study, newly diagnosed PD patients were started either on rasagiline or placebo for 6 months in a double-blinded manner. After 6 months, the placebo patients were converted to rasagiline and all patients were followed for another 6 months. At the end of the study, the patients on rasagiline for 1 year were slightly better than those that were on it for only 6 months. These results suggested disease modification because symptomatic benefits should be the same for both groups since they were both on drug for the last 6 months of the study. This was a relatively small study and there were some other potential confounds so a larger study with a similar design was undertaken a few years ago (The ADAGIO Study). The results of this study have not yet been released but a recent press release from rasagiline's manufacturer Teva, stated that the study met all endpoints. Based on the results of these 2 studies, it has been reported that Teva has applied for a disease



modification indication for rasagiline. We are all excited to review the data from ADAGIO since this appears to add strong evidence for neuroprotection. This would be the 1st and only compound ever to receive this indication for PD. We do not know if selegiline would perform in a similar manner as rasagiline since it is now generic and will likely never be subjected to a delayed start study.

What are the steps in developing a new drug, from basic science to pharmacy?

Development of new drugs takes many years and is extremely expensive. The 1st phase is to identify a molecular target for the drug. For example, the target for ropinorol is to bind and activate dopamine receptors to improve PD symptoms. The target for rasagiline is to inhibit MAO-B to slow disease progression. Choosing and validating new targets are some of the more difficult aspects of drug development. After target selection, druggable compounds are synthesized and tested biochemically, in

cells and in animal models for their effectiveness and safety (pre-clinical phase). Compounds that pass pre-clinical testing are next tested in humans for safety (Phase 1). These studies usually involve relatively few subjects for a short period of time but they are very closely monitored. If the compound passes Phase 1, then a double-blind trial is usually undertaken to determine the best dose of the drug and if the compound is safe and effective (Phase 2). If the drug still looks promising after Phase 2 testing, a larger, controlled trial is undertaken to establish effectiveness and side-effects. Successful Phase 3 trials often lead to a request for approval from the FDA for a specific indication. Some drugs that have already been approved by the FDA for a specific indication or disease, will be further tested for other disorders or indications (Phase 4).

Since successful development of new targets are often unsuccessful, many companies will attempt to develop new drugs mainly for established targets. This approach keeps the costs down and improves the likelihood of getting a product to market but delays the development of truly novel medications. Thus, most newer drugs on the market are simply slightly improved versions of drugs already available.

We would Like to thank our sponsors and Donors. Their Generosity Helped to make the Walk so successful.

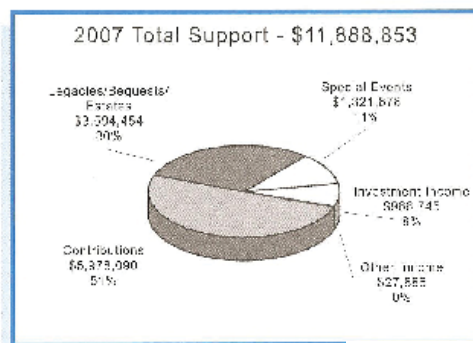
Accent on Seniors
Caret LA
Continuity Care Staffing Services, Inc.
ALLPOINT Home Health
The Leeza Gibbons Memory Foundation
Cameron Medical Supply
Pineapple
Purpose, Inc.
U.S. Bank
Wells Fargo Home Mortgage
The Accredited Family of Home Care Services

Wise Senior Services
Hallmark Cheviot Hills/
Hallmark West Hills
Accessible Design &
Construction
AccentCare
Dynamic Nursing &
Home Care
Home Tech Industries,
Inc.
Homewatch Care Givers
California Telephone Ac-
cess Program
Caring Companions,
PDC, Inc.

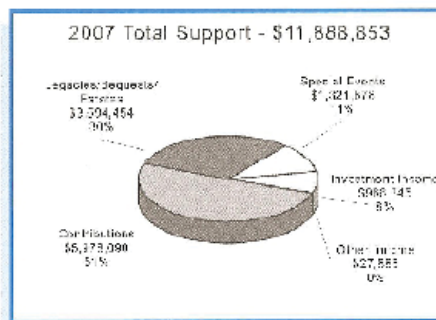
Center for Health Care Rights
Wells Fargo Home Mortgage
VITAS Hospice Services, LLC Westside M.A.P.S.
Westside M.A.P.S./co/AllPoint
PAREXEL International/California Clinical Trials
All Point Home Health
Sunrise Senior Living, Inc.
Sheridan In Home Care
Brookdale Ocean House
Accredited Home Care Services
Belmont Village Assisted Living of Rancho Palos Verdes
Grandview Palms
International Passport & Visa
Showerbuddy
Health Care Marketing Services
Bruno Independent Living Aids
Best Bath Systems
DKN
Handybar (Avenue Innovations)
Karman Healthcare, Inc.

Nuprodx, Inc.
Open Sesame Door Systems Inc.
Otto Bock Healthcare
Savaria Concord Lifts Inc.
Belmont Village of Hollywood Hills
Adam M. Fine
Medtronic
Activa Therapy Consultant/Medtronic
Dashaway Company
Jewish Community Foundation/Fred & Lenore Kayne Fund
The Walking Company
Vernalis Pharmaceuticals Inc
Fred & Lenore Kayne Foundation

Dashaway Company
BridgePoint of Beverly Hills
Prudential California Realty
The Roll Company
Tudor House
Ralph's
ENERGYFIRST
Crystal Beverage Company
Larabar
Western Bagel Baking Corporation
Westside YMCA



Nationwide



Nationwide

Los Angeles Dodgers
Colbe'rt Alternative
Therapy
Sharon Scott
LivHome
Health Craft Products Inc.
Novo Nordisk Pharmaceu-
ticals
Joint Dynamics, Chiroprac-
tic, Pilates & Massage
American All Care Services

Medtronic
The Coffee Bean and Tea Leaf
Fashion Institute of Design and Merchandising
Brentwood Academy of Dance
Just Mom, Inc.
Red Cross of Santa Monica
Intercontinental Hotel



**Shout Hallelujah at Our House of Blues Gospel
Bbreakfast last December**

Coming Soon: A new and exciting membership program

Are you a member of APDA? If you're not already, you'll have a chance very soon.

In the next few months we'll be rolling out our all new membership program with a whole lot of new and exciting benefits. At this very moment we're working hard to create a membership program you'll want to join and to offer you the very best membership benefits we can - chock full of meaningful rewards and opportunities. The most direct benefit is the knowledge that your tax-deductible membership donation directly supports APDA in the important areas of research and education.

We're excited about the new membership program that's taking shape. Be looking for your very own membership invitation in the coming months. We look forward to welcoming our new and returning members to the APDA

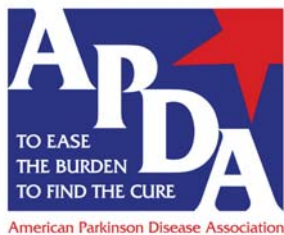


Tulips have been adopted as the symbol for the quest to find a cure for PD

Upcoming Membership Programs

PD Speakers Series
Provactive and informational topics in the fight against Parkinson Disease. Starting this fall.

Wine Tasting and Silent Auction
Join us for the fun in early November. It promises to be a great event.



Greater Los Angeles Chapter

Update

10850 Wilshire Blvd.
Suite 230
Los Angeles, CA 90024

Phone (800) 908-2732
(213) 725-6503