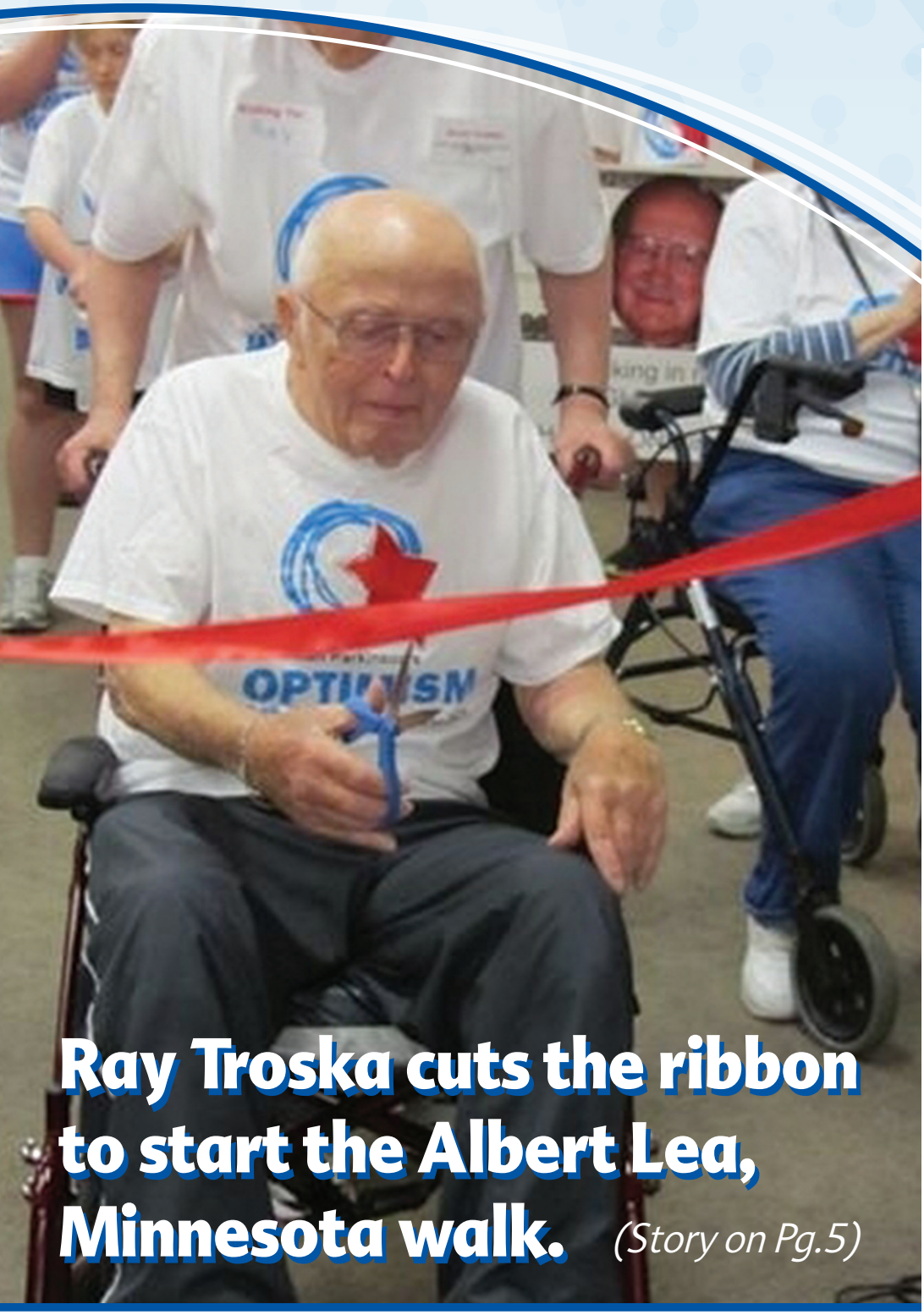
APDA QUARTERLY

American Parkinson Disease Association Newsletter · Fall 2013



Ray Troska cuts the ribbon to start the Albert Lea, Minnesota walk. *(Story on Pg.5)*

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APDA
TO EASE THE BURDEN TO FIND THE CURE
American Parkinson Disease Association

Dear Friends,

One of the hallmark features of our great organization is the many collaborations in which we participate throughout the country. We know there are diverse organizations providing direct service, advocacy, education and support of the Parkinson's community and whenever possible, APDA has partnered with these groups on both a national and local level. The same holds true with our support and collaboration within the research community as we partner with many outstanding academic and medical institutions through our research grants programs.

Recently I attended a meeting of the National Institute of Neurological Disorders and Stroke (NINDS) Udall Center directors' meeting where leaders of various PD organizations had an opportunity to discuss their organizational priorities with the leaders from NINDS and these distinguished researchers. We also discussed ways that our organizations could collaborate to further our missions and in our case at APDA to "Ease the Burden - Find the Cure" both within the non-profit arena and within the research community.

I know that here at APDA we are working hard to further our mission, but I am also equally supportive of working together with these various groups to multiply our efforts – especially as it relates to advocating for more federal support of research and support dollars for our PD families. I wish to thank all of our APDA supporters who over the years have contributed to further APDA's mission as well as those who have worked collaboratively with our partners across many organizational boundaries. It's one of the reasons why I am so optimistic about our future!

Thanks again,

Leslie A. Chambers

Leslie

Did You Know?

1. Your contribution may be worth twice as much to help "Ease the Burden – Find the Cure." Ask your human resources department if your employer has a matching gift program.

2. There are many ways to remember APDA in your will. You can donate a fixed amount or percentage of your estate, specify certain stocks or real estate, or establish a charitable remainder trust to allow your beneficiaries to receive income before APDA benefits from your gift. Call 800-223-2732 for our free publication, "The Importance of Having a Will."

3. An APDA charitable gift annuity or deferred gift annuity guarantees income for the life of one or two beneficiaries and your legacy to Parkinson's disease research and patient education and support afterwards. Call 800-223-2732 for our free publication "Charitable Gift Annuities: Guaranteed Payments for Life!"

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Low Blood Pressure & Parkinson's Disease

By Lawrence I. Golbe, MD

In recent years, the non-motor aspects of PD have received much-needed attention. One such feature of PD is a tendency toward low blood pressure. This is caused by actual involvement in the disease process of the nerves in the heart, where abnormal clumps of the protein alpha-synuclein accumulate as they do in the brain.

It's common for those with PD to experience light-headedness upon standing, especially from a squatting or recumbent position. Rarely this causes fainting. It can be prevented to a great extent by making sure you get plenty of salt and fluids and by avoiding dehydration while exercising or out in the heat. Sometimes, high blood pressure that was diagnosed many years earlier is still being treated with blood-pressure-lowering medications, which can now be reduced or eliminated.

In an ironic twist, most PD medications aggravate this tendency to low blood pressure. They do this by enhancing the action of dopamine in the brain. The addition of a PD drug can therefore reduce the blood pressure enough to cause symptoms of light-headedness or fainting for the first time. This can be avoided by minimizing the drug's dosage, by taking it on a full stomach to slow its absorption into the brain, by eating smaller, more frequent meals or by wearing pressure stockings. As is the case for PD itself, keeping the body's salt and fluid requirement satisfied also helps. If these measures fail, there are prescription drugs that can raise blood pressure such as fludrocortisone (Florinef®), midodrine (Proamatine®) and pyridostigmine (Mestinon®). But these must be used carefully lest they raise the pressure too much, especially when one is supine.

A rare disorder that can resemble PD features more severe low blood pressure. Called multiple system atrophy or MSA (formerly "Shy-Drager syndrome"), it also causes more problems with balance and coordination than does PD and responds poorly to carbidopa/levodopa (Sinemet). In MSA, the low blood pressure can be one of the most disabling features. Fortunately, that is almost never the case in PD. In fact, the tendency of low blood pressure in people with PD is the probable explanation for their low risk of strokes and heart attacks. ★

Dr. Golbe is Professor of Neurology, Director of the Division of Movement Disorders, and Director of APDA's Center for Advanced Research at Rutgers Robert Wood Johnson Medical School, New Brunswick, N.J.

University of Virginia Reports Advances Utilizing Focused Ultrasound in Surgeries

By Madaline B. Harrison, MD

The development of techniques for neurosurgical treatment in Parkinson's disease has provided substantial benefit to individuals whose symptoms are no longer satisfactorily controlled by medication. Two techniques being used are deep brain stimulation (DBS) and radiofrequency lesioning. Both require placing a small hole in the skull and passing an electrode into structures deep in the brain that control movement, most commonly the thalamus, subthalamic nucleus (STN) or the globus palildus (GP).

In DBS, a stimulating electrode is left in place and connected to a pulse generator, a computer-controlled device (similar to a pacemaker) that delivers continuous stimulation to the targeted area.

Radiofrequency lesioning uses radio waves to heat a small area and create a thermal lesion in the brain tissue usually in either the GP or thalamus. Radiofrequency lesioning was used extensively in the past, but not as commonly today because it can only be applied safely to one side of the brain and the treatment is not adjustable like DBS. DBS can be performed on both sides of the brain and in a reversible/adjustable fashion to modulate electrical activity. Benefit with both of these approaches has been well established in PD.

MR-guided focused ultrasound (MRgFUS) is a new technology in which sound waves (ultrasound) are focused on the targeted region and produce acoustic energy that also heats a small area of brain tissue and creates thermal lesions. This can be done without making a hole in the skull or placing electrodes or other devices directly into the brain. The intensity of the sound waves can be gradually increased while the targeted area is monitored during the procedure with MR imaging and thermometry (measurement of tissue temperature) in the brain to assess symptom response and side effects in real time and adjust the treatment. It has FDA approval for treating benign tumors in the uterus and bone pain from cancer metastasis but is still experimental for use in the brain. As this treatment involves making a lesion, it is currently only being investigated for treating symptoms on one side of the body.

Before MRgFUS is available for routine use in Parkinson's disease or other neurological conditions, testing must be done in clinical trials to establish both safety and effectiveness, just as medications are studied before the FDA approves them for widespread use. Studies of MRgFUS in the brain are in the very early stages. A pilot study has been completed at the University of Virginia in essential tremor, which is another neurological disease that causes tremor. APDA's Center for Advanced Research at the University of Virginia is collaborating in designing and conducting additional studies to evaluate the use of MRgFUS in Parkinson's disease. While the prospect of surgery in the brain that does not require incisions or burr holes in the skull is exciting, much more work will need to be done before we know for certain whether MRgFUS will become another new technique for surgical treatment in Parkinson's disease. ★

Dr. Harrison is Professor of Neurology and Director of APDA's Center for Advanced Research at the University of Virginia.

APDA'S 2013 Optimism Walks

With 25 events completed to date, APDA's 2013 Optimism Walks campaign has exceeded last year's revenue, having topped more than half a million dollars. Proceeds from these events support research and the Information and Referral Center network. The Greater Los Angeles and Massachusetts chapters have reached record-breaking results and were the two largest events held this year. Visit www.apdaparkinson.org for 2014 walk schedule.

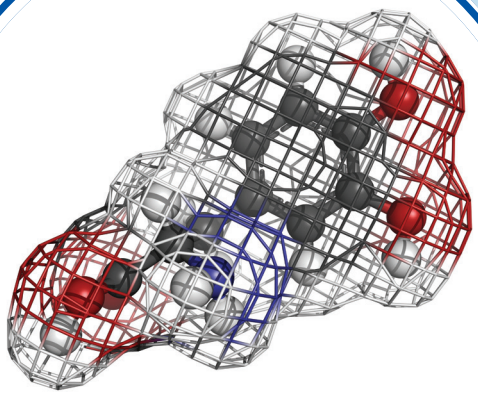
A record number of walkers ring Reebok International Headquarters in Canton, Mass. to raise $166,781 (exceeding its goal by more than $30,000).

Greater Los Angeles Chapter president Patrick LoSasso, left, and members of his board, Dr. Nicholas Szumski, Dr. Neptune Mizrahi, Judy Yaras, and Sandy Yaras get ready for the 700 participants who will raise a record-breaking $298,000.

Ask the Doctor

By M. Maral Mouradian, MD

Q: I have been using Sinemet® for about five years, and it basically doesn't help. Are there other drugs or combinations that I could discuss with my neurologist?



Levodopa Molecule

A: Sinemet® (carbidopa/levodopa) is the most effective medication for Parkinson's disease. It contains L-dopa, which is changed in the brain into dopamine, the very chemical that is deficient in Parkinson's disease. Several other drugs that can be taken orally have become available for Parkinson's disease since L-dopa was discovered fifty years ago, but none match L-dopa in its ability to control the disease symptoms.

So, when Sinemet® does not help control the symptoms of someone with Parkinson's disease the first question that needs to be addressed is whether the patient is taking enough. This possibility should be thought of before considering adding other, less-effective medications. The dose range for L-dopa is fairly wide, and typically physicians initially prescribe a small dose with the intent to build it up gradually depending on how the patient responds both in terms of benefit and also in terms of side effects such as nausea.

The second detail that needs to be explored is whether it does not help at all or it does so but only for a brief period of time after taking each dose. The last scenario is not uncommon in patients with Parkinson's disease who have taken the drug for a few years when the effectiveness of each dose becomes gradually shorter, known as the "wearing-off" phenomenon.

If indeed there is no appreciable benefit at all despite achieving a reasonable dose, especially in the higher end of the dose range, the next important question that needs to be considered is whether the patient truly has Parkinson's disease or one of the other Parkinson-Plus conditions. These are a handful of diseases that appear to have similarities to Parkinson's disease, including slow movements, poor coordination, and impaired walking and balance, but also have other manifestations that help an experienced neurologist tell them apart from Parkinson's disease.

These conditions, also known as atypical parkinsonisms, have different brain pathologies than Parkinson's disease, and they do not respond nearly as well to anti-parkinson medications including L-dopa. Therefore, for someone who has been taking Sinemet® for five years, an important question would be whether the drug helped initially and what the course of that response has been over the years. These nuances in diagnosing and managing Parkinson's disease for each particular patient are best handled by neurologists who have specialized training and experience with this disease. ★

Dr. Mouradian is the William Dow Lovett Professor of Neurology, and Director, Center for Neurodegenerative and Neuroimmunologic Diseases at Rutgers Robert Wood Johnson Medical School, Piscataway, N.J., and a member of APDA's Scientific Advisory Board.

APDA 2013-2014 Research Funding

Supporting research is a vital part of APDA's function and during its half-century history has been a funding partner in most of the major scientific breakthroughs–from Dr. George Cotzias's discovery that high-dose oral levodopa is effective in treating PD symptoms to Dr. Roger Duvoisin's Contorsi family research that established the role of heredity in PD. Today, through the guidance of its Scientific Advisory Board (SAB), a panel of leading experts in all areas of PD, APDA continues to support research including the pioneer studies establishing the benefits of exercise and the effect of environmental toxins.

In May, under the chairmanship of David G. Standaert, MD, PhD, the SAB selected 12 grant applications (eight research grants and four post-doctoral fellowships) for funding. Following are synopses of the post-doctoral awards, each being a one-year, $35,000 fellowship to support post-doctoral scientists whose research promises new insights into the disease and with such support will enable the scientist to position the work to a level eligible for greater funding.

MIAN CAO, PhD

Yale University School of Medicine
Howard Hughes Medical Institute

Title: The Function of Parkin-mediated Ubiquitination in Synaptic Function

Relevance to PD: *"I expect that studies on the functional significance of the endophilin-Parkin interaction will advance knowledge of mechanisms in synaptic vesicles trafficking and synaptic transmission. More importantly, they will shed new light on cellular mechanism important in PD."*

DIRK LANDGRAF, PhD

Whitehead Institute for Biomedical Research

Title: Investigating Alpha-synuclein Toxicity by Analyzing Single-cell Dynamics

Relevance to PD: *"My research will contribute to a better understanding of the disease pathology at the cellular level and will provide novel mechanistic insights regarding alpha-synuclein toxicity. Furthermore, using the single-cell analysis platform to investigate potential drug candidates will provide novel insights in the action of promising small-molecule compounds and may lead to the identification of novel effective therapeutics."*

JOÃO Paulo Lima Daher, MD, PhD

University of Alabama at Birmingham

Title: Defining LRRK2 Action in a-Synuclein Induced Neurodegeneration

Relevance to PD: *"I hope to understand the potential role of LRRK2 in modifying neuroinflammatory responses and associated neurodegeneration in a-synuclein-injected rats. This is critically required to improve our understanding of the molecular mechanisms of PD... I also hope that this model may reveal whether LRRK2 and a-synuclein function in a common pathogenic pathway and could potentially serve as a relevant pre-clinical model of PD to test LRRK2 kinase inhibitor in order to halt or slow the underlying progress neurodegeneration/ neuroinflammation in (PD)."*

CATHY N.P. LUI, PhD

Northwestern University

Title: Nanoparticle-driven Neuroprotection of Dopamine Neurons

Relevance to PD: *"Current therapeutic strategy for PD focuses on symptomatic relief. An unmet challenge has been a successful development of treatment options that slow the progression of the disease. Our proposed research will determine if NMDA receptor knockdown by siRNA-NPs has long-term therapeutic potential to slow disease progression. Our proposed preclinical studies will provide the basis to translating work into a clinical setting."*

Educational Material and Patient Support Resources

APDA is the source of many free educational and patient/caregiver support materials. Most publications listed below can be downloaded from the website www.apdaparkinson.org, publications page. Single copies are available by writing to the national office or calling 800-223-2732, faxing to 718-981-4399, or contacting any of the APDA I&R centers, also listed on the website.

Free subscriptions to a monthly e-newsletter and "Tip of the Month" feature are available on APDA's website home page. Lotsa Helping Hands, a private care-giving coordination service that allows family, friends, neighbors and colleagues to create an on-line community to assist caregivers with daily tasks can be reached by clicking the "Ease the Burden" button.

APDA's National Young Onset Center is located at Central DuPage Hospital, 25 North Winfield Rd. Winfield IL, www.youngparkinsons.org, 877-223-3801, info@youngparkinsons.org.

APDA's National Resource Center for Rehabilitation provides direct telephone (888-606-1688) and e-mail (rehab@bu.edu) access to a licensed physical therapist at Boston University's Sargent College, for questions about exercise, information about programs in the caller's area and educational materials.

APDA's National Veterans Center is located at 975 Kirman Ave., Reno, Nev. 89502; 888.838.6256 ext. 1715, susan.gulas@va.gov.

Booklet

(order by letter)

A. Parkinson's Disease Handbook
B. Young Parkinson's Handbook
C. Be Active
D. Speaking Effectively
E. Good Nutrition
F. Aquatic Exercise for Parkinson's Disease
G. My Mommy Has PD...But It's Okay!

Supplements

(order by number)

4. Keys to Caregiving
5. Hospitalization of a Parkinson's Patient
6. The Living Will and Durable Power of Attorney for Health care
7. Parkinson's Disease and Oral Health
8. The Family Unit and Parkinson's
9. Maintaining Independence
13. Medical Management of Parkinson's Disease and Medications Approved for Use in the U.S.A.
16. When Should Parkinson's Disease Patients Go to the Emergency Room?
17. Neuro-Opthalmology and PD
20. Fatigue and Parkinson's
22. Depression and Parkinson's
23. Incontinence and Parkinson's
24. Employment and Parkinson's
25. Constipation and Parkinson's
26. What is Dysphagia?
27. Cognitive Changes in PD
28. Too Little Exercise and Too Much Sitting: A Recipe for Change

Other Publications

- Basic Information about Parkinson's Disease
- National Young Onset Center
- Medications to Be Avoided or Used with Caution in PD
- 34 Helpful Hints to Improve the Quality of Life of People with Parkinson's
- The Importance of Having a Will

Websites

- www.apdaparkinson.org
- www.reno.va.gov/parkinsons/parkinsons.asp

Available for Download at www.apdaparkinson.org

- Be Independent: Equipment and Suggestions for Daily Living
- Dr. Andrew Weil's Recommendations for Healthy Aging (Supplement 21)
- The Challenge of Parkinson's Disease: Adapting to a Nursing Home

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