



The Shaky Times

-- Online Edition --

September 2017

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Abraham Raja shows us what's new in the PNMD library

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Neurologyadvisor.com writes on how visions changes may be an early indication of Parkinson's

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Telemedicine as Effective as In-Person Care for Parkinson's Disease

Source: Neurology and University of Rochester Medical Center

New findings from a nationwide program that links neurologists with patients with Parkinson's disease in their homes via video conferencing shows that telemedicine can successfully deliver quality care. The study, which appears today in the journal *Neurology*, points to a new way to improve care for people who suffer from the disease, but may have not have access to a neurologist.

"Virtual house calls for chronic diseases like Parkinson's are not only as effective as in-person care but broader adoption of this technology has the potential to expand access to patient-centered care," said Ray Dorsey, M.D., the David M. Levy Professor of Neurology at the University of Rochester Medical Center (URMC) and lead author of the study. "We now have the ability to reach anyone, anywhere but the promise and benefits of telemedicine will not be fully realized until the changes are made in Medicare policy."

"Telemedicine is especially valuable to patients in remote, rural, and underserved areas because it gives them the ability to consult specialists they would otherwise have to travel hours to see," said Peter Schmidt, Ph.D., Senior Vice President, Chief Research and Clinical Officer of the Parkinson's Foundation. "The Parkinson's Foundation aims to narrow these gaps in Parkinson's care, which is why we are working with experts from URMC, a Parkinson's Foundation Center of Excellence."

The results in the paper come from the Connect Parkinson project, a research study funded by the federal Patient-Centered Outcome Research Institute. Connect.Parkinson is led by URMC in collaboration with the Parkinson's Foundation and with additional support from PatientsLikeMe, the Michael J. Fox Foundation for Parkinson's Research, SBR Health, Vidyo, and IDSolutions. The study is the first national randomized controlled clinical trial of telemedicine for Parkinson's disease.

It is estimated that 40 percent of people who have Parkinson's disease do not see a neurologist soon after diagnosis. This places them at significantly greater risk of falls leading to hip fractures, ending up in a nursing home or hospital, and even death. This challenge of providing care to these individuals will become ever greater as the population ages—it is projected that the number of people with Parkinson's disease will double by 2030.

The most significant barriers to appropriate care for Parkinson's patients are distance and disability. Most movement disorder specialists are located in academic medical centers in large urban areas. Most patients live in suburban and rural areas, have impaired mobility and driving ability, and are faced with the challenge of making frequent trips to the doctor's office - a task that becomes more difficult as the disease progresses.

The goal of the Connect Parkinson study was to see if telemedicine would allow neurologists to deliver care to patients in the comfort of their homes. A total of 195 individuals with Parkinson's from across the U.S. were selected to participate in the study. Participants either received care through their primary care physician or had that care supplemented with up to four visits via video conference with the neurologist they had not seen before.

Parkinson's disease particularly lends itself to telemedicine because many aspects of the diagnosis and treatment of the disease are "visual" - meaning that the interaction with the doctor primarily consists of listening to the patient and observing them perform certain tasks such as holding their hands out or walking.

The researchers found that the telemedicine visits were as effective as in-person visits in the doctor's office, with the quality of life reported by the participants as no better or worse for people who received care in their homes compared with those who received standard care. The virtual house calls also saved patients an average of 169 minutes and nearly 100 miles of travel per visit.

While the current study is one of several that have demonstrated the potential benefits of telemedicine, wide-spread adoption of this technology is hindered by federal healthcare policies. Approximately two-thirds of Parkinson's patients are on Medicare. However, the program does not reimburse for in-home telemedicine care. Legislation has been introduced in Congress to allow Medicare to expand reimbursement for telemedicine.

"We can shop, bank, make travel reservations, take classes, and buy groceries via the internet from the comfort of our own homes, but too many patients still cannot access health care," said Dorsey. "Telemedicine is an option if you are a veteran, a member of the Armed Services, a Medicaid beneficiary, or a Canadian, but not if you have a chronic condition and are a Medicare beneficiary."

The PNMD Library

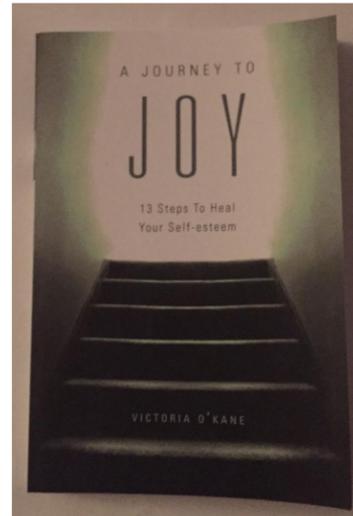


Abraham Raja, the PNMD librarian is always on the lookout for new books, periodicals, medical journals and company information that provide information and insights into Parkinson's Disease, medical research on the disease and other related topics.

The book for September is "The Journey To Joy" by Victoria O'Kane.

Abraham noted, "I have been looking for a book to help our members to understand, minimize, manage self internalization numerous situations (personal or other wise) and hopefully improve quality of life, regardless of PD."

The library is open for business at the monthly meeting. Peruse the free booklets, brochures and other items of interest. Check out a book. Have you read a book on Parkinson's that others may like? Give Abraham the name and it will be added to the library. Donate books of interest. Sharing helps everyone.



Member Profiles

This month, we just ran out of time. Between potential profile subjects' schedules and my travel schedule, we couldn't get a finished member profile done in time to get this out. Hopefully, we shouldn't have it happen again as I'm trying to get some profiles done in advance for future publication.

If you would like to tell your story, let me know. I think some of the most interesting articles we can read are people's stories and especially how they overcame or dealt with adversity like Parkinson's. Those stories can be inspiring, humorous or sometime just informational about what someone did to affect their situation. So contact me if you would like to tell your story. I can be reached at kevin@oakvillelane.com. Please put Member Profile in the subject line so I'll recognize what it is right away.

Vision Changes May Precede Parkinson's Disease

Source: Neurologyadvisor.com

Changes in vision may be an early sign of Parkinson's disease, according to research published in *Radiology*. The study included 20 newly diagnosed Parkinson's patients who had not yet received treatment, and a control group of 20 people without the disease.

Magnetic resonance imaging (T1-weighted and diffusion-weighted imaging) with a 3-T magnetic resonance imager revealed that the Parkinson's patients had significant alterations in optic radiation connectivity distribution, with decreased lateral geniculate nucleus V2 density, an increase in optic radiation mean diffusivity, and a reduction in white matter concentration.

Voxel-based morphometry analysis also revealed a significant reduction in visual cortical volumes, as well as reduced chiasmatic area and volume.

"Visual processing metrics may prove helpful in differentiating Parkinsonism disorders, following disease progression, and monitoring patient response to drug treatment," lead researcher Alessandro Arrigo, MD, a resident in ophthalmology at the University Vita-Salute San Raffaele of Milan, said in a news release from the Radiological Society of North America. "We're excited by our findings. However, this is just a starting point."

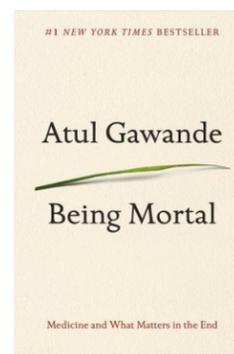
Amy Van Voorhis reviews Atul Gawande's "Being Mortal: Medicine and What Matters in the End"



Being Mortal: Medicine and What Matters in the End is an excellent book about a topic that most of us would rather not think about - the realities of aging and death. But I believe this is a 'must read' for anyone who will eventually come face to face with these realities - in other words, all of us. The author, Atul Gawande, is a practicing surgeon and medical school professor, and also writes for The New

Yorker magazine.

Modern medicine has greatly increased life expectancy, allowing most of us to live past the point where we are able to live independently. The author urges us to think about this eventuality and prepare for it by thinking about the things we really care about, the things that define quality of life for us. He points out that the medical profession tends to see aging and death as clinical problems to be overcome with medical procedures, rather than focusing on enabling the patient's well-being and quality of life at the end. He discusses assisted living, nursing homes, hospice, advance directives,



and the importance of having the 'hard conversation' with loved ones about end of life wishes.

Dr. Gawande writes eloquently and illustrates his points with moving stories of his own patients, friends and family members. He has managed to write a fascinating and even enjoyable book that makes it easier to think about this scary topic!

If you would like to review a book from our library, please contact Howard Zalkin via email at hzalk510@gmail.com

Volunteers needed and appreciated

Many of you may not realize that PNMD is largely a volunteer organization. People help with the audio visual equipment, food service, meeting organization, bookkeeping, publishing and more. We currently have a big need for one to two people to help Rynette in the kitchen on the days we have our meetings. She's responsible for the coffee, food prep, presentation and clean up afterward. We all enjoy the benefits of her service. If you can spare some time during the meeting, especially before the general session and right after, please let co-president Howard Zalkin know at hzalk510@gmail.com. He can fill you in on other needs that the PNMD has with regard to audio-visual and other assistance that would benefit the organization.

Announcements, Meetings and How to Reach Us

Donations

Helen M. Henry in memory of Barbara Kingshill

Is There Treasure In Your Driveway?

You can stop paying insurance and registration—and get a tax deduction. Donate your car to PNMD. Just call: 877-999-8322

Important:

Be sure to tell the operator that you wish to donate your car to Parkinson Network of Mount Diablo. Or just use this link for our dedicated online donation form: <http://www.v-dac.com/org/?id=943297100>.

If you have any questions, call the vehicle donation program at 877-999 8322. Or contact Howard Zalkin at hzalk510@gmail.com.

The September Meeting Featured Speakers

The **September 16th meeting** will feature Dr. Marilyn Stebbins from UCSF along with UCSF pharmacy students will present a discussion, **Pharmacological Frontier of Parkinson Disease**.



Dr. Stebbins joined the faculty at the UCSF School of Pharmacy in 1998. Her clinical work has focused on developing innovative pharmacy practice models in the physician group practice setting, primarily for under-served populations. Her teaching has been in the areas of Medicare Part D, innovative practice models, health policy, managed care and leadership development.

Joining Dr Stebbins in the presentation are pharmacy students Truc Dinh, Jenna Lam, Felice Wu, and Agnes Lau.

General Meeting Information:

Board Meeting:

First Monday of each month, 10:15A.M. Hillside Covenant Church, 2060 Magnolia Way, Walnut Creek.

General Support Group Meeting:

The Parkinson Network of Mt. Diablo Support Group meets on the third Saturday of every month, from 9:00 a.m. to noon at Grace Presbyterian Church, 2100 Tice Valley Blvd., Walnut Creek. All are welcome and there is no charge. No RSVP's needed.

Here is the agenda:

9:00 to 10:15 a.m. – Three concurrent Support Group meetings:

Men with Parkinson's Disease Only: For men newly diagnosed or who've had PD for years: time to share, laugh, and learn from each other. Meeting location is the Fireside Room at Grace Church. Contact person is Gregg Riehl (jgriehl@gmail.com) at (925) 254-8349.

Women with Parkinson's Disease Only: For women newly diagnosed or who've had PD for years: time to share, laugh, and learn from each other. Meeting location is the Library at Grace Church. Contact person is Sandy Clark (sandchu@aol.com) (925) 944-0769.

Caregivers Only: Caregivers discuss issues relating to their roles. Meeting location is the Sanctuary at Grace Church. Contact person is Norman Kibbe (nkibbe@aol.com) (925) 935-9322 .

10:15 a.m. to 10:30 a.m. -Assemble in Oak Room. The PNMD Library, with books, flyers, videos, etc. is open at this time. Sunrise Bistro will provide refreshments that will be underwritten by Acadia Pharmaceuticals

10:30a.m. to 10:45a.m. Welcome new members announcements

10:45 a.m. to 11:45a.m. (In Oak Room) Guest speaker: Dr. Marylyn Stebbins. See her info above.

11:45 a.m. –noon-Q&A, Wrap up: General questions may be directed to Howard Zalkin at (925) 939-4210 ; Lance Gershen, Program Chair (925) 932-1028; or Sandy Mitchell, Asst. Program Chair (925) 687-3976. Web site: <https://pnmd.net>

Contact Us

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Caregiver Services: Norman Kibbe (925) 935-9322
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Donations and Memorials: Please mail to P.O. Box 3127, Walnut Creek, CA 94598.
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randolphsegura@gmail.com.
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