DAPS

Dallas Area Parkinsonism Society

6370 LBJ FREEWAY • SUITE 176 • DALLAS, TX 75240 • 972-620-7600 APRIL 2010

february general meeting report

parkinson's disease: top 5 questions

by Cindy Weatherall, DAPS Board Member

DAPS was pleased to welcome Elizabeth Peckham, DO, to our February general meeting. Dr. Peckham, a movement disorder specialist with the Baylor Headache and Movement Disorder Center, presented her informative program entitled, "Parkinson's Disease: Top 5 Questions," which addressed the most common questions she fields from new and returning people with PD.

1 What is Parkinson's Disease, and what is the difference between PD and Parkinsonism?

Parkinson's Disease is a degenerative disease caused by loss of dopamine-producing cells in the brain. A diagnosis of PD can be made when a person presents with any two of the following four motor symptoms: slowness, stiffness, resting tremor, and balance difficulties. People are often surprised to discover that tremor does not have to be present for the PD diagnosis. Non-motor symptoms are often present as well, including decrease in the sense of smell (this symptom may occur 15 years or more prior to diagnosis), chronic constipation, anxiety, depression, and problems with memory. About 70% of people diagnosed with PD would be considered "typical" cases.

Parkinsonism refers to an entire spectrum of symptoms and includes numerous other neurological disorders. People with "atypical" cases may experience early memory loss, early falls and balance difficulties, bladder problems, and eye dysfunctions. Motor symptoms are more likely to be symmetric in atypical cases than in typical PD.

2 Why did I get Parkinson's?

The reasons for development of PD are still being defined, but there is strong evidence for genetic and environmental causes. Five genes associated with PD have been identified. Environmental associations for PD include head trauma, including having multiple concussions, and environmental toxins (exposure to some recreational drugs, well water, some herbicides and insecticides, and byproducts of welding).
Some studies show that consuming caffeine and smoking cigarettes provide a protective effect against PD, although certainly smoking cannot be recommended! For many people with PD, caffeine intake may increase tremors.

Continued on page 3

april 2010 general membership meeting

Parkinson's Awareness Luncheon

Monday, April 12, 2010 12:30 p.m.

University Park United Methodist Church
4024 Caruth
at Preston

Reservation
by April 8
$10 per person

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Dallas Area Parkinsonism Society

Dedicated to impacting and improving the quality of life for Parkinson's patients and their families

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NEWSLETTER
Ann Staton, Editor

The DAPS newsletter is published monthly as an information guide only, and does not serve as legal or medical advice. We welcome your feedback, contributions or requests. Please send to or contact:

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member's profile

carl benning

Many of us holding this newsletter know, but some of us may not know, it takes lots of volunteer effort to make DAPS work. Some of our members work for DAPS virtually every day. Others put in fewer, but very important hours on a variety of jobs. The people doing these jobs have different levels of involvement with Parkinson's. Quite a few actually have PD. Many are spouses; some are children; I am a brother-in-law.

Our subject today, Carl Benning is one of those who has volunteered, even without a close involvement with PD. He was actively involved in the care of his mother-in-law with Parkinson's, but she died sixteen years before he ever heard of DAPS. He was recruited by Charley Shuffield to be our Treasurer. Charlie was one of the few DAPS people who had no direct family involvement with PD. Carl is retiring after three years as Treasurer; keeping the books, paying the bills, making the deposits and generally looking after the Society's finances.

Carl is a 1953 graduate of the US Naval Academy. He joined the fleet off Korea in the late stages of the hostilities. From there he went to his most interesting assignment. The French were being thrown out of Indo China. The 1954 Geneva Accords would divide the country into North and South Viet Nam. The US Navy helped to evacuate Vietnamese Catholics from Haiphong to the south. Carl made three trips, each time taking 3,000 people on a boat that was built for half that number.

After his naval service, Carl earned a master's degree at the University of New Mexico. He worked for Sandia Corp and the Texas Instruments. He and his wife Jacqueline moved to Dallas in 1969. She developed diabetes. In 2005 she chose to stop dialysis and died from kidney failure.

Carl sold his house and moved to Preston Tower. That's where Charlie recruited him for DAPS. Carl is normally a "morning person", but one evening in 2007 he was in the laundry room around 8 pm. Mary was there sewing buttons. One thing led to another. They are now married and have a home on Encore Drive.

Carl's son, James is an optometrist. He and his wife Karen have three daughters; a recent graduate of Texas Tech, a junior at UT Austin and a senior in Plano who is headed to the University of Arkansas.

Thanks, Carl, for your efforts as Treasurer. We hope we'll continue to see you in the DAPS community.

parkinson's disease: top 5 questions

Continued from page 1

3 What treatments are available?

Since the underlying cause of Parkinson's Disease is loss of dopamine-producing neurons in the substantia nigra portion of the brain (about 75% of these neurons have already died by the time symptoms appear), the goal of treatment is to provide dopamine to the brain, or find ways to mimic the effects of dopamine using other treatments. There are numerous medications used to control symptoms. The best choice must be made for each individual, with consideration given to the person's age, predominant symptoms, stage of PD, and other diseases the patient may have.

The combination of carbidopa/levodopa (Sinemet) is still the gold standard for treatment of most PD patients. Levodopa is converted into dopamine, so it provides a direct way to resupply the brain. Carbidopa is added so that more levodopa is converted in the brain, and not in other parts of the body, where the extra dopamine is not needed. Carbidopa also reduces the nausea associated with levodopa.

Medications that activate the same receptors that dopamine would normally affect include pramipexole (Mirapex) and ropinirole (Requip). Rotigotine (Neupro) was available in a patch applied to the skin, but the product was recalled.

Amantadine (Symmetrel) can be effective for some patients with PD. Its exact mechanism of action is not known, but it does increase the release of dopamine from nerve cells, has an effect on glutamate receptors, and has anticholinergic properties, all of which can reduce some PD symptoms.

Another class of drugs, monoamine oxidase -B inhibitors (MAO-B inhibitors) prevents the degradation of dopamine, so more is available for use in the brain. This class includes selegiline (Eldepryl) and rasagiline (Azilect).

The breakdown of dopamine is also decreased by using a catechol-O-methyltransferase inhibitor (COMT inhibitor). Entacapone (Comtan) is such a drug. It is often used in combination with levodopa/carbidopa in a single tablet (Stalevo).

Anticholinergic medications may be used to help decrease muscle stiffness, tremor, and saliva production. These include benztropine (Cogentin), trihexyphenidyl (Artane), and diphenhydramine (Benadryl).

An injectable drug which directly stimulates dopamine receptors is apomorphine (Apokyn). The injection is given under the skin, and provides "rescue" from the "off" periods that some PD patients experience on their other medications.

Medications that could be classified as "miscellaneous" for use in PD include memantine (Namenda), which anecdotally helps some patients with gait problems; and methylphenidate (Ritalin), which, based on a case series study, may be helpful in people who have significant "freezing" motor symptoms.

In addition to medications, some patients may be candidates for deep brain stimulation surgery, in which an electrode is placed in the brain to deliver electrical impulses to a targeted area in order to reduce severe PD symptoms.

4 What is going on in research?

Research continues into the causes, treatment, and prevention of Parkinson's Disease. Genetics, environment, and their interaction are targeted.Some labs are working to discover the causes of cell death by studying the mitochondria of cells: what stresses cause these "power-houses" to break down and can those stresses be prevented or treated?

Other investigators are attempting to alter particular genes by attaching normal DNA to harmless viruses, allowing the viruses to infect cells, and create new genes that will allow the cell to function normally. After pre-clinical studies with cell cultures and animals, there have been two Phase I human trials with a very small number of advanced-stage PD patients. This method of treating PD in the general population will require much more study.

The use of trophic factors (which are proteins produced by the body and are necessary for proper functioning of cells), is also in small Phase I trials.

Researchers are interested in finding treatments that can protect neurons from damage. Rasagiline (Azilect) is probably the best compound studied at this time, but others, such as Coenzyme Q-10, creatine, and minocycline may prove to have some benefit.

Stem cell research continues, but there is only one current study using human embryonic stem cells, and that is being conducted with patients whose spinal cords have been severed. There is some evidence that skin cells may be induced to become stem cells, which might then be used for treating PD. Three trials, all outside the U.S., are underway for this purpose.

Different methods of delivering medications are also being developed. Continuous infusion of levodopa via a pump similar to those used by diabetics to deliver insulin might provide more continuous relief from symptoms. Transdermal patches could be used once drug stability issues are addressed. A nasal spray is being studied for apomorphine.

Continued on page 4

questions and answers

with Dr. Elizabeth Peckham
Feb. 2010 DAPS general meeting

Disclaimer: *This information is provided for informational purposes only and is not intended as medical advice or as a treatment guide for patients. Please check with your personal physician for any specific questions regarding your medical care.*

Q Are younger patients more responsive to medications?

This is unknown. Long-term planning is very important for younger patients, though.

Q How can someone find out if they have genetic markers for PD?

At this time, there are only five genes identified that are associated with PD, and their specific functions are under investigation. Since, currently, there would be no change in treatment, there is really not a good reason to find out if the markers are present.

Q Is Botox ever used for PD patients?

Botox injections may be helpful for treatment of dystonias, particularly those of the feet, hands, eyes, and neck.

Q Is there a correlation between acting out dreams and PD?

Yes, the acting out of dreams (which is often more disruptive to the partner than to the dreamer), is a sign that may appear long before other symptoms. It is a result of an REM-sleep disorder. The use of clonazepam (Klonopin) at bedtime may be helpful.

Q Can PD patients drink alcohol?

Because side effects of alcohol, especially sedation and hallucinations, may be worse in PD, the individual needs to be very cautious with any alcohol. People who have balance difficulties should probably not drink alcohol at all as it would increase the risk of falls.

Q It seems that doctors treating PD try a variety of medications because they are not sure what will work. Is this a common approach for other diseases?

Yes. Diseases which produce a variety of symptoms, and may have different underlying causes, are often difficult to treat the same way in all patients. Migraine headaches, multiple sclerosis, and other diseases require this approach.

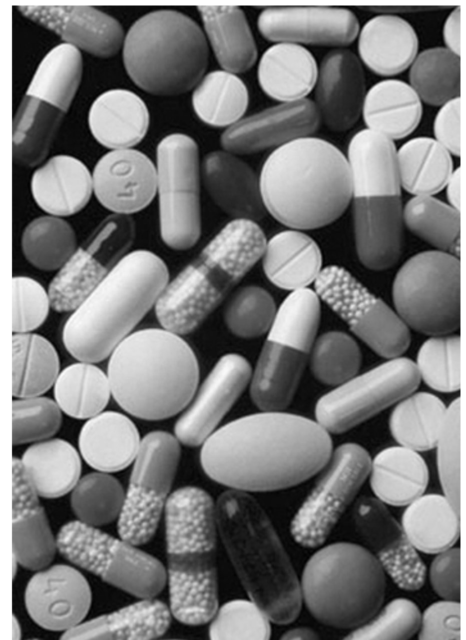
Q Why are all the human research studies so small?

Phase I clinical trials are evaluating the safety of treatments, and only about 20 patients are needed for these. As the treatments move into Phase II and III trials, the number of patients required increases substantially.

appreciation

Roger (Hill) and I appreciate all of the volunteers, helpers; especially Barbara and Thomas, church folks, cooks; and all the others who work so tirelessly... Love to all and thanks a million...I am sure that we have the "bestest" Parkinson's Group. Mari

The Parksonsonian and families really appreciate the church and the program SG provides. Thank you to each of you for all you do to keep our Ministry going and strong. Charlene Noe, Facilitator for South Garland Baptist Church DPS Location



parkinson's disease: top 5 questions

Continued from page 3

5 What can I expect in 5, 10, or 20 years?

People who are newly diagnosed with Parkinson's Disease often want to know what changes they can expect over time. However, it is not possible to predict the progression of the disease in a particular patient. The best advice Dr. Peckham gives to patients is to be proactive in managing their condition. Exercise! Exercise! Exercise! Numerous studies show that exercise affects many aspects of brain function, including decreasing depression and increasing the production of important trophic factors. Stay informed and attend support groups. Seriously consider any opportunities to participate in research studies.

The "old" way of managing PD was to increase or change treatments as the diseased progressed. The "new" way of thinking about PD is to modify the progression of disease by increasing physical activity, enriching the environment (increasing brain activity), and eating a diet rich in antioxidants.

Medicare Caps on Rehab Therapy Reimbursements Effective January 1, 2010

by Peter Schmidt, Ph.D.

Parkinson's disease patients and those who care for them should be aware of a change in Medicare's caps limiting outpatient rehab services. These therapy caps went into effect on January 1, 2010 and apply to outpatient physical therapy, occupational therapy and speech-language pathology services.

A limit of $1,860 in reimbursement applies to all who receive outpatient therapy, with the exception of hospital outpatient departments. Thus, those who receive therapy services with a skilled nursing facility (Part b), a therapist's or physician's private practice, a home health services agency (Part b), or a rehabilitation agency are subject to these caps. Once the limit of $1860 has been reached, beneficiaries who require additional services in a 12-month period are responsible for 100% of the cost.

According to the American Physical Therapy Association, approximately 13% of Medicare beneficiaries who receive rehabilitation services exceed the arbitrary limit on coverage.

These caps were originally imposed by the Balanced Budget Act of 1997. In the past, Congress voted to allow Medicare beneficiaries to exceed the cap if the services were deemed medically necessary. This year, Congress did not vote to allow exceptions and the cap limit went into effect on January 1. While both the House and Senate versions of health care reform legislation addressed the therapy cap by extending the exceptions process temporarily, failure to enact reform means that Parkinson's patients will only receive Medicare reimbursement for up to $1,860 of therapy services, unless those services are provided in a hospital setting.

Physical therapy and speech therapy, in particular, have been demonstrated to have a significant positive impact on the health and well-being of people with Parkinson's, including improving speech and swallowing, gait and balance and helping to prevent falls. In addition, many people with Parkinson's have one or more other conditions, such as arthritis, for which ongoing therapy is essential.

The National Parkinson Foundation and the Parkinson Action Network (PAN) have together identified this as a high priority issue. PAN is currently working with a broad coalition to craft a legislative strategy in Washington to remedy the situation as soon as possible. People with Parkinson's, those who care for them and healthcare providers should contact their member of Congress to urge that this issue receive the highest priority and that any solution be retroactive to January 1, 2010.

Patients who are currently receiving rehabilitation therapy should:

- Determine whether hospital-based outpatient services are available in your area. These are not subject to the cap. To look for physical therapy services, visit http://www.apta.org
- Keep track of all costs for physical or speech or occupational rehabilitation therapy services as those exceeding the cap may be reimbursable once Congress takes action.

For providers of rehabilitation services:

- Be aware that the billing code for the Medicare exception, Modifier KX is no longer a valid modifier. Claims with this code will be rejected for all services after January 1, 2010.

We will follow up with additional information when our coalition has identified specific legislation that will address this problem. In the meantime, work with your provider to identify a physical therapy, occupational therapy, and speech therapy plan that will work for you given these caps.

Best regards,
Peter Schmidt, Ph.D.
Chief Information Officer
Vice President, Programs

memorials, honors, donations

February 1 thru February 28, 2010

In memory of **Shirley Don Bigney**
From: Dave Wick

In memory of **Bing Borschow**
From: Margie & Sylvan Landau

In memory of **Johnnie Dondelinger**
From: Sarah Atwood

In memory of **Albert Feinberg**
From: Margie & Sylvan Landau

In memory of **Henry "Hank" Gilliam**
From: Sarah Atwood

In memory of **Elsie Graves**
From: Ron & Tina House

In memory of **Allen J. Hargis**
From: Alice M. Hargis
Mr. & Mrs. Walter R. Wagener

In memory of **Dan Johnson**
From: Sarah Atwood

In memory of **Marianne Lichtenstein**
From: Lisa & Jim Albert
Sarah Atwood
Jenny & Izell Bankston
Don & Barbara Bennett
Jane Bock Guzman
Margie & Sylvan Landau
Irv & Cindy Munn
Patricia L. Peiser
Deanne Savage
Stefani Shanberg
Bob & Ann Staton
Lindsey & Herb Weiner

In memory of **Edna Osborn**
From: Margaret A. Fowler
Carolyn Wallen

In memory of **Margaret M. Powell**
From: Barb & Larry Helms
Robert Martin

In memory of **Charlie Shuffield**
From: John & Pat Adams
Sarah Atwood
Carl & Mary Benning
Ann Long
Patsy Michalski
Stella Novit
Minne Siegel
Sherri Steinford
Barbara G. Taylor
Z Gallerie

In memory of **Maurine Adams Thurman**
From: David & Betty Coe Manuel

Donation to DAPS
From: Arapaho PAGE
Edna Buentipo
Custer Road PAGE
General Meeting
Irving PAGE
Preston Hollow Caregivers
Preston Hollow PAGE
Skillman PAGE

Your donations are tax deductible.

daps' april luncheon

The Stonewall Jackson Elementary School Choir is composed of 4th and 5th graders who have made the commitment required for this extra-curricular activity. They sign up for the group, attend rehearsals before the beginning of the school day, and must maintain good grades to participate.

Their leader, Mr. Curtis Butler, graduated from Oral Roberts University with a major in Fine Arts and has implemented a well-rounded music program for the school. His efforts and those of his students will benefit our members and their guests at DAPS' April Luncheon.

world parkinsons congress 2010

Re-printed courtesy of World Parkinson Coalition

The World Parkinson Coalition has finalized the design of the provisional program for the second World Parkinson Congress to take place in Glasgow, Scotland from September 28 - October 1, 2010. The WPC 2010 is following on the success of the first WPC in 2006 that attracted nearly 3,200 delegates from 56 countries and will be an international, interdisciplinary forum showcasing the latest developments in the world of Parkinson's disease. (PD).

Unique in the Parkinson's community, the WPC 2010 is open to people touched by PD, including researchers, physicians, physiotherapists, nurses, speech therapists, patients, caregivers and anyone else working in the field of PD. The program will cover topics of interest to all members in the community when it covers medical and scientific research, education and training, best-care initiatives, and quality of life issues. Presentations will be offered through an extensive program including plenary sessions, debates, symposia, and workshops devoted to prevention, diagnosis, treatment of and future research of PD.

We welcome you to join us in September 2010 for what we expect to be the Parkinson's event of the year. Whether you attend for the outstanding sessions, or to spend time in the lively Renewal Room or even because you have submitted a poster for the Living with Parkinson's poster session we think you will get something out of the meeting. For more information or to view the provisional program email info@worldpdcongress.org or go to www.worldpdcongress.org.

NO CHARGE
speech therapy and group exercise

CARROLLTON

ST. ANDREWS CHRISTIAN CHURCH
3945 N. Josey Lane
Group Exercise
Wednesday 9:45 a.m. to 10:45 a.m.
Speech Therapy
Wednesday 10:45 a.m. to 11:30 a.m.

DALLAS

BAYLOR INSTITUTE FOR REHABILITATION
909 North Washington Street
Water Therapy
Wednesday 11:00 a.m. to 12:00 p.m.

DALLAS YOGA CENTER
4525 Lemmon Ave., 3rd Floor
Yoga for Parkinson's
Friday 11:00 a.m. to 12:00 p.m.

LAKESIDE BAPTIST CHURCH
9150 Garland Road
Group Exercise
Wednesday 9:30 a.m. to 10:30 a.m.
Speech Therapy
Wednesday 10:30 a.m. to 11:15 a.m.
Partners in Care Group
2nd Wed. each month 10:30 a.m. to 11:30 a.m.

PRESTON HOLLOW UNITED METHODIST CHURCH
6315 Walnut Hill Lane
Speech Therapy
Tuesday 11:30 a.m. to 12:15 p.m.
Group Exercise
Tuesday 10:30 a.m. to 11:30 a.m.
Thursday 10:30 a.m. to 11:30 a.m.
Friday 10:30 a.m. to 11:30 a.m.
Partners in Care Group
Tuesday 10:30 a.m. to 11:30 a.m.

SKILLMAN CHURCH OF CHRIST
3120 Skillman St., FLC Building
Group Exercise
Monday 9:15 a.m. to 10:15 a.m.

ST. LUKE COMMUNITY UNITED METHODIST CHURCH
5710 East R.L. Thornton Freeway
Group Exercise
Monday 10:00 a.m. to 11:00 a.m.

DUNCANVILLE

TRINITY UNITED METHODIST CHURCH
1302 S. Clark Road
Group Exercise
Monday 6:30 p.m. to 7:30 p.m.

GARLAND

SOUTH GARLAND BAPTIST CHURCH
1330 E. Centerville Road
Speech Therapy
Thursday 9:30 a.m. to 10:15 a.m.
Group Exercise
Monday 10:30 a.m. to 11:30 a.m.
Thursday 10:30 a.m. to 11:30 a.m.
Partners-in-Care Group
Thursday 10:30 a.m. to 11:30 a.m.
Discussion Group
Monday 9:30 a.m. to 10:30 a.m.

IRVING

FIRST UNITED METHODIST CHURCH
211 W. Third Street
Group Exercise
Tuesday 9:45 a.m. to 10:45 a.m.

PLANO

CUSTER ROAD METHODIST CHURCH
6601 Custer Road
Group Exercise
Monday 9:45 a.m. to 10:45 a.m.
Thursday 9:45 a.m. to 10:45 a.m.
Speech Therapy
Thursday 11:00 a.m. to 11:45 a.m.
Partners-in-Care Group
Monday 9:45 a.m. to 10:45 a.m.

RICHARDSON

ARAPAHO UNITED METHODIST CHURCH
1400 W. Arapaho at Coit
Group Exercise
Monday 10:00 a.m. to 11:00 a.m.
Wednesday 10:00 a.m. to 11:00 a.m.
Friday 10:00 a.m. to 11:00 a.m.
Partners-in-Care Group
1st Wed. each month 10:00 a.m. to 11:00 a.m.

Call DAPS at (972) 620-7600 for more information.

aid and attendance

Please pass this along to all veterans, families of veterans or individuals with veterans in their family.

"Aid and Attendance" is an underutilized special monthly pension benefit offered by the Veterans Administration for veterans and surviving spouses who require in-home care or live in nursing homes.

To qualify, a veteran (includes the surviving spouse) must have served at least 90 days of active military service, one day of which is during a period of war, and must be discharged under conditions other than dishonorable.

The veteran's benefit is $18,234 annually (paid monthly) and an increase to $21,615 if a veteran has a dependent.

The surviving spouse alone is $11,715 annually.

For more information, call 1-800-827-1000

Visit http://www.va.gov/ (type "Aid and Attendance" in the search block), or contact your local VA office.

Apply on-line at http://vabenefits.vba.va.gov/vonapp/main.asp

PSS: Here is a good link to articles on Agent Orange: http://www.chicagotribune.com/health/agentorange/

Never again will one generation of veterans abandon another."

april 2010 calendar of events www.daps.us

general meeting
Monday, April 12 - 12:30 p.m.
Parkinson's Awareness Luncheon
Program: Children's Choir from
Stonewall Jackson Elementary School
University Park United Methodist Church
4024 Caruth at Preston

open board meeting
Monday, April 19 - 1:00 p.m.
University Park United Methodist Church

next month
Monday, May 10 - 12:30 p.m.
Speaker: Christopher Ging
Board Certified Acupuncturist
University Park United Methodist Church

partners-in-care groups
Led by Charlotte Webberman, ACSW, LMSW

Every MONDAY: 9:45 a.m. - 10:45 a.m.
Custer Road Methodist Church
6601 Custer Road, Plano, Texas 75023

Every Tuesday: 10:30 a.m. - 11:30 a.m.
Preston Hollow United Methodist Church
6315 Walnut Hill Lane

Every 2nd WEDNESDAY of each month:
10:30 a.m. - 11:30 a.m.
Lakeside Baptist Church, 9150 Garland Road

Every 1st WEDNESDAY of each month:
10:00 a.m. - 11:00 a.m.
Arapaho United Methodist Church
1400 West Arapaho at Coit

Every THURSDAY: 10:30 a.m. - 11:30 a.m.
South Garland Baptist Church, 1330 East Centerville Road

disclaimer: The contents or opinions expressed in this Newsletter are those of the individual writers or presenters and do not constitute an endorsement or approval by DAPS staff. Please consult your personal physician regarding your individual medical problems.

For change of address or corrections, please indicate the changes on this page and send or fax it to DAPS or email: daps125@sbcglobal.net

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