



The Newsletter of the Veterans Health Administration's
Parkinson's Disease Research Education & Clinical Center (PADRECC) SOUTHEAST

Exercise Class for Vets with PD Underway at McGuire VAMC!

By Zaynah Outubuddin

Anyone happening to stroll into the multipurpose room on a Wednesday or Friday morning would be met with the wonderful sight of a large group of Parkinson's disease patients and their spouses stretching arms and legs all while simply sitting. One leg stretch to loosen the hamstring, another to work the quads. Bend one arm in a particular direction to stretch the triceps, and a head roll to relax the neck. Basic techniques and maneuvers that are taught in high school gym classes are many times forgotten along with the concept that the simplest ways may sometimes work the best.

McGuire VAMC's PADRECC has recently begun a group exercise program for Parkinson's patients led by Susan Cornell, a personal trainer and group exercise instructor for the past 3 ½ years. She teaches at the John Rolfe Family YMCA, the Tuckahoe Family YMCA, and now here at the PADRECC. This vivacious, friendly, and more than helpful Yankee began working with PD patients a little over a year ago.

In comparison with her general YMCA class, Cornell says the main difference between that and her PD classes are "the level of mobility and range of function. At the YMCA, I use free weights and exercise machines. We do different types of things here, but it still works on the same things – we're just attacking them differently," she said.

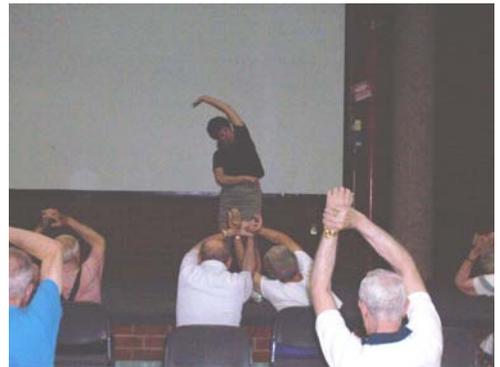
Here at the VA, her first class began with having each individual introducing him or herself, followed by a general overview on the importance of exercise, especially for one with a movement disorder.

"If you have a movement disorder, you gotta move," she said.

During her lessons, Cornell has mentioned following John Argue's methods of exercise from his book, "The Art of Moving," which covers exercise techniques from the basic level to intermediate level showing how to work out all parts of the body for varying levels of PD patients.

The main focus of what both Argue and Susan teach, however, is not what everyday gym-goers aim for, such as the typical fat burn or muscle buildup. While those are important factors to consider when exercising, for PD patients, it is far more beneficial to target exercises that will aid in improving daily movement and speech. Argue's book mentions ways to handle certain situations in which a person may freeze or fall. And, in dovetailing her lesson with

Summer 2006 Issue



"Moving to agility, balance and joy"



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Our team of caring and qualified professionals consist of full-time, part-time, government, contract and fee-basis employees. Many staff have academic affiliations at Virginia Commonwealth University (VCU) Medical Center.

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Published twice a year, winter and summer editions. Submissions/ideas are welcome and will be considered for publication. Please send to the editor lynn.klanchar@va.gov or call (804) 675-6952.

From the editor

Dear friends,

Every which way I turn I hear about exercise and the importance of physical activity. Keeping sailors fit and healthy was part of my job at the US Navy's Center for Health Promotion. That was before coming to Richmond to work with veterans who have Parkinson's disease. It doesn't surprise me that exercise is a recurring theme at our monthly PD support group meetings.

Hal Newsom's book called "H.O.P.E., Four Keys to a Better Quality of Life for Parkinson's People", is a quick read and chock full of hope. HOPE stands for Help, Optimism, Physician and Exercise. He says that some days he feels like the Tin Man in *The Wizard of Oz* from the stiffness and rigidity that PD can cause. Exercise is the lubricant for his body!

Recently the *Richmond Times-Dispatch* featured an article about a Parkinson's exercise class at the local YMCA. PADRECC is pleased to secure the services of Susan Cornell, a certified personal trainer and group exercise instructor for some part-time work with our veterans who have PD. She is versed in the John Argue Method for PD called *The Art of Moving*. Don't miss Zaynah Qutubuddin's cover story about this!

In May, the VA launched the *MOVE!* Campaign. It is part of a public health approach to reduce the rates of diabetes and overweight in the veteran population. MOVE stands for Managing Obesity and Overweight for Veterans Everywhere. It's focus is on behavior, nutrition and you guessed it, physical activity! The *MOVE!* web site has some great resources to help get you motivated to exercise, plus tips for vets with physical limitations. www.move.va.gov

If exercise has never been a discipline in your life, no better time than now! What is the best exercise? The one that you will do. Find activities you enjoy. Work out with a partner or friends. I hope you like reading this edition of the PADRECC News!

Keep moving to agility, balance & joy!
Lynn



How to Enroll in PADRECC Southeast



Who is eligible for PADRECC?
Veterans who received an honorable discharge from any branch of the service & served on Active Duty during war or Peacetime & meet eligibility requirements for VA health care benefits.

How do I apply for enrollment & get an appointment?
First step is completing a Veterans Affairs (VA) health care benefits application. Call **(877) 222-8387** or go to www.va.gov. Once enrolled, your VA doctor can make a referral to PADRECC Southeast at **(804) 675-5931**. We can also work with your current Neurologist or use Telemedicine.

Research Opportunities at PADRECC SE
Available to veterans & non-veterans diagnosed with PD.
You do not need to be a veteran or enrolled to participate in some research.

Clinical Care

VA News

NOTICE: New System for PADRECC Follow-up Appointments

The month you are due for a follow-up appointment, you will receive a letter in the mail asking you to call the clinic and make that appointment. This allows you to:

- Take responsibility in managing your health care
- Coordinate with other pending appointments
- Avoid a “no-show” appointment

In the past, we automatically made you a follow-up appointment. The letter will instruct you to call PADRECC SE at (804) 675-5931 or toll-free at (800) 784-8381 ext 5931 to schedule your appointment. Thank you for your cooperation with this VA initiative!

INFO on Veterans Affairs Data Security Issue

In May, electronic equipment was stolen from a VA employee's home. It was subsequently recovered in late June. The laptop contained personal information on up to 26.5 million veterans and some spouses, as well as on as many as 1.1 million military members on active duty, 430,000 members of the National Guard, and 645,000 members of the Reserves. No health records or financial information was lost. VA has taken a number of steps to address this issue, including one year of free credit monitoring to people whose sensitive personal information may have been stolen. People who believe they may have been affected by the data theft can go to www.firstgov.gov for more information. VA also continues to operate a call center to contact to get information about the incident and learn more about consumer identity protections. That toll free number is 1-800-FED INFO (1-800- 333-4636. The call center is operating from 8:00 am to 9:00 pm (EDT), Monday-Saturday as long as it is needed.

Parkinson's Disease Support Groups

PADRECC Support Group

Hunter Holmes McGuire VAMC

1201 Broad Rock Blvd., Richmond, VA
Room 2K-113/115

1-3 pm

2006 dates & topics

Thursdays

Jul 27 – Botox Treatment: Indications for PD use
Hernan Gatuslao, MD, Neurologist, Richmond

**Aug 24 – Dementia Overview, Caregiver Stress,
Techniques for Communicating**
Mary Ann Johnson, Alzheimer's Association

Sep 28 - PD Issues: Social Worker's Perspective
Gayle Jackson-Lewis, MSW, Richmond VAMC

Oct 26 – APDA I&R Center of Virginia
*Susan Dietrich, Coordinator and
Meet the New Movement Disorder
Specialist*

Anna Hristova, MD, PADRECC Southeast

**Nov 16 – Veteran Health & Wellness (featuring
My Health_{Vet}: VA's on-line personal
health record system)**

Deborra Schumacher, LPN, Patient

Education Resource Center, Richmond VAMC

Dec 14 - Holiday Gathering

Contact: Lynn Klanchar (804) 675-6952

Richmond Metro Chapter APDA

www.parkinsonrichmond.com

Educational focus: 3rd Sunday – 2 pm

Health South, 5700 Fitzhugh Avenue

Contact: Kathy Morton (804) 730-1336

Discussion format: 1st Tuesday - 7 pm

Circle Center, Broad St, Methodist Home

Contact: Ann Spinks (804) 355-5717

Young Onset Support Group

Contact: Cheryl Majeske (804) 932-3846

cherylmajeske@hotmail.com

Hampton Roads Area Chapter APDA

www.hrparkinsons.com

Meetings in Virginia Beach & Chesapeake

(757) 495-3062

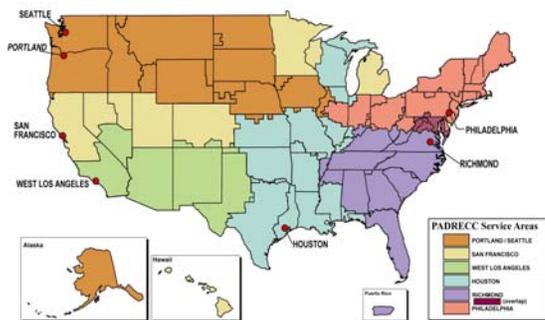
Williamsburg Parkinson's Support Group

2nd Monday each month -1:30 pm

5700 Williamsburg Landing

Contact: Bob or Joan Byrne (757) 898-6674

Recommended Service Areas for PADRECCs



PADRECC Southeast based in Richmond, Virginia serves many states in the Southeast Region of the country.

Question: How can I find a support group if I don't live in the Richmond area?

Answer: American Parkinson Disease Association (APDA) provides a list of support groups throughout the US and can be found through its Information & Referral (I&R) Centers. Go to www.apdaparkinson.org call (800) 223-2732 or call the nearest APDA I & R Center.

APDA I&R Centers serving the Southeast:

Birmingham AL: (205) 833-4940/934-9100

Hot Springs AR: (501) 321-2811/922-4976

Jacksonville FL: (904) 953-7030

Pompano Beach FL: (800) 825-2732

St. Petersburg FL: (727) 898-2732

Atlanta GA: (404) 728-6552

Durham NC: (919) 681-2033/668-2938

Memphis TN: (901) 516-0677

Nashville TN: (615) 342-4635 or

(800) 493-2842

Charlottesville VA: (434) 982-4482

More sources of support group information:

Parkinson Association of the Carolinas

(704) 248-3722 www.parkinsonassociation.org

Serving North and South Carolina

Parkinson Foundation of the National Capital Area

(703) 891-0821 www.parkinsonfoundation.org

Serving the Washington DC Metropolitan area

Parkinson's Disease Foundation (PDF)

Parkinson's Information Service (PINS)

(800) 457-6676 www.pdf.org

National Parkinson Foundation (NPF)

(800) 327-4545 www.parkinson.org

World Parkinson Congress Report



The World Parkinson Congress (WPC) was a unique international event held at the Washington Convention Center in Washington DC on February 22-26, 2006. The event was organized by the World Parkinson Congress, Inc., and supported by the Movement Disorder Society, the National Institutes of Health, the US Army Medical Research Acquisition Agency, and multiple professional and patient voluntary organizations. PADRECC's National VA Parkinson's Disease Consortium was represented as an Organizational Partner of the Congress. This first time ever meeting of the Congress brought together over 3,100 members of the Parkinson's community: leading researchers and clinicians in the field of Parkinson's disease, allied health professionals, and people with Parkinson's and their caregivers. This format surprised many, but it worked to create a climate of collaboration among all the groups with a common goal of expediting the discovery of a cure and best treatment practices to make life better with PD. For more information on World Parkinson's Congress, visit www.worldpdcongress.org. The next WPC is slated for June 2009 in Paris, France!

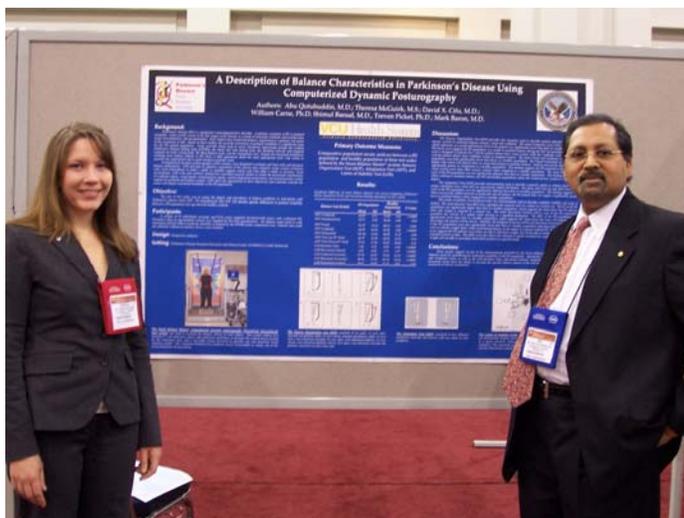


Entrance to WPC Exhibit Hall containing hundreds of exhibits by vendors, PD organizations, research posters, and an art gallery "Creativity and Parkinson's."

PADRECC Richmond/Southeast distinguished themselves with a number of research posters presented at the World Parkinson Congress. Guided Poster Tours were held as a way for conference participants to talk directly to the researchers or presenters about their work.

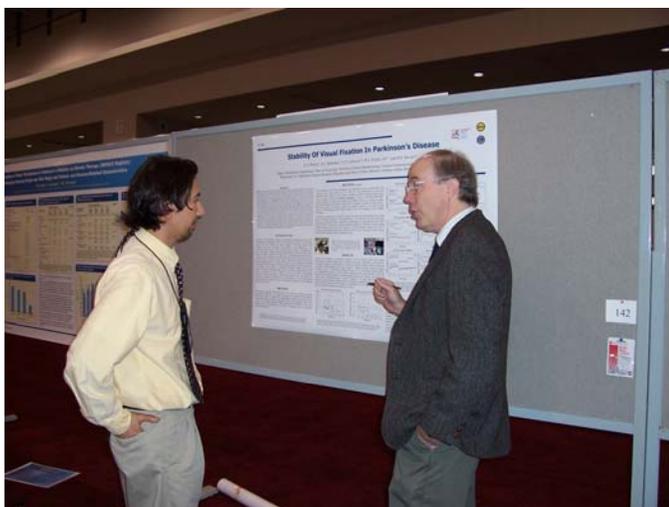
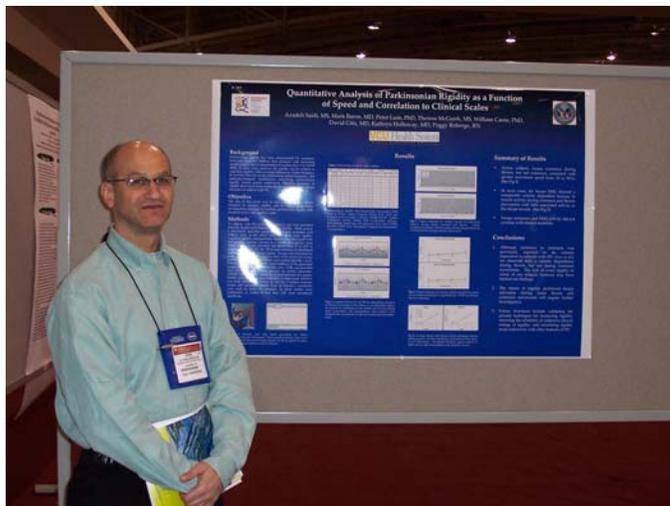


Philadelphia PADRECC representatives manning the **National VA PD Consortium** booth. **Dawn McHale** (l) is the current National Coordinator for the VA PD Consortium with **Yuri Romaniuk** (r) the past coordinator.



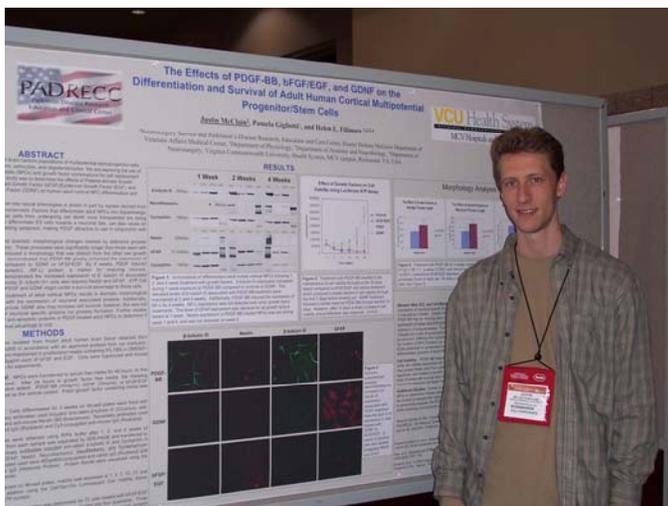
Theresa McGuirk, MS (l) and **Abu Qutubuddin, MD** (r) from Southeast PADRECC presented the poster "**A Description of Balance Characteristics in Parkinson's Disease Using Computerized Dynamic Posturography**." The aim of the study was to measure and evaluate balance in individuals with Parkinson's disease using computerized dynamic posturography (CDP).

Mark Baron, MD, Director of Southeast PADRECC stands near his research poster presented at the WPC. The poster was titled **“Quantitative analysis of Parkinsonian rigidity as a function of speed and correlation to clinical scales.”** The study used a robotic arm device to measure elbow rigidity over a wide range of speeds for elbow flexion and extension.



Paul Wetzel, PhD (r) explains his research to Yuri Romaniuk (l) on **“Stability of visual fixation in Parkinson’s disease.”** Paul works at Virginia Commonwealth University (VCU) and Southeast PADRECC doing research on eye movements that may offer a potential objective measure to assist in early clinical diagnosis, and ongoing assessment and Treatment of PD.

Justin McClain, Virginia Commonwealth University (VCU) graduate student, stands near his research poster presented at the WPC. The poster was titled **“The effects of Platelet-derived Growth Factor (PDGF) on differentiation and survival of adult human multipotential progenitor/stem cells.** **Helen Fillmore, PhD** and **Pam Gigliotti** at Southeast PADRECC were co-authors of this work which is exploring the use of adult human neural progenitor cells and growth factor combinations for cell replacement therapies.



EXERCISE RESOURCES FOR PARKINSON'S

"I do not try to dance better than anyone else. I only try to dance better than myself."

Mikhail Baryshnikov

\$ COST MONEY \$

General Parkinson's Disease Exercise Class, at John Rolfe Family YMCA, and **Young Onset PD Exercise Class**, at John Rolfe YMCA and Tuckahoe YMCA, in Richmond, VA. For more information call (804) 360-8767.

Parkinson's Disease and the Art of Moving, book by John Argue. 220 pgs. Shows how to better flexibility, balance, gait, & communication. Video companion is 187 min., guides you through all exercises in the book. 2 DVD or VHS set. (510) 985-2645 or www.parkinsonsexercise.com

Water Exercises for Parkinson's: Maintaining Balance, Strength, Endurance, and Flexibility, by Ann Rosenstein. 242 pgs. www.idyllarbor.com

The Exercise Program, by the Parkinson Disease Foundation. 3 sets of exercises designed for PD patients. 3-ring binder with flip-chart pages and two cassette tapes. (800) 457-6676 or www.pdf.org

Motivating Moves for People with Parkinson's The Parkinson Disease Foundation presents Janet Hamburg's 90 min. seated exercise program. VHS or DVD. (800) 457-6676 or www.pdf.org

Sit and be Fit, by Mary Ann Wilson. Numerous DVDs, Videos, CDs, and Cassettes that contain exercise programs which are suited to people with PD including a Parkinson's Specialty Video. (509) 448-9438 or www.sitandbefit.org

Walking Poles for Exercise Walking poles offer several benefits to people with Parkinson's disease. <http://www.walkingpoles.com>

\$ FREE \$

Parkinson Disease: Fitness Counts, by Heather Cianci. 35 pgs. Descriptions of exercises to maintain flexibility, strength, and aerobic conditioning. National Parkinson Foundation. (800) 327-4545 or www.parkinson.org

The StEP Kit, includes a 30-min. exercise video for people with Parkinson's from Stalevo. (866) STEP-KIT or (866) 783-7548 or www.stepkit.net

Just For You: An Exercise Program, by Mirapex. 30 min. exercise video for PD patients. Copies available at PADRECC, call Lynn Klanchar (804) 675-6952

Parkinson's Disease and Exercise, 3 pg. fact sheet on the web produced By the Better Health Channel for the govt. of Australia that gives some quick facts on exercise and a sample exercise program. <http://www.betterhealth.vic.gov.au>

The Role of Exercise in Parkinson's disease, link on European PD website that contains info. and short video footage of exercises for PD. <http://www.parkinsonpoly.com>

Ten Basic Exercises for the Parkinson's Patient, article by The Center for Neurologic Study (CNS) with basic everyday exercises and activities for people with PD. <http://www.cnsonline.org>

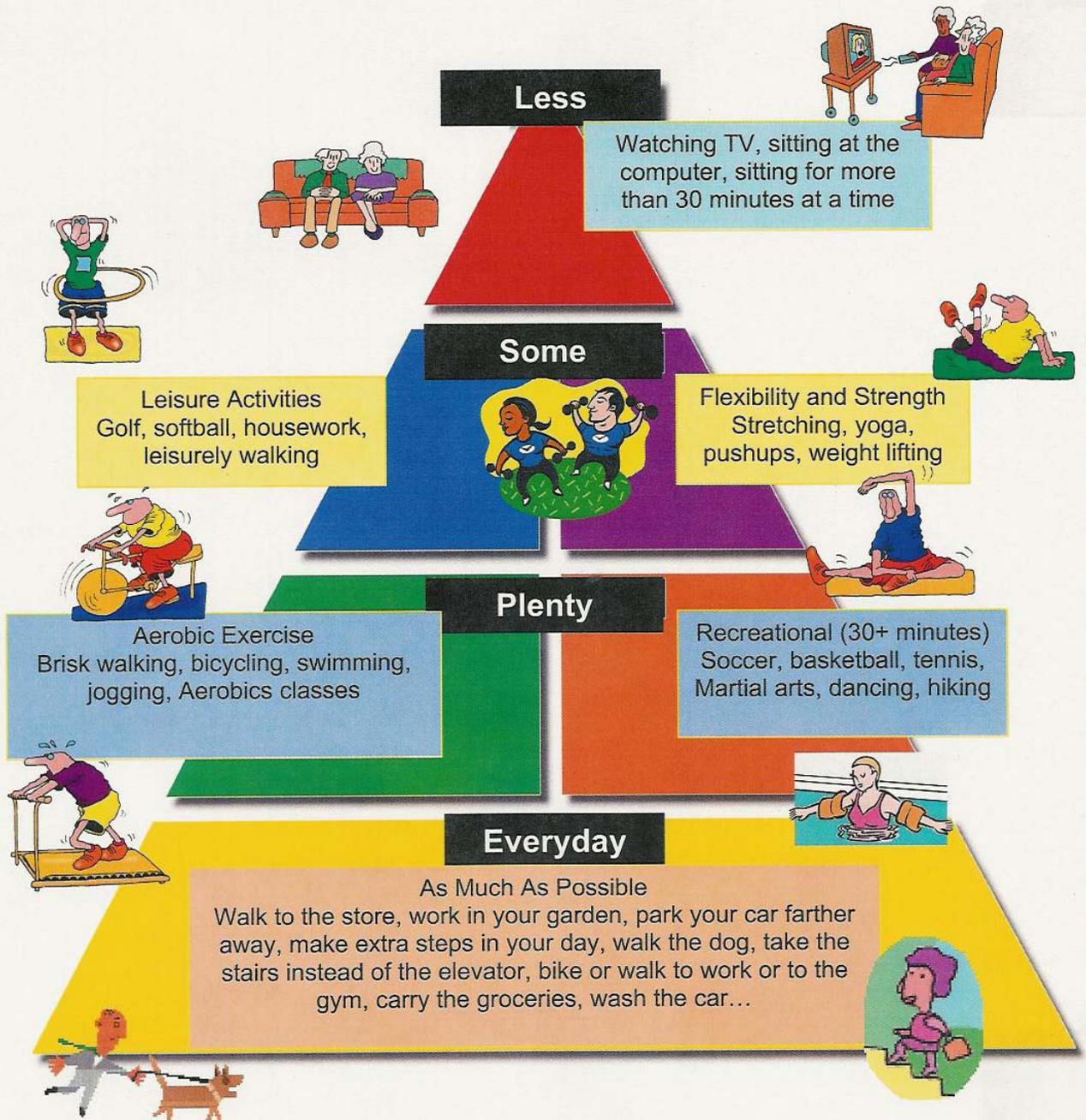
PADRECC Exercise Class, June 28 – Sept. 27 at McGuire VA Medical Center, Richmond VAMC. Wed and Fri from 11am-12pm. **Class currently filled.** To get on waiting list, contact Lynn Klanchar (804) 675-6952/5931.

Remember doing these FUN things as a kid? To improve and strengthen your speech & breath:

- Blow some bubbles
- Buy a train whistle and practice being the engineer!

Physical Activity Pyramid

Be creative in finding ways to stay active!



MOVE!

P26 Version 2.0



PARKINSON'S DISEASE COMMUNITY EDUCATION DAY OCTOBER 7, 2006

For People & Families Living with Parkinson's Disease

**Holiday Inn Select, Koger South Conference Center
1021 Koger Center Blvd., Richmond, VA 23235**

Hotel/conference center is located off of the Midlothian Turnpike (Route 60 West)

AGENDA

- 8:15 – 9:15 am Arrival, Check-In & Continental Breakfast
- *8:30 – 9:00 am* "Parkinson's Disease 101"- Miriam L. Hirsch, MS, RN
* optional session for those newly diagnosed
- 9:15 – 9:30 am Welcome & Introductions
- 9:30 – 10:15 am "What is Parkinson's Disease?" - Fred Wooten, MD
- 10:30 – Noon KEYNOTE: "Nutrition & Parkinson's Disease" -Jackie Nielsen, MS, RD, CDE
- Noon – 1:15 pm LUNCH/Raffle & Door Prizes
- 1:15 – 2:00 pm "Complementary Medicine & Movement Disorders" - Anna Hristova, MD
- 2:15– 3:00 pm BREAKOUT SESSIONS (Choose one session)
A. "Role of Exercise for People with PD"
Laura Lee, MD, MBA with Susan Cornell, Fitness instructor
B. "Living Well with a Chronic Illness"
Scott Wylie, PhD

Call to receive a complete brochure and registration form

Sponsors:

- PADRECC Southeast
- APDA Richmond Metro Chapter & Circle Center Support Groups
- APDA I & R Center of VA
- UVA Health System
- VCU Medical Center

Brochures will be available in late July.

Those on the PADRECC SE mailing list will be mailed a brochure.

Questions, registration or more information

PADRECC: (804) 675-6952 or toll-free (800) 784-8381 ext. 5931 (Lynn Klanchar)

REGISTRATION DEADLINE: September 29, 2006

Registration Fee: \$15.00 per person *by check payable to "Parkinson's Conference"*

*Conference fee covers program, conference materials, and lunch.

Mail to: Hunter Holmes McGuire VAMC, PADRECC #127, Room 2C-114, 1201 Broad Rock Blvd, Richmond, VA 23249

Accommodations at Holiday Inn Select Koger South: a block of rooms are reserved for Oct 6-7. Room rate is \$84.00 plus tax. Ask for Group Block PD1.

Call (800) 397-1034 or (804) 379-3800

PADRECC Southeast NEWS

People



Vanessa Banks, Program Support Assistant. On the frontline of customer service since March 2006. She is the helpful, courteous person who answers the PADRECC phone, schedules appointments, and greets you at check-in.

Dustin Dyer (l) and **Zaynah Outubuddin (r)** are summer employees helping with a wide variety of work at PADRECC such as clinical research, database maintenance, support groups, and exercise classes. Dustin starts med school in September & Zaynah returns to her undergraduate studies.



Congratulations to **Kathryn Holloway, MD**, PADRECC's Neurosurgical Director on these multiple achievements! She was recently promoted to full Professor in the Neurosurgery Department at Virginia Commonwealth University (VCU) Medical School. Dr. Holloway has been elected to the Executive Council of the American Society of Stereotactic and Functional Neurosurgery as well as the Senior Society of Neurosurgery.



David X. Cifu, MD, Associate Director of Research for PADRECC is also serving as Chief, for the Polytrauma Rehabilitation Center at the McGuire VAMC, one of four VA Polytrauma Centers of Excellence. Dr. Cifu is a physiatrist and Chairman of the Herman J. Flax MD Professor of PM&R at VCU.



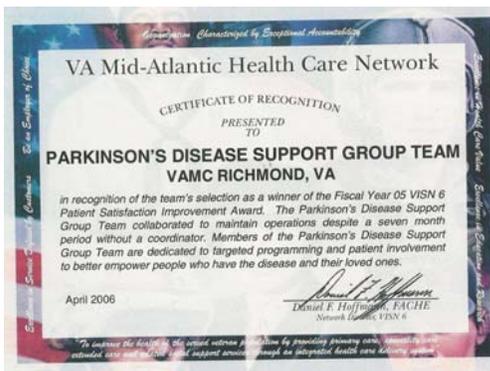
Please welcome **Anna Hristova, MD**, to the PADRECC SE staff! Dr. Hristova is a neurologist and movement disorder specialist. She serves PADRECC as Associate Director for Patient Care Services and also sees patients at VCU Medical Center Department of Neurology. Born and educated in Bulgaria, Dr. Hristova has done Movement Disorder Fellowships at Kansas University Medical Center and Columbia University in NYC.

Events & Awards



Mr. Michael Phaup, Director at McGuire VAMC, helped out with Parkinson's Disease Awareness Month activities by cutting the cake at April's PD Support Group meeting.

The Parkinson's Disease Support Group Team was honored to receive a VISA 6 Patient Satisfaction Improvement Award for Fiscal Year 2005. Daniel F. Hoffman, FACHE, Network Director for VISA 6, presented the award in April.



Peggy Roberge, RN (l) & **Cathy McGrady, AO (r)** man the table on May 12th. Research Appreciation Day at the McGuire Research Institute. This yearly event thanks those who participated in clinical trials.

PADRECC

In 2001, the Veterans Health Administration (VHA) created six **Parkinson's Disease Research, Education and Clinical Centers** (PADRECC) in an effort to improve care for veterans suffering from Parkinson's disease and to pursue treatments and a cure for this condition. **The centers are located in Philadelphia, Richmond, Houston, Portland/Seattle, San Francisco and West Los Angeles.**

Richmond/Southeast

The Hunter Holmes McGuire VA Medical Center in Richmond, Virginia is home to the PADRECC for the southeastern region of the United States.

PADRECC Clinic and other services: interdisciplinary assessment and treatment, clinical trials, physician consultation, medical management, surgical interventions, neuropsychological services, physical and occupational therapy, speech therapy, nursing services, caregiver resources, educational materials, community education programs and support services.

A **Telemedicine Clinic** is also available for veterans with Parkinson's disease living in the Southeastern region of the US who cannot easily travel to Richmond for an appointment.

Hunter Holmes McGuire VAMC

1201 Broad Rock Boulevard, Room 2C-114

Richmond, VA 23249

Phone: (804) 675-5931 or toll-free (800) 784-8381 ext. 5931 Fax: (804) 675-5939

Richmond PADRECC website: www.va.gov/netsix-padrecc

National VA PD Consortium

National Veterans Affairs Parkinson's Disease Consortium was established to synergize the effectiveness of VA clinicians and to fortify the VA's commitment to veterans with PD and other movement disorders. Membership is free.

Contact the Consortium Coordinating Center at (215) 823-5934 or visit the National PADRECC website:

www.parkinsons.va.gov

Exercise Class *continued from page 1*

Argue's suggestions, Susan's main goal for her first class was to teach everyone how to get up on his or her own from a fallen position.

"God forbid if I don't teach you anything else, just learn this," she told everyone on the first day.

She had every person get themselves onto the mats provided and roll onto their backs. In this position, she had everyone doing stretches to work the abs and side muscles, and from there, demonstrated step by step just how to go from being on the floor to pulling oneself up onto a chair without aid. Some in the group were able to master this method rather quickly while others found some difficulty in it. But regardless the amount of time that even the last person took, he or she was finally able to pull him or herself up onto the chair.

Each class begins with a simple warm-up and then Cornell proceeds to work a certain area of the body. The first three lessons consisted of a general workout, moving on to the upper body in the second class, and then postural reflexes of the lower body in the third. But no matter what she teaches, Cornell continually stresses the importance of learning to climb back up onto a chair from the floor.

"I really need people to get up on their chairs," she said. "It's exhausting for them to do that multiple times so we have to keep working at it."

The stretches that Cornell teaches, she says can be done, "in front of the TV watching the evening news."

Patricia O'Grady seemed to agree with this statement. The wife of Al O'Grady, who has been fighting with PD for over 10 years, said that being in this class has motivated her husband to work out at home and said, "I think she [Cornell] is doing a great job moving all of our muscles at one time or another."

Her husband responded that he has been trying to keep up at home and enjoys the class. "We've done several stretches I haven't used before, so I'm learning something new." He does plan to see the class through to the end.

Any time a person feels a stab of pain in their knee or feels a little bit sick, he or she automatically turns to the line of pill bottles. While medications do help relieve pain, Cornell staunchly sticks to her motto that, "When there is a cure, exercise is going to be a be a part of it."

She agrees that research is beneficial. But even though there is so much research perpetuating throughout many facilities in the nation, there is no certainty to when a final discovery might be made. Cornell believes that it is "exercise that can hold things at bay," and help patients suffering from disorders at the present instead of sitting at home and waiting for the magic cure for countless years.

"Take an easy chair with a remote and it's only going to get worse," Cornell said. "Don't let denial get you. Don't let depression get you. Get to a support group. Keep moving. And always have a sense of humor."





Mailing List or Address Change?

If you received this newsletter with a mailing label, you are on our mailing list. If not, and you would like to receive future mailings, complete this form, detach and mail to PADRECC SE, Hunter Holmes McGuire VAMC, 1201 Broad Rock Boulevard, Rm 2C-130, Richmond, VA 23249 or call (804) 675-6952.

PLEASE PRINT

Name: _____

Address: _____ Apt # _____

City _____ State _____ Zip _____

Phone number: (____) _____

Email address: _____

Summer 2006 Issue

PADRECC NEWS

Parkinson's Disease
Research, Education & Clinical Center
Richmond/Southeast
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Veterans Affairs Medical Center
1201 Broad Rock Boulevard
Neurology Service #127
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