

Neuropsychiatric Aspects of Parkinson's Disease

Dr. Guillermo Moguel-Cobos



People request to be evaluated for Parkinson's disease when they begin to have the classical motor symptoms of this disease. We are familiar with these symptoms: slowness (bradykinesia), stiffness (rigidity), resting tremor, and poor balance. But what we never think about are the psychiatric or psychological aspects

of Parkinson's disease.

The psychiatric symptoms of this entity are becoming more prevalent and noticeable as we begin to treat the motor symptoms in a more efficacious way. We can expect to see the following symptoms:

1. Depression
2. Anxiety
3. Psychosis
4. Dementia
5. DDS (Dopamine dysregulation syndrome)

Depression is the most common psychiatric syndrome/symptom of Parkinson's disease, present in almost 70% of the patients. It is not a simple reaction to the disability of the disease, but another symptom caused by low dopamine (the neurotransmitter involved in Parkinson's disease); it is a non-motor symptom. In fact, it might predate the motor symptoms of Parkinson's disease by years. Sadness, poor motivation, lack of appetite, insomnia, pain, guilt, and thoughts of death are some of the symptoms of a depressive state. Depression in Parkinson's disease is predisposed by cognitive decline, age (older than 40 years), right sided disease, advanced disease, impaired activities of daily living, high dyskinesias, significant

off periods (wearing off), rapid progression of disease, and medical co-morbidity. If not identified by the medical physician, this should be brought up in the clinic visits. The good news: there are several treatments that ameliorate this symptom such as maximizing Parkinson's disease treatment and the use of antidepressants.

Anxieties are other symptoms of Parkinson's disease. They can involve symptoms of general anxiety disorder (worrying all the time), to social phobia (fearing social interactions/situations). One that is particularly related to the wearing off phenomenon or "freezing" is panic disorder which is not a psychiatric disorder per se, but a reaction to the immobility in public or at home, and to falling. This last symptom should decrease when the "freezing" episodes are better controlled. Social phobia is another anxiety disorder still being studied in its potential relationship to Parkinson's disease. Social phobia isolated from Parkinson's disease (in the general population) is caused by low dopamine levels. From this, it is logical to think it might correlate with the degree of impairment of Parkinson's disease. But it may also relate to the low dopamine levels of Parkinson's disease that affect emotional areas of the brain causing this anxiety disorder without necessarily correlating to the motor

symptoms. In one of our studies, higher levels of social anxiety were seen in untreated Parkinson's disease patients regardless of their motor impairment.

Psychosis is another psychiatric disorder of Parkinson's disease ("the hallucinations"). Psychosis can occur in up to 8-30 % of patients. It could be a cause of skilled nursing facility placement. Psychosis can happen at anytime in the illness. It can happen early in the disease (usually associated with dose of medication and motor fluctuations) and in the

INSIDE

Care Options
Page 3

MAPC Outreach Program
Page 12

Mo Udall
Page 14

The Southwest Parkinson News contains information provided as a service and is not intended to constitute medical advice or views. Patients should discuss information regarding medical management with their physician.

Continued on page 2

Continued from page 1

later stages, (associated with cognitive dysfunction). There are several classes of hallucinations and the most common ones are

1. Presence 64%
2. Visual 10-30%
3. Tactile 8 %
4. Auditory 6-10 %

The hallucinations in the absence of cognitive dysfunction are called “benign”, meaning there is preserved insight i.e. patients know what they are seeing or feeling is not real.

Psychosis can also present with illusions (distortion of an image into another), and delusions (fixed false belief). These happen usually in the more cognitively affected patients.

Psychosis treatment can be difficult, especially since the treatment consists of the use of antipsychotics that affect the motor system i.e. they aggravate Parkinson’s disease. However, treatment can begin by lowering dosages of anticholinergics and dopamine agonists (i.e., benadryl, amantadine, Mirapex and Requip). If symptoms persist, two agents have proven to be efficacious; clozapine (clozaril) and quetiapine (seroquel) which do not worsen the motor symptoms of Parkinson’s disease.

Dopamine dysregulation syndrome is another syndrome of Parkinson’s disease that is becoming more prevalent. It is defined as the use of Parkinson’s disease medications beyond that necessary to control the motor symptoms. The fear is the untreatable part of it. Treatment can ameliorate it though. This syndrome is caused by a dependency on Parkinson’s medications. It is similar to drug abuse, but in Parkinson’s it is more complex than that, as patients do need these medications even though what we see on the outside might be similar. The behaviours that patients with this syndrome display are compulsive gambling, hypersexuality, compulsive eating, compulsive shopping, and aggression to others.

Finally, we must also discuss deep brain stimulation surgery (DBS) as a risk factor for development of psychiatric symptoms. DBS surgery is associated with suicide, depression, mania, hypersexuality, cognitive dysfunction (dementia), psychosis, and apathy. It depends on the surgical site, whether it is bilateral or unilateral, left or right, and other risk factors. To prevent this from happening, patients should carefully be screened by a team

that includes a movement disorder specialist, psychiatrist or neuropsychologist, and a surgeon.

In summary, Parkinson’s disease presents with many psychiatric symptoms aside from motor symptoms. It is important to recognize and give them importance in order to treat them adequately for a better quality of life for Parkinson’s disease patients. Fortunately, there a number of treatments to deal with these particular symptoms.

Welcome New Movement Disorder Fellows at MAPC!

Dr. Nicklesh Thakur



I am a new movement disorder fellow at the Muhammad Ali Parkinson’s Center with a focus on Deep Brain Stimulation Surgery (DBS). My interest in DBS began during my neurology residency at University of Texas Houston Medical School.

I was amazed at the dramatic benefits DBS provided for Parkinson’s disease, Essential Tremor, and Dystonia patients, and thus decided to participate in this fellowship. I am also an Arizona native and my hobbies outside of medicine include golfing, hiking, snowboarding, and outdoor sports.

Dr. Guillermo Moguel-Cobos



I am one of the new movement disorder fellows at the Muhammad Ali Parkinson’s Center. Originally I am from Mexico and came to the United States in 2001 to start a residency in psychiatry. After a few years of training, I realized that neurology was a better field for me. I finished my neurological training at the Barrow Neurological Institute.

My plans are to stay in the US for some period of time working as a clinician and to dedicate some time to clinical research.

Good Bye and Good Wishes

Dr Holly Shill is a remarkable person that our team feels very privileged to have worked with. When I asked my colleagues what they would miss the most about Holly I got several responses: the genuine regard with which she holds all of us as colleagues; her rapport, compassion and care for her patients; her dedication to people with PD and their families; her ready smile and availability to answer questions; her humility. Holly is a great team player and we are honored to have had the privilege to have been on her team.

While we are sad that she is leaving us and are sorry to see her go we have nothing but best wishes for her in her new position and opportunities at Sun Health. We know that she will always be part of our team.



August Luncheon at Muhammad Ali Parkinson Center Kicks-Off Professional Care Providers Educational Program

Jean June

Twelve healthcare provider agencies recently participated in a Parkinson Care Series Kick-Off Luncheon at the Muhammad Ali Parkinson Center. The luncheon was held to introduce Parkinson specific training opportunities to agencies with national, regional and local affiliations. The agencies represented healthcare providers that ranged from skilled nurses, dementia care specialists, speech, physical and occupational therapists, certified nursing assistants as well as personal/companion care assistants. Also present were assisted living facility teams along with several residential care homeowners.

In response to your shared concerns that agencies are lacking information about managing the specific needs of people with Parkinson's disease, we brought together an interested group of professionals who have supported our Center in the past. Each agency received a comprehensive set of materials produced by The Parkinson Foundation of the Heartland. The Parkinson Care Series provides extensive written and DVD presentations that include eight modules focusing on the following topics: An intro-

duction to Parkinson's disease Treatments, Emotional Health, Speech, Exercise, Activities of Daily Living, Fall Prevention and Nutrition. Upon completion of each module, individuals take a written test to substantiate their increased knowledge. The participating agencies will assure that their caregivers have completed the required testing to become Parkinson Proficient in the recognition process.

We look forward to receiving feedback, in the next few months, from the community of care providers and you, the recipients whom we trust will experience the benefits of the training from the Parkinson Care Series. Together, we will continue to maintain and develop partnerships in Arizona, with a desire to improve the delivery of healthcare service that will enhance your quality of life at every step in your journey with Parkinsons disease.



**“THE PARKINSON CONNECTION:
AN INTERACTIVE FORUM FOR THE PARKINSON COMMUNITY”**

Novartis Pharmaceuticals Corporation and the National Parkinson Foundation invite you to attend a groundbreaking one-day event for all those whose lives are affected by Parkinson disease

Please join the Muhammad Ali Parkinson Center and hundreds of Parkinson disease patients and care partners nationwide for this exciting patient education program:

Date

Saturday, September 30th

Time

Registration: 9:30 am
Program: 10:00 am to 2:15 pm

Location

St Joseph’s Hospital and Medical Center
MacAulay Office Building
500 W Thomas Road
GRAND CANYON ROOM – 2nd Floor

This event will be viewed live at our location, via Webcast.

Learn about

the latest treatment options, tips for communicating with healthcare providers, and instruction on exercise and voice techniques

Hear from

leading Parkinson disease experts including:

Matthew Stern, MD, University of Pennsylvania
Mark Stacy, MD, Duke University Medical Center
Becky Farley, PhD, PT
Cynthia Fox, PhD, CCC-SLP, University of Arizona.

For more information & to reserve your seat call

Muhammad Ali Parkinson Center 602-406-4921

Art of Moving

M.A.Coles OTR/L, D.O'Donnell CTRS, H.A.Shill M.D.

Barrow Neurological Institute • St. Joseph's Hospital and Medical Center, Phoenix, AZ

The “Art of Moving” Method is an exercise program developed by John Argue specifically for people with Parkinson’s disease. The program is designed to increase flexibility, strength, balance, coordination, improve voice clarity and strength and delay progression of PD symptoms. The moves are simple based on yoga, tai chi, dance, and theater skills. Every portion of the body is covered with attention to stiffness and muscle weakness that may accompany Parkinson’s disease.

The evaluation consisted of 48 subjects who participated in weekly 60 minute class sessions repeated for 12 weeks. The PDQ-39, a Parkinson disease specific instrument designed to measure aspects of health, was applied at the beginning and end of the 12 week block. The instrument provides scores from 0 to 100 in 8 categories as is evident in Table 1. The lower the score, the better the result. Change scores were calculated for the 48 subjects and a paired t-test was used to determine statistical significance.

Table 1: Impact of Art of Moving on PDQ-39 Test Score Results

Category	Pre-class Mean Score	Post-class Mean Score	P value
Mobility	43	40	.14
ADL	40	36	.04**
Emotional Well Being	29	30	.74
Stigma	19	22	.14
Social Support	15	17	.26
Cognition	41	41	.96
Communication	34	38	.13
Bodily Discomfort	40	41	.84
Total Score	44	40	.05**

** Statistically significant

While the majority of categories did not show statistically significant improvement, the activities of daily living reassuringly, did, as did the resultant total score. This encouraging result warrants further study to more specifically understand how “Art of Moving” influences ADL. Also, it is thought that Communication may benefit from further study since it was likely that people’s attention to communication difficulties was highlighted as a result of the “Art of Moving” classes and progress will thus be more likely measured in subsequent studies.

Volunteers Wanted!

Do you have a few hours a month that you would like to spend helping those who have Parkinson’s disease or those who care for people with Parkinson’s disease? If so, the Muhammad Ali Parkinson Center (MAPC) has an opportunity for you. The MAPC sponsors 23 support groups around the state. Many of these groups need help such as greeting the support group members at each meeting, calling to remind members of an upcoming meeting or assist the facilitator with other group activities. Please call Kris at 602-406-4931 or 1-800-287-7122 if you are interested in volunteering.

Outstanding Parkinson's Support Group Activity in Prescott

We recently interviewed Kay Bolander, the Prescott Parkinson Support Group Leader to get her feedback on interesting highlights of the group during her tenure. Kay is intimately familiar with Parkinson's since she is also a caregiver to her husband, Don, who has had Parkinson's for 26 years and is doing very well.

The Prescott Parkinson Support group was formed 20 years ago and has been meeting regularly on the third Thursday of each month (9:30-11 am; Trinity Presbyterian Church on the corner of Park and Copper Basin road). The attendance at these meetings is at least 25-30 Parkinsonians and their caregivers although the mailing list is at least a 100. It is for patients of all ages and caregivers, family and friends. A number of members have had Parkinson's disease for more than 20 years and are doing well.

Kay told us that the major objective of the Prescott Support group is educational. A large lending library of Parkinson's books is provided as well as free handouts of National Parkinson Foundation (NPF) booklets and many articles from newsletters. Members are encouraged to subscribe to 4 or 5 quarterly newsletters from various PD foundations and educational videos are both

shown and loaned out. New members are given a "New Patient Folder" which includes basic information about Parkinson's disease, a list of local neurologists and group member addresses and phone numbers. These brochures are placed in doctors' offices, the library and other places throughout town.

The second main objective of the group is to provide encouragement to its members. The group enjoys many speakers on a variety of topics. Recent topics include the new Medicare drug plan, the Arizona Long term Care program (ALTCS), and potential legal issues such as updating power of attorney documents and wills.

A second Parkinson's group was formed 3 years ago at the local VA hospital by two VA nurses. It meets the 4th Monday of the month (4:15 – 5:30pm, VA Domiciliary Reflection Room). Many of the other Prescott group also attend these meetings and it is an alternative for those who cannot attend the morning meetings. This group recently hosted a talk by Dr. Holly Shill of the Muhammad Ali Parkinson Center. An excellent article was published in the Prescott Courier which stimulated new membership for both groups.

News from the Arizona Chapter of the National Parkinson Foundation

Bernard Barber, Ph.D. President

The Annual Meeting of the NPF Chapter will be held at the Shepherd of the Valley Lutheran Church, corner of 15th Ave. and Maryland on November 3rd, 2006. Continental breakfast will be served at 9:00 AM and the meeting will start at 10:00 AM.

The program will include results of research on Parkinson's disease, discussion of the various exercise programs as a function of the stages of P.D, progress reports on scholarship grants and use of the Daily Status System Inventory to aid the doctor- patient relationship

The expanded Newsletter will be forthcoming and will contain updates on significant research findings.

The AZ chapter of the NPF has lost Board Members, Gordon Giles and Jim Thomas to Parkinson's disease. Joan McKenzie and Patty Melcher for personal reasons are on extended leave.

We are in need of volunteers to serve on the Board. Please, if it is possible to help us, contact Bernard Barber at 602 971 5690 or E mail: dbbarber@cox.net.

Recreation and Education — September-December 2006

In order to plan safe and effective classes, **all** classes require pre-registration. Classes are only \$5 per class, payable by class or by session. For further information and to register, please call the Therapeutic Recreation Coordinator, Darolyn O'Donnell, at 602-406-6903

Avondale / Litchfield Park / Goodyear

Exercise

The Art of Moving Exercise Class
Thursday 10 am;
September 7 - November 22
Skyway Church of the West Valley
14900 W. Van Buren, Goodyear

Carefree / Cave Creek / North Scottsdale

Exercise

The Art of Moving Exercise Class
Tuesday 1-2 pm;
September 5 - November 21
Sonrise Community Church
29505 N. Scottsdale Rd.
(Scottsdale & Dixileta Dr.)

Chandler

Exercise

The Art of Moving Exercise Class
Wednesday 3:30 – 4:30 pm;
September 6 - November 22
Village Oaks Assisted Living
1919 W Carla Vista Drive
(Dobson & Chandler Blvd)

Fountain Hills

Exercise

Fridays 9-10 pm;
September 8 - November 17
Fountain Hills Senior Center
13001 N. La Montaña

Mesa / East Mesa

Exercise

Mondays 1- 2 pm;
September 11 - November 20
Red Mountain Multigeneration Center
7550 E. Adobe Road, East Mesa

Exercise

Wednesdays 1- 2 pm;
September 6 - November 22
Apache Wells
2274 N. 56th Street
(Between Becker & Higley)

Tai Chi

Thursday 11 am-12pm;
Through July 27
The Springs of East Mesa 
6220 E. Broadway
(Between Power & Recker Roads)

Phoenix

Exercise

The Art of Moving Exercise Class
Tuesday 2-3 pm; Sept 5 - Nov 21
Muhammad Ali Parkinson Center
500 West Thomas Road, Suite 720

Voice Class

Tuesday 3 – 3:30 pm; Sept 5 - Nov 21
Muhammad Ali Parkinson Center

Yoga

Wednesday 12-1 pm; Sept 6 - Nov 22
Muhammad Ali Parkinson Center

Tai Chi

Thursday 11 am-12 pm; Sept 8 - Nov 17
Muhammad Ali Parkinson Center

Aquatics

Friday 1:30-2:30 pm; Sept 8 - Oct 27
Muhammad Ali Parkinson Center

Scottsdale

Tai Chi

Thursday 10 –11 am;
September 7 - November 16
Freedom Inn, 15436 N. 64th Street
(Greenway & 64th St.)

Exercise

The Art of Moving Exercise Class
Tuesday – 10 – 11 am;
September 5 - November 21
Freedom Inn, 15436 N. 64th Street
(Greenway & 64th St.)

Sun Cities

Exercise

The Art of Moving Exercise Class
Thursday - 1-2 pm;
September 8 - November 17
Care from the Heart
9885 W. Union Hills Drive, Ste. 100
(99th Ave & Union Hills)

Exercise

The Art of Moving Exercise Class
Monday-2 Classes: 9-10 am, 10-11 am
September 11 - November 16
Shepherd of the Hills United
Methodist Church
13658 Meeker Blvd, Sun City West
(Meeker & R.H. Johnson)

Sun Lakes

Exercise

The Art of Moving Exercise Class
Time: TBA
Location: TBA

Prescott

Exercise

The Art of Moving Exercise Class
Tuesday 11 am - 12 pm
Yoga Shalla, 322 W. Gurley Street

Non-MAPC Sponsored

Art of Moving & Aquatics

The following Art of Moving classes are also available in the valley at the following locations. The Muhammad Ali Parkinson Research Center does not directly sponsor these classes. If you are interested please call the appropriate contact. Class fees vary.

Peoria

Exercise

Tuesday 2:00-3:00 pm
Arrowhead Community Hospital-
Wellness Connection
Instructor and Contact Person:
Ariel 602-973-8693

Scottsdale

Exercise

Thursday – 2:00-3:00 pm
HealthSouth – Outpatient
(southwest side of the building)
9630 E. Shea Blvd.
Instructor: Melinda Theobald
Contact Person:
Melinda Theobald 480-551-5423

Aquatics

Mondays & Wednesdays
12:00-1:00 pm
HealthSouth – Outpatient
(southwest side of the building)
9630 E. Shea Blvd.
Instructor: Melinda Theobald
Contact Person:
Melinda Theobald
480- 551-5423

**PD 101**

Parkinson's 101 is a 4-week seminar course, 2 hours each session, for people with Parkinson's disease and their families. The course covers basic neurology and the symptoms of Parkinson's disease, medication, nutrition, exercise, mind-body connections such as sleep disorders and depression, caregiving, how to talk to your doctor and any other topics of interest to the group.

Instructors: Margaret Anne Coles & Darolyn O'Donnell

Phoenix

Muhannamd Ali Parkinson Center
500 W Thomas Rd., Suite 720
Phoenix, AZ 85013
Time: Wednesdays, 3-5 pm
Dates: September 6th, 13th, 20th, 27th

Sun Lakes

Sun Lakes Health Center
2510 S Alma School Rd.
Time: Thursdays, 9:30-11:30
Dates: Oct. 26th, Nov. 2nd, 9th, 16th

Sun Cities

January 10, 17, 24, and 31
Wednesdays, 1:30-3:30 pm
Shepherd of the Hills United
Methodist Church
13658 Meeker Blvd., Sun City West
(RH Johnson/Meeker)

**Personal Computer Assistive Technology Workshop**

This workshop is intended to provide both a broad overview of the many options available to assist you, as well as specific instructions on how to make using your personal computer easier and less frustrating. Detailed handouts will be provided.

The workshop topics include: demonstration of Assistive Technologies - devices and software that make using your computer easier and less frustrating; talking to your computer; slowing things down so you can keep up; devices to stabilize your mouse when you have tremors.

Mesa

Mesa Senior Center
247 N. MacDonald, Mesa
Dates: Monday October 16th
Time: 1- 3:30 p.m.

Glendale

Beatitudes Center D.O.A.R.
555 W. Glendale Ave. (Glendale & 7th Ave.) Phoenix
Dates: Thursday January 11th, 2007
Time: 1- 3:30 p.m.

West Valley

Location: TBA
Dates: Spring 2007
Time: TBA

Parkinson's Plus Syndromes

This is a 4-week course specifically for people with Parkinson's Plus Syndromes (PSP / MSA) and their families. Topics include diagnosis, disease symptoms, treatment, nutrition and managing the disease and its progression.

Phoenix

The Beatitudes
1616 W. Glendale Ave.
Time: Monday, 1 – 3 pm
Dates: Oct. 23 - Nov. 13th

PD 202

By popular demand, PD 202 is being offered to provide in-depth information and practical suggestions, concentrating on the most bothersome non-motor symptoms impacting quality of life in Parkinson's disease. Topics covered include fatigue and energy management, working through depression and anxiety, cognitive changes and keeping your relationships healthy and balanced. Like PD 101, PD 202 is a 4-week seminar course, 2 hours each session, for people with PD and their families.

Sun Cities

February, 2007
Time/Dates: TBA

Mesa

March, 2007-The Citadel
Time/Dates: TBA
520 S. Higley (Broadway/Higley)

**Managing Late Stage Parkinson's Disease**

Over time and years of living with a progressive chronic disease, people begin to find the basic activities of everyday living more and more difficult. This program is designed as a hands-on 4-week workshop, providing strategies and recommendations to help people who have the disease help themselves by developing a sense of independence and in turn help their caregivers in a carepartnership manner. This portion will also teach caregivers how to physically care for someone with advanced PD. Secondly, the program is focused on caregivers to help them care for themselves and remain in charge of their own lives.

Sun Cities

March, 2007
Time/Dates: TBA



Support Group Calendar

Contact Kris Watts at (602) 406-4921 for detailed information regarding meeting locations, dates and topics of a support group near you.

Parkinson's Disease

Young Onset Groups

The Bobbling Babes Support Group

This is for Young Onset Women with PD age 30-50's
For the months of Sept., Nov., Jan., March, & May this group meets at:

Chompies Bagel Factory
1160 E. University Dr
Tempe, AZ 85281
2nd Monday of the Month 4:00-5:30 pm

For the months of Oct., Dec., Feb., April, & June this group meets at:

Paradise Bakery
20199 N. 67th Ave
Glendale, AZ 85308
2nd Monday of the Month 4:00-5:30 pm

Young Onset Men's Group

This is for those with PD age 30-50's
For the months of Sept., Nov., Jan., March, & May this group meets at:

Chompies Bagel Factory
1160 E. University Dr
Tempe, AZ 85281
4th Monday of the Month, 4:00-5:30 pm

For the months of Oct., Dec., Feb., April, & June this group meets at:

Paradise Bakery
20199 N. 67th Ave
Glendale, AZ 85308
4th Monday of the Month, 4:00-5:30 pm

Young Onset Carepartner Group

Meets every other month in Mesa
Call for meeting date, time, & location
This is for those whose spouse/partner are age 30-50 with PD

Specialty Groups

Deep Brain Stimulation (DBS)

Muhammad Ali Parkinson Center
500 W. Thomas Rd Ste 720
Phoenix, AZ 85013
4th Friday of the Month, 1:30- 3:00 pm
This is for those who have, are going to have or would like to have DBS surgery.

Singing Group

"The Tremble Clefs"
Scottsdale Civic Center Senior Center
7375 E. 2nd St.
Scottsdale, AZ 85251
Every Tuesday, 4:00-6:00 pm



Caregiver Groups

Caregiver Wellness

Muhammad Ali Parkinson Center
500 W. Thomas Rd Ste 720
Phoenix, AZ 85013
Every Tuesday, 2:00- 3:30 pm
Coincides with PD Exercise Class

Caregiver Wellness

Mesa Senior Center East
7550 E. Adobe Rd
Mesa, AZ 85207
3rd Wednesday of the Month, 1:30-3:00 pm
Will not start until October

Caregiver Wellness

Skyway Church of the West Valley
14900 W. Van Buren
Goodyear, AZ
2nd Thursday of the Month, 10:00 am-1:00 pm

East Valley

Sun Lakes

Sun Lakes Clubhouse
Sun Lakes, AZ
3rd Thursday of the Month, 1:00-2:30 pm

Mesa

Mesa Senior Center East
7550 E. Adobe Rd
Mesa, AZ 85207
1st Monday of the Month, 1:00-3:00 pm

Mesa Senior Center

247 N. McDonald
Mesa, AZ 85201
3rd Monday of the Month, 1:30-3:00 pm



Central Scottsdale*Brighton Gardens*

6001 E. Thomas Rd

Scottsdale, AZ 85251

3rd Friday of the Month, 2:00-3:30 pm

North Scottsdale*HealthSouth Rehab Center*

9630 E. Shea Blvd.

Scottsdale, AZ 85260

2nd Friday of the Month, 1:30 pm

Fountain Hills

Fountain Hills Community Center

13001 N. LaMontana Dr

Fountain Hills, AZ 85268

1st Wednesday of the Month, 9:00-10:30am

Phoenix**North Central***Beatitudes Center D.O.A.R.*

555 W. Glendale Ave,

Phoenix, AZ 85021

2nd Thursday of the Month, 1:30-3:00 pm

Black Mountain*Classic Residence Care Center*

7501 E. Thompson Peak Prky

Scottsdale, AZ

3rd Tuesday of the Month, 10:00-11:30 am

West Valley**Sun City West***Shepherd of the Hills United Methodist Church*

13658 Meeker Blvd.

Sun City West, AZ 85375

3rd Tuesday of the Month, 3:00-4:30 pm

Glendale*Arrowhead Hospital*

18701 N. 67th Ave

Glendale, AZ 85308

3rd Friday of the Month, 10:30-12:00 pm

Will not start until October

Northern Arizona**Prescott***Trinity Presbyterian Church*

630 Park Ave.

Prescott, AZ 86303

3rd Thursday of the Month, 9:30-11:00 am

VA Hospital*ECRCII Conference Room*

2nd Floor

Prescott, AZ 86303

4th Monday of the Month, 4:15- 5:30 pm

Verde Valley*Sedona Winds Retirement Village*

405 Jacks Canyon Road

Village of Oak Creek

3rd Friday of the Month, 2:00pm

Kingman*Kingman Regional Medical Center*

Dell Webb Conference Room

1st Wednesday of the Month, 1:00-2:00 pm

Lake Havasu City*Senior Center*

450 S. Acoma Blvd.

Lake Havasu City, AZ 86403

2nd Wednesday of the Month, 1:30-3:30 pm

Outside of Arizona**El Paso, TX***Sierra Medical Center Hospital*

1625 Medical Center Drive

El Paso, TX. 79902

2nd Saturday of every month

Contact:

Edmundocastaneda@aol.com

Other Movement Disorders**Multiple System Atrophy (MSA)/ Progressive Supranuclear Palsy (PSP)***Muhammad Ali Parkinson Center*

500 W. Thomas Rd Ste 720

Phoenix, AZ 85013

2nd Friday of the Month, 11:00- 12:00am

Facilitator: Kris Watts 602-406-4921



Meet the Instructor Randi Rotwein-Pivnick, M.A., MFT, CPT

Randi has over twenty years experience in the fitness industry. She is a certified personal trainer, exercise instructor/consultant, published author of newspaper and magazine articles, creator of exercise programs for 'special populations'.

She is also a licensed Marriage Family Therapist with a private practice in Gilbert. Because of her education and work experience in both the physical and emotional arenas, she believes in the strong connection between body and mind, and is a firm believer that exercise can help improve not only one's mood, but one's outlook on life as well.

Throughout her career, Randi has worked with numerous individuals and groups that had 'special needs' due to illness or injury. However, it wasn't until someone very near and dear to her was diagnosed with Parkinson's disease that she became interested in using her fitness expertise to work with this population.

For the past year and a half, Randi has been teaching an ART OF MOVING class in Chandler where she works with participants on balance, flexibility, strength, coordination, voice power and speech clarity. She has completed a workshop with John Argue, author of Parkinson's Disease & the Art of Moving in addition to having a B.A. in Exercise Science and Personal Training Certificates from NASM and ACE.

Randi says that these classes aren't just about exercise and mobility. "There is a strong emotional component as well. The people in the group are a network of information and support for others with Parkinson's. Friendships have formed and there is a true concern for others throughout the group. Additionally, there is a lot of laughing and joking that goes on during the hour we are together. I think we all (including me) get a wonderful emotional lift as well." Randi also states that the improvements she has witnessed (both physical and psychological) from week to week are amazing and make her job a very rewarding one.

Randi lives in Las Sendas Mountain (in Mesa) with her husband and her 105 pound 'puppy' Murray. If she isn't teaching class, at work in her private practice, or doing her own workout, she can usually be spotted hanging out with her 'buddy' Murray.



How are we doing?

Margaret Anne Coles

Our goal at the Muhammad Ali Parkinson Center is to maintain or improve quality of life for people with Parkinson's disease and their families regardless of where the Parkinsonian receives his or her medical care. It is of the utmost importance to us that our programs do that but we also want to make sure we are meeting your needs, that you are satisfied with the services and programs that we are providing and that you are having fun! That is why at most every program you are asked to complete evaluation forms or other paperwork. Thank you to all of you who have done that for us. It is through your feedback and comments that we are able to improve and expand our programs and ensure your needs are being met on an ongoing basis.

We thought you might be interested in what we learned last year.

Recreation Programs:

- Last year we had 17 classes in nine communities
- Recreation class attendances at 2512, increased 19% over the previous year
- Although quality of life scores did not show statistically significant improvements, there were improvements in 7 of the 8 subscales and in total quality of life for people who participated in the Art of Moving exercise classes once a week. This demonstrates that our Art of Moving Exercise program was able to maintain self-reported quality of life in spite of the progressive nature of PD
- Client satisfaction with Recreation

classes was at the 90%+ level for most aspects we measured like time of day, location and length of class. 100% of people agreed that they were treated with respect and dignity and that staff was courteous and friendly

- Recreation classes had the most impact, as reported by people with PD, on mobility and balance; 60% of attendees reported improvements in more than one area.
- 2/3 of people who attended the Art of Moving classes said the positive effects lasted 2 days or more
- A poster "The Influence of the Art of Moving Exercise Program on Quality of Life for People with PD" was presented at the first World Parkinson Congress
- Golf clinics were expanded to 2 sites; one West Valley and one East Valley; 50 people with PD participated; a PD Golf League was initiated at Augusta Ranch in Mesa
- Golf Clinic satisfaction was rated at 3.8 on a 4 point scale compared to 3.7 in the previous year

Education Programs:

- PD 101 was presented 6 times, including Lake Havasu, with over 200 people attending
- PD 101 satisfaction was rated 3.9 on a 4 point scale. Two groups rated the program at 4.0. Some of the classes have stayed together and formed informal support groups
- Caregiver Workshops were presented 3 times, including Prescott, with 30 participants. Satisfaction rating was 3.8 on a 4 point scale
- Two Fall prevention workshops were presented with about 30 people attending

- A 3-week Parkinson Plus program was developed and presented once with 35 attendees. Satisfaction rating was 3.8 on a 4 point scale
- The annual Mo Udall Educational Symposium was held in 2 locations. Rasheda Ali was the keynote speaker. Over 340 people attended; satisfaction rating was 4.7 on a 5 point scale (compared to 4.5 the previous year)
- Thirty Support Groups were supported or facilitated. Newly formed groups included a Caregiver Group at the MAPC, Young Women's Group and a Fountain Hills Group.

Multidisciplinary Assessment Clinic:

- Multidisciplinary Assessment Clinic was expanded to twice a month. Forty-three new patients and 13 return patients were seen. People from across the country have come to Arizona to attend the Multidisciplinary Assessment Clinic.
- Satisfaction rating for the Multidisciplinary Assessment Clinic is 3.8 on a 4 point scale
- Preliminary Self-efficacy scores which we measure at the first visit and again 6 months later show significant improvements in self-efficacy or people's ability to be in control of their PD and its management on a day to day basis.

Ali Care:

- The Ali Care program provided medication to 31 people and assisted another 13 people to enroll in drug assistance programs. Average medication cost for the year was close to \$2000 per person

Newsletter

- The Southwest Parkinson News with a circulation of 5500, was published three times

Website and E-Learning:

- Our Website , www.maprc.com, continues to have significant traffic and has proven to be a good vehicle to make people aware of the MAPC and our programs
- One e-learning module is under development and should be ready to unveil on the internet in the coming year.

Registry

- Registrants increased by 807 (46%) from 1747 to 2554
- There are people in the Registry from every State and several other countries
- We have an 86% response rate on the 6-month update questionnaires

Based on everything you have told us we plan on continuing with all of these programs making some changes based on your great suggestions. As well we will be adding several new programs and support groups this year. Look out for the What's New article in this edition!

New MAPC Programs for Fall 2006/Spring 2007

Darolyn O'Donnell

When the first community programs rolled out four years ago, the programs delivered were not proposed on what we perceived to be valuable in improving the lives of those living with PD, but were based on the hard-fact results of a largely circulated client-reported needs assessment. During our travels, we have continued to listen while interacting face to face and through program evaluations. We have used this important feedback to develop new programs as well as improve existing ones. The result is an exciting set of programs for this fall and spring 2007.

PD 202

By popular demand, PD 202 has been invented. Importantly, it is not a continuation of PD 101 but rather is directed towards the problems we heard most frequently expressed during PD 101. The majority of concerns revolved around how to deal with the more troublesome non-motor symptoms that negatively impact quality of life. Therefore, PD 202 is focused on providing in-depth information and practical suggestions, giving people hands-on information, resources and tools to help manage these symptoms as best they can. Topics covered include fatigue and energy management, working through depression and anxiety, cognitive changes and keeping your relationships healthy and balanced. Like PD 101, PD 202 is a 4-week seminar course, 2 hours each session, for people with PD and their families.

Managing Late Stage Parkinson's Disease- for Patients and Caregivers

Over years of living with a progressive chronic disease, people begin to find the basic activities of everyday living more and more difficult. This program is designed as a hands-on, 4-week workshop, providing strategies and recommendations to help people who have the disease help themselves by developing a sense of independence and in turn help their caregivers in a care partnership manner. This program will also teach caregivers how to physically care for someone with advanced PD. Secondly, the program is focused on caregivers to help them care for themselves and remain in charge of their own lives. We are well aware that caregivers are looking for more assistance and resources in order to fulfill this important role and our mission is to increase services available to help them do so. In the past, we offered half-day caregiver workshops. This series includes more specific information and experiential practice formerly provided in the caregiver workshop and hence replaces the workshop in a more beneficial manner.

Parkinson's Plus

This program was introduced last spring at the request of patients and physicians. This year we have added an additional week to add more comprehensive information. It is now a 4-week course specifically for people with Parkinson's Plus Syndromes (PSP/MSA) and their families. Topics include diagnosis, disease symptoms, treatment, nutrition and managing the disease and its progression.

We are very pleased to offer these new programs this season and look forward to seeing you all. Please keep us on your radar and let us know if you have any suggestions or ideas for current or future programs.

Status of Research Programs for Parkinson's Disease

Lynn Marlor

The research staff at Barrow Neurological Movement Disorders Clinic is continuing to enroll patients in 3 clinical research studies for Parkinson's disease. These research studies include 1 for genetic research and 2 medication "Off" time studies. The "Off" time study is evaluating a medication that has been approved by the FDA (Stalevo)

There is no cost for any of the studies. All clinic visits, tests and medications are paid for by the study sponsors. The patients will be followed closely by the clinical research study staff Holly Shill, MD, Richard S. Burns, MD, Anwar Ahmed MD and Lynn L. Marlor BSN, MSHS.

Genetic Studies

The primary purpose of the Gene-PD Study is to examine changes in DNA caused by Parkinson's disease to see how inheritance may play a role in neurological disease. Eligible subjects are persons diagnosed with PD and with family members diagnosed with PD. The family members can be child-parent or siblings.

In the current ascertainment study design living pairs of affected family members results in the recruitment mainly of sibling pairs, as few families have living affected members in two generations. Therefore the study sponsor has decided to expand the recruitment efforts to include Parkinson's disease affected

subjects who report PD affection in a deceased or otherwise unascertainable parent and their unaffected siblings and parent when possible.

Family members can be local or out of the area. If the relative is out of state the questionnaire can be administered by telephone and the blood samples drawn at their local lab. The study consists of one visit where subjects are asked to respond to a questionnaire and have blood samples drawn.

Stalevo Studies®

One of the primary difficulties for Parkinson's disease patients is the "wearing off" of medications between doses. The two Clinical Research Projects using Stalevo® are designed to evaluate this problem. Stalevo® is an FDA approved medication that is a combination of carbidopa, levodopa and entacapone (the active ingredient in Comtan®).

The two studies are Stalevo® immediate switch vs. delayed start study and Stalevo® vs. immediate release carbidopa/levodopa

Stalevo® immediate switch vs. delayed start study:

The purpose of the Stalevo immediate switch vs delayed start study is to evaluate the effects of immediate versus delayed switch to Stalevo on motor function and quality of life in patients with Parkinson's disease with end of dose wearing off.

All patients will receive open-label (no placebo) treatment

with Stalevo® tablets. Patients will be randomized on a 1:1 ratio into 2 groups, the immediate-switch group and the delayed switch group. The treatment phase will last up to 20 weeks. All patients completing this phase will be eligible to continue Stalevo® for an additional 8 weeks. Patients will be ineligible for the study if they have taken Stalevo® or Comtan® in the past. They must be taking immediate release carbidopa/levodopa 25/100 at least 3 times but not more than 6 times daily.

Potential study participants must have a clinical diagnosis of Parkinson's disease with at least 2 of 3 symptoms (rigidity, resting tremor, bradykinesia).

Stalevo® vs immediate release carbidopa/levodopa:

This research study is being done to determine if the combination of carbidopa/levodopa/entacapone (Stalevo®) provides greater benefit in treating the symptoms of Parkinson's disease (end of dose wearing off) than the same dosage of a standard formulation of immediate release carbidopa/levodopa without entacapone (Sinemet®) when used as initial levodopa therapy in patients with early Parkinson's disease.

All patients in this study will receive the same dosage strength of carbidopa/levodopa (25 mg of carbidopa and 100 mg of levodopa regardless of whether they receive Stalevo or Sinemet (there will be no placebo

given). The study will include 7 office visits and 2 telephone contacts and will last a total of 39 weeks.

Potential study participants must have a clinical diagnosis of Parkinson's disease with at least 2 of 3 symptoms (rigidity, resting tremor, bradykinesia).

Patients having a diagnosis of Parkinson's disease for more than 5 years prior to screening cannot be included in the study. The potential study participant cannot have taken carbidopa/levodopa or entacapone or tolcapone for more than 30 days or any time within 4 weeks prior to the baseline visit.

Several studies are planned to start in the fall. Barrow Neurological Movement Disorders Clinic will continue to work on projects sponsored by the Parkinson's Study Group (PSG) and National Institute of Neurological Disorders and Stroke (NINDS) in addition to pharmaceutical industry sponsored studies. Further information on a new large scale NINDS study will be forthcoming in future issues.

Barrow Neurological Movement Disorders Clinic is continually starting new research studies. If a patient is interested in participating in a project they should call Lynn L. Marlor, BSN, MSHS, Research Nurse Clinician at 602-406-6259 for complete information as these listings may change.



Power over Parkinson's

CONFERENCE

Join us November 11, 2006 at the JW Marriott Resort & Spa in Phoenix, for our first annual **Power Over Parkinson's** conference.

Janet Reno will be our keynote speaker!

Other speakers include Padma Mahant, MD, Johan Samanta, MD, Michele Tagliati, MD, and Becky Farley, PhD, PT.

Call (602) 239-3542 or (800) 541-4960

Thank you, Rasheda Ali!

By Debbie Castaldo,
Barrow Neurological Foundation

Rasheda Ali Walsh is a knockout in so many ways. The stunning and poised daughter of Muhammad Ali is an accomplished wife, mother, daughter, speaker, author, actress and friend. She is also a tireless advocate, educator and fundraiser for Parkinson's programs around the world.

For the last several years she has worked with the team at the MAPC to raise awareness and funds for the world-renowned program named for her beloved dad. Her mission to raise awareness and funding for programs that support patients and their families coupled with her determination to find a cure is evident in all that she is and does.

From radio, television and promotional appearances to book signings of her book *I'll Hold Your Hand So You Won't Fall: A Child's Guide To Parkinson's Disease*, Rasheda has made an extraordinary effort to be a voice for her family and those touched by Parkinson's disease. We are very fortunate to have the loyal support of such a dynamic woman.

For more information about Rasheda Ali visit her website at www.rashedaali.com

Donors give more than \$2 million to MAPC

Donors contributed more than \$2 million to the Muhammad Ali Parkinson Center between July 1, 2005, and June 30, 2006. The gifts came from individuals, foundations and other groups who recognize the important work of the Center.

Gifts ranged from the \$1,950,000 contributed by the Celebrity Fight Night Foundation after their annual fundraiser in March to many, many \$5 gifts from grateful patients and families. In all, 352 donors gave to the Center.

"An overwhelming number of the gifts for the MAPC were tribute gifts," says Kelli Smith, vice president of Operations at Barrow Neurological Foundation. "Most contributions were in the \$25-50 range, but we also had several large individual gifts, including one \$20,000 contribution."

Besides the contribution from Celebrity Fight Night, the Foundation received:

- \$21,000 in tribute gifts
- \$34,000 from "An Affair to Remember"
- \$9,000 from the Arora Charity Golf Tournament
- \$5,100 from readers of the Southwest Parkinson Newsletter
- \$24,000 from grateful patients and families.

Contributions also came from employee giving programs and other sources. "Every gift contributes to the health of the Muhammad Ali Parkinson Center," says Mary Jane Crist, vice president of BNF. "Because of the community's strong support, the Center is able to provide a wide range of services to people with movement disorders."



Without these gentlemen,
there would be no Barrow Neurological Institute.

Charles Barrow's gift in 1959 enabled Dr. John Green and St. Joseph's to build the Barrow Neurological Institute.

Philanthropy works.

Our job is to show you how.
Please contact the Office of Philanthropy at St. Joseph's Hospital and Medical Center (602-406-3041) for more information.

P.S. We are very tax deductible.

Southwest Parkinson Report, 500 West Thomas Road, Ste. 720, Phoenix, AZ 85013, (602) 406-4931

Margaret Anne Coles, Editor, Program Coordinator

Gay Samuelson, Editorial Assistant

Kristina Watts, Patient Services Coordinator

St. Joseph's Hospital and Medical Center Marketing Department, layout

The Southwest Parkinson Report contains information provided as a service and is not intended to constitute medical advice or views. Patients should discuss information regarding medical management with their physician.

This newsletter is supported by Shamrock Foods.

CHW Arizona Muhammad Ali Parkinson Center Resource Center

500 W. Thomas Rd, Ste. 720
Phoenix, AZ 85013

Address Service Requested

Non-profit Org.
U.S. Postage
PAID
Permit No. 685
Phoenix, Arizona



This is how your name appears on our mailing list. Please notify us of any errors and/or duplicate mailings by returning the attached mailing label to us or by including your account number appearing on your mailing label with all correspondence.