Welcome to the inaugural 
Exercise4BrainChange® Essentials

Series presented by Dr. Becky G. Farley, CEO/Founder of the nonprofit, Parkinson Wellness Recovery in Tucson, AZ

My dream is that no one after a diagnosis of Parkinson's disease should ever leave the physician's office without HOPE, without a message of what you CAN do to use your full potential everyday and how Exercise4BrainChange can help your medications work better and possibly help you produce more dopamine for longer. However, there are barriers to exercise for people with PD. People are rarely told to exercise at diagnosis or referred to an exercise specialist therapist despite the evidence, and despite the American Medical Association's “Exercise as Medicine” initiative. Many people are even told there is nothing they can do. Not True! Instead, you need to be empowered at diagnosis, to capitalize on the positive placebo effect - that if you believe you are going to get better, you will. Exercise isn't easy. It takes effort. You have to DO it and not stop, and you can’t buy an exercise pill. At PWR! we believe that everyone should have access to empowerment, education, and research-based Exercise4BrainChange, both at diagnosis and throughout life and we are knocking down barriers to change healthcare paradigms to make it available TODAY.

In this foundational series I would like to talk first about “WHY” exercise. Future series will focus on the details about the WHAT and HOW of Exercise4BrainChange®. The information below is what every person needs to hear at diagnosis and then to be repeated over and over for life. This is part of what we teach rehab and fitness professionals in our PWR! Workshops and it is what we talk about at every individual's appointment at PWR!Gym.

1. Get Educated/Empowered!
   - Exercise is more than strength, flexibility, coordination, balance, or cardiovascular function....it is a physiological tool that can optimize brain health, repair damaged circuits, decrease symptoms (motor and non motor), and improve FUNction. The data challenges the assumptions of current rehabilitation models that PD is a neurodegenerative disease with no potential for brain change, repair (neuroplasticity) or behavioral recovery. This research has ignited an EXERCISE REVOLUTION for people with PD. Yet, many physicians, therapists and communities remain unaware of the scientific literature.
   - There is a reference list below. Take it to your physician.
   - What are you waiting for? When you have a neurodegenerative disease, you want more than general exercise, you want to optimize your exercise program to trigger physiological mechanisms that may slow disease progression or at the very least, help the brain do more with less dopamine.
   - Two types of exercise programs are essential –
Exercise 4 BrainChange®  
Continued from previous page

Vigorous Aerobic Exercise and Skill Acquisition (targeted practice to learn a new skill or relearn an old skill). These two essential “physiological tools” go hand and hand and may even work best when performed simultaneously. So learn how to use high effort and vigor (repetitive practice of bigger and faster movements) to practice those skills that interfere the most with your mobility. We will talk more about these details in the next series.

2. Get Started NOW. Don’t wait until you are de-conditioned and have lost mobility to find a therapist that is a PD exercise specialist. You need to focus on a PD-specific exercise program NOW. Be proactive, find out what you CAN do. No matter how good you feel you move, you have more potential – USE IT. Everyone at diagnosis has some degree of bradykinesia or rigidity. These symptoms change how you move and exercise can target these symptoms starting on day 1.
   • Studies show that at the time of diagnosis, people with PD are already less active than their healthy peers, having often withdrawn from sports or recreational activities. This level of reduced activity may be due to subtle PD-specific changes in energy production and movement efficiency and in internal motivational circuits that drive motor activity. Circuits that aren’t used, shut down, or do something else. Even if you don’t think you have mobility problems, get a PD-exercise specialist to help you know how to focus on those skills that you want to keep and improve participation in your favorite activities.

3. Avoid inactivity/stress/anxiety/depression. These symptoms are catalysts in the degenerative process and may accelerate deficits. Optimize your wellness (rest/diet/stress/health/lifestyle). Get an activity monitor, enrich and empower your life with friends, groups – do what you like to do, put yourself 1st so you can keep living your life WELL.
   • A compromised nervous system (due to a degenerative process), is highly vulnerable to bouts of inactivity and stress. If you get sick or are injured, your system will take longer to recover. After an illness or injury, you need to get a tune-up with your physical therapist to get back to baseline and reach your full potential.
   • Research suggests that the benefits of training will deteriorate without continuous practice/use. Consider that greater levels of daily activity AND at least annual bouts of more intensive problem-specific practice will be necessary to maintain benefits gained and optimize benefits from exercise. Make the commitment. This is just like getting a check up from your physician every 6 months.

4. Find a TEAM. You can’t do it by yourself. Put together your PWR! team of PD health and wellness specialists and friends/support. Don’t blame yourself or try to do it all yourself. To GET BETTER and STAY BETTER it takes daily practice. It takes pushing yourself beyond what feels comfortable. This is a hard pill to swallow for people with PD who also deal with non motor symptoms, like depression, anxiety, apathy or fatigue. These types of symptoms rob you of the ability to recognize when you aren’t doing enough, reduce your energy and motivation to do more to help yourself GET BETTER, and actually create psychological barriers to YOUR success.
   • That is why you need a TEAM that includes family/friends, physicians, support groups, exercise groups, and a PWR! Trained Therapist and Fitness Instructor that knows how to give feedback, to educate, and to empower you to do more. Your TEAM is an external source of motivation and triggers feelings of empowerment and control and self-efficacy which further help your brain function. When you believe that YOU CAN GET BETTER, you DO.

5. Find a Coach. Find a PWR! Therapist to be your COACH for life. Take full advantage of your insurance coverage EVERY YEAR. Go see a physical/occupational and speech therapist that specializes in working with Parkinson’s disease every year for an assessment and intensive bout of training to work on a customized PD-specific research-based exercise program, to set specific GOALS, and to re-energize you to participate fully in community programs and life. Continue to ask for re-assessments every 3-6 months to “recharge” your FUNction and your brain. Get a 1-2 day tune-up or check up from your therapist anytime.

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you think that you are losing the gains you made in therapy.

6. Optimize your medications. Find a board certified neurologist that specializes in movement disorders that will work with you to optimize your ability to participate in work, life, and play. Someone that is not just focused on symptoms, or drugs, but YOU and your quality of life.
   • Exercise studies have shown that people that see a movement disorders neurologist report better quality of life (QoL). If your QoL is worse, you are fatigued or can’t fully participate in exercise, ASK QUESTIONS. Get second opinions. If you are unable to sleep, your meds are not working like they used to, or you develop muscle cramps or dyskinesias (involuntary movements that are side effects of dopamine medications), you NEED to see your doctor.
   • Don’t put off taking dopaminergic medications if your QoL or ability to exercise and participate in life is suffering. Get second opinions.

7. Medications alone are NOT enough. Studies show that Medication plus exercise is better than medication alone. Optimal medication can help you get more out of life and exercise.
   ✓ Exercise targets many different motor and non motor symptoms
      • Motor: Rigidity, Bradykinesia, Incoordination
      • Emotional: Depression, Anxiety, Apathy
      • Cognitive: Attention, Executive FUNCTION
      • Autonomic: Sleep, Constipation, Pain
   ✓ Medications for PD primarily target the dopamine-related motor symptoms
      • Motor: Rigidity, Bradykinesia, Incoordination
      • Emotional: NO
      • Cognitive: NO
      • Autonomic: NO

Welcome to the Parkinson Exercise Revolution
I look forward to hearing from you.
Send us your questions:
info@pwr4life.org

Becky G. Farley, PT, MS, PHD
CEO/Founder Parkinson Wellness Recovery

Dr. Farley is a physical therapist, neuroscientist, and Parkinson exercise specialist. In 2003, she created the first amplitude focused physical and occupational therapy exercise approach for individuals with PD called LSVT® BIG. She has now moved on to create PWR! -a more comprehensive neuroplasticity-principled framework that allows the training of larger and faster functional movements to be integrated into other research-based therapy or community approaches. Instead of a strict protocol, limited to rehab and trained in 2 positions, PWR! advocates for the repetitive training of 4 foundational skills (PWR!Moves) to be trained in any position, by rehab and fitness professionals in any setting or activity. Research has shown that these foundational skills become impaired in PD and interfere with everyday mobility. That is why PWR!Moves should be the PD-specific skill acquisition part of your Exercise4BrainChange program. This type of generalized functional amplitude training allows continuous access to PD-specific exercise programming in rehab and community settings. This paradigm will help people not only get better, but to stay better and may help to generalize exercise benefits to other environments and activities.

References:
**2015 SAVE THE DATES!**

**9th Annual Walk the Fight- Saturday**  
**February 7, 2015**

Join us to help raise awareness for the Parkinson’s disease in Arizona. Activities include the 5K walk or timed run, 2 blk fun walk, children’s activities, resource fair and a movement pavilion showcasing other exercises that are beneficial for those living with Parkinson’s. In it’s 9th year, Walk the Fight for Parkinson’s is presented by the Parkinson Network of Arizona with proceeds from the walk going to help support the community outreach programs of the Muhammad Ali Parkinson Center at Barrow Neurological Institute in Phoenix. Come and help us Walk the Fight for Parkinson’s disease! Event runs from 9:30 am – 1:30 pm

**Location:** Tempe Town Lake Beach Park  
**Cost:** $20 for adults registering to walk—includes shirt. Children age 15 and under are free. Additional shirts may be purchased.  
**Phone:** (602) 618-7478  
**Event url:** www.walkthefight.kintera.org

**Annual Mo Udall Educational Symposium**  
**Saturday, February 21, 2015**

We are excited to offer a star studded program for this year’s symposium featuring Dr. Michael Okun, Medical Director of the National Parkinson Foundation and Professor at the University of Florida Center for Movement Disorders and Neurorestoration. Additional speakers will be announced closer to the symposium. The symposium will be available by webcast for those who cannot attend in person. Watch your mailbox for details.

**Location:** Barrow Neurological Institute,  
Phoenix AZ  
**Cost:** Free  
**Time:** 9:00am – 2:00pm

**Paws for Parkinson’s in Prescott Valley**  
**Saturday, April 25, 2015**

Want to get up north, join others with Parkinson’s, bring your pup and walk together? Then join us for Paws for Parkinson’s benefiting the Parkinson’s community in Yavapai County. This 1.6 mile walk includes a picnic lunch, prizes, a resource expo, contests and activities for people and pets. It’s FUN FOR EVERYONE!

**Location:** Mountain Valley Regional Rehabilitation Hospital, Prescott Valley, AZ  
**Cost:** $20 for adults registering to walk. Children age 15 and under are free  
**Phone:** (602) 618-7478  
**Event url:** www.paws4pd.kintera.org

**3rd Annual Delbert Johnson Memorial Golf Invitational**  
**Thursday, April 16, 2015**

Pinnacle Peak Country Club will once again be hosting the Delbert Johnson Memorial Golf Invitational. Join us and raise money and awareness for Parkinson’s while enjoying a day on the links. Entry fee includes lunch, 18 holes of golf, a putting contest, raffle entry, dinner and awards presentation.

**Location:** Pinnacle Peak Country Club,  
Scottsdale, AZ  
**Cost:** $550 per golfer  
**Event url:** www.parkinsonnetworkaz.org
Tips for the Caregiver
Nancy Bivins, LMSW

Following the diagnosis of Parkinson’s disease, as the care partner, you will find that your role changes over time. You may, for instance, need to assume the task of writing checks if your loved one has a tremor and writing is difficult. Taking on that responsibility is relatively easy and life goes on with little or no lifestyle disruptions.

As the disease progresses, the amount of assistance that is needed will also change. You will find that as needs increase, responsibilities and tasks are shifted to the most logical person, you. You may be the spouse, adult child, significant other or friend, but whatever your relationship, you are the most important person in the life of the person living with PD (PLWP).

This shifting of responsibilities is a gradual process and it is easy to understand that over time you may become overwhelmed without realizing what is happening to you. If you find that you are having feelings of needing help to manage, please consider the following tips.

1. **Don’t compare yourself to someone else.** We certainly can learn techniques and strategies to cope with stress, but keep in mind that we are all wired differently. Some are naturally nurturing and patient, while others find it difficult. Also, care partners may have health issues of their own. Just because others are managing in a particular way does not mean that you must do the same.

2. **Evaluate your self-talk.** If you find yourself thinking or saying phrases like, “I’m exhausted,” or “I can’t go another day,” it is time to make some changes. Listen to what you are saying and then spend some time to understand what this means for you specifically.

3. **You do not have to do everything yourself.** Identify what needs to be done to keep your household running and then ask yourself these questions: a) Does it really need to be done? b) Am I the only person who can do it? c) Can someone else do an acceptable job? You may decide that the responsibility that has been tended to weekly may fare well if done only once monthly, or that the job could be done by someone you hired, or perhaps a friend could help. Remember, it is permissible to enlist the help of others.

4. **Listen to those who know you best.** If your family and/or friends are expressing concern for your well-being because they believe that you do not have adequate relief from your physical, emotional and mental demands, it is wise to carefully consider their perspective. There is a saying, “it is difficult to see the picture when you are part of the frame.” Sometimes those closest to you can have a better understanding of your needs then you, because you are so close to the situation. If others are saying that you look tired and stressed, take their concern seriously, don’t just discount them.

5. **If you recognize that there needs to be a change, act on it.** Although you and others may know that there needs to be a change it is easy to delay action, because you don’t know what to do or where to start. Keep reading.

6. **Seek help from others to make a plan.** There is no such thing as a “Parkinson’s Plan.” Your situation is unique because you and your loved one are unique. The plan for you may be as simple as a leisurely walk and a drink in a coffee shop to relax and recharge. Perhaps a short getaway over a long weekend for rest and relaxation is adequate. However, if a more complex intervention is needed a meeting with the social worker at the Muhammad Ali Parkinson Center (MAPC) is only a call away. The social worker is available to help you and your loved one develop a plan that is specific to you. You may be at the “fact finding” phase of your plan, which involves talking about your preferences, learning about different care options, and understanding the differences in cost.

For many people, the only thought that comes to mind when they hear the words “care options,” is that of people sitting in wheelchairs lining a long hall. Since the population is aging, many different living possibilities now exist, along with many home care agencies that can augment care in many ways from taking your loved on an outing to preparing a meal. All of this for the purpose of keeping your loved one safe, as active as possible and socially engaged.

7. **Be agreeable to change your plan.** Most likely you will change your plan more than once and possibly frequently. Be flexible, open to continuous evaluation and willing to change as needed. Remember, you cannot steer a parked car.

Contact Nancy Bivins, LMSW at the MAPC by calling 602-406-4266 or email Nancy.Bivins@Dignityhealth.org.
Congratulations to Julio Angulo!

We have an artist in our midst who is blossoming into a famous painter and ceramicist! Kudos to Julio Angulo, Ph.D. for having his pottery piece accepted into the Parkinson’s Disease Foundation’s (PDF) 2015 annual Creativity and Parkinson’s Calendar. Along with this honor, AbbVie Inc. has chosen Julio’s painting Sonoran Night as the image for a greeting card to be sent to 3,000 clinical trial participants! This is the first time he has been chosen by AbbVie for their greeting card and the second time he has been honored to have one of his works of art selected for the PDF calendar. Julio had never painted before being diagnosed with Parkinson’s. After diagnosis, he started participating in MAPC painting workshops and creative activities. Julio had worked with clay before his diagnosis but noticed his work changed because of Parkinson’s. Since he had lost some manual dexterity his pots became rougher and more textural. Both his paintings and tea pots are beautiful and true works of art. Julio’s quote in the PDF calendar encourages everyone with PD to get involved in creative activities. States Julio, “When I paint or work with clay, my Parkinson’s disease recedes. I get excited, energized and engaged in what I am doing. Parkinson’s places limits on my body, but not on my imagination or spirit. It is still possible to soar.”

Powerful Tools for Caregivers

This 6 week program provides information to improve caregiving ability by promoting self-care and increasing self-confidence. This series will help you improve your communication skills, reduce your stress and work through difficult emotions such as guilt, anger and depression.

2015 Sun City West Series
Desert Palms Presbyterian Church
13459 W Stardust Blvd  Sun City West  85375
• Powerful Tools
  Thursdays, 10:00-11:30 am, Jan 8- Feb 12, 2015
• Boot Camp
  Thursday, 9:30am-12:30pm, February 19

2015 Fountain Hills Series
Fountain Hills Village
16455 East Avenue of the Fountains
Fountain Hills 85268
• Powerful Tools
  Thursdays, 10:00-11:30 am, Feb 26 - April 2, 2015
• Boot Camp
  Thursday, 9:30am-12:30pm, April 9
Recreation and Education

In order to plan safe and effective classes, all classes require pre-registration. Exercise classes are only $5 per class. Education classes are free. For further information and/or to register, please call: Patty Hatton, 602-406-3840.

Ahwatukee

**Tai Chi**
Wednesdays, 11 am - 12 pm;
Jan 7 - May 27
Mountain Park Senior Living
4475 E. Knox Road

Avondale / Litchfield Park / Goodyear

**Art of Moving**
Thursdays, 10 - 11 am, Jan 8 - July 30
Skyway Church of the West Valley
14900 W. Van Buren, Goodyear

**Parkinson’s Dance**
Mondays, 1 - 2:15 pm, Jan 5 - July 27
Steppin’ Out Performing Arts
13331 W. Indian School Rd #208 B
Litchfield Park
(Osborn & Indian School)

Fountain Hills

**Art of Moving*** 9 - 10 am
PWR!Moves™ 10 - 11 am
Fridays, Jan 9 - May 29
Fountain Hills Senior Center
13001 N. La Montana

**Expressive Arts***
Thursdays, 1:30 – 3 pm, Feb 26 &
March 5, 12, 19 & 26
Fountain Hills Senior Center
(see above)

*In order to participate in the Fountain Hills exercise classes you must be a member of the Fountain Hills Activity Center. Annual Membership fee (Jan 1 – Dec 31) is $20.00 for Fountain Hills residents and winter visitors with a Fountain Hills address; $30.00 for non-residents. Members are able to participate in many activities at the Center.

Mesa / East Mesa

**PWR!Moves™**
Mondays, 12:30 – 1:30 pm
Mountainside Fitness
480-899-1865
1253 N. Greenfield Rd
(NE corner of Greenfield & Brown)

**Tai Chi**
Thursdays, 11 am – 12 pm
Jan 8 – July 30
Victory Lutheran Church, 5946 E. University (University & Recker)

Phoenix

**All of the classes in Phoenix are held at the MAPC Community Outreach and Wellness**
240 W. Thomas Rd., Suite 302

**Neurologic Music Therapy**
Mondays, 2:30 – 3:30 pm
Jan 5 - May 18

**Voice Classes**
Tuesdays, 11 am – 12 pm,
Jan 6 - July 28
Wednesdays, 1:15 - 2:15 pm,
Jan 7 – July 29

**PWR!Moves™**
1:15 - 2:15 pm, Tuesdays,
Jan 6 – July 28
3:30 – 4:30 pm, Thursdays,
Jan 6 – July 28

**Art of Moving**
2:30 - 3:30 pm, Tuesdays,
Jan 6 – July 28

Scottsdale

**Art of Moving**
Tuesdays, 9:30-10:30 am;
Jan 6-July 28
Elizabeth Keith Movement Education
16620 N. 40th St, Suite D-5
(40th St south of Bell in PV)

**Parkinson’s Dance**
Thursdays, 11:30 am – 12:45 pm,
Jan 8-July 30
Elizabeth Keith Movement Education
Suite D-2 (see above)

**Yoga for EveryBody, Mind and Soul!**
Mondays & Wednesdays, 2 - 3 pm; Jan 5-July 30
Assumption Greek Orthodox Church – Community Room
8202 E. Cactus Road

**PWR!Moves™**
Wednesdays, 12:15-1:15 pm
Mountainside Fitness
480-899-8889
11611 E. Sahuaro Dr
(NE corner of 116th St & Shea)

**Tremble Clefs Singing Program**
Thursdays, 4 - 6 pm
Granite Reef Senior Center – City of Scottsdale
1700 N. Granite Reef Road
(Granite Reef & McDowell)
Sun Cities

**Art of Moving**
Mondays, 10 – 11 am, Jan 5-July 27
Shepherd of the Hills United Methodist Church
13658 Meeker Blvd, Sun City West
(Meeker & RH Johnson)

**Art of Moving**
Thursdays, 1 - 2 pm, Jan 8 – July 30
American Lutheran Church of Sun City
17200 N. Del Webb Blvd
(Del Webb just south of Bell)

**PWR!Moves™**
Wednesdays, 11 am - 12 pm; Fridays 1 – 2 pm
Mountainside Fitness
623-889-0374
15445 W. Bell Road
(SE corner of Bell & Reams)

**Tremble Clefs Singing Program**
Wednesdays, 10 am - 12 pm
Shepherd of the Desert Lutheran Church
11025 N. 111th Avenue, Sun City

**Expressive Arts**
Fridays, 10 – 11:30 am; Feb 13, 20, 27 & Mar 6, 13
Lord of Life Lutheran Church
13724 W. Meeker Blvd.

Sun Lakes

**Art of Moving**
Mondays, 10:30 – 11:30 am, Jan 5-July 27
Sun Lakes United Methodist Church
9428 E. Riggs Road, Room 10

**Tai Chi**
Thursdays, 11 am – 12 pm, Jan 8 – July 30
Sun Lakes Country Club – Mirror Room
Sun Lakes United Methodist Church
9428 E. Riggs Road, Room 10

PD 101
Parkinson's 101 is now available on demand. Simply go to www.maprc.com. Click on the link next to the picture of Muhammad Ali and his wife Lonnie, once the next page opens click on the on the right hand side of the page “Watch Parkinson’s 101 Online”.

**North / Central Phoenix**
Saliba’s Extended Care Pharmacy
21025 N. 8TH Way, Phoenix 85024
Thursdays, 1:30-3:30 pm, Feb 5, 12, 19 & 26

**Central Phoenix – Evening Program**
Barrow Neurological Institute-Goldman Auditorium
350 W. Thomas Road – first floor
Mondays, 5:30-7:30 pm, April 6, 13, 20 & 27

PD 202

All of the following Educational Sessions are held at the Muhammad Ali Parkinson Center- Wellness Center
240 W. Thomas Road, Suite 302

**Education Session for those Newly Diagnosed with PD**
MAPC, 2nd Thursday of each month, 1:30-3:30 pm

**Beginning the PD Journey – Education Series for Newly Diagnosed**
MAPC, Mondays, 10:00 am -12 pm, Feb 16, 23 & March 2 & 9

**Mastering Your Anxiety: a Brief Course Especially for Persons with Parkinson’s Disease**
MAPC, Fridays, 1:30-3:00 pm, March 6, 13, 20, 27 & April 6

**Powerful Tools for Caregivers**
**Sun City West Series**
Desert Palms Presbyterian Church
13459 W Stardust Blvd, Sun City West 85375
- **Powerful Tools**
  Thursdays, 10:00-11:30 am, Jan 8- Feb 12, 2015
- **Boot Camp**
  Thursday, 9:30am-12:30pm, February 19

**Fountain Hills Series**
Fountain Hills Village
16455 East Avenue of the Fountains, Fountain Hills 85268
- **Powerful Tools**
  Thursdays, 10:00-11:30 am, Feb 26 - April 2, 2015
- **Boot Camp**
  Thursday, 9:30am-12:30pm, April 9
Specialty Groups

Young Onset Wellness Group
For those aged 30-50’s
Monthly Meetings/Outings
Held monthly at varying locations
- Northwest Valley
  Contact Carl Ames at cames62@gmail.com
- Northeast Valley
  Contact Brian Vietri at bvietri@msn.com
- Southeast Valley
  Contact Brian Baehr at bbaehr@grayhawk.com

Quarterly Dinner Meetings
Muhammad Ali Parkinson Center
Contact Kris Watts 602-406-4921
East Valley

Sun Lakes
Renaissance Retirement Community
9508 E. Riggs Rd,
Sun Lakes, AZ 85248
2nd Thursday of the month, 2:00-3:30 pm
Contact Kris Watts 602-406-4921
or Shantel Kaycey at 480-883-2706

Sun Lakes Carepartner Wellness
Sun Lakes Country Club- Phase 1
25601 N. Sunlakes Blvd
Sun Lakes, AZ 85248
1st Friday of the month, 1:00-3:30 pm
Contact Kris Watts 602-406-4921
This group is for carepartners only

Ahwatukee

Mountain Park Senior Living
4475 E Knox Rd., Phoenix, AZ
1st Friday of the Month,
10:30-12:00 pm
Contact Kris Watts at the MAPC
602-406-4921

Chandler/Gilbert

Mercy Gilbert Medical Center
Conference Room #3
3555 S. Val Vista Dr.
Gilbert, AZ 85257
4th Friday of the Month,
1:30-3:00 pm
Contact Kris Watts at the MAPC
602-406-4921

Fountain Hills

Fountain Hills Community Center
Fountain Hills Community Center
13001 N. La Montana Dr, Fountain Hills, AZ 85268
First Wednesday of the month, 9:30-11:00 am
Contact Mary at 480-209-8755

Fountain Hills Caregiver Wellness
Fountain Hills Community Center
13001 N. La Montana Dr, Fountain Hills, AZ 85268
1st Monday of the month, 10:30-12:00 pm
Contact Jim 480-209-8755
This group is for carepartners only

Mesa

Red Mountain Multigenerational Center
7550 E Adobe Rd, Mesa, AZ 85207
1st Monday of the Month,
1:30-3:00 pm
Contact Kris Watts at the MAPC
602-406-4921

Fellowship Square
35 W. Brown Rd, Mesa, AZ
1st Wednesday of the Month,
1:30-3:00 pm
Contact Debbie Harwood at Fellowship Square 480-290-7950

North Scottsdale

Desert Mission United Methodist Church
7373 E Dixileta Dr
Scottsdale, AZ 85266
1st Thursday of the month,
10:30-Noon
Contact Marilyn Ware
480-488-8538

HealthSouth Rehabilitation Hospital
9630 E. Shea Blvd
Scottsdale, AZ 85260
2nd Friday of the month
10:00am- Noon
Contact Patty Hatton at the MAPC
602-406-3840

Phoenix

North Central
Beatitudes Church/Duet-Patio Room
555 W. Glendale Ave
Phoenix, AZ 85021
2nd Wednesday of the month
1:30-3:00 pm
Contact Kris Watts at the MAPC
602-406-4921

Evening PD Support Group
Muhammad Ali Parkinson Center, Conference Room B
240 W. Thomas Rd., Suite 301
Phoenix, AZ 85013
4th Tuesday of the month
5:30-7:00 pm
Contact Patty Hatton at
602-406-3840

Winter 2015 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.
Support Groups continued

Anthem

Location Varies
2nd Tuesday of the Month,
2:00-3:30 pm
Contact Alice 623-551-9726

West Valley

Sun City West
Shepherd of the Hills United Methodist Church
13658 W Meeker Blvd
Sun City West, AZ 85375
3rd Tuesday of the month
3:00-4:30 pm
Contact Regina Thibideau at 623-584-4999

Surprise/Sun City Grand
Cimarron Center
17100 W. Clearview Blvd
Surprise, AZ 85374
1st Tuesday of the month
10:00-11:30 am
Contact Patty Hatton at 602-406-3840

Glendale
HealthSouth Rehabilitation Hospital
13460 N 67th Ave
Glendale, AZ 85304
2nd Tuesday of the month
1:00-2:00 pm
Contact Trent Tripp at 623-878-8800

Avondale/Goodyear Carepartner Wellness
Skyway Church of the West Valley
14900 W. Van Buren
Goodyear, AZ 85338
2nd Thursday of the month
10:00-11:00 am
Contact Brett Peterson at Beatitudes Center D.O.A.R. 602-274-5022
This group is for carepartners only

Southern Arizona

Casa Grande
Robson Ranch Grill
5687 N Robson Blvd
Eloy, AZ 85131
1st Monday of the Month,
10:00-11:30 am
Contact Kris Watts at the MAPC
602-406-4921

Yuma
Daybreakers Café
10800 E Frontage Rd
Yuma, AZ 85367
1st Monday of the Month,
9:00-11:00 am
Contact Beverly at 928-246-2876

Northern Arizona

Prescott
First Lutheran Church
231 W. Smoke Tree lane
Prescott, AZ 86301
3rd Thursday of the Month,
10:00-11:30 am
Contact Kay Bolander at 928-778-2242 or
Alan Richardson at 928-442-1380

Prescott CarePartners
Mountain Valley Rehabilitation Hospital
3700 N. Windsong Dr
Prescott, AZ 86314
2nd Thursday of the month
10:00-11:30 am
Contact Kay Bolander at 928-778-2242

Kingman

Kingman Regional Medical Center
Del Webb Wellness Center
1719 E. Beverly Ave, Kingman, AZ 86409
3rd Tuesday of the month, 1:00 pm
Contact Pam Kowalski at 928-263-5640

Verde Valley

Verde Valley Medical Center
Outpatient Rehabilitation Services-Conference Room B
269 S. Candy Lane
Cottonwood, AZ 86326
2nd Friday of the month, 3-4:30 pm
Contact Judy Talley at 928-202-7952

Western Arizona

Lake Havasu
Community Presbyterian Church
3450 Chemehuevi Blvd
Lake Havasu City, AZ 86406
2nd Wednesday of the month
1:00-2:00 pm
Contact Paula Anderson
928-855-6000
(Alzheimer/Dementia Connection of Lake Havasu)
Aileen Fuller

Aileen Fuller is well known in MAPC Circles. She has been a faithful and motivated participant in MAPC exercise classes, a weekend warrior in one of the first and subsequent Baehr Challenges and a big fan of NASCAR. She is also well known outside the MAPC as an active member of her church, a bridge player, cake decorator, quilter, gardener and an active and loving mother, grandmother and great-grandmother. This is one lady who hasn’t let Parkinson’s disease slow her down.

Aileen was diagnosed with Parkinson’s disease in August of 2010 by her family physician of over 40 years. She feels very fortunate to have been diagnosed so quickly because many wait several years to be properly diagnosed. Her first thought was gratitude that it wasn’t something much worse. Because of her personal experience in coping and managing a congenital condition her youngest son was born with, she knew she would do whatever was in her power to live well with PD and that she would get through it.

Aileen wanted to go to a place where she could be treated by the best. After reading an article in Phoenix Magazine about the Muhammad Ali Parkinson Center she made an appointment to be treated by one of the Movement Disorders Specialists at the Center. She also found her way to the community outreach programs, took advantage of education programs by taking PD 101, and joined multiple exercise classes. She absolutely believes in the power of exercise in fighting PD symptoms and immediately increased her activity level. Her advice? “Exercise! It’s better than medicine.” Currently she is active in yoga, PWR!Moves™ and PWR!Circuit™.

Aileen admits she knew she would not exercise at home on her own: “I knew I wouldn’t!” She also states, “The classes are my support group. We talk about how we are doing and what we’ve learned along the way.” Aileen’s thoughtful and generous spirit is appreciated by the MAPC staff and class participants. Noticing that some yoga class participants were uncomfortable on the floor during yoga, Aileen surprised everyone by coming to class one day with over a dozen miniature pillows and pillow cases that she had made on her home sewing machine. To this day, she maintains the pillows by laundering the cases after class and making sure they make it back to the next one.

Aileen maintains a positive attitude and a true “I can figure this out” attitude in managing her PD. She states her biggest problems are fatigue and frustration because she can’t do things as fast as she used to. Aileen lives alone and in her day to day routine doesn’t have anyone to assist her or help out with household chores. Because of this she has had to develop patience and figure out how to do things to maintain her independence. For example she recently started having trouble buttoning buttons. She found an adapted button hook that allows her to button her shirts on her own. Right now she is looking for an easier way to peel potatoes. She won’t give up on this problem, along with other issues that may come up, until she has exhausted all possibilities. Aileen considers her ability to problem solve not only necessary but empowering as she continues to live her life independently.

When asked about her best experiences in the last couple years she doesn’t hesitate: The Baehr Challenge and NASCAR with her brother and family. The Baehr Challenge creates awareness regarding fitness as a treatment for Parkinson’s Disease and includes a staggered obstacle course. Aileen participated on the first ever MAPC team, and with staff and fellow persons with Parkinson’s completed the course in fine form. Aileen never missed a beat while climbing over hay stacks, under ropes, and walking on a balance beam. “It is fun to do all those things you thought you would never do and be safe because they (Baehr Challenge staff) were around to help us.” She loves her NASCAR experience with her brother and ten other family members and friends. The first year they made a big fuss of her birthday weekend by renting a motor home and playing together at the races all weekend. Everyone had so much fun they went again the next year and it is now an annual event!

The beauty of Aileen’s journey with PD is seen through her busy and rich life that includes family (her biggest blessing is her children) and friends. She is an inspiration to all who meet her and those in the MAPC community feel fortunate to know her.
The Baehr Challenge Oktoberfest

Approximately 800 people attended the block party celebration that included live music, unlimited food, authentic Oktoberfest games, fine craft ales, mugs of beer, glasses of wine, a spectacular silent auction and grand prize raffle trip for two to Sonoma Valley, California.

The Baehr Challenge for Parkinson’s Research is pleased to announce that Oktoberfest raised $26,000.00. The proceeds were divided among the Michael J. Fox Foundation to fund scientific research for better treatments and a cure; as well as local valley Parkinson’s organizations, including The Muhammad Ali Parkinson Center at Barrow Neurological Institute and the Banner Neuro Wellness Centers in Gilbert and Sun City. These local services guide and support people with Parkinson’s and their families.

Thank you for your generous support of the Baehr Challenge Oktoberfest for Parkinson’s event. See you all again next year!

PD 101 is Now Online!

Do you live too far to make it to a PD 101 series location? Does the PD 101 program never seem to quite fit with your busy schedule? Not anymore. Great news - thanks to our technological capabilities, facilities and informatics team here at the Barrow Neurological Institute, PD 101 is now available online for you to view at your convenience.

Here’s how: Please visit our website, www.maprc.com. Click on the “Parkinson’s Disease 101” link next to the picture of Muhammad and his wife Lonnie on the right hand side. It will take you to the MAPC education page. On the right side of the education page, click on “Watch Parkinson’s Disease 101 Online”. It will open to four segments of PD 101 (each approximately 2 hours) to be viewed at your leisure; you can start, stop and restart anytime.

The first session provides an overview of Parkinson’s, inclusive of a brief history of PD, demographics, basic neurology, possible causes, etc. The second session covers everything you need to know about the medications used to manage the symptoms of PD (how each class of medications work, how to take your medications for optimal effectiveness, common side effects, along with tools and tips such as daily diaries to keep track of your medications). Deep brain stimulation is also included in this second session. The third session is all about therapies and exercise - the latest research and how you can best include these in your self-management plan. Not only will you find ways to keep your body strong, you will also learn how crucial exercise is in creating brain change and neuroplasticity, strengthening the voice and helping to maintain a safe swallow, and how exercise helps manage non-motor symptoms. The last session is a combination of a variety of topics that will be helpful as you navigate your course - everything from driving to how to talk to your doctor.

Education is extremely important in the self-management of chronic disease. You simply cannot manage what you do not know. Information is power and will help you manage the day to day challenges you and your loved ones face with Parkinson’s disease. Time to go to www.maprc.com, where your education sessions are waiting for you.

If you would like the accompanying handout for all 4 sessions, please email darolyn.odonnell@dignityhealth.org and the handouts will be emailed to you in PDF format.
A UNIQUE RETREAT!
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Questions: Contact Lynne Brenner

[lynne@pwr4life.org](mailto:lynne@pwr4life.org) or call 520-591-5346

Presented by world renowned Parkinson expert

Becky Farley PhD, MS, PDT

For more info go to [www.pwr4life.org/retreat](http://www.pwr4life.org/retreat)
Clinical trials are opening at the Muhammad Ali Movement Disorders Center. We are currently enrolling participants in the Amantadine Study. Amantadine ER is being studied for the treatment of levodopa induced dyskinesia (LID). Amantadine has long been used for reducing LIDs but has required dosing 2-4X daily. Amantadine ER is an extended release formulation that will require only one dose per day. It is hoped the result will be adequate control of LIDs with minimal impact of amantadine on nighttime sleep since the 1X daily dose will occur in the morning. This is a blinded study. Some participants will receive active study drug and some will receive placebo. Neither you nor the study staff will know what you are taking. There will be an open label extension which means everyone receives the study drug after the first study is completed.

We are currently enrolling in the INTREPID Study. This study is evaluating a new Deep Brain Stimulation system manufactured by Boston Scientific. The device has been approved for use in Europe, Israel and Australia. Currently, it is under study in the US. The advantage of this system is that it is the only device that allows physician manipulation of current flow. We presently have two people who have the device in place. Both are doing well. We are excited about having more people participate in the study because positive results will translate into potential commercial availability of this device in the US.

We have more new trials coming. Participation in clinical trials is important if we are going to continue to find new and innovative therapies to treat people living with Parkinson Disease. If we do not have a trial that fits you interest, please review what is available at www.clinicaltrials.gov or www.foxfinder.com.

If you are interested in a clinical trial or if you have questions, please call or email Mary Dunn, RN, CCRP at 602-406-2929 or Mary.Dunn@dignityhealth.org.

Correction

In the Fall 2014 edition of the Southwest Parkinson News, the article on the Michael J. Fox and AbbVie joint health initiative Partners in Parkinson's gave an incorrect website address. The correct website for this program is:

partnersinparkinsons.com

We apologize for any confusion this may have caused.
Summary of PDF Research Results for 2014
http://en.wikipedia.org/wiki/Parkinson’s_Disease_Foundation

The Parkinson’s Disease Foundation provided $5.1M in funding in 2014 and the following are some of the key findings of this year’s research efforts:

- Studies at the PDF Research Center at Columbia University Medical Center using mouse and human neurons suggest that the immune system may be attacking cells in people with Parkinson’s suggesting that it may, in part, be an autoimmune disease.
- Using human nerve cells, researchers at Massachusetts General Hospital are showing success using a small molecule NABs to reverse the toxic effects of alpha-synuclein which accumulates in brain cells of people with Parkinson’s.
- Mouse and fruit fly studies in Tel Aviv University show that mannitol, a common sweetener, appears to prevent alpha-synuclein clumping.
- The development of a “triple-hit” hypothesis which suggests that several cell malfunctions contribute to neuronal death in Parkinson’s is currently under investigation. This is based on results showing mitochondrial damage early in the course of PD and the build-up of alpha synuclein in nerve cells in the gut in people with PD before any movement symptoms have developed.

Quinine Inhibits Alpha Synuclein Clumping

Researchers at Tel Aviv University have shown that quinine, a compound that inhibits certain cellular pathways and is able to cross the blood/brain barrier, is effective in preventing clumping of alpha synuclein in petri dishes and in fruit flies. The next steps will be testing in mouse models and ultimately human beings if the molecule is both safe and effective in the animal models.

Brisk Walking Improves Many Parkinson’s Symptoms
http://www.pdf.org/fall14_science_news/#walking

Researchers at the University of Iowa, led by Ergun Y. Uc, M.D., worked with 60 people with mild to moderate PD who were on average 65 years old. Participants continued their usual PD medications, and walked for 45 minutes, three times a week, for six months, using safe routes suggested by their trainers. Participants wore electronic monitors for heart rate and walking speed. At the beginning of the study, and at regular intervals thereafter, the researchers assessed participants on levels of aerobic fitness, cognition, severity of PD movement symptoms, and on some quality of life measures.

Results

- Aerobic walking was safe; no serious adverse events were reported.
- Participants showed significant improvement in maximum oxygen consumption, gait speed, movement symptoms, fatigue and depression.
- Participants improved on measures of quality of life, such as fatigue and depression, and ability to focus and filter out distracting information (a common problem in PD).

Women and Parkinson’s Disease
PDF News Review Fall 2014 www.pdf.org

Current data suggests that women are slightly less likely to get Parkinson’s disease than men. They seem to show delayed onset of motor symptoms but there is some evidence they are more prone to depression and medication-associated dyskinesias. Women with PD tend to have more difficulty than men with daily activities like walking and getting dressed but show less cognitive impairment and are less likely to show behavioral problems, e.g., wandering, physical and verbal abuse.

We all know that Parkinson’s disease can be a different disease from one person to another but we are now recognizing that gender may be one of the factors causing some differences.
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.

If you would like to receive a free subscription to Southwest Parkinson Report, please contact a MAPC staff member or call 602-406-4931 to register.

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.

Leave your legacy with Dignity

Support the patient care, medical research, teaching and community outreach at Barrow Neurological Institute and St. Joseph’s Hospital and Medical Center with a gift in your will or trust.

To learn how you can partner with us in providing world-class medicine for future generations, call 602-406-1025, email alan.knobloch@dignityhealth.org or visit www.planyourlegacy.stjosephs-phx.org.