

## Back in the Game: The Parkinson's Pyramid "A Neurologist with PD fights back"

—David Heydrick, MD, MS

Recently, during a junior bicycle road race, my oldest son, 14 year-old Scott, had a mechanical problem with his bike at the start, and after fixing the bike, he was minutes behind the leaders. Much to the amazement of all watching the race, over the next 20 minutes Scott closed the gap and ultimately in a sprint to the finish, took third place and a medal. I asked Scott how he found the guts to accomplish the feat. He stated, "You're not a quitter and neither am I."



I am a former mechanical engineer turned Neurologist. In 2002, I noticed slow finger tapping in my right hand, which turned out to be the first symptoms of fairly rapidly-advancing Parkinson disease (PD), at least initially. By the end of 2004, the symptoms had progressed to include profound tremor on my entire right side: *face* – such that I couldn't give public talks or talk at length to patients, *arm/hand* – such that I couldn't write or button my shirts or eat with my right hand, and *leg/foot* – such that I couldn't drive more than a few miles safely and couldn't exercise very well. I also had slowness of movement (bradykinesia), foot dystonia, profound fatigue, and pain from rigidity. All these symptoms made it impossible for me to be a good husband or father. As a former college baseball pitcher, the activity I missed the most was playing ball with my sons. Most of the PD medication made me sick even at low doses. I had to quit my job as a private practice Neurologist and use my

disability insurance policy. With little alternative, I had Deep Brain Stimulation (DBS) in 2005.

DBS worked well for me, easing many of my symptoms, especially the tremor and rigidity. I came off medication. At this point, wanting to preserve my newly re-acquired quality of life as long as possible, I realized I needed neuroprotective therapy, i.e., therapeutics which would slow down neuron premature death and the progression of PD. Unfortunately, I also knew there was

no neuroprotective agent proven effective by "evidence-based medicine." So, I began reviewing new and old bench/animal/human-study literature with an eye toward what some leading scientists were calling for lack of a better term -- a "therapeutic cocktail" to fight premature neuronal death. They of course were talking about a combination of compounds and drugs which would take years to test

and develop. What I began noticing, however, (and it was profound when taken as a collective whole) was that there were lifestyle factors available now which were being studied in the lab in cell cultures and in animals which protected dopamine neurons from dying. For example, regularly exercising rats generated a protective growth factor in the basal ganglia of their brains, or anti-oxidant compounds found in common foods such as broccoli or curry spice protected against cell death, or the anti-inflammatory abilities of some forms of stress reduction offered protection. Conversely, the

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## Back in the game (continued from p. 1)

science showed what common sense dictates: a sedentary, stressed-out lifestyle with poor nutritional choices (and possibly too much medication) may hasten the disease process.

As I began to incorporate these concepts into my own lifestyle and continued to review and compile the science literature, two things happened: 1) by 2006 I actually was better, not worse -- motor symptoms under control, less fatigue and pain, clearer think-

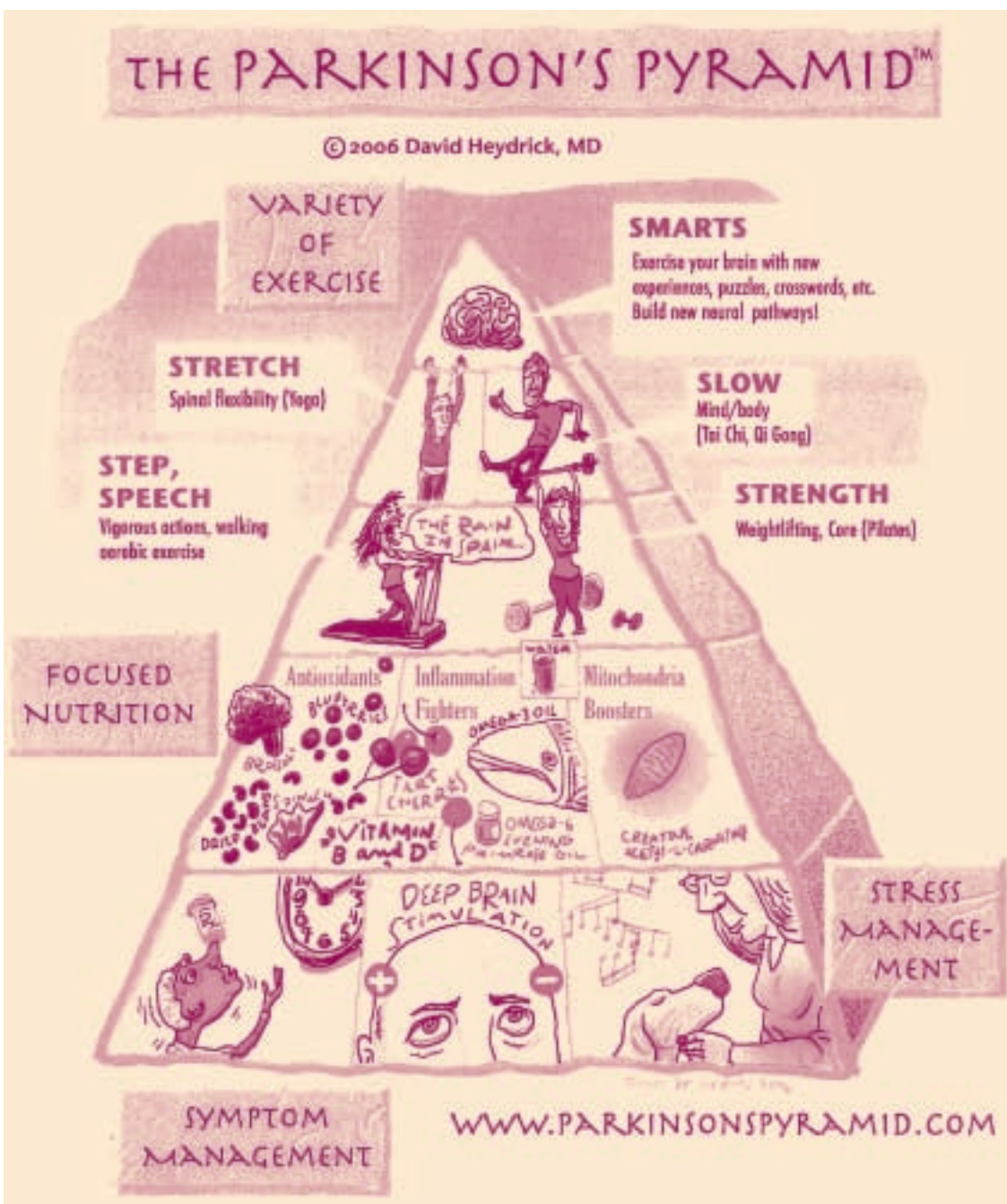
ing. I was so much better that in July 2006, Scott and I rode 500 miles in a week across Iowa on a regular bicycle as part of the Pedaling for Parkinson's team and I was able to play baseball with my sons again, and 2) the literature kept accumulating and validating my choices. I realized that ALL the lifestyle elements - stress reduction, low-dose medication or surgery, focused nutrition and a variety of exercise - not only contributed to my body and brain's health, but also were inter-related such

that any one element could affect any other in positive (e.g., antioxidant diet improves lung function) and also negative ways (e.g., stress diminishes the neuroprotective effects of exercise).

Hence, the Parkinson's Pyramid™ was born. I first presented the concepts at the World Parkinson Congress in February 2006, not realizing the impact it would have on so many people with PD. The Parkinson's Pyramid™ is an empowering integrated health strategy,

a "lifestyle cocktail" based around the symptom-improving and (theoretical but rational) neuroprotective effects of stress reduction, wise symptom management, focused nutrition, and a variety of exercise.

The Parkinson's Pyramid™ can be used by people with Parkinson's and their caregivers to take charge of their health, with the goals of increasing Quality of Life, giving insight into ways to fight back, and optimistically raising the chances that an individual patient will be better-functioning a year from now (which is counter to conventional teaching about neurodegenerative diseases). General information can be found online at [www.parkinsonspyramid.com](http://www.parkinsonspyramid.com). A book, *Back in the Game: The Parkinson's Pyramid™* is planned for release in late 2007.



## Welcome Claudia Martinez

My name is Claudia Martinez, and I am originally from a tropical city in Colombia, South America. I have been living in Phoenix for four years now, and I found out about the Muhammad Ali Parkinson Center last year, thanks to my advisor at the ASU gerontology's graduate certificate. At that time I was looking for an organization where I could work towards the betterment of the Hispanic community, and the idea of starting a new program for Spanish speaking patients with Parkinson's disease and their caregivers, at the MAPC, seemed perfect for my gerontology internship and my personal goals. On top of that, my father had struggled with Parkinson's disease for many years before he passed away, while I was still living in Colombia. This fact only made feel even more motivated about the possibility of helping families like mine, which have to adapt in order to live with Parkinson's disease.

Fortunately for me, what started as an internship turned into the MAPC's newest program: Hispanic Outreach, and I am really pleased to be part of this exciting and most needed initiative. I am currently focused in two main goals: to educate the Hispanic community about Parkinson's disease, and to start developing programs for patients and caregivers. During the first year we will be implementing PD 101, the Powerful tools for caregivers' workshop, and supports groups, all in Spanish!



## 1st Annual "Walk The Fight" 5K or 2 Block Walk-A-Thon

### Raises Funds for Parkinson's Disease While Offering a Day of Education and Fun

"The weather could not be better" exclaimed Rashida Ali Walsh, daughter of Muhammad Ali and honorary chairperson of the walkathon, as she formally started the Walk held under sunny skies on Sunday, February 18, 2007 at beautiful Tempe Town Lake in Tempe, Arizona. Rashida was particularly pleased at the number of participants that came from Los Angeles, New York and Las Vegas to attend the event. She met several families who moved to Phoenix primarily to be near the Muhammad Ali Parkinson Center.



The crowd of walkers in red t-shirts exceeded 200 and the corp of volunteers in blue t-shirts exceeded 50 as the group split into two courses, one 5k or a little over 3 miles and the second course 2 blocks long with people walking on their own, with canes and walkers and even mobility scooters. There were many families with children in attendance and a lot of moms pushing strollers.



Over \$14,000 was raised with all profits going to the Muhammad Ali Parkinson Center. The walk was made possible through generous corporate sponsors including Valient Pharmaceuticals, Medtronic, Healthsouth, Jackson White Attorneys At-Law and Teva Neuroscience.

Prior to the walk the crowd gathered around the Health Fair with over 35 exhibitors. The participants were able to talk to representatives of drug companies and health related companies from all over the Phoenix area.



The walkathon was created and put on by the Parkinson Network of Arizona, an affiliate chapter of The National Parkinson Foundation and the Foundation For Parkinson's and Neurological Research. This will be a yearly event with all profits going directly to the Muhammad Ali Parkinson Center.

## Help Organize the First PNA Jazz & Blues Festival

The Parkinson Network of Arizona an affiliate chapter of the National Parkinson Foundation plans to put on its 1st annual Jazz and Blues Festival complete with raffles and auctions November 4, 2007 in Scottsdale, Arizona. All profits will go to The Muhammad Ali Parkinson Center. Anyone interested in working on the organizing committee please call chapter President Jack Goldwater at (480) 883-2002.

## Audio Programs Provide Respite To Many

**Joelene Robinson, M.A., C.Ht. creates custom programs for MAPRC**

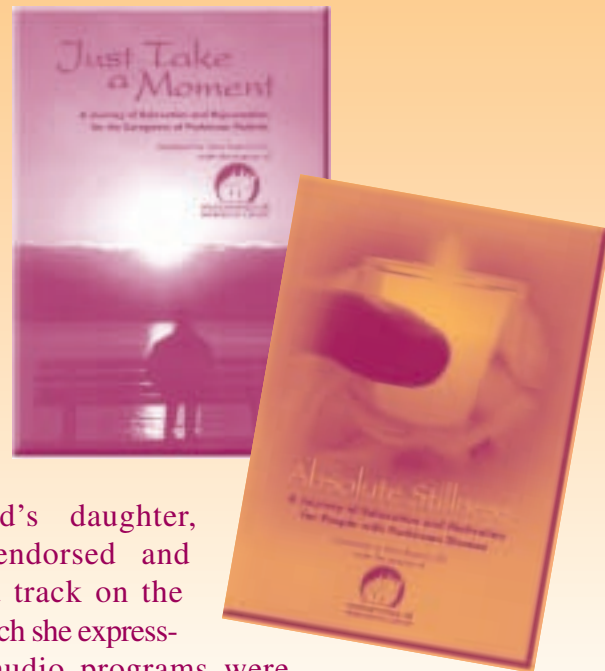
### How it all began...

It all started five years ago when William Homeier met Joelene Robinson at a conference in Florida. Her angelic voice and wellness business, Voice Essence, LLC, captivated him, and they began an association and a friendship. For some time, William has greatly admired Muhammad Ali's hero's journey and was moved to be involved in his efforts to relieve the suffering many experience with Parkinson disease. He saw an opportunity to combine two things he truly believes in: Joelene's soothing, calming and inspirational messages and the Muhammad Ali Parkinson Center. When William made the introduction, the center immediately recognized the need for her products and services, and the process was under-way.

### The Creative Process

For her research on what was to become two separate customized audio programs, Joelene held two discussion groups; one for people with Parkinson and the second for their caregivers. The objective was to determine the specific wording and language that would be most beneficial for each group to hear to experience greater relaxation, peace, inspiration and motivation during the course of their stressful day. Based feedback from both groups, Joelene also created tracks to enhance communication, compassion and reestablish loving connection with loved ones called, "Coping and Communicating" and "For the Parkinson Patient's Spouse." Joelene also did research to understand the condition and how it relates to increased stress and the correlation between the mind and body.

She then combined her diverse array of expertise as a voiceover artist, Certified Hypnotherapist, her Master's Degree in Applied Psychology, Neuro-Linguistic Programming, guided meditation and visualization, and Soul Medicine, and created two exquisite Audio Programs (with customized music) called "Absolute Stillness", for people with Parkinson and "Just Take a Moment", for their caregivers. She was also a featured speaker at the Mo Udall Educational Symposium in Phoenix in February, in which she shared relaxation and anxiety management techniques and tips.



Muhammad's daughter, Rasheda endorsed and recorded a track on the CDs, in which she expresses, "The audio programs were designed with distinct tracks that help you take care of yourself, assist you with simple, yet profound, effective methods to support your needs with short breaks to relax your mind and body, while creating a protected space where you can rest in calm, stillness and inner peace. Most importantly, they remind you of the essence of who you truly are, apart from your physical condition or your responsibility as a caregiver."

Who would have known a chance meeting years ago would result in such a meaningful synergy of creativity, healing and love.

The CDs are available on-line at [www.voiceessence.com](http://www.voiceessence.com) for \$19.99 per CD. A set of both CDs is available for only \$36.99, both include sales tax, shipping and handling.

You can also order by check or money order. Please make your check payable to Voice Essence, LLC and mail it to:

**Voice Essence, LLC**  
212 26th St. #297  
Santa Monica, CA 90402

A portion of the proceeds from sales will be donated to the Muhammad Ali Parkinson Center.

# Join Us For Dance

Darolyn O'Donnell



Celebrities competing in *Dancing with the Stars* are not the only ones mastering the rumba and the samba these days. People with Parkinson's disease and their partners have also caught the dance fever and are participating in a new ballroom dancing class offered this spring by the Muhammad Ali Parkinson Center.

The class has mastered some of the basic steps that are then put together in creative sequences as the couples glide across the ballroom floor. It is amazing how creatively the dancers come together with different combinations of box steps, turning box steps, rock steps, and underarm turns, to name a few. "Add some flavor to it" instructor Kathleen Henry calls out in attempts to encourage the dancers to put personal flare into it. "But I don't even have the right ingredients" quips back one of the students, with a smile from ear to ear.

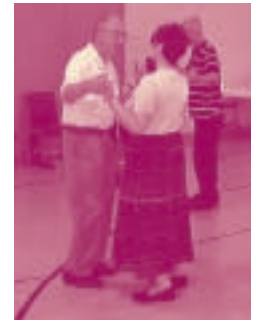
In this class, all of the dancers do have the right ingredients. They have enthusiasm, positive attitudes, a sense of spirit and an admiral ability to let it all go and give it their best.....and, of course, a terrific sense of humor. No one here expects to be mistaken for Ginger Rogers or Fred Astaire, not yet anyway. All of the moves are modified to meet the individual abilities of each of the students. For instance, there are lots of underarm turns, spinning couples embraced arm in arm, some romantically gazing into the eyes of their spouse of sixty years, some dancing and laughing with new found friends from class. There



haven't been any dramatic dips, lifts or catches quite yet, at least not any intentional ones. When it comes to a dance class for people with Parkinson's disease, everyone involved knows "hit the dance floor" can have a double meaning, but it certainly doesn't stop anyone from challenging themselves to move to the rhythm of the music.

After all, music makes people want to move. Currently there are several studies researching the power of music in helping people with Parkinson's disease move. According to Enrico Fazzini, MD, a neurologist at New York University Medical Center, "Music helps reconnect PD patients to what PD takes away: the ability to move automatically." In Brooklyn New York, The Mark Morris Dance Group is in its sixth year of providing weekly-customized dance workshops for people with Parkinson's disease and their caregivers through a partnership with the Brooklyn Parkinson Group. Here, faculty member Misty Owens is writing a master's thesis on dance therapy and Parkinson's.

Meanwhile, back at the class here in the Valley, students are perfecting the foxtrot, merengue, electric slide and assorted "free styles". We didn't claim to stick with ballroom dancing, we go wherever the music takes us or moves us. Seated or standing, in one place or across the dance floor, walker or no walker. And as a group, who knows where it might take us? You might be pleasantly surprised to happen upon a performance at an upcoming Mo Udall symposium.



*Special thank you to the Prince of Peace Lutheran Church located at 3641 N. 56th Street for the donated use of their beautiful gymnasium and to instructor Kathleen Henry for all of the extra preparation time and "flavor".*

**For more information, call 602.406.6903.**

# Interdisciplinary Clinic – What Have We Learned?

Margaret Anne Coles

We are well into our third year of our Interdisciplinary Assessment Clinic and I would like to share with you some of the findings.

Clinics are held for a full day, twice monthly, the 2nd and 4th Tuesday of the month (except August). People with Parkinson's disease and their families attend the clinic and over the morning receive hour-long individual assessments from a skilled team knowledgeable about PD. The team includes experts from Physical Therapy, Occupational Therapy, Speech Therapy and Social Work. During lunch, which is provided, MAPC staff is present to answer questions and provide information. Following lunch each participant meets with one of the assessment team experts to hear the results of the assessments and to discuss short and long term recommendations.

Thirty to forty-five days after attending the Assessment Clinic each participant receives a phone call and is asked to complete a short telephone satisfaction survey regarding their experience with the assessment clinic. The results are based on a 4-point scale with 4 being the highest score. Based on the reports of over 100 people the results are very positive and we are proud of what we have been able to achieve. The average scores for the more than 100 people are:

• Clinic organization	3.8
• Questions asked focus on daily issues of PD	3.6
• Clinic experience useful	3.9
• Therapists professional and courteous	3.9
• Literature provided expanded knowledge	3.7
• Recommendations helpful	3.8
• Recommend the clinic to others	3.8

Unlike other interdisciplinary clinics our focus is on function or the impact that Parkinson's disease has on daily activities and the ability to live day to day. We are interested in knowing what problems are being experienced, addressing those problems and providing suggestions/recommendations to increase function and improve quality of life.

One of the ways to do this is by measuring self-efficacy.

Self-efficacy is an important concept in a chronic disease such as PD because it reflects how well people are "managing" their Parkinson's disease. Self-efficacy is defined as "people's beliefs about their capabilities to produce designated levels of performance that exercise influence over events that affect their lives". Self-efficacy affects how an individual approaches the challenges presented by PD. Research has shown that people who are efficacious, who manage or control their disease, have more personal accomplishments, have reduced stress and have a lowered vulnerability to depression. This all translates into maintaining or improving function and quality of life.

Six months following their assessment clinic visit participants are called and asked to complete a self-efficacy questionnaire, which they also completed the day of the assessment clinic visit. When we compare the two surveys, the information we have collected to date is showing us that people who have attended the assessment clinic have improved their 6month self-efficacy over their initial assessment. Personal testimony suggests people are surprised at the ability to measure progress quantitatively and when they observe their positive progress it heartens and inspires them.

During this year our assessment clinic has grown in popularity – not just in Phoenix but also around the country. We have had people come from ten states, including Hawaii, Alaska and New York. As well we have had professionals from other facilities interested in starting interdisciplinary assessment clinics of their own, attend our clinic to see how we conduct business so that they might emulate our successful model.

In short, we have created a unique outreach program that is eliciting positive, powerful testimony that lives of people with PD are being improved. This program, unlike the typical clinic experience, focuses on easing people's daily living, both physically and psychologically. Providing quantified progress and simple, but effective tips for success is truly revolutionizing how people with PD and their caregivers think of themselves.

## Recreation and Education — May-August 2007

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 10-11 am;  
January 4 - July 26  
Skyway Church of the West Valley  
14900 W. Van Buren, Goodyear

### Carefree / Cave Creek / North Scottsdale

#### Exercise

The Art of Moving Exercise Class  
Tuesday 1:30-2:30 pm;  
January 2 - May 22  
Sonrise Community Church  
29505 N. Scottsdale Rd.  
(Scottsdale & Dixileta Dr.)

### Chandler

#### Exercise

The Art of Moving Exercise Class  
Wednesday 3:30 – 4:30 pm;  
January 3 - July 25  
Village Oaks Assisted Living  
1919 W Carla Vista Drive  
(Dobson & Chandler Blvd)

### Fountain Hills

#### Exercise

Fridays 9-10 pm;  
January 5 - June 15  
Fountain Hills Senior Center  
13001 N. La Montaña

### Mesa / East Mesa

#### Exercise

Mondays 1-2 pm;  
January 15 - July 30  
Red Mountain Multigeneration Center  
7550 E. Adobe Road, East Mesa

#### Tai Chi

Thursday 11 am-12pm;  
January 11 - July 26  
The Springs of East Mesa  
6220 E. Broadway  
(Between Power & Recker Roads)

### Phoenix

#### Exercise

The Art of Moving Exercise Class  
Tuesday 2-3 pm; January 2 - July 31  
Muhammad Ali Parkinson Center  
500 West Thomas Road, Suite 720

#### Voice Class

Tuesday 3-3:30 pm;  
January 2 - July 31  
Muhammad Ali Parkinson Center

#### Tai Chi

Thursday 11 am-12 pm;  
January 4 - July 26  
Muhammad Ali Parkinson Center

#### Aquatics

Mondays 1-2 pm; May 7 - June 29  
Muhammad Ali Parkinson Center

#### Exercise

The Art of Moving Exercise Class  
Thursday 1-2 pm;  
January 4 - May 31  
Shepherd of the Hills Congregational Church  
5524 E. Lafayette Blvd.  
(56th St., South of Camelback)

### Prescott

#### Exercise

Mondays & Wednesdays 10-11 am;  
Yavapai Regional Medical Center-Wellness Center  
930 Division Street  
Registration & Information  
928-771-4783

### Scottsdale

#### Exercise

The Art of Moving Exercise Class  
Tuesday – 10-11 am;  
January 2 - June 26  
Freedom Inn, 15436 N. 64th Street  
(Greenway & 64th St.)



**Sun Cities****Exercise**

The Art of Moving Exercise Class  
 Thursday - 1-2 pm;  
 January 4 - July 26  
 Care from the Heart  
 10032 W. Bell Road Suite #108

**Exercise**

The Art of Moving Exercise Class  
 Monday-2 Classes: 9-10 am, 10-11 am  
 January 8 - July 30  
 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  
 Monday—10:30-11:30am;  
 January 8 - July 30  
 Sun Lakes Education Center  
 25105 S. Alma School Rd., 2nd Floor  
 (Alma School & Riggs)

**Ballroom Dancing Basics -  
Let's Get Dancing!**

Register now for all sessions.

**Phoenix/Scottsdale**

Fridays 1-3 pm  
 September 10 - October 26  
*Prince of Peace Lutheran Church - Gym*  
 3641 N. 56th Street  
 (NE corner of 56th Street & Indian School)

**ART OF MOVING**

(Non-MAPRC sponsored)

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

**Scottsdale****Exercise**

Thursday – 2-3 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 12-1 pm  
 HealthSouth – Outpatient  
 (southwest side of the building)  
 9630 E. Shea Blvd.  
 Instructor: Melinda Theobald  
 Contact Person:  
 Melinda Theobald 480- 551-5423



## 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

This group meets 8 times a year at 6:30- 8:30pm  
Call for next meeting date

*Rock Bottom Restaurant and Brewery*  
21001 N Tatum Blvd  
Phoenix, AZ 85050-4206

*This is for those whose current age is 30-50's*

#### Specialty Groups

##### 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

*Skyway Church of the West Valley*  
14900 W. Van Buren  
Goodyear, AZ  
2nd Thursday of the Month,  
10:00 am-11:00 am

#### 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  
Every 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

##### Spanish Let's Talk (Platiquemos)

*Muhammad Ali Parkinson Center*  
500 W Thomas Rd, Ste 720  
Phoenix, AZ 85013  
2nd Saturday of the Month, 10:30-11:30 am  
Segundo sábado del mes, 10:30- 11:30 am  
Favor llamar a Claudia 602-406-2453

**West Valley****Glendale**

*Arrowhead Hospital*  
18701 N. 67th Ave  
Glendale, AZ 85308  
3rd Friday of the Month,  
10:30-12:00 pm

**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

**Payson**

*First Southern Baptist Church of Payson*  
302 S Ash St  
Payson, AZ 85541  
1st Thursday of the Month, 11:30-1:00 pm

**Southern Arizona****Casa Grande**

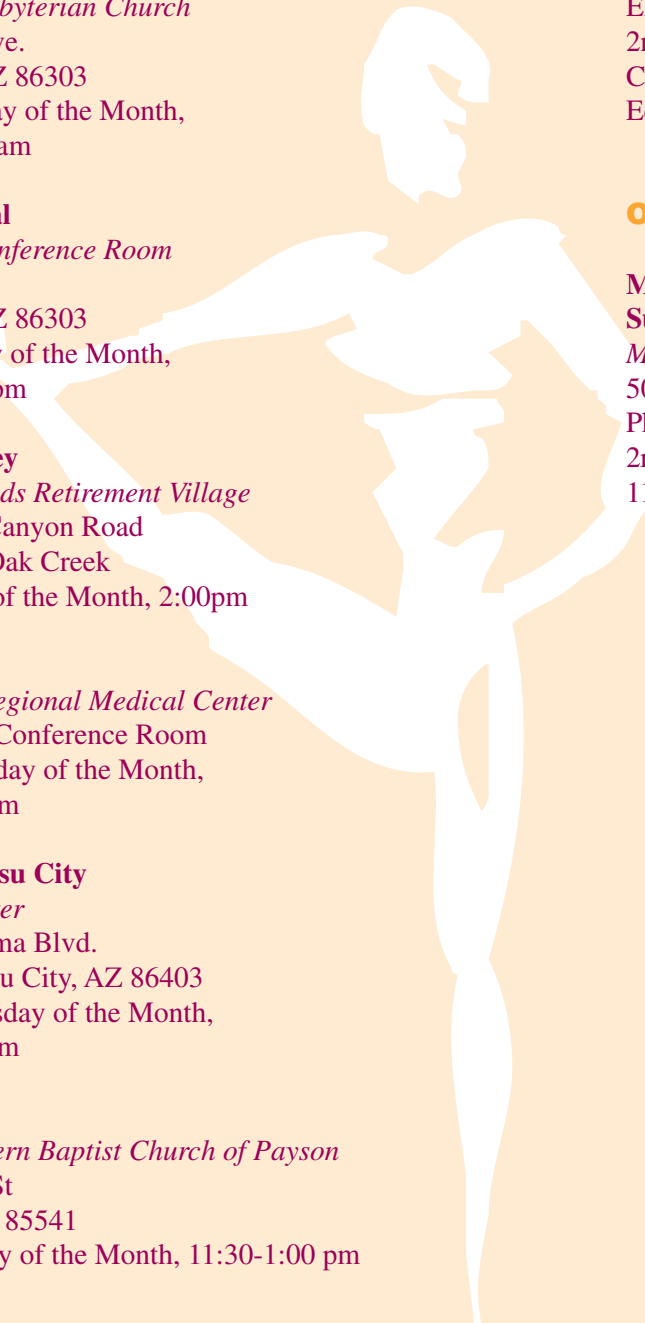
*Casa Grande Public Library*  
449 N Dry Lake  
Casa Grande  
3rd Tuesday of the Month, 1:30- 3:00 pm

**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 Research Center*  
500 W. Thomas Rd Ste 720  
Phoenix, AZ 85013  
2nd Friday of the Month,  
11:00- 12:00pm



# PD FOR DUMMIES

## Book Review

*This is a book that has obviously struck a chord with at least two people with Parkinson's Disease from our MAPC family. Both have kindly agreed to share their thoughts about the book in the reviews.*

It's one of those familiar, ubiquitous, yellow and black, paper back editions that belong to the "Dummies" series of books. The subject is Parkinson's, and the title is "Parkinson's Disease for Dummies," written by Michele Tagliati, MD and Gary Guten, MD. Dr. Tagliati is a movement disorders specialist with extensive experience in the treatment of Parkinson's disease. Dr. Guten is an orthopedic surgeon and a Parkinson's patient.

This book is a must read for the newly diagnosed person with Parkinson's. It's an easy to read format written for an audience that includes the person with Parkinson's, his or her care partner, family, and friends. It's a 352 page book composed of six parts, examining the physical, emotional, and financial components of living with Parkinson's disease. Twenty four chapters address the mountain of issues about the inevitable stages of progression and coping with this chronic disease. The beginning chapters define Parkinson's disease (PD), and describe the symptoms and stages of progression. Specific information in these chapters includes a discussion of the latest medications and their side effects, current treatments for PD, physical therapy, speech therapy, and alternative treatment therapies. Dieting and exercise has its own chapter. Anxiety and depression are covered in another chapter. No issue is left unexamined.

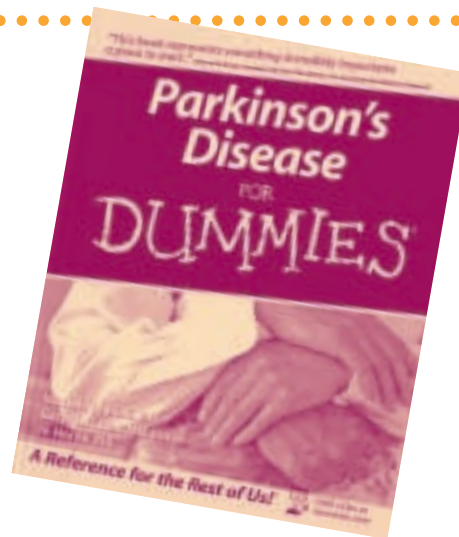
Later chapters include valuable information for both the newly diagnosed person as well as the person who has already been living with Parkinson's. These chapters address questions about adjusting your daily routine and coping with the progression of PD symptoms. Subjects of these chapters include driving a car with Parkinson's, fatigue, falling, constipation, urinary issues, and dementia.

Dr. Tagliati and Dr. Guten devote an entire chapter to the care partner in this

book. We always talk about the person that has Parkinson's, but how do the roles change for a care partner? When does the care partner become a caregiver? Are you in this for the long haul? Do you know how to delegate? Dealing with burnout. These, and other issues that the care partner will face are the subject of this chapter. A list of eight web sites just for care partners is included in the Appendix .

Chapter 20 examines financial and legal issues, and Chapter 21 looks at housing options. Have you prepared a living will and given durable power of attorney to someone you trust? Have you thought about home health care or assisted living? In Chapter 21, you'll find a checklist for evaluating an alternative living facility.

"Parkinson's Disease for Dummies," does not include any topics about research or scientific investigation of a cure for Parkinson's. This book is a pragmatic guide for the newly diagnosed. It defines Parkinson's disease and acknowledges how this life altering diagnosis is about to change the way you live. Each chapter is focused on a different issue of PD, and gives you practical ways to manage your life with Parkinson's. Every person newly diagnosed with PD should add this book to his or her must read list.



If only I could have read this book when I was first diagnosed in late 2005---how much easier my whole life would have been!

While I was waiting for three months for my first available appointment with my Movement Disorder Neurologist, I intelligently read every book available at

the Phoenix Public Library directed towards Parkinson disease patients. By the time I first met my physician I was a depressed and sorry person with lists of local care facilities, prescription possibilities for failure, and totally resigned to my final life of hopelessness and despair. Unfortunately, the books were presented with only factual negative reasoning that was easily misinterpreted by me.

PD for Dummies is written with positive formats in a factual but progressive way. The chapters do not conclude that the present incurable disease is destined for a negative life style for the patient. I appreciated that I could accept and absorb and react to only that part that affects me now. In other words... my primary treatment is still working but I know that it won't last forever. On the other hand, I don't have to absorb all of the information about later medications and their possible non successes. I could be thankful and hopeful that I am being medicated with the proper drugs for my condition today and have as much information as I need now.

I am aware that I will not get better - but I didn't feel it necessary to look forward to all of the bad things that may befall me later. The book allowed me to accept my present limitations without fear of later pitfalls that my never happen or may be years away. The book allowed me to accept my condition with grace and the comfort of knowing that I will not fall apart tomorrow. (Maybe in the future- but not to worry today!)

The nutrition and financial and legal aspects of Parkinson's are written plainly and with common sense instead of unintentional scare tactics.

This book has given me more confidence than any other book, seminar, or program that I have had presented to me so far. I have a new outlook on the situation. So I have P.D.....I'll do the best I can for now and leave the worrying about the future to when I need those chapters! At some point in the future, I'm sure those chapters will be guiding and easily accepted by me when I need the next step resolved. In the meantime- I will concentrate on my condition today- knowing that I don't necessarily have a bleak present or desolate future with this ailment.

## Zelapar: An “Old” Drug (Selegiline) in a New Form

Dr. A. Lieberman

Zelapar is selegiline. The difference, and a major one, is that Zelapar dissolves on the tongue, is rapidly absorbed in the blood stream: it does not have to and should NOT be swallowed. Because Zelapar by-passes the stomach, the intestine, and the liver, Zelapar reaches the brain more rapidly. As a rule 1.25 mg of Zelapar on the tongue, the standard dose, is 4 times as potent as 5mg selegiline swallowed into the stomach i.e. 1.25 mg of Zelapar is at least equivalent to 5.0 mg of selegiline. There is more than a difference in potency, the 5.0 mg of selegiline that is swallowed is changed by the liver:

75% of the selegiline that is swallowed is changed i.e. metabolized by the liver. This means that only 25% of the swallowed dose is available to be transported to the brain. 75% of the swallowed dose of selegiline is changed into metabolites: some of them may be beneficial, many are not. Zelapar, absorbed on the tongue, is a “cleaner” drug than swallowed selegiline: there are few Zelapar metabolites. Zelapar, although it is selegiline, because of the way it is delivered to the brain, is, in effect a new drug.

In the brain, Zelapar blocks or inhibits, an enzyme called Monoamine Oxidase type “B”, abbreviated MAO-B. This enzyme is found INSIDE nerve cells or neurons. The enzyme is associated with the mitochondria. The mitochondria are the power plants or fuel cells of the neuron. Each of the 100 billion neurons in the brain has between 200 and 2,000 mitochondria. The number of mitochondria depends on the activity of the cell. The neurons of the substantia nigra, the region of the brain affected by PD, contain 2,000 mitochondria per cell.

The neurons of the substantia nigra change the amino acid L-dopa, or levodopa, into dopamine. Dopamine is the chemical that regulates movement. Too little dopamine and movement is slow as in PD. Too much dopamine and movement is rapid and uncoordinated, as in the involuntary movements or dyskinesia of too much levodopa. Once dopamine is formed inside the neuron, the concentration is regulated by the enzyme MAO-B. The enzyme MAO-B breaks down, degrades, or metabolizes dopamine. Zelapar blocks MAO-B inside the neuron, which results in the dopamine that is formed lasting longer. Zelapar is a way of extending the duration of action of levodopa.

Zelapar because it increases and prolongs the effects of levodopa, either the levodopa normally formed in the neurons, or the levodopa that is formed from carbidopa/levodopa (Sinemet) given by mouth, decreases the “wearing off” that occurs in all patients after they have been on carbidopa / levodopa for several months or years. Patients in whom Zelapar is added to carbidopa/ levodopa usually experience a decrease in “wearing off”, they are “on” for a longer period of time, at least 2.5 hours more per day, and they may have less dyskinesia. Zelapar, through its unique delivery system in by-passing the stomach, the intestine, and the liver, is a useful addition to the drugs available for the treatment of PD.

### Common questions:

**Question 1: I am on carbidopa/ levodopa (Sinemet) plus entacapone (Comtan) in the form of Stalevo. How does Zelapar differ from Stalevo?**

**Answer 1:** Comtan alone or in Stalevo blocks or inhibits an enzyme called COMT. COMT is present OUTSIDE cells i.e. COMT circulates in the blood, and it is present inside cells. Comtan blocks COMT, it blocks circulating COMT and COMT inside cells. However, since Comtan does NOT enter the brain, it does not block COMT inside the brain. Comtan is an effective way to prolong the actions of carbidopa/ levodopa. It does so by making more levodopa available to the brain. This is different from the way Zelapar works. Zelapar protects the dopamine that is formed from levodopa inside the brain. Comtan (Stalevo) and Zelapar complement each other. Comtan makes more of the “raw material” levodopa available, Zelapar utilizes the “raw material” dopamine more efficiently. If you are currently on Comtan (Stalevo) and are not doing well, you should ask your doctor if you might benefit from the addition of Zelapar.

**Question 2: I am on selegiline (Eldepryl) or in the past I was on selegiline, should I consider Zelapar?**

**Answer 2:** If you are on selegiline and are doing well there is no advantage in switching to Zelapar. If you are on selegiline and are not doing well, or if you were on selegiline and did not do well or it did not seem to work, ask your doctor about Zelapar. Zelapar, although it is selegiline, because of its formulation, is essentially, a new drug. If you had a side effect, an adverse reaction, on selegiline the probability is that you will have it on Zelapar. Remember Zelapar because it is more potent may result in more benefits, and, pos-

sibly, more side effects.

**Question 3: Is Zelapar more effective than Azilect or rasagiline?**

**Answer 3:** Azilect, or rasagiline, is a new drug that blocks the same enzyme, MAO-B as Zelapar. Rasagiline in addition to blocking MAO-B may have other effects. These will be discussed in a separate article on rasagiline. Zelapar and Azilect have not been compared directly, one on one, thus at this time no one can say if Zelapar is more potent, equally potent, or less potent than Azilect.

The side effects linked to Zelapar, selegiline, and rasagiline (Azilect) another MAO-B inhibitor, result from their ability at a higher dose, a dose higher than that used in PD, to block another enzyme in the brain called MAO-A. MAO-A is found in neurons different from those containing MAO-B. Some drugs, a class of drugs used in psychiatry to treat severe depression, have the ability to block MAO-A. The enzyme MAO-A in addition to being found in the brain is found in the body, especially in the stomach and intestine. MAO-A in the stomach and the intestine renders harmless certain chemicals called amines that are found in some foods. The principle amine is tyramine. Tyramine is found in aged or fermented cheese, red wine, pickled herring, and smoked or cured meats such as bacon.

Tyramine if it is not inactivated by MAO-A, can raise blood pressure resulting in strokes or heart attacks. This is called the “cheese effect” because of the high concentration of tyramine in aged or fermented cheese. Patients who take a class of drugs called MAO-A inhibitors are warned not to eat the above foods because of the possibility of a “cheese effect.” This warning does not apply to people who take selegiline swallowed by mouth in doses NOT more than 10 mg per day, or Zelapar not more than 2.5 mg per day. At a dose of 2.5 mg or less, Zelapar blocks ONLY MAO-B which is not involved in the “cheese effect.” Above 2.5 mg per day Zelapar, or 10 mg per day of selegiline begin to block MAO-A as well as MAO-B.

A second cause of concern is the interaction of drugs such as Zelapar, selegiline, and rasagiline with anti-depression drugs. The commonly used anti-depression drugs fall into three categories. One is a class called TCA, for tricyclic antidepressants. The most commonly used TCAs are Elavil, Norpramin, and Tofranil. A second class is called SSRI, for selective serotonin reuptake inhibitors. The most commonly used SSRIs are Prozac, Lexapro, Paxil, and Zoloft. A third class is called SNRI, for selective norepinephrine reuptake inhibitors. The most commonly used SNRIs are Cymbalta and

Effexor. A fourth class is Wellbutrin. All of the above drugs raise the levels of dopamine, norepinephrine, and serotonin in the brain. They do this through a different mechanism than blocking the breakdown of the chemicals. Because the anti depression drugs raise the levels of the chemicals dopamine, norepinephrine and serotonin there is the potential for additive, and usually adverse, effects of combining an anti depression drug with MAO-A inhibitors, and probably with MAO-B inhibitors. As a rule, if a patient is on an anti depression drug, Zelarap should not

be used. These restrictions also apply to drugs such as amphetamine or Ritalin. These restrictions also apply to over-the-counter drugs like ginkgo, and St John's Wort.

A third cause of concern is the interaction of drugs such as Zelarap, selegiline, and rasagiline with over-the-counter cold preparations that contain the amines phenylephrine, pseudoephedrine, or diet pills that contain Dexatrim.

## No Regrets:

Thoughts to share from John Yonushonis  
CLU, CLTC, President Foundation for  
Parkinson's and Neurological Research  
[www.ffpnr.org](http://www.ffpnr.org)

This is a story, albeit a true story. It is a story about me but it is also a story about you. We do not exist in this Parkinson world and we do not exist in these Parkinson bodies we live in alone. We exist together.

Every time one of you, my brothers and sisters with this disease gets the courage to go out to dinner, gets the courage to go out for a walk or in my case finish a half marathon, every time one of you takes this disease by the scruff of its ugly neck, says that you will live the rest of your life without regrets and to the best of your ability, we all celebrate. And every time one of us falls, we all wish to pick you up and hold your hand and help you through the next incident, because we all know another is coming. It may be me or it may be you. We just pray for each other's strength and to handle it well.

Two years of diminished flexibility. Co-workers knowing that I was coming because I dragged my feet. The loss of flexibility to play golf and no more throwing the football with the kids. Going to parties and wondering why my face felt so stiff and my eyes were behind a mask. The fatigue. The anxiety. This was me but most likely it was also you.

Then the diagnosis. The tears, the fears and the wondering. For those of us that went on-line for solace we found more reasons to worry. Those damn medications; those that make us feel better while making us feel so bad.

Then one day the realization that there is a way to fight back. With the help of the Muhammad Ali Parkinson Center and motivation from my wife, Ann and my family I found out that I could challenge every day that I live. First I was not going to be embarrassed and I was going to tell everyone I know and come in contact with that I have Parkinson's. I wanted them to be aware so that they could recognize the disease and help others that may also have Parkinson's. Next, whether it was reading a book, doing a puzzle, going to a museum or on a walk with my wife Ann and my



Wheaton terriers, everything I started doing was to increase my physical abilities and try to expand my mental capacities.

Wow, what a challenge for me and for you. There are days that I would rather not expand but those had to be fought through. Days that the cramps and pain were intense – that had to be dealt with by toughness. It is me and all of you

on our daily pursuit of life and I was going to go through the one life I have with no regrets!

I got a phone call from my sons Ian and Josh – “Dad, why don't you do the marathon with us?” To which I promptly replied, “Are you crazy I have Parkinson's disease”. To which they promptly replied “So what”

I started training the next day, arising at 6 every morning to walk (or in the beginning shuffle) my pre-plotted course. All was going well when 10 weeks before the event I pulled a ligament in my heel. I would not let this pain stop me. Plenty of ice each day got me

through the pain. Five weeks before the race I was suspected of having a cancerous growth that needed to be removed requiring a several hour operation (it was benign). When I went to train again the stitches poked my legs to the point of bleeding. I went on. The final week, with far less training that I should have had, the final strike to my body – my left arch collapsed. No time to quit now. Daily trips to the hot tub, followed by ice. By this time the stitches were out so how could I complain?

I met Ian, Jeanine, Josh and Kelly for the P.F. Chang Rock & Roll Marathon. They ran the full marathon and I ran the half marathon finishing in 3 hours and 40 minutes – glad for it to be over and I have **NO REGRETS**. Six weeks in a soft cast was my badge of honor.

My thought to all of us is to remember we are not alone. We are a strong community that will help each other learn to live the rest of our lives with no regrets. As you go through your day think of everything that is out in this world that will challenge your body and mind. Take the challenges and enjoy the hurdles and let's enjoy life together.

**Call me** at 602-469-1203, or 602-510-1567 anytime you would like to talk, but for now it is off to yoga..

# Join a Clinical Trial and Foster Research Learning

Lynn Marlor

Only 2-3% of adult patients participate in clinical trials which is a serious impediment to understanding the cause of disease and hence its improvement. You can personally help drive fundamental understanding of PD by participating in a clinical research study. Choosing to participate in a clinical trial is an important decision. Before deciding to do so you should have a basic understanding of the clinical trial process.

## What are the benefits and risks of participating in a clinical trial?

### Benefits

Clinical trials that are well-designed and well-executed are the best approach for eligible participants to:

- Play an active role in their own health care.
- Gain access to new research treatments before they are widely available.
- Obtain expert medical care at leading health care facilities during the trial.
- Help others by contributing to medical research.

### Risks

There are risks to clinical trials.

- There may be unpleasant, serious or even life-threatening side effects to experimental treatment.
- The experimental treatment may not be effective for the participant.
- The study may require more of the subjects' time and attention than would a non-protocol treatment, including trips to the study site, more treatments, hospital stays or complex dosage requirements.

## How is the safety of the participant protected?

The ethical and legal codes that govern medical practice also apply to clinical trials. In addition, most clinical research is federally regulated with built in safeguards to protect the participants.

The trial follows a carefully controlled protocol i.e. a study plan, which details what researchers will do in the study. As a clinical trial progresses, researchers report the results of the trial at scientific meetings, to medical journals, and to various government agencies. Individual participants' names

will remain secret and will not be mentioned in these reports.

## What should people consider before participating in a trial?

People should know as much as possible about the clinical trial and feel comfortable asking the members of the health care team questions about it, the care expected while in a trial, and the cost of the trial. The following questions might be helpful for the participant to discuss with the health care team. Some of the answers to these questions are found in the informed consent document.

- What is the purpose of the study?
- Who is going to be in the study?
- Why do researchers believe the experimental treatment being tested may be effective? Has it been tested before?
- What kinds of tests and experimental treatments are involved?
- How do the possible risks, side effects, and benefits in the study compare with my current treatment?
- How might this trial affect my daily life?
- How long will the trial last?
- Will hospitalization be required?
- Who will pay for the experimental treatment?
- Will I be reimbursed for other expenses?
- What type of long-term follow up care is part of this study?
- How will I know that the experimental treatment is working? Will results of the trials be provided to me?
- Who will be in charge of my care?

## Presently we have 3 active enrollment clinical research studies at Barrow Neurology Movement Disorders Clinic:

### 1. NET-PD Large Study.

The study will test the ability of the drug creatine to slow the clinical decline of Parkinson's disease. The National Institutes of Health is sponsoring the study. In relatively small and brief studies in people with Parkinson's disease, creatine has been well tolerated. Doctors now intend to carry out a large trial to continue looking at the safety of creatine and to see if it is effective in slowing clinical decline in people with Parkinson's disease. Patients diagnosed with Parkinson's disease within 5 years and who are being treated for the disease may be eligible.

Most Parkinson's disease treatment trials focus on treating the symptoms of the disease. The NET-PD LS Study and another new study will assess agents that have the potential to slow the progression of PD. The new study will evaluate the use of coenzyme Q10. This study will

be starting in the next few months.

## 2. Gene-PD

This is a long-term genetic study that has been ongoing since 1998. The primary purpose of the Gene-PD Study is to examine changes in DNA among people with Parkinson's disease to see how inheritance may play a role. Eligible subjects are persons diagnosed with PD and with family members diagnosed with PD. The family members can be child-parent or siblings. Subjects can also be included if they have a deceased parent with PD and a living sibling whether they are affected or not. Family members can be local or out of the area.

Subjects complete a brief questionnaire, a physical examination and a blood draw.

## 3. 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.

There is no cost for any of the studies. All clinic visits, tests and medications are paid for by the study sponsors.

*Several studies are planned to start in the immediate future. If you are interested in participating in a project please call Lynn Marlor, Research Nurse Clinician at 602-406-6250. If a study is not available at the present time that will meet your needs you can be added to a waiting list. You will be contacted when a study becomes available.*

# 13th Annual Celebrity Fight Night Nets \$4.4 Million for Charity

The stars aligned on March 24 for the 13th Annual Celebrity Fight Night, held at the JW Marriott Desert Ridge Resort and Spa in Phoenix. The celebrity charity event attracted more than 1,300 guests and raised \$4.4 million for worthy charities, including its primary beneficiary, the Muhammad Ali Parkinson Center.

“Our guests’ profound generosity touches me deeply year after year, and this event was no exception,” said Jimmy Walker, Founder and Chairman of Celebrity Fight Night Foundation.

Muhammad Ali was joined by an array of celebrities, athletes and guests including Billy Crystal, Emmitt Smith, Kareem Abdul-Jabbar, Tony Hawk, Michael Irvin, Michael Johnson, Matt Leinart, Larry Fitzgerald, Kurt Warner, Ben Roethlisberger, Vince Young, Kevin Sorbo, Doug Flutie, Derrek Lee, Alice Cooper, Shaun White and Buzz Aldrin.



Fourteen-time Grammy Award-winning producer David Foster led the evening's musical entertainment, which included performances by Reba McEntire, Michael Clarke Duncan, Carlos De Antonis, Josh Groban, Lucia Micarelli, Neil Sedaka, Michael Bubl , Pam Tillis and Diana Ross.

The live auction brought heated bidding for some impressive prize packages: a round of golf and private lunch with Phil Mickelson (\$500,000, the largest winning bid in Celebrity Fight Night's history); dinner with Muhammad Ali (\$400,000); dinner with Reba McEntire at her Beverly Hills home (\$250,000); a power lunch with Donald Trump in New York City (\$350,000); a one-of-a-kind 2007 Roush “Blackjack” Stage 3 Mustang (\$225,000); a private island retreat in Fiji (\$150,000); and the chance to attend the 50th Annual Grammy Awards paired with an unbelievable guitar collection (\$150,000).



Muhammad Ali Awards were presented to Sharon Stone–Humanitarian Award; Donald Trump–Entrepreneur Award; Steve Nash–Sports Achievement Award; John Elway–Sports Legend Award.

The Celebrity Fight Night Foundation provides critical funding for the patient-care, education, outreach and research activities of the Muhammad Ali Parkinson Center. The Center's staff, physicians and patients are profoundly grateful for the Foundation's support!



Without these gentlemen,  
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## 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.

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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.

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