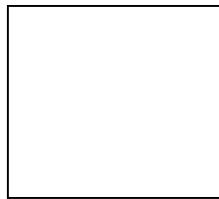


American Parkinson Disease Association, Inc
5368 Fredericksburg Rd, Suite 200
San Antonio, TX 78229-6108



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AAPSG Support Groups
All Support Group Meetings are for PD Patients,
their Caregivers, Family and Supportive Friends.

Alamo Area Parkinson's Support Group

Second Monday every month, 1 PM
Sunset Ridge Church of Christ, 95 Brees Blvd, San
Antonio

Young-Onset Parkinson's Support Group

Second Saturday every month, 10 AM
Newforest Estates, a Wellstone Retirement
Community, "Auditorium", 5034 New Forest Dr,
San Antonio, (Behind Sam's store at the Summit
Parkway exit on Loop 410 NW)

Boerne Parkinson's Support Group

No longer meeting - call Dianne Johnson, RN, at
210-567-6688, or E-mail diannejohnsonrn@aol.com
for info.

DBS Support Group "Live Wires"

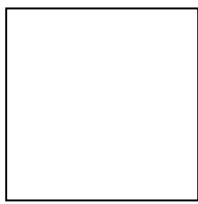
Fourth Saturday every month, 10 AM - Location
varies; call Sandra Farris, 830-257-3811
sandraf@windstream.net or Judy Hoopman 830-
997-7705 ralanh@ktc.com for current location.

Caregivers Only Support Group,

Third Friday every month, 1 - 2 PM
Warm Springs Rehabilitation Facility, room132
resource center, 5101 Medical Dr, San Antonio
POC: Dianne Johnson, 210-567-6688, 651-9835,
E-mail diannejohnsonrn@aol.com .

Lower Rio Grande Valley PD Support Group

Third Tuesday in Sept–Nov, & Jan–May 2:30 PM,
Golden Palms Retirement Center,
2101 Treasure Hills Blvd, Harlingen, TX.
For more information call Pauline and Bill Frink at
956-421-3360, E-mail mrspgfrink@rgv.rr.com .



American Parkinson's Disease Association, Inc
 Alamo Area Parkinson Support Groups
 5368 Fredericksburg Rd, Suite 200, San Antonio, Texas 78229-6108
 Phone 210-349-0096, www.aapsg.org
 APDA I & R Center Phone 210-567-6688

Quarterly Newsletter, April 2007

Editor: Dianne Johnson

Local News

Executive Board, 2005-2007

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You may leave a message for any AAPSG Officer or Board Member at 210-344-8828.

Walk for Fred

Walk with us on Saturday, April 14, at Crossroads Mall 4522 Fredericksburg Rd from 9 AM to 10:30 AM. Fred Dyas, the president of the Alamo Area Parkinson's Support Group, is living with PD and the 2007 walk honors his dedication to the steps to find a cure and his spirit for life.

PARK: Street level on the Fredericksburg Rd side of the mall near Hobby Lobby and Jo-Ann Fabrics.

ENTER: Use the main mall entrance (street level) between Hobby Lobby and Jo-Ann Fabrics

WHEN/WHERE: Registration begins at 8 AM (you can walk early if you like!) in the area near Burlington Coat Factory. Registration is \$25 per person and includes a t-shirt and car magnet.

INFO: Call 210-344-8828 if you need assistance or details. On Page 5 & 6 of this newsletter is a copy of the registration/ sponsorship form for this event.

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The following article is by Nina Brown and was printed recently in the Houston Area Parkinson Society Newsletter "HAPS HAPPENINGS" www.hapsonline.org, 713-626-7114. It is too good not to share with all of you.

COPE WITH HOPE

This article may seem familiar, but it's so important, it bears repeating. When I was diagnosed with Parkinson's disease in 1985, I realized that living with a "progressive" disease was going to require continuing adjustments and accommodations through the years and that the word "*cope*" would hold new importance in my vocabulary. I also recognized that the decision as to *how* I would cope was mine, as it is yours. I chose to focus on the positive. Life is certainly more difficult for me today, but whatever the circumstances, I still feel a smile and a positive attitude make it easier to face the future. I'm not suggesting a "don't worry, be happy" attitude; but life should be looked at as an adventure to be lived rather than a problem to be solved. Perhaps some of the following suggestions will be helpful.

Concentrate on the positive. You may not have the ability to change what is happening to you, but you *can* change how you relate to it. People generally find what they expect to find. Listen to that little voice in your head as you tell yourself how you are doing. Listen to the louder one as you tell others. If you expect to feel bad, your body won't disappoint you. You will feel bad. If you expect to feel good, there's a greater possibility you *will* feel good. It's also easier for family and friends to offer support to someone with an optimistic attitude.

Parkinson's has been described as a "yo-yo" disorder, one hour up, the next down, one day good, the next bad. It helps to remember that one bad day is only one bad day. It does not constitute a trend. Assume tomorrow will be better. According to studies on the "placebo response" your mind can help heal your body when bolstered by hope and expectation. Better symptom control lies not only with pills or surgery, but with ourselves as well.

Acceptance. Acceptance does not mean you need consider yourself "sick." Parkinson's is just something I have like brown eyes; so I refuse being referred to as a "patient" unless I'm in a doctor's office. Unlike having a headache though, Parkinson's can be difficult to hide. It's easier not to try. Be open with others. I have found that people are interested in learning about the disease and are appreciative that you shared the information. Rather than think of Parkinson's as a problem, consider it more a situation, a challenge, an opportunity to make changes in your life. You will be less anxious, less frustrated and less stressed, which will result in fewer symptoms.

Become informed. Knowledge is the first positive step toward being in control. Be responsible for your own health care. You know your body best. It's vitally important to read everything you can find! {Request free publications from the national Parkinson's organizations}, request to be put on mailing lists for newsletters and medical updates, use the Internet and attend lectures. You'll better understand why symptoms occur which will allow you to know what questions to ask and how to properly describe the problem when you see your physician. Find a doctor who has knowledge and experience in treating people with Parkinson's, one who is interested, patient, understanding, cooperative and willing to take the time to work with you. Your pharmacist is another good resource for information. Join a support group for valuable, shared, personal advice and support.

Set achievable goals. You may need to set new and more achievable goals because of the limitations Parkinson's has placed on you. It's important to learn to pace yourself. When adapting to a less active schedule, there is a tendency to overdo when you feel good. After a busy period, schedule activities that don't require a lot of energy. Have an alternative in case your symptoms require you to cancel a planned event. Planning ahead gives you the flexibility to accomplish things when you feel good. For instance, you can shop in advance for birthday and anniversary presents. Address cards

ahead of time.

Keep a sense of humor. Laugh at yourself. A laugh a day is more important than an apple in keeping the doctor away. When a chuckle would feel good, go to the closest drug store or card shop and tickle your funny bone by reading greeting cards. A laugh is much better for your immune system than getting angry or frustrated.

Simplify your life. Learn to say “no” without feeling guilty. Find easier ways to do things. Determine your priorities- Eliminate the unnecessary.

- . Call stores to make sure they have the item you need.
- . Shop during off-hours to avoid crowds and lines,
- . Get a disabled parking permit.
- . Use stores that deliver or have drive-up facilities.
- . Use a cordless telephone; keep a telephone by your bed; consider using a headset so you don't have to hold the receiver; use an automatic dialer and/or a speaker phone.
- . Always carry extra medication with you. Get a sports bottle to have water for taking pills.
- . Keep a written schedule of your medication. Buy a pill container that has a weeks worth of dividers. This saves time and identifies if you've taken a particular dose.
- . Get a timer to remind you when medication is due.
- . Use stick-on labels or a pre-inked rubber stamp when you need to write your name or fill out forms.

Keep active. Exercise, both mental and physical, is essential in maintaining your lifestyle. It prevents your muscles from deteriorating, strengthens them, reduces tension and rigidity, improves your ability to rest and sleep and enhances other bodily functions. Walking is one of the best exercises. Choose activities that let you play. Take dancing lessons or enjoy some of the less strenuous sports such as golf, tai chi, bowling, horseshoes or swimming. The more active you are, the longer it will be before you need physical, occupational or speech therapy. Exercise *can* be fun.

It's also important to keep active socially. Don't allow yourself to become isolated. Participate in support groups to meet new people, develop new friendships and help avoid depression. Instead of focusing on yourself, help someone in need. It will get your mind off of yourself and you'll remember how much you have to be thankful for.

Have faith and never give up hope. Living with PD was once described as a little like venturing into the Himalayas while most others travel less rugged slopes. We can grumble about how steep and hazardous the climb, preoccupied with the expense of our climbing gear, the physical exhaustion and the fear as the slopes turn into shear walls of granite. Or, we can live in the moment and focus on appreciating the spectacular beauty found only in such imposing terrain. No one can take this choice from us.

While my heart goes out to all who live with this disease, have faith that with the research being done, the hope of finding a cure appears closer than ever. But I also know “hope” needs “help” and actively working as an advocate for Parkinson's and stem cell research to help find that cure gives me strength, courage and energy. I invite you to join me and ***cope with hope.*** Nina Brown, HAPS

[NOTE: The following poem was written by Rita Wright and is proof that a person with PD can still live a good and productive loving life. So take what life gives you and REJOICE.]

From a Mother to Her Daughter

I was living my life as I darn well pleased
When the man of my dreams said, “Marry me,
please”
And before too long, I found myself the mother of two
Now the day's almost gone before I'm half way
through

With the cooking and cleaning and daily chores
And the only time I "go out", it's McDonald's or the
grocery store
But, with my boy now three and my girl almost seven
I considered my life was the "next thing to Heaven."
In between car pools, soccer games and the PTA,
I still had time to relax, watch TV and do some
crochet
At 32, I had changed enough diapers – two kids were
enough I smugly decided – we'd take up a hobby and
do other stuff
Satisfied and content that my job was well done
My home was complete with my daughter and son
Acting like real people, sans diapers and bibs, we
Gave away their baby things, including the crib.
I was beginning to imagine all the things we could do
With little to pack and fewer bags to hunt through

I thought my family wonderful; my life was grand
Everything was going just as we'd planned
When God looked down and said with a sigh,
"I've made some plans for you, by the by.
So sit back and listen and I'll fill you in
On what's going to happen between now and then."

Your age doesn't matter or what people think
If they ask any questions, say you have ME to thank
It doesn't matter to me if you think you're too old.
Or have heard all the stories friends & relatives told
32's the right age for you, I think, to have another
baby,
Be the mother of three, so ready or not, that's the
way it will be!

You'll need to replace all the things that you sold
And quit going on and on about how you're too old
You're lucky I'm giving you this special gift,
So quit listening to others and wondering, "What
if...?" Having children keeps you young and you're
going to find that being too old was all in your mind.
So go buy a new play pen, more diapers and bibs
And see if your neighbors are through with your crib
Oh, and a few of those pacifiers will be just the thing
To keep her from fretting ..., if you know what I
mean.
And, yes, I said "she" so you can junk all that blue
Because I've chosen a little girl that's just perfect for
you
Having another baby will give you something to do
And it's going to be more fun than a new hobby
would be, too

And although you know it won't really make you
younger,
Looking after a 'few' children is going to make you
stronger
And keep you, oh, so busy, you won't have the time
to think about it any longer."
Now awake half the night and up with the dawn
It's a struggle to hold my eyes open and my body
turned on
Bathed and powdered, rocked and fed,
She's finally asleep; I can put her to bed
While she sweetly naps amid ruffles of pink,
I've fallen asleep on my feet at the sink!
Grabbing car keys and purse, I rush toward the door,
Trip over their toys and sprawl flat on the floor
I could swear those were picked up and all put away
Just a while ago, this morning – or was it yesterday?
The carpet is soft and feels like a bed to this tired
Old body and poor aching head
But three pair of eyes look on with concern, so I
Readily assure them, "It's only rug burn."
Six little hands "help" me up off the floor and
With three "boo-boo" kisses we head for the door
And my smallest one says with a lop-sided grin,
"Do 'gin, Mommy, Do 'gin."
Although I thought I was too old – the Lord said not to
mind what the world thinks is unimportant – kids are
the ties that bind
We hold our children's hands but they hold our hearts
And whether we're young or old, it's never too late to
start
Listening to the Lord and accepting the things He has
planned and counting it a blessing even when we
don't understand

I'm so very grateful to the Lord for the way
He overlooked my self-centered thoughts that day
Too surprised and struck dumb you could say, to
protest,
We accepted His gift with reluctance, at best
But He showered us with blessings and gave us to
understand
That He was our Father and the One holding our
hands

And when He sent you to us, Oh, boy! What a joy
When both Wendy and Gary considered you their
new toy!
We give thanks each day for the Lord sending our
way a little girl to treasure, and love beyond measure,
Never dreaming what joy would be coming to us
through
The gift that He gave us – and that gift was YOU!
Mother & Daddy 02-24-2007

CONTINUED FROM PAGE 5

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APDA

The American Parkinson Disease Association (135 Parkinson Ave, Staten Island, New York 10305, Tel: 1-800-223-2732, or www.apdaparkinson.org e-mail apda@apdaparkinson.org) is the country's largest grass roots organization serving the Parkinson's community. It is a 501c(3) not-for-profit organization and receives no government or public funding. The local Alamo Area Parkinson's Support Group is an APDA Chapter. Each year APDA contributes more than \$3 million for research and more than \$3 million for direct patient and caregiver support. APDA funding is entirely dependent upon contributions from businesses, foundations, but mostly, from individuals and fund raising events like our Walk-A-Thon on 14 April. (Nationwide \$353,000 was raised by Walk-A-Thons. All Walk-A-Thon funds go directly to APDA's research programs.) Donations can be sent to AAPSG by sending a check made out to AAPSG to Joan Duval 8507 Chesham San Antonio, TX 78254

NPF Web Changes

Please note that NPF forums (AsktheDr, AsktheSurgeon, and others – see below) have changed servers, so you must go to www.parkinson.org to sign up for the free new forums. Go to the website, click forums, fill out the one page registration and get a new username and password. The old sites have been closed. If you have trouble registering e-mail webmaster@parkinson.org and ask for help.

Michael S. Okun, MD, NPF

The following NPF forums are currently available; more will be coming soon:

Ask The Doctor: The Doctor answers medical questions regarding PD and related matters.

Ask The Speech Clinician: A team of experts answer questions regarding speech and people with PD.

Ask The Dietician: Kathrynne Holden, MS, RD, answers questions regarding dietary matters and PD.

Ask The Surgical Team: Kelly D Foote, MD and Michael Okun, MD answer questions about surgical matters and PD.

Preguntele al Medico: Ramon L Rodriguez, MD contesta a preguntas médicas con respecto la enfermedad de Parkinson y a materias relacionadas.

Caregivers Forum: A place where caregivers of people with PD can converse and address their unique concerns.

Open Forum: An un-moderated public forum for open discussion among PD patients and caregivers.

Young Onset Forum: A chat room for discussion among those with Young-Onset PD.

Questions & Answers

Q. My husband has had hallucinations since starting Sinemet three years ago. He was recently taken off Sinemet and put on Requip but still had hallucinations. He was taken off all PD meds for three weeks but still has hallucinations. Do you think he could still have some of the PD meds in his system even after three weeks?

A. It is possible. He also needs to be checked for infections and for other causes of dementia. Usually sinemet has washed out of the body after 3 weeks, and when you see this response you suspect Lewy Body Disease or AD (or another dementia). Clozaril or Seroquel may be the next step.

Michael S. Okun, MD, NPF

Q. I have cramps in my groin muscles or calf muscles. Sometimes when I brush my teeth my arm cramps. My hands cramp when I drive. What are some possible causes?

A. If you have PD you could be under medicated and be experiencing off dystonia---treat by changing medications and dosages through your doctor.

Now, be aware there are many causes of cramping and these may also include problems with blood levels of electrolytes, muscle disease, and several other possibilities. Bottom line: See a neurologist for diagnosis before attempting focused treatment.

Michael S Okun, MD, NPF, AsktheDr

Q. My father takes levodopa 4 times during the day and a controlled release tablet at night. He often misses doses during the day. We try to remind him but we aren't with him all the time as

he is still working. What is the best way to handle missing medication times? Do you take the medicine as soon as it is remembered? What if he has missed a dose realizes it, but has just eaten? We realize that taking the medication on an empty stomach is better for absorption but in the case of getting back on track with dosing what is best? How bad is it that he misses his timing of this medication?

A. This is a not a good pattern. It is best to get a beeping watch; use supervision; and/or use another strategy. With PD you have to be religious with doses to be successful. There is no harm in missing doses and popping when you remember; but I highly advise against making this a habit! Michael S. Okun MD, NPF AsktheDr

Freezing/Gait Problems & DBS

The general rule is that if freezing and gait problems significantly improve with medication (sinemet or levodopa) even for just 1 hour or so, then they will probably improve with DBS. If there is no change in your gait despite taking a good dose of sinemet, then DBS will probably not help your gait.

Consult a good DBS center so that you get a thorough evaluation and your expectations are set correctly. Hubert H Fernandez, NPF, AsktheDr

Medication Averages

Average is different from person to person. What is important is that the current medications (be it a large dose or a small dose) is giving you adequate coverage to control your symptoms and are not causing significant side effects. I have patients who only need 1/4 of sinemet 3 times per day because they become dyskinetic with anything more than that, and I have patients who take medications every hour, round the clock. Hubert H Fernandez, NPF, AsktheDr

NOTE: That is why you have to work closely with your doctor on your medications. What works for me will hurt you.

HAVE A BLESSED EASTER

PD Vision Problems

Here, listed, are two useful, published papers relating to PD vision problems.

One or both used to be in NPF online library. Interested people may access these papers on your website or at the web addresses given below.

Eyeglasses for People with Vertical Eye Movement Disorders and/or Ambulation Disorders - Eyeglasses for People Missing Lower Halves of Visual Fields

http://www.abledata.com/abledata_docs/Eyegaze_Disorders.htm

http://www.abledata.com/abledata_docs/EyeGazeDisorders.PDF

http://www.abledata.com/abledata_docs/Eyegaze_Disorders.txt

Assistive Technology for People with Parkinson (or a similar) Disease and Impaired Vision

http://www.abledata.com/abledata_docs/NIRE_PD_Vision.htm

http://www.abledata.com/abledata_docs/NIRE_PD_Vision.pdf

http://www.abledata.com/abledata_docs/NIRE_PD_Vision.txt

Donald Selwyn - at the N.I.R.E.

This is terrific. Michael S. Okun, MD, NPF

Rotigotine Patch

The Rotigotine patch is for treatment of early-stage PD. A multi-center, randomized, double-blind study was designed to evaluate the safety and efficacy of the dopamine agonist rotigotine, supplied via a once daily skin patch versus placebo in patients with early-stage PD. The lead investigator of the study, Ray L Watts, MD, concluded that Rotigotine, administered a dose of 6mg per day, was effective in the treatment of early-stage PD. In addition, rotigotine appeared to be well-tolerated by patients.

Useful Web Sites

World Parkinson Disease Association
www.wpda.org

Americans with Disabilities Act
www.ada.gov 1-800-514-0301

Social Security Administration
www.ssa.gov , 1-800-772-1213

The Rose

It is only a tiny rosebud...
A flower of God's design;
But I cannot unfold the petal
With these clumsy hands of mine.
The secret of unfolding flowers
is not known to such as I...
The flower God opens so sweetly
In my hands would fade and die.
If I cannot unfold a rosebud
This flower of God's design,
Then how can I think I have wisdom
To unfold this life of mine?
So I'll trust in Him for His leading
Each moment of every day,
And I'll look to Him for His guidance
Each step of the pilgrim way.
Unknown

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