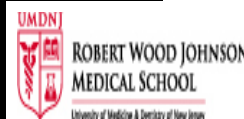


The Parkinson's Bulletin

Fall Edition

September-November 2007



Fall 2007

ROBERT WOOD JOHNSON
UNIVERSITY HOSPITAL

*The NJ/APDA Parkinson Disease Information
and Referral Center*
(732) 745-7520-office (732) 745-34110-fax

Genetics and Parkinson's Disease

Lawrence Golbe, MD, Professor of Neurology
UMDNJ-Robert Wood Johnson Medical School



INSIDE THIS ISSUE:

Genetics and PD	1
Coordinator's Corner	2
President's Notes Housing Options	3
Upcoming Fall Events	4
Southern NJ PD Conference!-Nov 10	5
Coping with Depression	7
Lending Library NIH Study	8
Depression & Social Support Study	8
PD and Creativity	9
Treating Parkinson's Related Constipation	10
Bulletin Mail Add or Change Address	16

A question I often hear from families of my patients with PD is "will we get this?" The short answer is "probably not." The slightly longer answer is that each child of someone with PD has a 5% to 6% chance of developing PD some time during life. This compares with the 2% chance for someone with no relatives with PD. Persons with two relatives with PD on the same side of the family, such as a parent and uncle or parent and grandparent, have about a 20% to 25% chance.

But just because PD tends to cluster in families doesn't prove that it's genetic. Families tend to be exposed to the same environments, and exposures to certain chemicals in air, water or food, none of which have been specifically identified yet, are suspected of contributing to the causes of PD.

A study of twins that may have answered the question of whether PD is mostly genetic or environmental appeared in 1999. When a trait or illness is entirely genetic, pairs of identical twins will often be concordant (that is, they with both have it or not have it). When it's environmental, they are no more likely to be concordant than pairs of fraternal twins, who are no more closely related than any two siblings. In this study, researchers found people with PD who were members of twin pairs. They then examined the other member of the

pair. In only a few cases did the other member obviously have PD. In the discordant pairs, the unaffected twin underwent a special kind of positron emission tomographic (PET) scan that measures the amount of dopamine in the brain. The result was that reduced dopamine stores were present in nearly all of the outwardly unaffected members of identical twin pairs but in only a small fraction of the outwardly unaffected members of fraternal twin pairs. This shows that genetics plays a subtle but very important role in PD, but that other factors can affect the age at which the disease appears.

This interplay of genetics and environment in fact forms the current theory of the cause of PD. Most researchers think that PD is the result of an inherited predisposition to an environmental toxin. We still don't know what specific gene or genes are involved in that predisposition and we don't know what specific toxin or toxins are to blame.

It may seem that if both toxins and genetic defects are necessary to cause PD, then it would be easier to avoid or eliminate the former than to fix the latter. This is true only up to a point because we don't know what specific toxins are responsible for most PD and they may prove to be things that are difficult to avoid. Also, while genetic defects are presently very difficult or impossible to fix at the level of the DNA, their bio

(Continued on page 2)

Save The Date!
Fall Conference
*Parkinson Disease
Management and
Treatment Options*

**Saturday,
November 10, 2007**

**10:00 a.m.
to
3:00 p.m.**

**The Mansion,
Voorhees, NJ
(See page 5)**



Coordinator's Corner

**Elizabeth Schaaf, NJ APDA
Parkinson Disease Information
& Referral Center**

Dear Friends,

I hope you had an enjoyable summer. I am looking forward to the cool weather of autumn!

We have a very busy season ahead with many different programs planned for you. In September and November, Dr. Jacob Sage, Professor of Neurology, UMDNJ-RWJMS, will be our guest for two Ask The Neurologist meetings; one in the evening and one in the afternoon. (Please see page 4 for details) You will have an opportunity to ask any questions you may have regarding PD and it's management.

On Tuesday, October 30, we will host Good Start! Program for people with Parkinson's and their families. This program is for those who have been diagnosed within the last three years. Dr. Lawrence Golbe, Professor of Neurology, UMDNJ-RWJMS will speak at this program. It will be held from 1:00 to 3:00 p.m. at Robert Wood Johnson University Hospital. Please call our office to register for this program. Space is limited. Lunch will be provided.

We will again facilitate a telephone support group beginning November 5. Please call DOROT to register for this program for people with Parkinson's and caregivers.; see page 4 for contact information. Space is limited. Call today!

Our fall conference will be on Saturday, November 10 at The Mansion in Voorhees, NJ, from 10:00 a.m. to 3:00 p.m. This conference entitled, Living Well With Parkinson's Disease: Management and Treatment Options is free and made possible by the generous support of Teva Neuroscience and the NJ APDA Chapter. See page 5 for registration details. We are in need of two or three volunteers to assist us on this day. Please call the NJ APDA I and R Center if you are able to assist.

Please see pages 4 and 5 of this newsletter for a listing of all special events for the fall. I hope that you will join us for one or more of the upcoming events.

Warmest Regards,

Elizabeth Schaaf

Elizabeth Schaaf
Coordinator, NJ APDA Parkinson Information and
Referral Center

Elizabeth.schaaf@rwjuh.edu

Genetics and PD (Continued from page 1)

biochemical results may be easier to fix. For example, we could find a medication that would reduce the activity of a protein that was rendered toxic by a manufacturing defect that was encoded in its gene. This is why much effort is now being devoted to finding genetic defects that contribute to the cause of PD.

One example of this approach is a defect in the gene that normally encodes a protein called alpha-synuclein ("sin-OO-kee-in"). This protein normally plays a role in making sure the tiny packets of dopamine are in the right place at the right time in brain cells. Several types of mutations in alpha-synuclein cause PD, but not because they impair its normal action. Rather, the mutant protein molecules tend to stick to one another to form fibers that are toxic to the brain cells. Although only about 20 known families worldwide have a mutation in alpha-synuclein, everyone with PD has proven to have those same abnormal fibers of alpha-synuclein. Whatever is causing PD, therefore, must be causing those fibers to form despite the absence of genetic defects in them.

Laboratory experiments with alpha-synuclein over the past 10 years have revealed much about their propensity to form fibers under certain conditions. This has yielded many new ideas for stopping the PD process in its tracks. Some of these are drugs that prevent normal alpha-synuclein molecules from sticking to one another. These drugs may enter clinical trials soon.

No one suspected that the alpha-synuclein protein was related to PD until its gene was discovered to be the one causing PD in one large family whose high frequency of the disease lent itself to a search of all the chromosomes. Other families with strongly hereditary PD have been similarly analyzed and have revealed other genes that have provided insights into "sporadic" (that is, apparently non-hereditary) PD that are just as important as those provided by the alpha-synuclein discovery.

The other defects do not cause their proteins to form toxic fibers, but operate through a simple loss of their normal function. For example, one gene causing PD in some families has been found to play an important role in the brain cells' garbage disposal system. This gene encodes a protein called "parkin." The garbage that cells must dispose of is mostly protein molecules that are defective, worn out or in oversupply. Such proteins, like alpha-synuclein, can clump together to form fibers that are toxic. Efforts to enhance the activity of parkin are under way.

Another good example of unusual hereditary forms of PD shedding light on all PD is the protein called LRRK2 (for leucine-rich repeat kinase). Defects in its gene are the most

(Continued on page 6)



President's Notes

**Benton Yip, President
NJ Chapter, American Parkinson
Disease Association (NJ APDA)**

As the newly-elected president of NJ APDA, I wish to thank everyone for having confidence in me. Though I am probably the youngest person to serve as a chapter president, I bring ideas, vision, energy, and a positive attitude. Having Parkinson's robs us of our energy and motivation. Tasks that we plan, at times, go unfinished. We want to go forward and sometimes, we get sidelined.

I want us to be pro-active in our lives. It isn't enough for us to be active and stay active in order to accomplish the many tasks on a daily basis but also to maintain our dignity and to remain strong. I encourage Parkinson individuals to get involved with the community, to share their experiences and wisdom. I encourage young professionals to be pro-active to provide us their skills and talent. I want high school students to step forward to lend us their enthusiasm and energy. I want the middle managers and senior executives to be pro-active for their expertise and leadership. If all of us put our efforts together, we can make our lives more comfortable, reach our goals sooner, and become happier.

My goals are simple. I want to raise money for research, promote awareness of Parkinson's, to increase our membership, and to encourage others to be pro-active. By helping to achieve these goals, I hope that we can achieve our mission in getting a CURE!

I want to thank Bill Lear for his stewardship in guiding NJ APDA over the many years (10) he served as president. I want to thank Elizabeth Schaaf, the coordinator for the NJ APDA I&R Center, for her hard work, devotion, and accomplishment in sustaining the I&R center. I wish to recognize Nikki Taussig for her work in keeping our financials in order and providing me counsel. Our vice president, Claire Salamon, has worked tirelessly in promoting PD awareness and works hard on state legislation that affects positively on our lives. I welcome Annie Konopka and Shirley Hom, our 2nd Vice President and Secretary, respectively, who join me on the board and who both bring the stability and ideas to make things work.

Join me in making my vision a reality and give APDA the energy and strength it needs to succeed. Through all our efforts, no doubt, a cure will be in sight.

Sincerely,

Benton Yip

Benton Yip
Yipcapital@yahoo.com



Housing Options

**Liz Salston,
Salston Eldercare**

Most of us would prefer to remain in the comfort and security of our own homes rather than move to an unfamiliar setting. Today there are a variety of available services which allow people to remain at home if that is their choice. However, the costs involved in bringing in a 24 hour paid care worker and expenses of adult day programs, which provide both socialization for elderly clients and respite for family caregivers, may motivate some families to look elsewhere for housing.

With the exception of some programs, providing a few hours each week, offered for Medicaid eligible or low income seniors, the government has yet to provide adequate funding sources to cover the cost of adequate home care services.

The decision to make a move for oneself or an aging loved one from the comfort and independence of his or her home to one of the many senior housing options is not one which should be taken lightly. Choices should reflect the levels of personal and medical assistance needed and the reasons for the move (i.e. safety concerns, medical issues, cognitive loss, home maintenance concerns). The discussion with your loved one should begin well in advance of the move in order to involve them in the process, make the best choice and ensure a smooth transition. Family members should be on the same page and work together to encourage the aging loved one that the move is one made with his or her best interests in mind. Hiring a professional geriatric care manager may help the family to narrow their search.

As recent as the 1980's nursing homes were the only available residential alternative to remaining in one's own home. Many healthy 70 year olds who had no other place to live moved into facilities which were designed on a 24 hour skilled medical care model. Over time the demand for less care and more quality of life services, including social and educational programs led to the development of assisted living residences. These residences provide a setting whereby the person has less responsibility for property maintenance, cleaning and cooking, but more oversight for their health. Many assisted living residences offer special units for residents with memory impairment who do not need the level of care provided in a nursing

(Continued on page 9)



Upcoming Educational Events Fall 2007

RWJUH Support Group Meetings

Young Onset Support Group Meeting

Third Wednesday of every month *
(exceptions: Nov 14 and Dec 12—due to the holidays)
7:00 p.m.- RWJUH Auditorium *

Later Onset Support Group Meeting

Third Thursday of every month*
(exceptions: Dec 13—due to holiday event)
12:30 p.m.—RWJUH Auditorium *

*Meeting room location is subject to change, please call
(732) 745-7520 for monthly location updates.

There are support groups that meet in most NJ counties,
please call (732) 745-7520 to find a local group.

Ask the Neurologist About Parkinson's Disease and Treatment Options

Wednesday, October 17, 2007, 7:00 p.m. to 9:00 p.m.

Young Onset Support Parkinson Support Group
Guest Speaker: Dr. Jacob Sage, Professor of Neurology,
UMDNJ-RWJMS, will answer your questions regarding
Parkinson's treatment options, research, etc.

Thursday, November 15, 2007, 12:30 p.m. to 2:30 p.m.

Later Onset Parkinson Support Group
Guest Speaker: Dr. Jacob Sage, Professor Neurology at
UMDNJ-RWJMS, will answer your questions regarding
Parkinson's treatment options, research, etc.

Good Start (Newly Diagnosed) Program!

Tuesday, October 30, 2007, 1:00 p.m. to 3:00 p.m.

Location: RWJUH Auditorium
Overview of Community Resources, and Q & A with
neurologist, Dr. Lawrence Golbe. Lunch provided.

Please see page 6 for more details.

University Without Walls Presents: Parkinson's Telephone Support Group Fall Series

This group is for person's with Parkinson's and Caregivers
Facilitator: Elizabeth Schaaf

November 5, 12, 19, 26 and December 3, 2007

7:00 p.m. to 7:50 p.m. Registration fee is \$10, and \$15
per series. Scholarships are available. To register, or for
more information, call Caregivers' Connections toll-free
(877) 819-9147, or Fran Rod, NJ Outreach Coordinator, at
(973) 763-1511. Space is limited. Please call today!

Southern New Jersey Fall Conference!

Living Well With Parkinson Disease: Management and Treatment Options

Saturday, November 10, 2007

The Mansion

Voorhees, New Jersey

This program is made possible by a generous
donation from Teva Neuroscience and
the NJ APDA Chapter

AGENDA

10:00 a.m. to 10:45 a.m.

Registration & Refreshments

10:45 a.m. to 10:55 a.m.

Welcome & Introductions

10:55 a.m. to 12:15 p.m.

The Medical Management
of Parkinson's Disease:

*Neuroprotection and Continuous
Dopaminergic Stimulation*

Daniel E. Kremins M.D., J.D.

12:15 p.m. to 1:15 p.m.

Lunch

1:30 p.m. to 2:45 p.m.

Coping with Non-motor Aspects
of Parkinson's

Matthew Menza, M.D.

*Program is free but space is limited;
please complete registration on page 5 or
call (732) 745-7520 by October 24, 2007.*

A SPECIAL THANK YOU!

Thank you to the following companies who generously
donated wonderful prizes for the March 31, 2007

Spring Conference

SERNENITY DAY SPA-South River
STOP AND SHOP-Dayton, NJ



Living Well with Parkinson's Fall Conference, November 10, 2007

Parkinson's Conference Registration Form November 10, 2007

Please send to: NJ APDA I & R, 120 Albany
Street, Suite 360, New Brunswick NJ 08901

Please print and circle menu selections:

Name _____
Chicken Marsala Filet of Tilapia Pasta Primavera

Name _____
Chicken Marsala Filet of Tilapia Pasta Primavera

Name _____
Chicken Marsala Filet of Tilapia Pasta Primavera

Name _____
Chicken Marsala Filet of Tilapia Pasta Primavera

Address _____

Daytime phone _____

Email _____

No fee but registration is required by
Wednesday, October 24, 2007.

You may also email your registration request
to Elizabeth.schaaf@rwjuh.edu; please
include all of the above information.

DIRECTIONS TO:

THE MANSION

3000 Main Street, Voorhees, NJ 08043

From Philadelphia / Center City

Ben Franklin Bridge to route 70 East
Follow to Route 73 South
Follow to Evesham Road
Turn right on Evesham Road
Continue for 1 1/2 miles
Turn left into Main Street Complex

From North East Philadelphia

Tacony Palmyra Bridge to Route 73 South
Follow to Evesham Road
Turn right on Evesham Road
Continue for 1 1/2 miles
Turn left into Main Street Complex

From Delaware / Maryland

Delaware Memorial Bridge to 295 North
Follow to Exit 32 (Route 561, Voorhees)
Follow to Evesham Road
Turn left on Evesham Road
Continue for 1 1/2 miles
Turn right into Main Street Complex
From North Jersey / New York

New Jersey Turnpike South to Exit 4

Follow Route 73 South
Follow to Evesham Road
Turn right on Evesham Road
Continue for 1 1/2 miles
Turn left into Main Street Complex

From Atlantic City Area

Atlantic City Expressway to Route 73 North
Continue on Route 73 North to Evesham Road
Turn left on Evesham Road
Continue for 1 1/2 miles
Turn left into Main Street Complex

A Study of Insomnia in Patients with PD

We invite PD patients who are suffering from sleep problems to find out more about this research study.

You must be between the ages of 35 and 85 years old.

By volunteering to be a participant you will be provide valuable information to our understanding of effective treatments for this disorder.

**Please call us at:
1-877-795-4673**

Genetics and PD (Continued from page 2)

common known specific mutation causing PD, accounting for 1% of sporadic PD and 5% of familial PD. The percentages are five-fold higher in certain ethnic groups such as Arabs and Ashkenazi Jews. LRRK2 appears to play a role in maintaining the mitochondria, the tiny factories in all cells that derive energy for the cell from sugar and oxygen. Drugs that protect mitochondria could prevent PD even in people with no LRRK2 mutation.

Two others that are less common are DJ-1 and PINK-1. Both of these proteins are thought to protect the brain cells from "oxidative stress." This is damage caused by normal by-products of the cells' biochemical reactions. The by-products damage components of the cells in the same way that water oxidizes steel to form rust.

Many other spots in the genome have been implicated as contributing at least a little to the cause of PD in at least a few people or families. But for these, the precise gene is not yet known or the evidence is not secure. One relatively easy way to find such genes is by evaluating "candidate genes" in large numbers of patients. This method has its pitfalls, but one of the genes it has implicated so far is the one encoding "tau" protein, which helps maintain the internal skeleton of the long "arms" that connect brain cells. Another is alpha-synuclein itself, which was specifically examined for a role in sporadic PD after its role in the one family mentioned above was found. For both tau and alpha-synuclein, the defects revealed to play a role in sporadic PD reside in the gene's "promoter," the region that controls the quantity of protein produced. A mere overabundance of either alpha-synuclein or tau can cause those proteins to stick to themselves and cause cellular mischief.

How can genetics play a role in PD sufferers who are the only ones in their families with the disease? First, many people with the beginnings of the disease in the brain do not yet have symptoms and the damage may remain too mild to cause symptoms even when the person dies in advanced age from something else. This is the implication of the twin study mentioned above. Second, for PD to occur, a number of genetic defects, some from one parent, some from another, may have to be present together. The chance of the same combination occurring in any two relatives may be small, just as the same combination of height, hair color, hair texture, eye color and nose shape may not be shared by two people in a family.

Before long, drug designers will find ways to throw a monkey wrench into one of the abnormal chemical

(Continued on page 9)

Good Start! Newly Diagnosed Program

***For People with Parkinson's
and their families***

(for those diagnosed within the last 3 years)

Tuesday, October 30, 2007

1:00 p.m. to 3:00 p.m.

Robert Wood Johnson

University Hospital, New Brunswick, NJ

Lunch provided

Overview of Community Resources

Q & A with Dr. Lawrence Golbe,

Professor of Neurology

Space is limited.

Please register by calling

(732) 745-7520.

Coping With Depression in Parkinson's Disease

**Roseanne DeFronzo Dobkin, PhD, Assistant Professor of Psychiatry
UMDNJ- Robert Wood Johnson Medical School**

Depression is the most common non-motor symptom observed in Parkinson's disease (PD), affecting up to 50% of patients. Many patients even report a history of depression prior to the onset of PD. The exact cause of depression in PD can not be neatly pinpointed. However, the high incidence of depression in PD likely results from the combination of the neurochemical changes associated with PD (i.e., less dopamine and serotonin available to help regulate mood) as well as how patients and families think, feel, and react to living with this medical condition.

Depression may be characterized by any combination of the following symptoms: sad, low, or irritable mood, feelings of guilt, agitation, helplessness, or hopelessness, loss of interest in activities or other people, decreased motivation to get things done, sleep problems (i.e., difficulties falling or staying asleep, waking up too early, sleeping too much), appetite changes (i.e., loss of desire for food, decreased enjoyment from eating, forcing oneself to eat, overeating), problems with memory and concentration, feelings of fatigue or low energy, and most seriously, thoughts that life is not worth living. For some patients, these symptoms may come and go intermittently throughout the day or week; for others, the symptoms of depression are continuous. The pervasiveness of depression in PD is of great importance as it has been linked with a faster progression of physical symptoms, greater cognitive decline, and poorer quality of life for people with PD and their families.

Despite this negative impact, the treatment of depression in PD is just beginning to be researched. While there is ongoing investigation as to the usefulness of antidepressants for treating depression in PD, there is general consensus that they may work. The choice of an antidepressant is usually based on the patient's medical history and most of these medications take at least three weeks to begin to produce symptom relief. Antidepressants work by targeting the chemicals in our bodies, such as serotonin, dopamine, and norepinephrine, that may be implicated in depression. Some common antidepressant medications include Prozac, Paxil, Zoloft, Lexapro, Wellbutrin, Effexor, and Cymbalta.

Similarly, non-medication approaches to coping with depression in PD, such as cognitive-behavioral therapy, also warrant investigation. Cognitive-behavioral therapy (also known as CBT) is a type of psychotherapy that addresses behaviors and thought patterns that contribute to depression. CBT is a standard treatment that has been widely researched, and found to be very effective for treating depression in people without PD. CBT may be used alone, or in combination with antidepressant medication. It may be a particularly useful option for patients who can't tolerate (i.e., had uncomfortable side effects), do not wish to take, or have not been sufficiently helped by antidepressant medication. However, until recently, there have been no attempts to evaluate this approach to treating depression in PD patients that present with unique physical, cognitive, and psychological concerns. This site is conducting the first large study, sponsored by the National Institutes of Health, to examine the impact of cognitive-behavioral therapy on depression in Parkinson's disease.

Several different CBT strategies can be used to help PD patients cope more effectively with the numerous symptoms of depression described above, as well as with the daily stress of living with PD. These include helping people develop strategies to increase their involvement in meaningful, pleasurable, and/or social activities, as well as ways to safely increase daily exercise. CBT can help individuals to problem-solve about their physical limitations, as well as to develop healthier ways of dealing with negative feelings such as sadness, irritability, anxiety, and anger. The treatment also seeks to help patients maximize control over their emotional reactions to stressful life circumstances. For example, patients are taught techniques for catching, labeling and re-evaluating negative thoughts that lead to increased depression (i.e., thoughts regarding disability, feelings of dependency, burden, and loss of control). For patients with insomnia, good sleep habits can be reviewed and incorporated into the patient's routine. Specifically, daily exercise, relaxing before bedtime, keeping regular sleep hours (i.e., going to bed and getting up at the same time everyday), and avoiding excess time in bed, daytime naps, caffeine or alcohol in the evening, and large evening meals may be helpful. And most importantly, individuals suffering from

(Continued on page 8)

Depression in PD (*Continued from page 7*)
 insomnia are taught to only use their bed for sleep (and sex!) and not for other activities such as paying bills, watching TV, or trying to solve the problem of the day. CBT also teaches friends and family members effective ways to offer social support in times of stress, as well as to reinforce the new coping skills that patients are trying to develop as part of their treatment.

In sum, depression is associated with great disability and distress for PD patients and their families. The good news is that several promising treatment options are currently being researched and developed. For more information about the cognitive-behavioral therapy research program (details on this page) for depression in PD, or for referrals to treatment resources in the community, please contact Dr. Dobkin at 732-235-4051. Information about additional clinical trials for depression in PD can also be found on clinicaltrials.gov.



LENDING LIBRARY AVAILABLE!!!

The Information and Referral Center has a lending library comprised of books, tapes and videos relating to Parkinson's Disease.

The March 29, 2008 PD Conference video is also available in DVD or VHS.

Call (732) 745-7520 to request this video and for a list of available videos and books.

Items are on loan for 30 day intervals and are mailed to your address.

Depression and Social Support in Parkinson's Disease (PD)

A study for PD patients and their families funded by the National Institutes of Health (NIH)

Do you have PD and suffer from these symptoms?

- ◆ Getting more and more isolated
- ◆ Feel sad or empty most of the day
- ◆ Difficulty falling asleep or staying asleep
 - ◆ Loss of interest in daily activities
 - ◆ Unable to concentrate
 - ◆ Feeling tired all of the time

HELP US FIND ANSWERS

Dr. Roseanne Dobkin at the Robert Wood Johnson Medical School in New Jersey is conducting a 10-week treatment study of depression in PD.

The study treatment does not involve medication and helps people to change thinking patterns and behaviors that may be related to depression.

All research care including an extensive psychiatric evaluation is provided at no cost to those who qualify. A friend, family member, or significant other will also be asked to participate in the study. *Participants are paid \$20.00 for each study evaluation.*

**For more information,
please call Dr. Dobkin at:**

732- 235-4051

Genetics and PD (Continued from page 6)

processes that are pointed out by these genetic studies, thereby halting the progression of PD.

So the study of the genetics of PD is just as important to the majority of those whose PD appears to be "sporadic" as to those who have relatives with PD. For not only do abnormal genes play a role in the cause of "sporadic" PD, any cure or prevention that arises from knowledge of PD genetics will benefit people with sporadic PD as well as those with familial PD.

##



Housing Options (Continued from page 3)

home. There are often additional charges for care services, such as medication reminders and personal laundry, which may not be included in the basic package. One should ask what specific services are included when looking at facilities.

Apartment style units are provided for residents with house-keeping and laundry services included. Three meals a day and onsite health services are provided as well. Costs average from \$3,000 to \$5,000 a month. Financial assistance for assisted living was not available through Medicaid in the early years, but today some coverage is available. When looking at facilities one should ask the sales or marketing representative whether Medicaid is accepted and on what terms. Some private long term care insurance policies provide payment for the cost of assisted living residences.

Both nursing homes and assisted living residences are regulated in New Jersey by the Department of Health and Senior Services. To call for information and complaints about recent surveys call 1-800-792-9770. There is also a county by county NJ Nursing Home and Assisted Living Report Card on line which provides ratings of facilities at web.doh.state.nj.us/apps2/healthfacilities/fsSearch.aspx.

Recent additions to the senior housing scene are Continuing Care Retirement Communities, CCRCs. These residential campuses provide residents with three levels of care from independent apartments or cottages to assisted living units, then to skilled nursing care, if the need arises. Assisted living and nursing homes provide care for residents with memory impairment in the same manner as free standing assisted livings or nursing homes. Social and educational programs, trips, swimming pool and fitness equipment are available for resident use. The independent apartments have full kitchens

(Continued on page 15)



PDCREATIVITY.ORG

The PDCreativity.org Project is a beacon of light in the darkness that is Parkinson's disease. The mission is to help improve the quality of life for people with Parkinson's (PWP's), by shedding light on the therapeutic value of creativity; and encouraging them to pursue their own forms of artistic expression, whether it is music, dance, photography, jewelry making, or painting. Features of the website include :

The Gallery:

the work of artists living with PD.

The Artists:

contact information and personal statements.

The Forum:

- Research related to quality of life.
- Resources listing classes that augment creativity.
- Happenings listing upcoming events.
- Comments/Articles highlighting personal triumphs, dealing with adversity, and tips on making your life easier.

Inspired by the first-ever World Parkinson Congress, held in February of 2006.

PDCreativity.org is dedicated to helping improve the lives of people living with Parkinson's disease.



Treating Parkinson's – Related Constipation

Robert S. Jenco, PharmD and Mary L. Wagner, PharmD, MS

Ernest Mario School of Pharmacy/Rutgers University

Constipation is a problem that affects more than half of patients with Parkinson's disease (PD). It can be caused by a lack of physical exercise or activity, poor nutrition and lack of fiber, a number of medications, and/or PD itself.¹ It is important to understand how to properly treat this problem. This guide is intended to help you understand the causes of constipation, and to familiarize you with various medications used to treat this problem, so that you and your doctor can work together to try to alleviate this condition.

What are the causes of constipation?

Parkinson's disease can cause damage to the part of the nervous system called the **autonomic nervous system**. This system regulates the movement of the involuntary muscles of the intestinal tract. Damage to the autonomic nervous system causes slowed digestion and movement through the tract.²

The most common cause of constipation is a **poor diet**, especially a **fiber-poor diet**.^{3,4} Fiber is an essential component of a healthy diet that is often overlooked. Some sources of fiber include fruits (dried fruits have more fiber), vegetables, beans, whole-wheat and whole-grain products, bran, oatmeal, and brown rice. The average American normally consumes less fiber than they should. After calculating your daily fiber intake, increase your fiber intake weekly by 5 g/day until you reach the recommended daily intake of fiber (20 to 35 grams per day).^{1,5,6} Below is a partial list of high fiber foods. The amount of fiber contained in other foods can be obtained by reading food labels or searching websites such as <http://www.wehealny.org/healthinfo/dietaryfiber/fibercontentchart.html>.

Food	Grams of Fiber per Serving	Serving Size
Cheerios™	1.1	1 oz
All-Bran	8.5	1/3 cup
Apple	3.5	1 medium apple
Prunes	3.0	3 prunes
String beans (cooked)	1.6	1/2 cup
Broccoli (cooked)	2.2	1/2 cup
Kidney beans (cooked)	7.3	1/2 cup
Lentils (cooked)	3.7	1/2 cup
Bran muffin	2.5	1 muffin
Whole-wheat bread	1-3	1 slice
Brown rice	1.0	1/2 cup
Sweet Potato	1.7	1/2 medium

Not drinking enough water can also cause constipation. Drinking enough water is important to prevent constipation, especially when consuming fiber supplements. Drinking between 6 and 8 eight-ounce glasses of water a day should be sufficient.^{1,4,5}

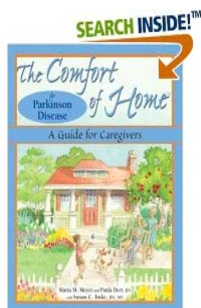
Serving size: Along with the proper daily fiber intake, it is important to eat the proper number of servings of each of type of food group daily. A general guide is as follows:⁷

- 2-3 servings of meat per day
- 4-5 servings of fruits & vegetables per day
- 2-3 servings of milk/dairy products per day
- 6-11 servings of whole-grain/bran bread and/or cereal per day

Lack of exercise and activity in general can increase constipation. PD patients can benefit in a number of ways from various exercises like aerobic activity, strengthening exercises, and range-of-motion stretching. Exercise and activity in general can help with constipation. Physical therapists are extremely helpful in showing you which exercises will be most beneficial and safe. You should consult with both your doctor and physical therapist before beginning any new exercise routine. Exercising at least 3 times a week is recommended in addition to getting adequate rest and relaxation.^{1,3,5}

Foods to Minimize: Excessive amounts of the following foods may *cause* constipation.¹

- Dairy products (milk, buttermilk, ice cream, cheese, yogurt, sour cream)
- Highly processed foods (white flour, white bread/crackers, pastries, pasta, white rice)
- Fast food and junk food
- Fried foods
- Eggs and meats
- Bananas
- Foods high in sugar (sweets, chocolate, gelatin with sugar)



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Table 2: Medications That Can Cause or Worsen Constipation^{1,3,5,6}

Types of Medication	Examples
PD medications	<ul style="list-style-type: none"> • trihexyphenidyl (Artane®) • benztropine (Cogentin®) • amitriptyline (Elavil®) • imipramine (Tofrani®) • bromocriptine (Parlodel®) • carbidopa/levodopa (Sinemet®, Parcopa®)
Narcotic pain medications	<ul style="list-style-type: none"> • oxycodone (Percocet®, Percodan®, Oxycontin®) • hydrocodone (Lortab®, Vicodin®, Vicoprofen®, many prescription-only cough syrups) • hydromorphone (Dilaudid®) • propoxyphene (Darvocet®, Darvon®) • fentanyl (Actiq®, Duragesic®, Fentora®) • meperidine (Demerol®) • codeine • morphine
Antacids	<ul style="list-style-type: none"> • aluminum-containing products • bismuth-containing products (Pepto-Bismol®) • calcium-containing products (Rolaids®, Tums®)
Calcium supplements	<ul style="list-style-type: none"> • Os-Cal®, Caltrate®, Citracal®, Viactiv® • generics/store-brands • prescription calcium products
Iron supplements	<ul style="list-style-type: none"> • Feosol®, Slow-Fe® • generics/store-brands • prescription iron products
Seizure/epilepsy medications	<ul style="list-style-type: none"> • phenytoin (Dilantin®) • valproic acid (Depakote®)
High blood pressure medications	<ul style="list-style-type: none"> • verapamil (Calan®, Verelan®) • diltiazem (Cardizem®, Cartia XT™) • clonidine (Catapres®) • methyldopa
Antipsychotics	<ul style="list-style-type: none"> • haloperidol (Haldol®) • clozapine (Clozaril®) • risperidone (Risperdal®)
Cholesterol medication	<ul style="list-style-type: none"> • cholestyramine (Prevalite®, Questran®)

Certain **medications** can also cause constipation, further worsening the constipation that is often already associated with PD. The following table lists the types of medications that can possibly cause or worsen constipation. Do not stop these medications, but ask your doctor if there alternative medications that can be used that have less risk of causing constipation.

What you can do to help

There are many types of laxatives available over-the-counter (OTC), but not all are safe to use. Some may be safe to use if instructed by your doctor. **As a PD patient who often experiences constipation, a change in diet and lifestyle should be the first treatment to try.** This is the safest and healthiest way to correct abnormal bowel function. It may take some time before these changes take effect and restore regularity, so try to be patient. Here are some suggestions:^{1,3,5}

Eat meals at the same time each day.

~ Add more fiber to your diet (see Table 1 above for food suggestions).

~ Drink at least 6 to 8 glasses of water each day.

~ Exercise or remain active as much as possible.

(Continued on page 12)

Constipation and PD (continued from page 11)

- ~ Drink warm liquids with breakfast.
- ~ Establish a fixed time every day for bowel movements.
- ~ Never put off the urge to move your bowels.

If after 2 weeks of dietary/lifestyle changes there is no improvement in regularity, **bulk forming laxatives** may be used. It is important to continue your healthy eating habits while taking these laxatives. **Stool softeners** may also be used in the event that the bulk forming laxatives do not provide relief soon enough and to help relieve straining during bowel movements. Stool softeners may be used together with bulk forming laxatives. Bulk forming laxatives and stool softeners are generally safe when used as directed. **Stimulant laxatives** and **hyperosmotic laxatives** may not always be safe and should **NOT** be used without the advice of a doctor or pharmacist.^{1,5} The differences between all these types of laxatives are explained below.

If, after dietary/lifestyle changes and using a laxative, one fails to have a bowel movement, a more serious underlying condition may be responsible for the constipation.

The following is a list of the various types of medications used to treat constipation along with a description of how they work:

Bulk Forming Laxatives^{1,5,6,8,9,10}

Bulk forming laxatives, or fiber supplements, are generally safe provided that one takes them as directed. They are the safest and most “naturally-acting” type of laxative. These fiber laxatives absorb liquid into the intestines to soften the stool. The bowel is then stimulated naturally by the bulky mass. These products are not habit forming and can be used daily both to help prevent and to treat constipation. It is important to take these products with at least 8 ounces of water, to drink 6 to 8 glasses of liquid daily, and to increase the amount of fiber taken gradually over 2 to 3 weeks. Not drinking enough water can result in an obstruction of the gastrointestinal tract. Increasing fiber intake too quickly may result in gas, bloating, and upset stomach. These products usually take anywhere from 12 to 72 hours to work. A doctor should be consulted if the use of these products does not resolve constipation after 2 weeks. Also, these bulk fibers may affect how well other medications work. Therefore, whenever possible, you should try to take these products at least 2 hours before or 2 hours after taking other medications

Bulk Forming Laxatives^{1,5,6,8,9,10}

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Stool Softeners (Emollients)^{1,5,6,8,9,10}

Stool softeners (also called emollients) are oral products containing the ingredients **docusate** and are generally useful only in preventing constipation and not in treating it. They work by allowing liquids to mix with the stool. Stool softeners do not cause a bowel movement, but they do help allow one without straining. These are not habit forming. In other words, they do not affect the body's ability to pass a stool naturally. They usually work in 1 to 2 days, but can take up to 5 days. If constipation does not resolve after 1 week of use, you should not continue to use a stool softener without consulting a doctor. Stool softeners are generally safe when taken as directed. However, you should not use them if you are taking the medications digoxin (Digitex®) or warfarin (Coumadin®). Some common side effects of docusate include bitter taste, abdominal cramping, nausea, and diarrhea.

Miscellaneous^{1,5}

Cod liver oil is a miscellaneous dietary supplement that may help relieve constipation. It is high in vitamins A and D and is safe to use regularly.

Stimulant Laxatives^{1,5,7,8,9,10}

Stimulant laxatives should only be used under the advice of your doctor. These oral tablets or capsules contain **senna, bisacodyl, casanthranol, cascara sagrada, castor oil, aloe, or dehydrocholic acid** as the active ingredient. Casanthranol, cascara sagrada and aloe should be avoided because they are not approved by the FDA.

(Continued on page 13)

Constipation and PD (Continued from page 12)

Stimulant laxatives work by increasing muscle contractions in the intestinal wall. Most usually take about 6 to 12 hours to work. Unlike bulk forming laxatives, stool softeners, and cod liver oil, they are habit forming, meaning one's body becomes dependent on the product and it gets harder to pass a stool naturally without the stimulant. Long-term use can even harm the bowel. They can cause side effects like abdominal cramping, nausea, incontinence, confusion, or irregular heartbeat. Bisacodyl is also available as a suppository, which acts by stimulating the rectum to empty the contents of the bowel. In order for the suppositories to work, there must be contents in the bowel. Because they can cause dependence, their use should be limited.

Saline Laxatives^{1,5,6,8,9}

Saline laxatives contain the ingredients magnesium hydroxide, magnesium citrate, magnesium sulfate, and sodium phosphate. One way they act is by drawing water into the intestine and bowel from other body tissues causing a watery bowel movement usually within 6 to 8 hours. These products may be harmful to patients with certain heart or kidney problems and should only be used under the direction of a doctor. They are mainly used for rapid emptying of the bowel and are **NOT** to be used long-term. They are available as oral preparations or enemas. The side effects are similar to stimulant laxatives and include lightheadedness, abdominal cramping, incontinence, and weakness.

Hyperosmotic Laxatives^{1,5,6,8,9,10}

The primary example of a hyperosmotic laxative is glycerin, which is available in suppositories. Glycerin suppositories usually produce a bowel movement within 30 to 60 minutes. Other hyperosmotic laxatives may contain the ingredients **lactulose (Enulose® – available only by prescription)** or **polyethylene glycol (Miralax®)** and are taken orally. Like saline laxatives, they act by drawing water into the bowel causing a bowel movement. These medications are relatively safe when used under the direction of a doctor.

Lubricant Laxative (Mineral Oil)^{1,5,6,8,9,10}

Mineral oil (liquid petrolatum) is a lubricant laxative that is usually taken orally. Some enemas may also contain this product. It coats the bowel in a waterproof film, which keeps the stool soft and makes passage easier. Mineral oil can be habit forming. This product should generally not be used long-term, unless directed by your doctor, because it can be absorbed into the body and cause additional problems. Some PD patients may develop difficulty swallowing, and mineral oil can pose a risk of choking or aspiration. If you develop any difficulty swallowing, make sure your doctor is aware

of it. If mineral oil is used, it should never be given to a patient while he or she is lying down. The patient must always be standing or seated in an upright position, and the mineral oil should be taken at least 30 to 60 minutes before lying down. Also, mineral oil can potentially interact with stool softeners containing docusate. Therefore if you are taking both mineral oil and a stool softener, you should try to take them at least two hours apart from each other.

Combination Products^{1,5}

There are a number of products that are available OTC that contain various combinations of the different types of laxatives mentioned above. Since they can pose the same safety risks as the individual products, and even more so, these combination products should only be used when instructed by your doctor. The combinations that are available include stimulants plus stool softeners (casanthranol and docusate products), bulk forming laxatives plus stimulants (psyllium and senna products), and hyperosmotic laxatives plus lubricant (magnesium hydroxide and mineral oil).

The following table lists some common OTC products used to treat constipation. There are many other products available that are not listed here. If you have a question about ingredients or whether a product is safe to use, ask your doctor or pharmacist.

Prescription Medications for Constipation

Lubiprostone (Amitiza®)¹¹

If other products fail to work, your doctor may try Amitiza®, a relatively new prescription medication used to treat chronic constipation. It does not reach significant blood concentrations or alter electrolyte concentrations in the blood. It works locally by increasing fluid secretion into the intestine, which helps increase the passage of stool. It also decreases bloating and abdominal discomfort. There is a low likelihood of drug interactions. Nausea, diarrhea, and headache are some of the more common possible side effects of this drug. While using this medication, you should not take any of the other products used for constipation unless instructed to do so by your doctor. Your doctor should also periodically reassess the need for continued treatment with this product as it has not been studied in patients with PD.

Tegaserod maleate (Zelnorm®)¹²

Zelnorm®, another prescription-only medication, was taken off the market by its manufacturer in April 2007 because the FDA found that this drug may cause serious heart-related side effects. It is not certain whether Zelnorm® causes heart problems. **If you have any leftover prescriptions or samples of this medication, you should not take this medication.**

(Continued on page 14)

Constipation and PD (Continued from page 13)

Table 3: OTC Products used to Treat Constipation^{1,5}

Types of Products	Active Ingredient(s)	Examples
Bulk forming laxatives	<ul style="list-style-type: none"> • Psyllium • Inulin • Polycarbophil • Methylcellulose • Microcrystalline cellulose & guar gum 	<ul style="list-style-type: none"> • Metamucil®, Fiberall®, Konsyl® • Fibersure®, Fiber Choice® • Fibercon®, Fiber-Lax® • Citrucel® • Benefiber®
Stool softeners	<ul style="list-style-type: none"> • Docusate 	<ul style="list-style-type: none"> • Colace®, Correctol®
Miscellaneous	<ul style="list-style-type: none"> • Cod liver oil 	<ul style="list-style-type: none"> • Cod liver oil
Stimulant laxatives	<ul style="list-style-type: none"> • Bisacodyl • Castor oil • Senna 	<ul style="list-style-type: none"> • Dulcolax®, Correctol®, Fleet®, Magic Bullet® • Castor oil, USP • Ex-Lax®, Senokot®, Black Draught®
Saline laxatives	<ul style="list-style-type: none"> • Magnesium citrate • Sodium phosphate • Magnesium hydroxide • Magnesium sulfate 	<ul style="list-style-type: none"> • Citroma® • Fleet Phospho-Soda®, Fleet Ready-to-Use Enema® • Milk of Magnesia products, Maalox®, Mylanta® • Epsom salts
Hyperosmotic laxatives	<ul style="list-style-type: none"> • Glycerin • Polyethylene glycol 	<ul style="list-style-type: none"> • Suppositories • Miralax®
Lubricant laxative	<ul style="list-style-type: none"> • Liquid petrolatum 	<ul style="list-style-type: none"> • Mineral oil, USP, Fleet Ready-to-Use Mineral oil Enema®
Combination products	<ul style="list-style-type: none"> • senna + docusate • magnesium hydroxide + mineral oil 	<ul style="list-style-type: none"> • Peri-Colace®, Senokot S® • Phillip's MO Suspension®

Conclusion

Always make sure **ALL** your doctors and your pharmacist are aware of **ALL** the **medications (prescription and OTC), vitamins, supplements, and herbal products** you are taking so they can check for any drug interactions or side effects. Whenever adding any new OTC or prescription product to your medication regimen, ask about any potential drug interactions and side effects that you should look for. Finally, when purchasing OTC products always be sure to check the ingredients. Many brands make products with similar names that may contain different combinations of drugs. If you are not sure, ask your pharmacist.

(Continued on page 15)

Constipation & PD (Continued from page 14)

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Housing Options (Continued from page 9)

allowing the residents the choice of preparing their own meals or partaking in meal plans in a communal dining room. A move into a CCRC is expensive, often requiring the purchase of a unit costing from \$200,000 to \$400,000 depending on the location and services offered. Monthly maintenance or service fees can run from \$1,000 to \$3,000 a month. Typically the cost of health care coverage is included throughout the length of stay and many people find these settings to provide peace of mind knowing that they have taken care of their health care needs for life.

Other community options exist for lower income individuals who may qualify for governmentally subsidized housing programs. Section 8 of Housing and Urban Development (HUD) provides independent or congregate units for income qualifying seniors. There are usually long waiting lists for these units. Information about these apartments is available through each county's Office on Aging or the local HUD office. There may be some recreational activities and communal meals available on site, and interested individuals should call their local senior housing office.

As the elderly population is our largest growing age group, baby boomers are looking ahead to develop community-based models which will include input from medical personnel, elder care professionals and planners. Some creative aging-in-place communities are already being built to meet today's more active and affluent seniors. Future housing models will need to provide less costly facilities and more care options for those who choose to remain at home.

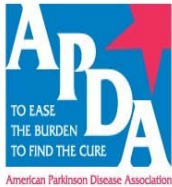
This article was submitted by Elizabeth Salston, a professional geriatric care manager located in East Brunswick. She can be reached at liz@salstoneldercare.com.



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Ask the Neurologist Programs

Wednesday, October 17, 2007-7:00 p.m. to 9:00 p.m.

Speaker: Dr. Jacob Sage, UMDNJ-RWJMS

Thursday, November 15, 2007-12:30 p.m. to 2:30 p.m.

Dr. Jacob Sage, UMDNJ-RWJMS

Robert Wood Johnson University Hospital

Parkinson's Disease Management and Treatment Options

Saturday, November 10, 2007

10:00 a.m. to 3:00 p.m.

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