

APDA'S INFORMATION AND REFERRAL CENTER COORDINATORS:

BY DONNA DIAZ, RN, MS AND
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Making the connection

People diagnosed with Parkinson's disease (PD) are presented with unique challenges. It requires effort and tenacity to understand and manage a chronic, progressive condition. Those living with PD have important questions to be answered and concerns to be addressed at various points on their journey. For instance, it is necessary for individuals to know where to gather information about their illness. In addition, they require effective tools to access the health care system in order to obtain sound medical treatment and care. Those afflicted with PD also need to understand how the disease will affect family, work, and social relationships. And these individuals often want to be aware of the impact PD will have on their life plans.



Lillian Scenna, LSW, (standing) I&R Coordinator at Maine Medical Center, provides information to a Center visitor.

The American Parkinson Disease Association (APDA) has a long standing commitment to provide those dealing with PD, whether as patients, family members, or health care providers, with "grassroots" assistance. This mission has fostered the evolution of a strong national network of support groups and Chapters run by devoted volunteers. To further complement its outreach, APDA developed the concept of Information and Referral (I&R) Centers. In 1974, the first of these Centers was opened in New York. APDA currently provides funding

for the operation of 62 of these across the continental United States. The Centers are strategically located throughout the country and hosted by academic medical centers, community hospitals, neurology practices and other pertinent agencies. Physicians experienced in the delivery of care to those with PD serve as medical directors. And, in order to ensure the vibrant, day-to-day operation of a Center, the APDA has a dedicated cadre of I & R Center Coordinators who help "Ease the Burden" of PD.

Who are these Coordinators?

APDA Coordinators come from a wide variety of professional backgrounds particularly the fields of nursing and social work. Others are rehabilita-

(Cont. on pg. 2)

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APDA'S INFORMATION AND REFERRAL CENTER COORDINATORS: (Cont. from pg. 1)

tion specialists in physical, occupational, and speech/language therapy. Many coordinators have impressive expertise in areas such as health psychology, finance, management, and public relations. And, there are those who come with experience in academic, research, law, and community service.

Although coordinator qualifications are diverse, what is universal to all is a passion to offer patients, families, and the general community a better understanding of Parkinson's. Ultimately, coordinators hope to empower the Parkinson community by providing the skills to successfully manage the formidable challenges presented by the disease.

What are the Coordinator's responsibilities?

Coordinators represent the APDA on a local or regional level. The coordinator position is generally funded 20 hours per week by APDA. At the Centers, Coordinators are continually establishing and prioritizing realistic and obtainable goals based on the needs of their communities.

Responsibilities of the Coordinators include:

- Providing information and resources about PD, current therapies, and emerging research
 - Offering programs to promote wellness and improved quality of life to those affected by this illness
 - Establishing and maintaining support groups
 - Offering consultation and assistance to volunteers
 - Fostering public education and awareness of Parkinson's disease
 - Providing a list of experts in movement disorders.
- On any one day, Coordinators may talk at length on

the telephone help-line (or via e-mail) with a newly-diagnosed person who is worried, a caregiver who is overwhelmed; a health care provider who is looking for a PD fitness program; a support group leader who is eager to hold an innovative meeting, or a local news reporter who is interested in recent research findings. Coordinators also have a strong presence in their communities. They crisscross their states, giving talks, running workshops, producing and distributing consumer-friendly publications, and, most importantly, meeting with the people they serve.

What are Coordinators' unique contributions?

As Coordinators spend time in their local settings, they often identify gaps in services that are essential for the well-being of the PD community. Based on talents and interest as well as available resources, APDA Coordinators have developed exciting novel programs.

For example, a number of Coordinators have designed and implemented comprehensive educational workshops for newly-diagnosed patients and families. These programs are in a "PD 101" format, i.e. they provide basic introductory information about the disease, treatment, support services, etc. In essence, these promote a good start for dealing with PD.

Coordinators also reach out to populations with certain needs. For instance, people living in rural areas that cannot easily attend PD-focused programs or access specialized neurological care are able to have their needs met through innovative interactive satellite conferencing. For people with other support constraints, Coordinators are able to offer information on services such as prescription coverage plans and in-home assistance as well as referrals for emergency response systems, respite care, fitness/aquatic therapy, and/or transportation programs.

In addition, Coordinators are well-positioned to understand the educational needs of health care providers. Many have developed curricula using a "train the trainer" model. For example, in order to ensure that nurses understand the importance of proper medication timing when patients are hospitalized, Coordinators will share correct information with a key staff person(s) who will then disseminate this to fellow staff members.

Recently implemented Coordinator projects have included initiatives such as design of a personal health record and communication booklet specific to PD as well as young-onset PD retreats that dovetail with the goals of APDA's national Young Onset Center in Illinois. And,

(Cont. on pg. 10)



*Susan Reese, RN, LCSW,
I & R Coordinator at
Glenbrook Hospital in
Illinois, welcomes partici-
pants at the 2008 "The
Art of Living with
Parkinson's Disease" art
show.*



Dear Reader:

As you do, I listen to all the doom-and-gloom economic reports, and I wonder it wouldn't it be nice if diseases were subject to recession?

Instead of sadly hearing about stock averages falling precipitously, we would hear about cancer, diabetes and neurological disease rates drastically dropping. Instead of industries shrinking or going bankrupt, fatal and degenerative conditions would be in jeopardy of disappearing.

But, unfortunately, that is not reality. Indeed, as the American economy weakens, the stronghold of debilitating diseases is inversely affected. Funds for research, education and patient support are threatened. Indeed, is there anyone who does not know of an organization or individual affected by the Bernie Madoff scam? Even one of our Centers for Advanced Research has lost a significant annual grant through the demise of a foundation, where assets disappeared overnight.

We are fortunate, however, that ours is the country's largest grassroots organization, support-

ing America's 1.5 million people with Parkinson's disease, their caregivers and families. We do not depend upon government or public funding, nor do we rely on the generosity of a small core of major donors. Our strength is in the contributions of people from Maine to Washington and Florida to California who faithfully send what they can, when they can, to help us meet our mission to "Ease the Burden – Find the Cure" for Parkinson's disease.

Our Scientific Advisory Board will be convening in the near future to evaluate promising new research and recommend their funding to our board of directors. We believe that not only will our present donors continue their contributions to the best of their abilities, but also they will encourage their friends and neighbors to help us maintain our commitment to research support.

While we are looking to a new administration in Washington to increase health and research funding as well as allow greater freedom for scientific research, we must also continue our individual efforts to stamp out Parkinson's disease.

Sincerely,

A handwritten signature in black ink, appearing to read "Joel A. Miele Sr.".

Joel A. Miele Sr., P.E.
President

RISK OF DEVELOPING PARKINSON'S AND ALZHEIMER'S DISEASES CAN BE DRAMATICALLY REDUCED

A report on "Environmental Threats to Health Aging", was published jointly by the Greater Boston Physicians for Social Responsibility and the Science and Environmental Health Network and is available online at www.agehealthy.org.

The study discovered a multitude of conditions in the environment – including nutritional, chem-

ical, physical and social – that have a direct influence on the risk of Parkinson's, Alzheimer's and related chronic diseases. It is clear from these findings that our activities in the areas of food and agriculture, energy, chemicals use, and social organization are key factors in the abnormal loss of neurological functions in older people throughout the modern world. ■



BY ENRICO FAZZINI, DO, PhD
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Q: My husband is 74 years old and has had Parkinson's disease (PD) for four years. He did fall from a tree 15 years ago and landed on the ground unconscious. Is this one of the ways PD can develop?

A: There have been instances in which Parkinsonism has developed from a head injury and there have also been cases where it was thought that PD began earlier than it would have started because of a head injury. However, it is not commonly believed that a degenerative disorder like PD could be caused by a head injury.

Q: I have a friend who is 57 years old and was diagnosed with PD about two years ago. About nine months ago he began to experience an awful taste in his mouth that he describes as sour with apples and it makes him nauseous. He is currently on Mirapex, Lipitor, Centrum Silver and a baby aspirin.

A: This is not a typical symptom of PD or a side effect of medications used to treat PD, but the medications he is taking should be reduced and discontinued as there is a good chance one of the medications is causing this symptom.

Q: I have had PD for seven years and I have recently developed problems with my blood pressure. At times it is very high and at other times I feel as if I am going to faint. I am taking Mirapex, Sinemet and Comtan 1 tablet of each, four times a day.

A: Patients with PD may develop orthostatic hypotension, a condition where there is a decreased ability of the brain to regulate blood pressure during changes in posture, such as going from sitting to standing. This can be aggravated by the blood pressure lowering effect of some of the medications used to treat PD such as Mirapex. In some cases patients may faint and fall causing injury. In these cases, it is important to minimize medication which can lower blood pressure. In addition, other medications such as Florinef and/or Midodrine can be used to raise blood pressure.

Q: My husband suffers from PD for 17 years. It is impossible to get his medications just right. He is either flailing and twisting or unable to move at all. We have been to a bunch of neurologists and they say he should have the Deep Brain Stimulation surgery. What do you think? He is on Requip XL 24 mg every morning, Sinemet CR 50/200 and Sinemet 25/100 and Comtan 200 mg five times a day and Azilect 1 mg a day.

A: It sounds like you have maximized the medications used to treat PD; he is on a high dose dopamine agonist (Requip XL), a good amount of L-DOPA and two enzyme inhibitors (Comtan and Azilect) without much benefit. The subthalamic nucleus deep brain stimulation surgery should stabilize the "on/off" fluctuations. ■

Whatever he gives, he gives his best *



Luke Lippert shows off what his lunker landers can land.

When Ron Lippert of Willmar, Minn. was diagnosed with PD in 1988 at age 38, his children were 6, 5 and 2 years old. Little did he think that a decade later his disease would become the rallying call for a family project that would raise awareness and funds for it as well as develop entrepreneurs of his two daughters and son, Luke.

The entrepreneurial venture began when Luke, 12, entered a school program called “Enterprising Kids,” giving youngsters an opportunity to sell their wares at a local mall for one day each October. Luke’s love of fishing was the lure in creating Luke’s Lunker Lander (LLL) – a customized series of fishing hooks and spinners to land the “big ones.” For you landlubbers, a lunker is a fish that is large for its species, usually a bass. Each model is \$2 and comes in an individual package with the chosen hook number,

pound test line, and a card explaining how the business began and information about APDA. Buyers can also choose bead, float and spinner, blade colors.

Living in the “Land of Lakes,” LLL had found a niche, and the entire Lippert family became involved. Mom, Scooter, suggested that a part of the proceeds be donated to APDA, and sisters Alex and Katie joined in to help their little brother. Ron contacted APDA for “Basic Information About Parkinson’s Disease” booklets, which are distributed at selling points. And what began as an entrepreneurial learning venture by Luke has turned into a significant family business.

To date LLL, has sold almost 1,000 lures and Luke has sent a check for \$200 to APDA and is looking forward to adding to that. Mom and dad are very proud of their children’s benevolent effort and their desire to make a difference in finding a cure for PD.

Interested fisherman can contact LLL at ronzie@charter.net for a complete order form. ■

* Samuel Johnson (1709-1784)

An APDA gift annuity assures a legacy plus a guaranteed income for life

The wisdom is that you can’t have everything. That may depend, however, on what one defines as “everything.” For instance, if looking for a guaranteed retirement income to last until death, and to include a spouse, to get an immediate tax deduction, and for good measure, leave a legacy to an important personal cause, then a charitable gift annuity may be just right.



While annuities’ glamour dimmed in the “bigger-is-better” economy of the past few decades, they are looking much more attractive for risk-averse investors with an eye on long-term security. “A charitable gift annuity takes away the fear of outliving your retirement investment, and particularly in this environment, that your portfolio may disappear,” says Joel Gerstel, APDA executive director. “While the payments may be a little less than that of

(Cont. on pg. 8)

IN THE NORTHEAST

Hope springs eternal in **Vermont** as evidenced from its spring lineup of events and locales. The state's Awareness Day event, "Parkinson's Perspectives," will take place at the Lake Morey Resort, Fairlee, April 11. The day-long program includes well-known speakers, concurrent sessions on various PD-related topics and lunch. And, the now-famous Vermont Rock-a-thon is scheduled for June 13 in Burlington. Hundreds of athletes and couch potatoes are expected to take to their rocking chairs and rock for research dollars. Coordinator Jean Baker always includes a little rock-and-roll music as well for those who can't sit too long.

New Jersey I&R coordinator Elizabeth Schaaf, who was a leader in art therapy for PD patients and caregivers and has lectured on the topic at international meetings, continues with a painting series, "Painting for Peace of Mind," at the Robert Wood Johnson University Hospital, New Brunswick, May 1. Elizabeth also coordinates a Parkinson's phone support group, "Living Well with PD," at 877-819-9147.

IN THE WEST

APDA's **Washington** State Chapter now provides podcasts on 11 topics, among them "PD 101," "Deep Brain Stimulation Therapy," and "Medications in PD." The podcasts, which are available for listing online, downloading to a computer or loading onto a portable device, are accessible on the Chapter's Web site www.waparkinsons.org. The Chapter is also interested in users' input for additional topics. For the more gregarious, the chapter's seventh annual Magic of Hope Auction and Dinner will take place at the Madison Renaissance Hotel, Seattle, May 9.

San Diego's annual Marion Brodie Educational Symposium will be at the Scottish Rite Conference Center, March 5. This year's topic for patients, caregivers, family members and healthcare professionals is "A Day in the Life."

The **Nevada** Geriatric Education Center, in partnership with APDA, will present "Parkinson's Disease: Sharing Wisdom" April 21. The full-day symposium at the University of Reno will feature APDA's 2007 Fred Springer Award recipient Dr. J. Eric Ahlskog, professor of neurology at the Mayo Clinic (Rochester, Minn.), among its eminent speakers.

IN THE SOUTH

The **Georgia** Chapter is looking to drive Parkinson's away with its annual golf tournament of the same name on March 14. The very popular event is held at the Smoke Rise Golf and Country Club in Stone Mountain, raising awareness about PD and funds for research and the chapter's respite program.

Here is an encouraging report for those wishing to raise funds for PD research but are hesitant because of inexperience. Faye Kern, Florida's west coast coordinator, reports that the **Tampa Bay Area** support groups joined forces for the first holiday market and netted \$17,358! The day-long collaborative effort on the grounds of the Tampa Garden Club on scenic Tampa Bay included lots of food and music, a cake walk for young and old, many merchandise vendors, a silent auction, clowns and Santa. Tom Curran, the local Fox News anchor, joined the festivities. Faye says with this success the first time out, everyone is looking toward next year. "Imagine what we can do with experience!" ■



For APDA executive director Joel Gerstel, right, the recent death of seven-term Rhode Island senator Claiborne Pell, sponsor of the Pell Grants that provides financial aid to U.S. college students, brought to mind their meeting at a Rhode Island Chapter symposium several years ago. During a program break, the highly respected senator, often referred to as quirky, gave the APDA administrator his insights as a Parkinson's patient.

Meet the new APDA chairman

Joel A. Miele Sr. was elected APDA's seventh president on Dec. 7 during the annual meeting in New York City. Mr. Miele has been a board member and officer more than 23 years.

A founding partner of the New York design, consulting, and forensic engineering firm Miele Associates, he is a highly honored engineer who has served as a New York City Planning Commission commissioner, and commissioner of the New York City Coastal Commission, the Department of Buildings, and the Department of Environmental Protection.

The new board chairman also has had a distinguished naval career and is a rear admiral on the retired list of the New York Naval Militia.

Mr. Miele lives in Queens, N.Y., where he and his wife of 50 years, Josephine, are active community members, serving on numerous boards and as volunteers. The Miele family are the parents of a son, Joel A. Miele, Jr. and two daughters, Vita Marie Chu, and Janet Ann Powers, and have seven grandchildren.

Also elected were Fred Greene, first vice president; Patrick McDermott, second vice president; John Marangos, third vice president; and Elliot Shapiro, fourth vice president. Sally Ann Esposito-Browne and Nicholas Corrado were re-elected secretary and treasurer, respectively. Immediate past president Vincent Gattullo and Richard Russo were elected to the executive committee, and J. Patrick Wagner and Jerry Wells were re-elected committee members.

Eight members were re-elected directors and six people were elected emeritus board members.

During the meeting, Dennis Dickson, MD, received APDA's Fred Springer Award, presented annually to a physician or scientist who has made a major contribution toward easing the burden and finding the cure for Parkinson's disease. Dr. Dickson is director of the Mayo Clinic Neuropathology Laboratory in Jacksonville, Fla., and Principle Investigator of the Morris K. Udall Center of Excellence for Parkinson's Disease at Mayo. He also is the director of the Udall Centers' brain bank and a member of the APDA Scientific Advisory Board (SAB). Frederick Wooten, MD, SAB chairman and professor of neurology at the University of Virginia, presented an update on the status of the disease and promising research. ■



Newly-elected chairman Joel A. Miele Sr., right, presents outgoing chairman Vincent N. Gattullo with a crystal thank you gift at APDA's annual meeting in December in New York.

APDA launches free e-newsletter

APDA's long-awaited e-newsletter was launched in January. The free monthly communication supplements APDA's Quarterly Newsletter that is received by more than 200,000 people internationally.

E-newsletter subscribers receive both the monthly newsletter, a "Parkinson's Tip of the Month," and periodic timely information about a PD issue.

"We are happy to be providing current news about what is happening in the fields of Parkinson's research and patient support and education," said Dr. Paul Maestroni, director of scientific and medical affairs, and editor of the hard-copy quarterly newsletter. "The e-newsletter's 'Parkinson's Tip of the Month' feature enhances APDA's efforts toward easing the burden for persons with PD, their families and caregivers."

Each issue includes an "Unsubscribe" button allowing for immediate discontinuation.

To subscribe send your full name and e-mail address to enews@apdaparkinson.org. ■

Real talk in real time: Indiana couple making a real difference for many with YOPD

By JULIE SACKS
DIRECTOR, APDA
NATIONAL YOUNG
ONSET CENTER

“We can still live life!” That’s what Rich Rozek, host of two PD Webcasts wants other young people with Parkinson’s disease and their families to know.

It’s been almost nine years since Rich was diagnosed with young onset Parkinson’s disease. “It’s been a struggle at times dealing with the changes, like losing some of the strength in my voice [a common side effect].” Rich may have some issues with his voice, but the honesty he and his wife Kim bring to their Web cast, “Parkinson’s Disease Talk Live,” streams through loud and clear.

Once a week, for the past year, the couple opened their life and their living room to the world. Their overall message is a positive one, but they are not afraid to deal frankly with serious issues. “We know what a tough experience this is to go through, especially at mid-life, when you’re worried about taking care of the family, dealing with a job – and life in general – it’s hard, very hard! The decisions we’ve made may not be right for other people, but we can tell them what we’ve learned from going through the process.”

“Parkinson’s Disease Talk Live” is currently being broadcast live at 11AM (CST) on Blog Talk Radio, one of the largest online talk show social sites. It is available for download and on Apple’s iTunes after the air date. Kim, who co-hosted the show previously, is changing her role slightly this year. “She’ll be working during the day,” said Rich, “but she’ll continue to call in from time to time to share that incredibly important spouse/caregiver perspective.”

Rich and Kim have recently launched a second Web cast, The PD Cyber Support Group. The PD Cyber Support Group airs the first Tuesday of every month from 7pm to 9pm (CST) on Talk Show, an online site for community calls. The new PD Cyber Support Group operates much as attending a local support group would. It simply allows people to participate and join the discussion, by phone or online, and to share their experiences by texting each other on our chat board - in real time... worldwide!

APDA’s National Young Onset Center is looking forward to collaborating with the Rozeks this year. Whether you are inspired to participate in their broadcasts or start something of your own, their success inspires us all to realize what a real difference we’re capable of making.

To find out more about these Web casts, go to: www.PDTALKLIVE.com. To learn more about other educational and support programs and services, visit www.youngparkinsons.org or call 877-223-3801. ■

An APDA gift annuity assures a legacy plus a guaranteed income for life *(Cont. from pg. 5)*

commercial insurers when the economy is healthy, the charitable gift annuity assures you, and if you choose, your spouse, guaranteed income for both your lives.”

This is how a charitable gift annuity works. A person or couple contributes an amount to a 501c3 charity to receive an immediate sizeable tax deduction, depending on the contribution and current tax bracket. A hypothetical 65-year-old buying a \$100,000 annuity with immediate payout would receive approximately \$5,700 a year. If coverage includes a 60-year old spouse, the payment would be \$5,300 a year at current rates. At a chosen date, usually retirement, the payments begin and continue until the death of the insured. If there is a spouse clause, payments would continue for his/her lifetime. The tax deduction would reflect their present federal and state tax bracket.

“Most not-for-profits use the American Council on Gift Annuities payout rates,” says Gerstel, “so the cause that will eventually benefit becomes an important factor in choosing.”

More information is available from APDA’s booklet, “Charitable Gift Annuities: Guaranteed Payments for Life,” or by talking with Mr. Gerstel at 800-223-2732. ■



MANAGING PARKINSON'S DISEASE

By ERWIN B. MONTGOMERY, JR., MD

PROFESSOR, DEPARTMENT OF NEUROLOGY

MEDICAL DIRECTOR, APDA INFORMATION & REFERRAL CENTER

UNIVERSITY OF WISCONSIN, MADISON, WI

There have been remarkable advances during the 30 years I have specialized in the treatment of Parkinson's disease. While we are able to do much more for many more patients, management of the disease has become more complicated. Each advance presents its own concerns.

Increasingly, patients and caregivers must assume a greater responsibility; indeed, they must engage in a partnership with physicians and healthcare professionals in the patient's care. These "tidbits" may not get discussed during the patient's visit with the physician or health care professional and are not intended to supplant or replace thorough discussions between the patient and/or caregiver and the physician or healthcare professional. They also do not contain or reflect all the information or knowledge a patient or caregiver should have. Consider this a guide for discussion on Rotigo-

tine (NeuPro® Patch), Ropinerole (Requip®), Promipexole (Mirapex®), and Carbidopa/Levodopa (Sinemet®)

Excessive Sleepiness:

Some patients taking these medications develop excessive daytime sleepiness that in rare cases has led to serious problems. Patients who have problems sleeping at night may be particularly prone to excessive daytime sleepiness. When patients are starting or increasing these medications, we often recommend they do so at a time where the demands for alertness, such as driving, are at a minimum as on a weekend. Patients who experience excessive sleepiness should avoid activities that require alertness, to prevent the possibility of injury to themselves or others.

Gambling and impulse control problems:

On rare occasions, patients on these medications may develop difficulty controlling their impulses. For example, some patients can develop an addiction to gambling, and substantial amounts of money can be lost before this is recognized. In addition to financial losses, this may cause severe stress in families. Patients, family members and caregivers should be on the lookout for these problems and consult with the health care provider if a problem is suspected.

Undergoing Surgery or Medical Procedures

Patients who undergo elective surgery or any medical procedure that may require withholding medications should consider a few issues. First, medications for Parkinson's disease should be continued with as little interruption or change in time of administration as possible. Patients often take their Parkinson's medications with a sip of water on the way to the operating room. Missing these medications could cause a worsening of the symptoms. There have been rare reports of a "neuroleptic-malignant syndrome" like condition associated with abrupt withdrawal of anti-Parkinson's disease medications.

Because the stress of surgery may temporarily worsen parkinsonian symptoms, it is important that the patient remain as physically active as possible, which may require the assistance of a physical therapist. In addition, the Parkinson's disease symptoms could complicate postoperative care. ■

This article was adapted from the Madison, WIS. APDA Information and Referral Center, March 2008 Newsletter.

APDA'S INFORMATION AND REFERRAL CENTER COORDINATORS: *(Cont. from pg. 2)*

because Coordinators understand that people with PD often have a desire to look beyond their disease and redefine themselves, they also assist individuals who wish to explore their imaginative spirit. Many coordinators have established avenues to accomplish this through PD artistic expression classes and creative exhibitions.

How does APDA promote Coordinators development?

Firstly, when Coordinators are newly-hired, APDA makes a concerted effort to offer each one a sense of organizational support as well as warm camaraderie from other members within the association. Most Coordinators are geographically separated not only from the national office in Staten Island, N.Y. but also from fellow coordinators who are usually operating across state borders. Therefore, in 2005 APDA developed a mentoring program to provide novice Coordinators with a general orientation as well as preparation and training from a core of experienced Coordinators. This occurs through site visits and follow-up communication and support by senior Coordinator mentors.

On an ongoing basis, all Coordinators are invited to attend the annual APDA national coordinator meeting. It is here, as a group, that Coordinators learn from guest experts as well as each other to expand their knowledge base and expertise. At this yearly convention, they are able to form strong connections with each other. These bonds continue when they return to their home Centers. Coordinators always feel they are an e-mail or phone call away from a trusted colleague.

APDA recognizes that Coordinators are unique Parkinson outreach specialists and, because of this, the national organization fosters and promotes their continued professional growth. Coordinators, some with many years of experience, have therefore become national Parkinson leaders in nursing, social service, and other disciplines. The Information and Referral Center Coordinators truly enhance the delivery of care in the field of movement disorders while working to fulfill the mission and goals of APDA.

How can you connect with your local Coordinator?

You can locate your nearest APDA I & R Center Coordinator by contacting the APDA National Office (1-800-223-APDA) or visiting www.apda-parkinson.org. Coordinators welcome and encourage calls, emails, and visit to their Centers. And, they look forward to meeting you in the community at support group meetings, educational seminars, health fairs, social gatherings, APDA Chapter events, and more!

Donna Diaz and Cathi A. Thomas are the Coordinators of the APDA I & R Centers at the Hospital of Saint Raphael in Connecticut and at the Boston University Medical Center in Massachusetts respectively. ■



Gigi Smith Gilcrease, RN, MBA, I & R Coordinator (3rd from right) at North Broward Medical Center in Florida, joins members of the APDA South Florida Chapter in recognizing the years of service of Lou and Edie Harris.

PNEUMONIA AND PARKINSON'S DISEASE

Researchers from the University of Pittsburgh School of Medicine reported in a recent issue of the journal *Dysphagia* that impaired coordination between breathing and swallowing might be the underlying cause of aspiration pneumonia in patients with Parkinson's disease. At least half of all Parkinson's patients report having difficulty swallowing, and a higher percentage show swallowing abnormalities on X-ray observation.

Aspiration pneumonia often develops as a complication of mealtime swallowing leading to the inhalation of food and drink. According to the researchers, the high prevalence of swallowing problems and risk of aspiration pneumonia in these patients may be due to flawed breathing and swallowing patterns.

These findings indicate that swallowing problems may be respiratory-based as well as neuromuscular-based, helping to explain why Parkinson's medications do not consistently help in improving swallowing.

MOTOR FLUCTUATIONS OF PARKINSON'S PATIENTS WITH ULCERS

Investigators in South Korea studied how *Helicobacter pylori* (HP) – the agent of gastric and duodenal ulcers – affects the clinical response to levodopa and whether its eradication could decrease motor fluctuation in patients with Parkinson's disease (PD). They compared the clinical response to L-dopa of HP noninfected and HP infected patients by reviewing home diaries. There were no differences in the age, disease duration, Hoehn and Yahr scale, UPDRS-III score, L-dopa daily dose, and frequency of dyskinesia between the HP noninfected and HP infected groups. HP infection can interfere with the absorption of L-dopa and cause motor fluctuations; elimination of this infection can decrease the motor fluctuations of HP infected PD patients. ■

CT SCANS and MEDICAL DEVICES



The US Food and Drug Administration (FDA) announced that computed tomography (CT) scans can cause some medical devices to malfunction. CT scans deliver X-rays to the body, and the FDA found that external and some internal medical devices can be damaged by them.

There have been no deaths reported from CT exposure, but some patients have reported problems with devices such as pacemakers, defibrillators, neurostimulators (used for deep brain stimulation), and internally and externally worn pumps that administer drugs. Some of the problems reported include changes in the rate that the pacemaker regulates the heartbeat and problems with insulin pumps. Also, CT exposure has caused neurostimulators to deliver shocks that were not intended.

The complications from CT scanning are different from the problems with magnetic resonant imaging (MRI). The FDA is not sure if the increase in the number of malfunctions associated with CT scans is caused by more CT scans being done, more of the devices being used by patients, newer machines delivering higher strength X-rays, or more people reporting the complications. Until the cause is determined, the FDA recommends that everyone involved in patients care, including X-ray technicians, know about implanted or external devices. If you have a neurostimulator, be sure that your healthcare provider turns it off during the scan. Afterward, your device should be checked to make sure it works properly, even if you turned it off during the scan. Do not hesitate to talk to your healthcare provider if you have any questions.

This article was adapted from the October 2008 newsletter of the APDA Alamo area Parkinson's Support Group in San Antonio, TX ■

URIC ACID AND PARKINSON'S DISEASE

Investigators in Israel and at the New Jersey School of Medicine and Dentistry found uric acid may play a role in the development and progression of Parkinson's disease (PD). Among PD patients serum urate (SU) levels were found lower than in controls. Uric acid is a natural antioxidant that may reduce oxidative stress, a mechanism thought to play a role in the pathogenesis of PD. High serum urate (SU) levels reduced the risk of developing PD and correlate with a slower progression of the disease.

It is possible that a high purine diet in patients with PD may slow progression of the disease. ■

COUGH MEDICINE AND DYSKINESIA IN PARKINSON'S DISEASE

A cough suppressant may help to control the involuntary movements (dyskinesias) that are a disabling side effect for people with Parkinson's disease taking levodopa.

Researchers at Oregon Health and Science University and at the Portland Veterans Affairs Medical Centre found that dextromethorphan, used in cold and flu medications including Robitussin and Vicks, suppresses dyskinesias in rats.

The same researchers also investigated BMY-14802, a drug previously tested in people with schizophrenia, and found it to be safe and work better in suppressing dyskinesias in rats than dextromethorphan. ■

Educational Material

Single copies of the following publications may be obtained free of charge by writing to the national APDA office or by calling 1-800-223-2732, faxing to 1-718-981-4399, or contacting any of the APDA Information and Referral Centers throughout the United States.



BOOKLETS

1. Parkinson's Disease Handbook (English, German, Italian, Spanish)
2. Young Parkinson's Handbook (English).
3. Be Active (English)
4. Be Independent (English)
5. Speaking Effectively (English)
6. Good Nutrition (English)
7. Aquatic Exercise for Parkinson's Disease (English)
8. My Mommy Has PD... But It's Okay! (English)

SUPPLEMENTS

- The Family Unit
- Hospitalization of a Parkinson Patient
- Fatigue in PD
- Healthy Aging
- Keys for Caregiving
- Medications to Be Avoided or Used with Caution in PD
- Neuro-ophthalmology and PD
- Medical Management of PD and Medications Approved for Use in the USA
- Depression and PD

BROCHURES

- A. Basic Information (English, Spanish, Chinese)
- B. How To Start a Support Group (English)
- C. National Young Onset Parkinson Disease (English)

DVDS

- Managing Parkinson's - Straight Talk and Honest Hope, 2nd Edition

WEB SITES

- www.apdaparkinson.org
- www.wpda.org

Materials concerning research in the field of Parkinson's disease, and answers to readers' questions are solely for the information of the reader and should not be used for treatment purposes, but rather as a source for discussion with the patient's health provider.