



The American Parkinson Disease Association

FALL 2007 NEWSLETTER

A Quarterly Newsletter by The American Parkinson Disease Association, Inc. ©2007

Embryonic Stem Cells *A Controversial Subject*

By: Jessica Hahn, Coordinator APDA Information & Referral Center, University of Wisconsin, Madison, WI

Embryonic stem (ES) cells can be a highly controversial topic to talk about. Some people know

exactly what they are, while others are less informed.

Human embryonic stem cells come from donated, “surplus” embryos produced by *in vitro* (test tube) fertilization. These embryos – originally produced to help couples conceive and, for one reason or another, not used by the couple – were donated for scientific research. These embryos were fertilized in a lab, and have never been inside a human body. Using these donated embryos, a team of Wisconsin scientists led by James Thomson established five independent stem cell lines in 1998. Those lines continue to be used for research today.

All embryos are donated with patient consent and couples often choose to discard the embryos they do not use or donate for research. As many who do the work ask, why not use the embryos to learn about reproduction and development, and to research cures for debilitating diseases, instead of discarding them?

Human embryonic stem cells are “blank slate” cells originating from the 5-7 day old blastocyst, or pre-implantation embryo. They have the potential to become virtually any cell in the body.

Embryonic stem cells have the

ability to multiply indefinitely when cultivated under laboratory conditions. Even though these cells have the ability to multiply indefinitely, scientists try to derive new lines because there is a limited genetic diversity in the existing federally approved lines. Secondly, the original lines were never intended to be used for transplantation, and were meant to be purely research lines. Future therapies based on human ES cell technology will benefit from lines that have been produced since technology has advanced. For instance, the original lines derived by Dr. Thomson were made using mouse cells to grow them on, and cow blood serum in the media that provide nutrition. Cell lines can now be produced without these animal substrates, making them safer for use in humans. As technology advances and we learn more about these cells, scientists will want to derive new lines in the best possible conditions to make them the best for research and therapeutic use.

Besides being able to grow these cells into many different kinds of cells in the human body, scientists are using them to investigate the first stages of development. If they can learn more about the earliest stages of

continued on page 3

INDEX

- 1 Embryonic Stem Cells
- 2 President’s Message
- 4 Q&A
- 5 F.Y.I.
- 9 Limiting Stress
- 10 Diet and Parkinson’s Disease
- 12 Information on Parkinson’s Disease

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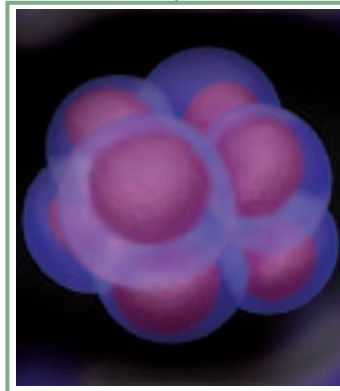
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VINCENT N. GATTULLO
PRESIDENT

Dear Reader:

One of the most rewarding experiences as APDA president is attending the biennial Chapter Presidents and I&R Center Coordinators Meeting, which brings together the people representing all areas of our commitment and mission to "Ease the Burden - Find the Cure." Our Information & Referral Center coordinators meet every year, but every other year, chapter presidents join them to hear from scientists and physicians, share successes, meet new members of the family and recharge their energy to continue our fight on behalf of persons with PD and their caregivers across the United States.

This year our meeting was in Boston. David Standaert, MD, PhD and Marie Saint-Hilaire, MD, members of our Scientific Advisory Board, made presentations; chapter presidents from Vermont to Washington shared successful fundraising ideas; and coordinators addressed topics ranging from effectively communicating with our communities to behaviors across generations, and invited speakers brought insight into individual and family resilience and the benefits of physical therapy in PD. And these

are just a sampling of a two-day dynamic conference that helps each of us do our part to better serve the Parkinson's community.

APDA's synergistic model goes beyond our own organization. Some of our chapter presidents and officers serve as state representatives for the Parkinson's Action Network, which provides the advocacy work for all national Parkinson's disease organizations, and we regularly call upon our national network in support of specific issues. Our support groups have hosted speakers from PDTrials.org, an organization that makes up-to-date information about clinical trials easily available and encourages participation in them, and we work with all organizations - governmental and independent - to reach our mutual goals.

A few months ago the National Institutes of

Health's National Institute of Neurological Disease and Stroke issued a report and recommendations on the workings of its 13 Udall Centers of Excellence. Among the foremost recommendations was the building of relationships with others in the Parkinson's disease field, and to facilitate collaboration among the centers.

It is only by cooperation and collaboration - in the labo-

ratory, in the halls of government, in the office, and in the community - that seemingly overwhelming challenges such as disease eradication can even be met.



Vincent Gattullo, president, and APDA founder Sophia Esposito Maestroni, are surrounded by (l-r) executive director Joel Gerstel; 2007 Salvatore A. Esposito, Sr. Award recipients David Richter, Eileen Giannetti, Dr. Ron Hendricks, and Keith Ciccone; and director of scientific and medical affairs Dr. Paul Maestroni at the biennial conference in Boston.



Vincent N. Gattullo
President

Tax Benefits for Gifts from IRAs

The new Pension Protection Act allows contributions from Individual Retirement Accounts (IRA) to charity without paying income tax on the distribution. Anyone 70 years or older is eligible to donate up to \$100,000, meeting all or part of the required minimum distribution, by Dec. 31, 2007, when the law expires.

For those planning charitable gifts and do not want the extra taxable income from their required distribution, the new law provides an opportunity for tax savings combined

with charitable giving.

There is no addition tax deduction for a gift of IRA funds through this law. Because you avoid income tax on any funds transferred to charity, you are in effect already receiving a charitable deduction for all those funds since all IRA funds are pre-tax dollars.

The institution holding the IRA account can provide detailed information and most have a special form to fill out. ■

Embryonic Stem Cells *A Controversial Subject*

development, this could someday lead to the prevention of birth defects, infertility and miscarriage.

People wonder, why not use adult stem cells instead of using embryonic stem cells? Wouldn't this be less controversial? Although adult stem cells raise fewer ethical concerns and have proven useful for treating some diseases, they have limited potential for a variety of reasons. First, even though researchers have been working with them for more than 30 years, they can't get them to grow or expand well in the laboratory. This means scientists would need to keep going back to the source to get more. Second, because they are taken from an adult, they are already somewhat specialized so their potential to replace damaged, defective or missing cells is limited. Also, in some of the body's major organs, such as the heart and brain, there are no adult stem cells, or they are rare and hard to obtain. But human embryonic stem cells grow well in the laboratory, can be cultured indefinitely, and can become any cell in the body, including heart and brain tissue.

More research is needed on how an embryonic stem cell can be manipulated to become a specialized cell or tissue. Placing pure embryonic stem cells in a specific location in the body with the hope that they will become a heart, kidney or lung will definitely not work. "Blank slate" cells transplanted into the body may form tumors containing several tissue types, not just the one that you want. But transferring pure populations of differentiated cells may be beneficial. Scientists have made much progress on growing different types of cells from these "blank slate" cells in the lab, including different types of neurons, blood cells, and heart cells.

Every year brings exciting new developments in the stem cell labs at The University of Wisconsin-Madison.

"Therapies using blood stem cells and bone marrow transplants for treating certain blood diseases have been developed over the last three decades and are in widespread clinical use. Yet most other potential applications using stem cells and novel regenerative medicine approaches are early in development. The basic biology of tissue regeneration remains poorly understood and is the subject of intense scientific investigation. Realizing the promise of regenerative medicine as these new therapies are pioneered will take decades", stated Tim Kamp, co-director of University of Wisconsin Stem Cell and Regenerative Medicine Center.

The newly organized UW-Madison Stem Cell and Regenerative Medicine Center's mission is to advance the science of stem cell biology and foster breakthroughs in regenerative medicine through faculty interaction, research support, and education. Dr. James Thomson's lab is working on several projects. Scientists in his lab continue to work on further optimizing the culture media to identify factors critical to self-renewal of embryonic stem cells. Improvements in this process will enable researchers to better understand the process of self-renewal and how these cells can be more easily differentiated into the various cells of the human body.

This is definitely not the only lab doing research on stem cells. The Stem Cell and Regenerative Medicine Center lists nearly 30 UW-Madison faculty researchers in the field on its Web site, at www.stemcells.wisc.edu. This brings in more ideas and diseases being studied. Some of the different diseases being worked on by these researchers are Parkinson's disease, spinal cord injuries, multiple sclerosis, heart disease, diabetes, ALS and birth defects. The university has also added more

courses and teachers on the science, business and bioethics of stem cells because of student demand. These new students will bring more ideas to stem cell research.

Using embryonic stem cells to replace dopamine neurons lost in people with Parkinson's disease may be possible someday, but not in the very near future. Attempts to treat humans with fetal cells (which are like embryonic stem cells) have been unsuccessful. It would be very unfortunate if people delayed having other types of therapy expecting to have stem cell treatments. We can, however, see embryonic stem cells being used in the future as a means of delivering other kinds of biological substances such as nerve growth factor, to the brain.

On average, scientific breakthroughs are incremental; it takes several smaller breakthroughs to add up to one major step in scientific discovery or medical treatments. Stem-cell research overall is progressing but funds have been limited which slows these little breakthroughs. Private support has been key to advancing stem cell research, but there is no dispute that additional federal money would allow scientist to do much more. ■

The author would like to thank Dr. Tenneille Ludwig at WiCell and Jordana Lenon at University of Wisconsin Stem Cell and Regenerative Medicine Center for their assistance with this article.

Resources:

www.stemcells.wisc.edu

www.news.wisc.edu/packages/stemcells/facts.html

www.wicell.org

<http://stemcells.nig.gov/info/basics/basics4.asp>

For more information, contact Jordana Lenon, University Relations Specialist at University of Wisconsin Stem Cell and Regenerative Medicine Center at 608-263-2982 or jlenon@primate.wisc.edu.



BY ENRICO FAZZINI, DO, PhD
Associate Professor Neurology
New York University, New York
University of Nevada, Las Vegas
N.Y. Institute of Technology, Old Westbury



Q: My husband is 82 years old and has started having difficulty breathing. He takes two Sinemet 25/100 with Comtan three times a day.

He does have swallowing difficulty, but the breathing problem is new. He has recently been checked by a heart doctor and there is no problem with his heart. We were wondering if Parkinson's can affect one's breathing.

A: All of the muscles of the body become more rigid as a consequence of Parkinson's disease. When the medications are working, the stiffness is lessened. When the medications are not working as well if at all, the stiffness increases. In your case, I believe that when the Sinemet and Comtan wear off, his chest muscles become stiffer so that he cannot expand his chest as easily when he takes a deep breath. In essence, PD produces restrictive airway disease. The problem would be lessened if he were placed on a different schedule. He needs a dopamine agonist like Requip, Neupro or Mirapex and to take less Sinemet more often with a portion of the Sinemet being controlled-release. Azilect or selegiline may also help to smoothen out the response of the PD medications.

Q: My husband, who has had Parkinson's for 28 years, drools excessively. I understand that Botox injections are helpful. I am looking for a physician in the Maryland/

Washington D.C. area who has had experience. Whatever help you can give me would be appreciated.

A: Excessive salivation is a common symptom of PD. This can be a problem especially at night during the winter because the saliva pools in the back of the throat while sleeping and becomes thick by the dry air causing thick choking phlegm. I prescribe glycopyrrylate (Robinul) which usually helps, although Botox injections can be used into the parotid and other salivary glands to decrease saliva production if the Robinul does not help.

Q: I have a friend who is 60 years old and was diagnosed with Parkinson's disease about two years ago. She seemed fine until she started taking Crestor, and I am wondering if statin drugs can cause Parkinson's. I know that some medications can cause diabetes. Also, she seems to be having a lot of difficulty walking now – she loses her balance.

My main reason for writing is to ask you what I can do to help her. It is heart – wrenching to see her health decline.

A: Statin drugs cannot cause PD. If anything, getting your cholesterol as low as possible and taking calcium-channel drugs which lower blood pressure may prolong life and decrease the risk and/or progression

of neurological degenerative diseases.

Q: I am a 70-year-old male and about a year ago began slight hand tremor while doing small, controlled movements. It seemed to start with my left hand but now it is present in both hands. I seem to have no other symptoms but am fearful that I have Parkinson's. My physician (GP) recommended that I quit drinking coffee which I did ..no change. He said he could not rule out Parkinson's. What are the early symptoms and how long do they last before, other more serious symptoms develop? Recommendations?

A: The tremor could be with action and not associated with any other signs, in which case it is essential tremor. It could be with action and associated with signs of lack of coordination, in which case it could be due to a problem with the cerebellum. If because of PD, it must be worst at rest than with action and associated with at least slowness of movement (bradykinesia) not explained by another cause (like an arthritic shoulder or wrist injury). The symptoms of PD are bradykinesia plus either rigidity, resting tremor or ambulation difficulty. The serious symptoms (falls and/or cognitive impairments) usually take 10-20 years to lead to disability although serious "on/off" fluctuations in response to medication usually occur after 10-15 years. ■

INDIVIDUAL EFFORTS RESULT IN THE GREATER GOOD

F.Y.I. is a guide to the efforts and successes and recognition of the hundreds of volunteers and staff who work daily to help ease the burden and find a cure for millions of persons with Parkinson's and their caregivers across the United States.

It may seem to start with an idea, or an opportunity, or seeing another event, but the true motivation to launch a successful fundraiser is the personal desire to help. The amounts raised may be great or small, but the efforts, energies and determination are priceless to APDA and those who benefit. Here are examples of people, who on their own, wanted to help APDA with its mission to raise funds for research and whose enthusiasm lead not only to financial success, but also inspiring others.

The Pine Belt Tulip Quilt Raffle

Still struggling to rebound from the devastation of Hurricane Katrina, APDA's Mississippi Chapter's new president, Rose Cutrer, welcomed the Pine Belt Support Group of Hattiesburg secretary/treasurer Bobbie McWilliams's offer to donate a tulip quilt that she had helped to make for a raffle. The queen-sized quilt was machine-made by Bobbie and her friends Catherine Squyres and Cora Wilkinson. With a goal of \$1,300, Bobbie, her husband, John, a PD patient, and her sister Tina Claburn sat outside the local Wal-Mart and Rammies Grocery for three days selling chances. The combination of talent, determination and salesmanship raised nearly \$2,000. ■



The Pine Belt quilt makers

Spa Day in Bellport

Three years ago former Senior Ms. New York State Carol Lenz opened her Bellport, N.Y. home on Long Island Sound for a spa day inviting friends and their friends for a day of exercise, dance, fashion and beauty lessons, massage, tennis and golf tips and luncheon by her pool. Diagnosed with PD in 1994, Carol's approach has been, "I could have felt defeated, but I can't. I'm a lot like Nelly Forbush in 'South Pacific.' I look at life joyfully and try to greet the world with a smile."

Her infectious strength of purpose has resulted in this year's Spa Day raising more than \$22,000 for APDA, almost tripling her contribution in 2006. ■



Carol and Gordon Lenz

Dinner in Massachusetts

Massachusetts Chapter President Keith Ciccone wanted to raise \$5,000 at a culinary exhibition fundraiser while "putting the 'FUN' back in 'FUNdraising,'" he said. Keith worked with local celebrity chef Kevin Crawley for the spring Coriander Bistro Cooking Demonstration, Dinner and Silent Auction. The event was proving fun, but it looked like Keith and his committee were going fall short of his \$5,000 goal until chef Crawley, impressed with the enthusiasm and hard work of the group, volunteered a surprise auction item, his going to the winner's home and preparing dinner for 12 guests, which sold for \$1,400, taking the event's proceeds to \$5,023.48! ■

APDA's new flyer, "**How To Start a Support Group**," is available by contacting Emily Cirorciari at 800-223-2732, ext. 115 or ecirorciari@apdaparkinson.org.

Support Group Success Secret: Dedication Has No Age Limit

APDA is proud to be the country's largest grassroots organization serving the Parkinson's community, and support groups are the "roots" of its "grassroots." This is the second in our series profiling outstanding support group leaders such as Janet Brown, whose volunteer effort is benefiting people with Parkinson's disease in the Boston area as well as her son Joel. A daughter was also diagnosed with PD at age 55.

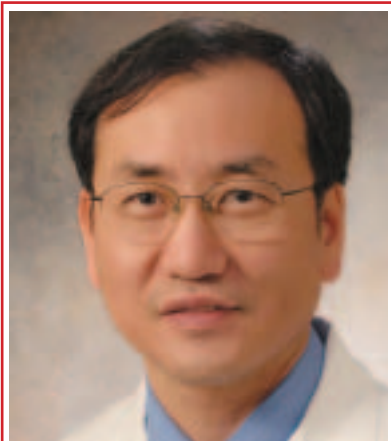
Joel Brown was 45 years old when he heard the diagnosis, "You have Parkinson's disease." His mother Janet, a widow and retired New York City social worker, knew his

needs as well as what the future would probably hold. In 1998 she moved from New Jersey to Topsfield, Mass. to "share a household." Not only did she become a caregiver but also a contributor in the Boston area's Parkinson's community on many levels.

"Janet is an amazing woman," says Massachusetts I&R coordinator Cathi Thomas. "She is a very active 87 year-old with a lot of good ideas that she sees to fruition for the Chapter as well as the Center." She also volunteers to maintain updated information about APDA's Massachusetts' 40-support group network, and assists at

continued on page 8

CHICAGO IS AN APDA K



Dr. Un Jung Kang

of psychiatry; Christopher Gomez, MD, PhD, professor and chair of neurology; and Xiaoxi Zhuang, PhD, assistant professor of neurobiology. Seven additional scientists work in various multidisciplinary fields of PD research.

The center's APDA funding supports promising seed projects. This year's four primary projects are the mitochondrial processing of PINK1 protein, recently recognized cognitive side effects of dopaminergic drugs, a genetic approach to understanding the initial cAMP-mediated signaling events in basal ganglia plasticity rel-

The University of Chicago is APDA's ninth and newest Center for Advanced Research. Under the direction of Dr. Un Jung Kang, the department of neurology's associate chair and associate professor, the center's key personnel are Harriet de Wit, PhD, professor

evant to L-Dopa-induced dyskinesia, and community-based biomarker studies and genetic epidemiology.

The center is also active in clinical trials and patient care including deep brain stimulation. The clinical team includes Dr. Richard Penn, an expert in functional neurosurgery, Dr. Arif Dalvi, a movement disorder specialist, and Joan Young, the center's coordinator.

Dr. Kang is a member of APDA's Scientific Advisory Board and the author/co-author of more than 80 professional articles, reviews, and book chapters. A graduate of the University of Chicago, he received his MD degree from Johns Hopkins University and trained in neurology and movement disorders at Columbia-Presbyterian Medical Center in New York. Prior to joining the University of Chicago's faculty, he held aca-



Julie Saks

KIND OF TOWN

ademic appointments at Cornell University Medical Center in New York, and the University of California in San Diego.

National Young Onset Center

As the pioneer in identifying and serving the challenges of people with young onset Parkinson's disease with the country's first dedicated Information & Referral Center, it is not surprising that APDA is also the first to establish a full-time national center. Julie Sacks, a licensed clinical social worker, accepted the position of center director in March and has begun a strategic planning process that includes expanding existing programs and services. A newly redesigned Young Parkinson's Newsletter and Web site, www.youngparkinsons.org are among the first of the changes expected. The National Young Onset Center will also be expanding its Person-to-Person program and developing new education and support initiatives that will better serve the needs of people who have been diagnosed young, their families, friends and health-care professionals. The center is at Glenbrook Hospital; 877-223-3801. ■

APDA Midwest Chapter and Information & Referral Center



Maxine Dust



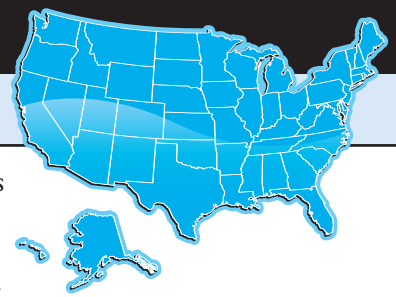
Susan Reese

Though officially separate entities, the Midwest Chapter and Chicago/Glenview I&R Center work closely to serve the entire state of Illinois and the northwest Indiana Parkinson's community. The chapter president, Maxine Dust, a geriatric nurse who has been president for 15 years, also serves as the Midwest chapter's regional representative on APDA's national board of directors. Susan Reese, who is an RN and clinical social worker, served as the young onset coordinator for a dozen years before the establishment of a full-time center. Dr. Michael Rezak is the center's medical director.

The chapter sponsors one of APDA's most successful annual walk-a-thons supporting scientific research and a golf outing in addition to publishing a newsletter, sponsoring an educational symposium, and funding "Time Out," a respite care program. The center offers free educational materials and diverse programs from art exhibitions to exercise classes. It also sponsors an annual full-day support group leaders' workshop.

Chapter contact information: Maxine Dust, 630-541-5194 or mandrdust@msn.com. Center contact information: Susan Reese, 800-223-9776, or parkinsonscenter@enh.org. ■





IN THE NORTH

More than 100 people attended the APDA Spring Conference in Roseville, Minn. Drs. M.C. Leisz and Gregg Dyste spoke on PD treatment options including mobility and activities of daily living and surgical management through deep brain stimulation. In October “Parkinson’s Particulars: A Public Forum on PD” was also sponsored.

IN THE SOUTH

The Georgia APDA chapter lost one of its champions on Oct. 17, when Ronald M. Dillion died at Georgia War Veteran’s Nursing Home, Milledgeville, after a 30-year battle with PD. Ron was a Korean War veteran, president of the Atlanta Chapter for six years and responsible for major corporate underwriting for many years. APDA southeast regional representative Barbara Berger, joined his wife of 50 years, Sondra Dillon, and his family and more than 150 mourners at the graveside service at Georgia National Cemetery for his funeral with military honors.

IN THE WEST

It’s been a busy time on the West Coast for APDA. The **Washington Chapter** sponsored its second annual PD Retreat at the Swedish Education Conference Center in Seattle; the I&R Center at **Cedars-Sinai Medical Center** presented “Parkinson’s Disease: Sharing Information and Wisdom;” and the **Northridge I&R Center** held two educational events in October – a deep brain stimulation seminar, and PD 101 Class, and

has a Parkinson’s Pathways Symposium scheduled in Feb. Awareness and networking successes were byproducts of the **Stanford, Calif. I&R Center’s** “Art-First Monday at Adualu” event. Owner-chef Calvin Schneiter donated 10 percent of the evening’s proceeds to APDA while introducing the work of Adam Bertolet, an artist whose family has been affected by PD.

APDA’s **Arizona Chapter** had another successful *Power Over Parkinson’s* team and pedal for Parkinson’s last month. Participants bicycled the perimeter of **Tucson** with 10,000 other cyclists in the 25th El Tour de Tucson, and hundreds of people who couldn’t make the actual ride, pedaled stationary bicycles *anywhere* on the planet – even at home – in the Indoor El Tour. The chapter also hosted the Coach Chuck Golf Classic Tournament, and a Power Over Parkinson’s Conference with the **Phoenix I&R Center**.

IN THE EAST

They know who let the dogs out on Long Island, N.Y. The annually anticipated and continually more successful Paws for Parkinson’s drew hundreds of dogs with their owners (who had to be on a leash) to Marjorie R. Post Park, where the Halloween-oriented event sponsored by the **Long Island Chapter and I&R Centers** were ready with an array of other events and prizes for the best costume. ■

APDA SUPPORT GROUP SUCCESS SECRET *continued from page 5*



Janet hosts an APDA exhibit

APDA events around the state.

“When Joel was diagnosed, he began attending the Young Onset Parkinson’s Support Group of Greater Boston,” says Janet. “I attended and

eventually became part of the group. There were no other young onset groups in 1998. A young onset group was started about two years ago. Since many of our members were not longer young, we changed the name in 2006.

Joel is now the coordinator of the Parkinson’s Support

Group of Greater Boston with Janet helping the 122-member group. The monthly meeting at Newton-Wellesley Hospital has a formal, but flexible format with a speaker (“We run the gamut of topics from service-dog projects to music therapy”), volunteer-supplied refreshments and either a general discussion or breakout meetings for patients and caregivers. Janet and a retired computer engineer group member with PD send out a monthly newsletter electronically as well as on hard copy. Much of the group’s success can be that, according to Janet, “we laugh a lot.”

Janet’s enthusiasm may be the result of her social work background or energy from a lucky metabolism. She has degrees from Adelphi College (now University) and Columbia University School of Social Work and worked for Cornell University Cooperative Extension in New York City. ■

LIMITING STRESS

By Faye Rhodes

No one needs to tell a person with Parkinson's disease (PD) that the stresses of life have a physical effect. When we are stressed, we shake harder, move slower, spend more time "off" and experience more of the pain of dystonia. If we're going to optimize our physical condition, we need a strategic defense.

What many people don't realize is that happy events can create nearly as much distress as unhappy events.

When I was newly married, I was working full-time, leading the APDA Massachusetts Chapter and maintaining a home. Since I also had a couple of grown sons living at home, the new step-parent factor came into play rather quickly. To top it all off, my new husband was the minister at a church 50 miles away, which meant he faced a grueling commute every day and I added another job pastor's wife. Marrying my husband was a very happy thing. But despite my marital happiness, the stress I faced was scaled up dramatically.

I've also faced the other kind of stress. During one six-month period my husband of 20 years left me, I became a single mother of three sons, my father was diagnosed with cancer, my mother was diagnosed with congestive heart failure, my son's best friend committed suicide and my car was totaled. I can testify that stress is stress. Good or bad, it's all the same in its effect.

A little bit of stress is a good thing. It prepares us for emergencies, sharpens us for competition and motivates us to solve our problems.

Unrelenting stress is another story.

While each of us needs to develop individualized strategies, there are some things all of us can do to protect our bodies, our relationships and our job performance from the consequences of stress.

Identify the Stressors in Your Life

While some of us are adrenaline junkies, others of us want nothing more than to spend weekends and quiet evenings at home. Some of us are natural leaders, others are only comfortable in supporting roles. Some of us run to our families for comfort, others of us run from our families for comfort. In other words, we're all different and we need to understand what it is that increases stress in our lives. Remember, a general cannot plan an effective battle strategy unless he knows his enemy.

Pay attention to what happens when a stressful event occurs. Are you sleep-deficient, embarrassed, frustrated, taking on too much responsibility, compromising your values, over-scheduled or overloaded? Are you involved with toxic people – people who cause you more harm than good?

Eliminate the No-Brainers

When you come up with your list, you may realize some things can simply be eliminated. If horror movies, action movies or "tear-jerkers" leave you sleepless, stop going to movies. If coffee leaves you jittery, switch to decaf or stop drinking coffee altogether. If city driving sends you over the edge, find someone to drive you, or take the train. You get the idea.

Re-examine the Commitments You've Made

Will the organization you lead really fall apart if you resign? Are you always the room mother at school? Most of us like to think we're indispensable, but that's almost never true.

Are you in a destructive relationship? Are your professional obligations kept at the expense of your health and your family's happiness? Are you living up to your own standards or someone else's? Are your standards realistic?

Get Help with Your Assessment and Goal Setting

This is where a professional counselor can be of great help. If you can't afford that option, find a friend and ask for honest observations. (Be sure you don't resent their observations.) Keep in mind, you don't have to tackle every challenge at once. Break down the work into small tasks. Achieving many small victories will encourage you over the long haul.

Many people find prayer or meditation effective as a tool for dealing with stress. If these are a part of your life, now is the time to put them into practice for your well being. There are a variety of counselors, teachers and clergy trained to assist you.

Schedule Downtime and Keep it Sacred

Be proactive about giving priority to restoration time. For my boss, an extrovert, that means he needs to spend time with lots of people and activity. For me, an introvert, that means spending time alone, with my husband or my knitting needles. Decide what de-stresses you and make it a priority – no matter what anyone else thinks! Develop new interests. Don't wait for your mid-life crisis! If you don't know how to relax, learn.

Get Exercise and Eat Healthy

Make changes gradually here. Walking a mile or two may be better and more sustainable for you than running or working out at a fitness club. Cutting out caffeine and eating more fruit and vegetables may make a marked difference in how you feel. Personally, I would not feel good if I eliminated ice cream from my diet, but I don't miss donuts and caffeine at all. People who set tolerable goals for diet and exercise are more likely to make progress than

continued on page 12

Diet and Parkinson's Disease

By Nan Millette

The most important dietary advice for a person with Parkinson's is to eat a healthy, balanced diet that includes a variety from the main food groups – plenty of fruit, vegetables, complex carbohydrates (like cereals, grains, fruits and vegetables), some protein and fluids. Current general dietary recommendations include:

- Maintaining energy intake at 25-30 calories per 2 pounds of body weight, with additional calories if dyskinesias are present
- A carbohydrate to protein proportion of at least 4-5:1
- A recommended daily protein allowance of 0.03 oz/lb of body weight.

Three balanced meals a day are recommended, although some people with Parkinson's may find it easier to manage more frequent smaller meals. If people with Parkinson's already eat a healthy, balanced diet, they may not need to make any dietary change.

Weight management

Having Parkinson's may have an effect on body weight. In some people, movement problems mean less exercise so they put on

weight. Excess weight can put a strain on the joints and make movement difficult, worsening Parkinson's problems. If people do put on a lot of weight or are overweight already, they may be advised to go on a calorie-controlled diet. However, in most cases, people with Parkinson's find that they lose weight because of:

- Loss of appetite
- Difficulty eating
- The extra energy needed to cope with the symptoms
- The body absorbing fewer nutrients.

Therefore, people with Parkinson's often need to be encouraged to eat more calories. Rather than having bigger portions, smaller tempting meals and snacks at regular times during the day may be more acceptable. High calorie foods like peanut butter, biscuits/desserts and milkshakes can help to increase weight.

Protein and medication

If people with Parkinson's have been prescribed levodopa, their doctors will have given them instructions on how this medication should be taken in relation to food.

If a high-protein meal is eaten at the same time as the medication is taken, less levodopa will be absorbed

into the intestines. Proteins are broken down into smaller

molecules called amino acids, which

can compete with lev-

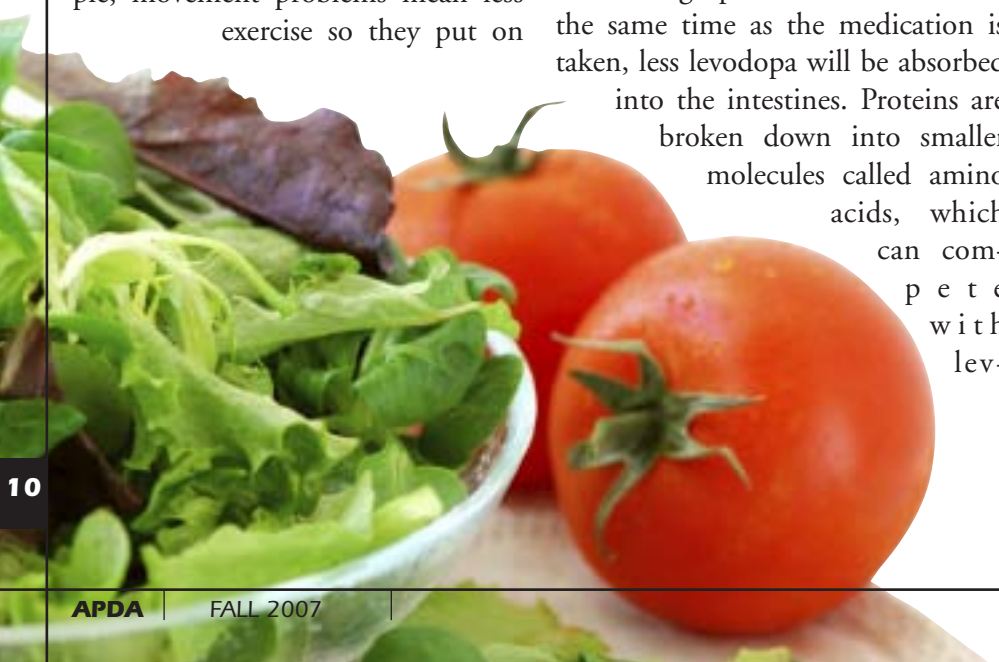
odopa (also an amino acid) for transport from the digestive tract to the bloodstream to the brain. Protein can interfere with the uptake of levodopa into the body and the brain, and therefore, reduce the effectiveness of the medication. Matters may improve if the normal daily intake of protein is taken all together in one meal at the end of the day. Foods low in protein should make up the bulk of other food intake. These include:

- Breads and cereals
- Vegetables and fruit
- Clear or vegetable soups (not creamed or containing lentils or peas)
- Spreads (honey, jam, vegemite)
- Sweets.

Another way to avoid the 'protein effect' is to take levodopa on an empty stomach (one hour before or after a meal), as long as this does not cause nausea. However, this does not help in all cases and some doctors will not recommend this change in diet. The diet should never be altered in this way without advice from a doctor or registered dietitian. Although protein may be taken at a different time of day, the total daily amount of protein should not be reduced, as the body needs it for tissue repair and to build the immune system. Most other Parkinson's medications do not have specific instructions about whether they should be taken with or without food.

Carbohydrates and sugar

As well as protein worsening motor fluctuations, people with advanced disease may find that their dyskinesias become worse after eating foods high in carbohydrate and sugar. However, carbohydrates should not be excluded from the diet, as they are



needed to maintain body weight and energy levels.

Fluids

Drinking plenty of fluids (8-10 cups a day) is an essential part of healthy diet and helps to relieve constipation – coffee and tea don't count because they are dehydrating.

A dry mouth is a common problem in Parkinson's. This can be eased by drinking more fluids, taking frequent sips of water, sucking ice chips, using a mouth spray or an oral rinse. Sucking a sweet or chewing gum can also help to produce more saliva and relieve a dry mouth. Unless advised otherwise by a doctor, people receiving Parkinson's medication can drink moderate amounts of alcohol.

Constipation

Constipation is a common problem with Parkinson's, because the illness reduces the action of muscles in the bowel. Regular mealtimes, a balanced diet, plenty of fluids and regular exercise can provide relief. If constipation becomes a more serious problem, medication will be recommended.

Difficulties with eating

Practical difficulties with eating food can also contribute to poor nutrition. The following tips can help.

Meal times

Hot meals can be served on a warming mat, in an insulated bowl, or can be reheated during the meal. This stops the food getting cold if eating is a slow process.

Problems with swallowing

Swallowing may be helped by:

- Yawning several times before a meal to relax the throat if it tenses up.

- Keeping the chin tucked down to the chest.

- Taking sips of water .

- Maintaining good posture and a comfortable position while eating.

- Putting only a small amount of food on a fork or spoon. This prevents spills and helps with swallowing.

If a semi-solid or pureed diet is required due to swallowing difficulties, a referral to a speech and language therapist and a dietitian is essential. Not all swallowing problems are due to Parkinson's and the cause of the problem should be confirmed before dietary changes are made.

Practical aids

- Hot drinks can be served in an insulated cup to stop them getting cold. Cups with a lid and spout can stop spillages and help with drinking.

- People should avoid overfilling cups. Using a straw may help.

Weighted cups can help prevent tremor when drinking.

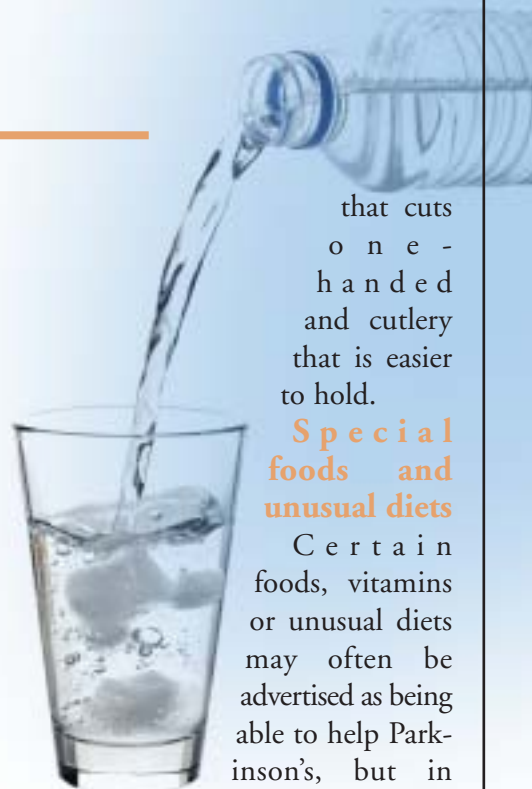
- Serve the meal on a raised level, e.g. put the plate on a small box or stand, so that the food is nearer the mouth. This helps with transferring the food from the plate to the mouth.

- Placing the elbows on the table to steady hands/arms when eating can help.

- Using an apron/bib with a plastic or easy-clean cloth for the table may help if spillage is a problem.

- A plate can be placed on a rubber mat to prevent slipping, and a clip-on ring can be added around the edge, to stop any food being accidentally pushed off the edge.

Other eating aids include a combined fork/knife, a 'rocking' knife



that cuts
o n e -
h a n d e d
and cutlery
that is easier
to hold.

Special foods and unusual diets

C e r t a i n
foods, vitamins
or unusual diets
may often be
advertised as being
able to help Park-
inson's, but in

most cases there will be no proof that this is the case.

Anyone with Parkinson's tempted by any unusual 'dietary therapies' should be encouraged to discuss this further with his/her medical team. ■

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This article was originally published in the Stanford, Calif. APDA I&R Center newsletter of March 2007.

AZILECT USED ALONE IN THE TREATMENT OF PD

Azilect[®] (rasagiline tablets by Teva) administered alone provided a consistent beneficial effect in the treatment of Parkinson's disease symptoms independently from the duration of the disease at the time treatment was started. Headache, joint pains and indigestion were the most common side-effects of the drug administered alone. ■

Information on Parkinson's Disease

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 62 APDA Information and Referral Centers.

EDUCATIONAL BOOKLETS

1. **Basic Information about Parkinson's Disease**
Brochure (English)
2. **Parkinson's Disease Handbook** - Symptoms, causes, treatment - booklet (English, German, Italian)
3. **Be Active** - A suggested exercise program for people with Parkinson's disease - booklet (English)
4. **Be Independent**- Equipment and suggestions for daily living activities - booklet (English)
5. **Speaking Effectively** - Speech and swallowing problems in Parkinson's disease - booklet (English)
6. **Good Nutrition** - booklet (English)
7. **Young Parkinson's Handbook** - booklet (English)
8. **Aquatic Exercise for Parkinson's Disease** - booklet (English)
9. **My Mommy Has PD... But It's Okay!** - booklet for young children.

The Next Step After Your Diagnosis: Finding Information and Support-Booklet can be obtained by calling 800-358-9295 and requesting booklet AHRQ Publication No. 05-0049

EDUCATIONAL SUPPLEMENTS

The Family Unit; The Fine Art of "Recreation & Socialization" with PD; Mirapex® in the Treatment of PD; Fatigue in PD; Healthy Aging.

NEW SUPPLEMENTS

Keys For Caregiving; Medications To Be Avoided or Used With Caution in PD, Neuro-Ophthalmology and PD.

UPDATED SUPPLEMENTS

Medical Management of PD and Medications Approved For Use in the USA

DVD

Managing Parkinson's - Straight Talk and Honest Hope. Created by the Washington State Chapter of APDA for newly diagnosed Parkinson's patients and their loved ones.

APDA WORLDWIDE WEB SITE

www.apdaparkinson.org for PD I&R Centers, Chapters, Support Groups, education and information material, meeting dates, publications, medical abstracts, clinical trials and research application guidelines.

WORLD PARKINSON DISEASE ASSOCIATION WEB SITE

www.wpda.org. A weekly updated source of world news.

LIMITING STRESS *continued from page 9*

those who start right off with unpalatable or overly ambitious goals.

Don't Worry About Things You Can't Control

This takes practice, but it's key to reducing stress in your life. Worrying doesn't fix anything. Prepare for stressful events (that job interview, church solo, professional presentation...), then do your best. You simply can't do more than that.

Try to Resolve Conflicts with Other People

If you aren't successful, you may need to limit or eliminate a troublesome relationship, look for other work, stay home for the holidays or get caller ID.

Get as Much Sleep as Possible

For people with Parkinson's, this can be a real challenge. Currently, I'm lucky if I get six hours of sleep at night. In order to get enough sleep I usually need a nap after work. Luckily, my husband and I are stay-at-home people, so it has not required a change of lifestyle. If your evenings are activity-filled, you may need to re-fuel and add a restorative nap to your schedule.

Try to Look at Change as a Positive Challenge

Consider change in your life an opportunity to grow and develop as a person. If you're competitive, take on the challenge of creating and reaching new goals. If you have never had to face radical changes before, this is your opportunity to discover new truths.

The fact is you can't control your circumstances or other people. The only thing you are solely in charge of is your attitude. It's fundamental to everything you do or attempt. It's the difference between being content and being miserable. If you refuse to take responsibility for your own attitude, you and everyone around you will suffer.

Seize the day and appreciate the heck out of it. ■

Ms. Faye Rhodes is a past president of the APDA Massachusetts chapter. This article was originally published in the Spring 2007 issue of APDA Young Parkinson's newsletter.

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.