

Parkinson's Patients Support Groups, Inc.

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Educating and Informing the Public about Parkinson's Disease

Winter Quarterly

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AN END OF YEAR MESSAGE FROM THE PPSG BOARD OF DIRECTORS

Dear Valued Reader:

PPSG is approaching its 31st year of continuous service to the Parkinson Community. We are an entirely volunteer organization providing services and resources to people with Parkinson's, their families and friends, caregivers and medical groups. We do this through many venues such as sending our printed informational packets for new patients and for caregivers, disseminating brochures and materials at seminars/educational programs, and updating our web-site; but most important is publishing of our 'top notch' newsletters for our readers. There is no cost to the individuals. This year we have maintained the number of pages and issues of our newsletters, although the major expenses are the newsletter printing and mailing. In order to provide these services, we have several suggestions:

1. **Make a Donation.** Please consider PPSG when making your end-of-the-year contributions. Any amount is appreciated.
2. **Subscribe Electronically.** This would reduce the mailing cost in addition to lowering cost of news mailing and printing.
3. **Volunteer.** If donating is difficult at this time, please consider helping out in the office with filings, assembling materials, or doing research. Contact us at PPSGinfo@yahoo.com.
4. **Update Your Address/Cancellation** Too often, the Post Office returns newsletters with the old addresses and charges us for processing.

With your support, valued reader, PPSG will continue to serve the Parkinson's Community.

We wish you the best of health and good fortune in the holiday season and the coming year.

Board of Directors
Parkinson's Patients Support Groups, Inc. (PPSG)

Hope for Stem-Cell Treatment of Parkinson's

By **Gautam Naik**

Researchers have used stem cells obtained from human embryos to successfully treat Parkinson's disease in mice and rats, a key step in the quest to develop a similar approach for people.

In a study published Sunday in the journal Nature, scientists described how they converted human embryonic stem cells into nerve cells that produced the brain chemical dopamine. When these nerve cells were transplanted into the brains of mice and rats, they released dopamine and got rid of the animals' Parkinson's symptoms. The cells were also successfully transplanted into rhesus monkeys, whose biology is closer to that of humans.

"We see a real opportunity to develop this into an actual cell therapy for patients," said Lorenz Studer, lead author of the paper and a stem-cell biologist at Sloan-Kettering Institute for Cancer Research in New York. "It is now more of an engineering problem than a scientific one."

Nerve cells use dopamine to help control muscle movement. In Parkinson's disease, the brain's dopamine-producing cells slowly get destroyed. This affects the brain's ability to send messages, leading to loss of muscle function, reduced movement and tremors. There are drugs that increase dopamine in the brain and help control symptoms, but they can cause side effects,

such as involuntary movements. Their benefits also tend to wax and wane as the disease progresses.

Some scientists are experimenting with cell-transplantation. They have used stem cells from mouse embryos to make dopamine-producing cells and treat Parkinson's in animals. But until now, a similar approach in mice using human embryonic cells hasn't worked well. Not only have human-derived dopamine cells not performed efficiently when transplanted into animals, they have also triggered the growth of unwanted tumor-like structures.

In those past experiments, scientists typically added two specialized proteins, known as growth factors, that turned embryonic stem cells into dopamine-producing nerve cells. Now, by adding a third substance, Dr. Studer and his colleagues were able to activate a vital biological pathway in the embryonic cells, thus making human dopamine cells that worked much better. Crucially, their approach didn't lead to tumor-like structures.

The researchers first experimented with mice that had no dopamine cells—after scientists' intervention—and thus suffered from Parkinson's disease on one side of their brain. When given an amphetamine, the stimulated mouse would move. But because only one side of its brain had dopamine cells, it triggered a much stronger movement on that side than on the other. That caused the animal to spin around up to 15 times a minute.

About 100,000 human-derived dopamine cells were then injected into the side of the mouse brain that lacked dopamine cells. Over a period of three to five months, as the transplanted dopamine cells took hold, the animal regained movement in that part of the brain.

Their rotational movements gradually declined, then stopped altogether. Similar results were seen in rats.

“This is a big leap in the effort to use cell-transplantation to one day treat Parkinson's patients,

” said Tilo Kunath, a stem-cell scientist at the University of Edinburgh, who read the study but wasn't involved in it. “To see a complete rescue, and a lasting rescue, is unheard of in these animal models.”

Millions of such cells would be needed to conceivably treat a person. Could Dr. Studer's technique be scaled up to produce vast numbers of dopamine-releasing cells? The Nature study suggests it may be possible.

As a final experiment, Dr. Studer's team produced, and then injected, seven million human-derived dopamine cells into each of two rhesus monkeys. The month-long test showed that the mass-produced cells could survive in the monkeys and also properly interact with the animals' existing cells.

Dr. Studer says he now plans to manufacture the human embryo-derived dopamine cells in a specialized facility under clinical-grade conditions and conduct longer-term animal experiments. If it all works out, in three to four years the cells could potentially be ready for human trials, he said.

<http://online.wsj.com/article/SB10001424052970204621904577018133476441946.html>

This article was forwarded by Jan Feller. Jan is a member of the Sunnyvale Support Group. Thanks, Jan!

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Introducing a New Board Member: Richard Simone

I was born in Milwaukee, WI, where I married my high school sweetheart just after graduating from Engineering school in 1965. We moved to Minneapolis, and then on to Cedar Rapids, Iowa, where I worked on mainframe computers. In 1972 I had the biggest break of my professional life – I lost my job! The only place I could find work was at a company I never heard of before, National Semiconductor, in a place called Silicon Valley. I had no idea what I was getting into, but I had a wife and 3 children under 5 to support. I needed the work. Beside, California sounded like a nice place to be given it was 20 degrees below zero in Iowa. Little did I know how many great opportunities were now available to me. I have had an incredible career in semiconductor development, added one more child to my family, and 40 years later had 10 grandchildren to boot. I was still active professionally – life was good.

I was diagnosis with Parkinson's Disease in April of 2010 after 18 months of trying to find out what was wrong with me. It took me the next few months to absorb this and to collect my thoughts on where my life was headed. There didn't appear to be an urgency about learning more or doing massive searches on the internet to learn all I could. My doctor assured me that I had 10, 15, and perhaps even 20 years before the disease took its toll. "See you in 6 months." While I was a healthy prostate cancer survivor, at 66 I could easily die from something else before PD became a major player. So I settled into a new regimen of taking 4 pills per day and allowing myself some room before "getting involved." I did take the time to tell my immediate family that I had PD. I told them that now I could do something about the symptoms I was experiencing. Indeed many of them were gone or reduced.

A month later I came across 2 articles that changed my life completely. They were challenges by two Silicon Valley giants, Andy Grove (retire CEO of Intel), and Sergey Brin (founder of Google). Andy has PD and Sergey is predisposed to getting it – he has the LRRK-2 gene. In short, both articles challenged the medical and research community to

change their methodologies and approaches to finding the cause, cure, and drugs for treating PD and other diseases for that matter. "Take a look at how fast-moving technologies in Silicon Valley are doing what they do and adapt a new way of thinking." I knew that I had found a new career and goal in life! I am a successful engineer who took part in what Andy and Sergey were talking about for close to 40 years. I was determined to join the fight and provide help and assistance to finding the cause and a cure for PD.

Since July of 2010 I have spent as much time as possible learning, networking, collecting data, and finding a new goal in my life. My new passion or dream if you wish is to put together a database containing 500K PD patients, all of whom can be reached via the internet. Some would call this a National Registry. Others who have tried might call it folly. But in Silicon Valley dreams do become a reality on a regular basis!

There are several good reasons to collect all of us PD patients into a database. Researchers can collect data from u. Others, who are looking for volunteers for clinical trials can get in contact with us via email. We can join together to approach the government for more funding. We can also join chat room discussions with other PD patients. And, I am certain there are other ideas I haven't thought of. NOTE: This database would be very protected and private, so that others won't have access to information you don't want to share.

During the last year I was fortunate to be introduced to PPSG. It didn't take long to see the many valuable services they offered. And they always had time to advise or direct me to resources and people that would help me with my personal goal. I was very impressed that a nonprofit, with no paid staff could do some much for the PD community for 30 years! That's amazing!! I was very honored when they invited me to join their board. I hope to provide PPSG with whatever assistance I can to keep it going for another 30 years.

**This newsletter was assembled by the
Morgan Center. Thank you!**

Germ in Our Mouths: Problems for More Than Just Teeth and Gums!

Dr. Ron Matsuura

If you do not or cannot remove all the bacteria in your mouth by brushing and flossing or using other teeth cleaning devices, you are putting yourself at risk for more than tooth decay(cavities) and gum diseases(gingivitis or worse, periodontitis) problems. Oral bacteria are now known for their association, influence and causing of medical problems including heart disease, strokes, diabetes type 2, respiratory disease, chronic inflammation, preterm and low-birth-weight babies, chronic inflammation and they even increase the risk of cancer and Alzheimer's disease.

These medical health diseases and problems are not minor, but major, health concerns.

Oral bacteria, the little tiny bugs that are always growing in our mouths, and the primary reason we are supposed to brush and floss 2-3 times per day, work like this. They are like schools of millions of little fish in the ocean, in that when food is found they swarm to the food. Whenever we eat or drink anything we put a layer of food and nutrition all over our teeth and gums. Bacteria in our mouths swarm to this nutrition like fish in the ocean. But bacteria do more. They form a protective film around themselves called a Biofilm. This Biofilm gets lodged and trapped between your teeth and gums in a little valley or crevice called the gum or periodontal pocket. The Biofilm is pretty much impervious to antibacterial mouthwashes and in addition the body produces a washing fluid in this pocket called crevicular fluid that washes away mouth rinses so that the medications in the mouthwash that are supposed to kill the bacteria, are not effective.

So how do we get rid of all this bad bacteria?

Well for the most part we have to do a super job of

brushing and flossing or using other devices to eliminate the bugs. Can we all do a super job each time? Doubtful. I am a dentist and each time I pick up my electric toothbrush, it takes me over 3 to 5 minutes to clean my mouth. This is after I floss and/or use my bristled toothpick device to clean in between my teeth. Even with all this time spent cleaning my mouth, I know I am still going to leave little globules of Biofilm bacteria behind and that millions of bacteria will invade my blood stream.

So how do these little germs cause and influence medical problems?

To explain a few...

For heart disease these bacteria infect the gums by way of gingivitis, which puts the bacteria directly into your bloodstream. This causes inflammation or chronic irritation to the inside lining of the blood vessels (veins and arteries). The body react to this inflammation by laying down fatty layers of plaque over this inflammation causing the diameter of the blood vessel to get smaller. In some cases it can clog and block the blood flow enough to cause heart disease and/or even a stroke.

Another example is that certain bacteria found in the mouth might trigger the formation of something called beta amyloids, which is a known cause of Alzheimer's disease.

Is there no hope? Are we all destined to put ourselves at a high risk of the medical problems listed above?

The good news is, not if we can help it. We can remove a lot of these germs from our mouths by spending more time doing a thorough job of brushing at least 3 times a day, and more times if you have gingivitis(gums that sometimes bleed when brushing or flossing. It is important to try to clean one surface of ONE tooth at a time. An electric tooth brush is the easiest to use to accomplish this in the least amount of time, which

is 3-5 minutes, longer than the two minutes that many power- assisted toothbrush timers beep at.

But didn't I say that even me trying to do a great job would leave some of these bad little bugs behind?

The answer is yes, so what I do is use a tray device similar to a bleaching or tooth-whitening tray which is custom made and I put in a non-medicine antibacterial gel (3% peroxide) and keep that in my mouth for about 15 minutes. I wear it in the shower so that I do not take any extra time out of my day, which often discourages using such a device. It is simple to use for most all of us.

I highly recommend using this device if you have personal or family history of any of the above medical problems or if you know you have gingivitis or even a high cavity rate. This device kills all the bacteria that cause gum disease as well as the different ones that cause tooth decay.

I use this device made by the "PeriProtect Company" religiously each day.

Yours for better overall health,

Dr. Ron Matsuura

Dr. Ron Matsuura is Phyllis Ng's dentist. Thanks, Dr. Matsuura!

Ulcer Bacteria May Contribute to Development of Parkinson's Disease

ScienceDaily (May 22, 2011) — The stomach bacteria responsible for ulcers could also play a role in the development of Parkinson's disease according to research presented May 22 at the 111th General Meeting of the American Society for Microbiology

"Infection of late middle-aged mice with a particular strain of the bacteria *Helicobacter pylori* results in development of Parkinson's disease symptoms after 3-5 months," says Traci Testerman of Louisiana State University Health Sciences Center, Shreveport, who presented the research.

"Our findings suggest that *H. pylori* infection could play a significant role in the development of Parkinson's disease in humans."

Physicians have noted a correlation between stomach ulcers and Parkinson's disease as far back as the 1960s, before it was even known that *H. pylori* was the cause of ulcers. More recently, a number of studies found that people with Parkinson's disease were more likely to be infected with the bacterium, and that Parkinson's patients who were treated and cured of infection showed slight improvement compared to controls that continued to deteriorate.

In Guam, a study of why some populations had a high risk of developing a Parkinson's-like disease discovered that a specific compound in cycad seeds eaten by these populations was neurotoxic. The compound, which resembles a cholesterol with an attached sugar group, is almost identical to a compound produced by *H. pylori*.

Testerman and her colleagues developed an animal model to more effectively understand the role of *H. pylori* and its modified cholesterol in Parkinson's disease. They infected young and aged mice with three different strains of the bacteria and monitored their locomotor activity and dopamine levels in the brain. Mice infected with one of the strains showed significant reductions in both.

"The results were far more dramatic in aged mice than in young mice, demonstrating that normal aging increases susceptibility to Parkinsonian changes in mice, as is seen in humans," says Testerman.

In order to determine whether the modified cholesterol or other substances could be responsible for Parkinson's disease development, they fed aged mice with *H. pylori* extracts. The mice did not become infected but developed the same symptoms as those infected with the bacteria, suggesting that the modified cholesterol or some other product contained within the bacteria contribute to disease development.

"Our mouse model demonstrates a direct effect of *H. pylori* infection on the development of Parkinson's disease. The observation that not all *H. pylori* strains are equally able to cause symptoms will allow us to investigate bacterial factors and/or immune response to *H. pylori* infection that increase the risk for Parkinson's disease," says Testerman.

<http://www.sciencedaily.com/releases/2011/05/110522141547.htm>

Caregiving Comes to the Backyard

Many adult children would prefer to be caregivers for their elderly parents. But caregiving isn't always practical.

Moving a frail elder into the caregiver's house often isn't possible because there may not be enough room. An assisted living building or nursing home is an option, but these buildings aren't always located close to the family, making it difficult for them to visit and stay involved in the elderly person's care.

A new caregiving alternative is the Med Cottage. It's a small portable house that can be installed on a property, say, in the backyard. The one-room Med Cottage includes a kitchenette, social area, bathroom and bedroom. It also has the medical equipment needed to care for an elderly person who requires nursing care. And when the adult caregiver cannot be on site, monitors and sensors allow the caregiver to check on the senior via a computer link.

"One of the greatest fears we have as we age is isolation from the family," says Ken Dupin, creator of the Med Cottage. "We're giving families the tools to keep their loved ones nearby and manage their care."

The idea for the Med Cottage started with Dupin's interest in the elderly. He's been a church minister for 30 years and often visited the elderly in nursing homes.

Dupin has also been earning a Ph.D. over the last several years at Virginia Tech University. He spent several semesters overseas during that time and noticed how other cultures treated the elderly with real respect. "That's how the Med Cottage got started," he says.

So Dupin formed a company, N2Care, to produce the Med Cottage. The company's offices are located at the research center on the campus of Virginia Tech. "Our slogan is 'family managed care,'" says Dupin.

Technology aids caregiving

The first Med Cottage was installed on a property in October. But Dupin has had a prototype up and running on the Virginia Tech campus for a while now.

The cottage itself is made of all steel with foam insulation. The structure is about 300 square feet in size. The Med Cottage includes a lift that can safely move someone from the bed to a wheel chair or into the shower. The lift system is installed in the ceiling of the Med Cottage.

The Med Cottage is also pressurized, creating a sterile environment for those with compromised immune systems. The process can also be reversed to keep pathogens inside the unit.

A lot of technology is built into the Med Cottage. The idea is to allow the caregiver to monitor the patient, while not feeling like they have to be present every minute. But because the Med Cottage is so close to the main house, the caregiver can quickly respond if needed.

A "feet sweep camera" allows the caregiver to check to see if the elderly person has fallen. The camera, which can be viewed remotely by the caregiver at a computer, is placed about a foot off the floor. The video stream only shows as high up as the elderly person's ankles so he or she maintains privacy.

A voice activated machine dispenses medication up to eight times a day. Other onsite tools can check a person's blood pressure, weight, and blood tests. Families can visit the elderly person via a video link such as Skype too.

Zoning laws need revamp

Each Med Cottage has its own website where information can be uploaded. Doctors and nurses from remote locations can check on the resident's vital signs and test results. Caregivers can monitor the elderly person through their iPhone, a computer, or iPad. "The computer software allows the family to participate in the process," says Dupin.

In about three months, consumers will also be able to purchase the Med Cottage technology and install it in their own homes. The software product is called Med Mind and costs about \$5,000. The Med Cottage building, complete with the technology, costs about \$85,000. The company will re-purchase used units at half that price. "That's a lot less than the cost of a nursing home," notes Dupin.

However, the Med Cottage may run afoul of local zoning laws. Many towns and villages do not allow even temporary structures to be put on a property.

But that's changing too. Dupin is working to revamp zoning laws to permit installation of the Med Cottage. Virginia and North Carolina just changed their laws. New York and California are considering changes too.

<http://www.chicagotribune.com/special/primetime/chi-primetime-medcottage-110911,0,1393746.story>

Bad Oral Health Increases Risks from Brain Surgery

13 July 2009

IT MAY be the last thing on your mind, but a trip to the dentist before brain surgery could prevent pneumonia.

Elderly people run a 20 per cent risk of developing pneumonia after major surgery, particularly if the operation is on the brain. Brain surgery weakens coughing and gag reflexes, making patients more likely to inhale bacteria from their mouth and nose.

To see if oral hygiene before an operation makes a difference, Almos Klekner of the University of Debrecen in Hungary and his colleagues examined the mouths of 23 elderly patients due to have a brain tumour removed. The five people who contracted pneumonia within 48 hours of the operation all had bad oral health, such as gingivitis. Klekner calculates that this ups the risk of infection at least three fold.

<http://www.newscientist.com/article/mg20327164.900-bad-oral-health-increases-risks-from-brain-surgery.html>

Low Vitamin B12 Levels May Lead to Brain Shrinkage, Cognitive Problems

ScienceDaily (Sep. 26, 2011) — Older people with low blood levels of vitamin B12 markers may be more likely to have lower brain volumes and have problems with their thinking skills, according to researchers at Rush University Medical Center.

The results of the study are published in the Sept. 27 issue of *Neurology*, the medical journal of the American Academy of Neurology.

Foods that come from animals, including fish, meat, especially liver, milk, eggs and poultry are usual sources of vitamin B12.

The study involved 121 older residents of the South side of Chicago who are a part of the Chicago Health and Aging Project (CHAP). The 121 participants had blood drawn to measure levels of vitamin B12 and B12-related markers that can indicate a B12 deficiency. The same subjects took tests measuring their memory and other cognitive skills.

An average of four-and-a-half years later, MRI scans of the participants' brains were taken to measure total brain volume and look for other signs of brain damage.

Having high levels of four of five markers for vitamin B12 deficiency was associated with having lower scores on the cognitive tests and smaller total brain volume.

"Our findings definitely deserve further examination," said Christine C. Tangney, PhD, associate professor in the department of clinical nutrition at Rush University Medical Center, and lead author of the study. "It's too early to say whether increasing vitamin B12 levels in older people through diet or supplements could prevent these problems, but it is an interesting question to explore. Findings from a British trial with B vitamin supplementation are also supportive of these outcomes."

On the cognitive tests, the scores ranged from -2.18 to 1.42, with an average of 0.23. For each increase of one micromole per liter of homocysteine -- one of the markers of B12 deficiency -- the cognitive scores decreased by 0.03 standardized units or points.

Tangney noted that the level of vitamin B12 itself in the blood was not associated with cognitive problems or loss in brain volume. She said that low vitamin B12 can be difficult to detect in older people when looking only at blood levels of the vitamin.

"Our findings lend support for the contention that poor vitamin B12 status is a potential risk factor for brain atrophy and may contribute to cognitive impairment," said Tangney.

Other researchers at Rush involved in the study were Dr. Neelum T. Aggarwal, Hong Li, Robert S. Wilson, PhD, Dr. Denis Evans and Martha Clare Morris, ScD.

The study was supported by the National Institute on Aging.

<http://www.sciencedaily.com/releases/2011/09/110926165852.htm>



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