

Parkinson's Patients Support Groups, Inc.

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Scientists Discover Genetic Mutation That Causes Parkinson's Disease

ScienceDaily (Sep. 8, 2011) — A large team of international researchers have identified a new genetic cause of inherited Parkinson's disease that they say may be related to the inability of brain cells to handle biological stress. The study, published in the September issue of the *American Journal of Human Genetics*, continues to fill in the picture of Parkinson's disease as a complex disorder influenced by multiple genes, say neuroscientists at Mayo Clinic's campus in Florida who helped lead the investigation.

Although to date, only a small number of families have been identified with this form of Parkinson's disease, the scientists say the study offers a direct insight into how the gene, EIF4G1, can lead to death of brain cells, resulting in Parkinson's disease and related neurodegenerative disorders.

This gene is unlike others that have been found to cause Parkinson's disease in that it controls the levels of proteins that help a cell to cope with different forms of stress, such as those routinely found in aging cells, says Justus C. Daechsel, Ph.D., a Mayo neuroscientist who is the study's co-lead investigator.

Given the function of this gene, this discovery opens up a new area of research within Parkinson's disease and other neurodegenerative diseases, adds study co-author Owen Ross, Ph.D., a Mayo Clinic neuroscientist. The insights gained from how mutations in EIF4G1 lead to cell death might help us develop new therapies to treat or slow Parkinson's disease.

This study began with the identification by French researchers of a large family in northern France with inherited Parkinson's disease. Researchers discovered the EIF4G1 mutation in the French family and in other affected families in the U.S., Canada, Ireland, and Italy.

Much is already known about the protein, EIF4G1. For example, when a cell is undergoing stress the EIF4G1 protein helps initiate the production of other proteins to help the cell cope. Such stresses occur naturally as people age, and if a brain cell cannot adequately respond, it will die. That inability to adapt led to Parkinson's disease in the families studied, Dr. Daechsel says.

This is the third gene that Mayo researchers have found which causes Parkinson's disease, according to Dr. Ross. He adds that Mayo researchers have also identified a number of genetic variants that increase a person's risk of developing the more common sporadic-late-onset form of the disease.

We believe that many of the genes implicated in familial Parkinson's disease may be playing a role in the sporadic form of the disease, because as many as 20 percent of individuals with Parkinson's report a first-degree relative with the disorder, Dr. Ross says. This latest finding adds another piece in the complex Parkinson's puzzle.

This newsletter was assembled by the Morgan Center in Santa Clara. Thank you!

Undetectable blood vessel damage linked to signs of age

Tiny clots in the brain may be the cause of some signs of old age such as stooped posture and restricted movement, say US scientists. Researchers examining the brains of 418 deceased patients found damaged blood vessels in 29% of them which would not have been picked up by normal scans. They said higher levels of damage were linked to more limited movement.

The researchers, writing in [the journal Stroke](#), said declining mobility should not be accepted as normal ageing.

Mild symptoms of Parkinson's disease - such as slow movement, rigidity, tremors and posture - increase with age and are thought to affect up to half of people by the age of 85.

Undetectable

A team of scientists at the Rush University Medical Center, in Chicago, carried out autopsies on the brains of nuns and priests who were taking part in the Religious Order Study. The brains were examined under a microscope for signs of damage which would be invisible to normal brain scans. "If there is an underlying cause, we can intervene and perhaps lessen the impact," said Professor Aron Buchman at Rush University Medical Center. They found 29% of patients with no previously detected sign of stroke had clotted or narrowed blood vessels. When comparing the severity of damage with a score of Parkinson's-like symptoms, the study said there was a link.

It concluded that damage, undetectable with current scanning techniques, "may contribute to the development of what is currently considered 'normal' age-related motor symptoms such as parkinsonian signs". However, it could not prove that the damage itself caused declining mobility, merely that there was a link between the two.

Lead researcher Prof. Aron Buchman said: "This is very surprising. Often the mild motor symptoms are considered an expected part of aging. We shouldn't accept this as normal aging. We should try to fix it and understand it. If there is an underlying cause, we can intervene and perhaps lessen the impact."

Dr Kieran Breen, director of research and development at Parkinson's UK, said: "We know that as people get older they are more likely to develop mini-strokes, so tiny that they cannot be detected by normal scanning techniques."

"Movement problems can occur that are similar to those experienced by people with early mild symptoms of Parkinson's.

As our brains get older many changes do take place, although there is no evidence from this study that these changes lead to full-blown Parkinson's."

<http://www.bbc.co.uk/news/health-14751999>

In Honor

Donations were recently received in honor of the following individuals: Frances Chen, Tony Garcia, Ed Lagrutta, and Frank Mues

In Memory

Donations were recently received in memory of the following individuals: Janis Aochi, Mary Alice Bigham-Hughes, Charles W Block, William F Chin, Leo Coulson, Irvin Cordoza, Harold Furst, Tony Garcia, Raymond Goldberg, Art Kezer, Mary Gene Longenecker, Paul J Meyer, Frank Mues, Anthony Ponza, Lynne Quintero, and Bruce Tune.

Thank you so much for your donations! Please use return address labels, to help us acknowledge your donation properly. Your generous contributions go to support newsletters, education and community awareness of Parkinson's disease. Please mail your donations to: **PPSG, P O Box 60188, Sunnyvale, CA 94088**

Rose Hips

From Wikipedia, the free encyclopedia

The **rose hip**, or **rose haw**, is the fruit of the rose plant. Rose hips are particularly high in vitamin C content, and rose hips also contain some vitamin A and B, essential fatty acids and antioxidant flavonoids. A study of a rose-hip preparation for treating rheumatoid arthritis concluded that there was a benefit, apparently due to both anti-inflammatory and anti-oxidant effects. Rose hips are also used to help prevent colds and influenza.

Generic vs. Branded Drugs for Parkinson's Disease Currently, there are multiple pharmaceutical companies that manufacture a generic formulation of carbidopa/levodopa, dopamine agonists, monoamine oxidase inhibitors and anticholinergics. If you have Parkinson's, are taking brand name medication and then are offered a generic substitution for one of your Parkinson's medications, you should know that the FDA requires that generic drugs must show an "essential similarity" to the branded drug prior to market approval, but that in some cases, this standard is not high enough. [A review supported by NPF](#) chronicles compelling evidence that if you are in more advanced stages of the disease, switching from branded drugs to generic, or from one generic to another, may have adverse effects. The authors, including NPF National Medical Director Dr. Michael S. Okun, believe that the standards for approving generic drugs for Parkinson's may not be strict enough to demonstrate that the generic alternatives are equally effective.

Work with your physician to develop a tailored treatment plan. Using generic drugs may provide a cost savings, but they may not be appropriate for you, especially if you already tolerate the branded drug.

If you make the switch, be sure to follow these tips:

- Report to your physician how effective the drug is
- Carefully keep a diary of any side effects
- Record dose adjustments that your physicians make (higher or lower)
- In general, try to stay with a single drug manufacturer for your generic medications (You may need to ask your pharmacist to special order for you)

When attempts to tailor drug therapy with a generic drug have been unsuccessful, have your doctor appeal to the insurance company for a branded drug. It is important to include meticulous details of the various adverse side effects with the generic medication in your appeal letter. If you have questions about this information, please call NPF's Helpline at 1-800-4PD-INFO (473-4636).

This article was forwarded by Steven Russell.

News and Events at the Parkinson's Institute

Stem Cell Awareness Day

Date: October 5, 2011

Time: 1:00 pm - 3:30 pm

Join us for our 3rd Annual Stem Cell Awareness Day and learn about the latest in research, stem cell legislation, funding, and how you can become a community advocate.

The Management of PD in your Everyday Life and Every Life Stage

Date: October 12, 2011

Time: 1:30 pm - 3:30 pm

Diamonds in the Rough

Date: October 15, 2011

Location: Diamond Creek Vineyards in Calistoga
Diamond Creek Vineyards Tenth Annual Fundraising Dinner to Fight Parkinson's disease

For more information, please contact [Mary Tunison](#), Directory of Development at the Parkinson's Institute, (408) 542-5606 or MTunison@thepi.org

Newly-Diagnosed Seminar

Date: November 3, 2011

Time: 1:30 pm - 3:30 pm

This seminar is a PD 101 with a movement disorder specialist who explains the ins and outs of living with PD and answers common questions for those diagnosed within the last 2 years with Parkinson's. Caregivers and family members are welcome to attend.

Family Treatment of PD

Date: December 6, 2011

Time: 1:30 pm - 3:30 pm

Everyone is in on the act. Family dynamics, the holidays, and stress; ways to help and how to communicate.

DaTscan, New Drug, Help with Early Diagnosis of Parkinson's Disease

By Irene Maher

tampabay.com - For decades physicians have had to rely largely on a keen eye and experience to diagnose Parkinson's disease. Now the pairing of a new drug and a high-tech nuclear brain scan is offering long-awaited help in recognizing the progressive movement disorder, which has neither a specific diagnostic test nor a cure. Any patient who has sought an elusive diagnosis knows the value of being certain of what you're dealing with. Plus, researchers hope that by finding Parkinson's earlier, it may be possible someday to halt the disease's progress.

The telltale signs of Parkinson's — among them trembling of the head, hands, legs or face, rigid posture, lack of facial expression — can range from severe to very subtle, especially at the early stages. Adding to the difficulty, other neurological conditions can be mistaken for Parkinson's, but require different treatments. Some prescription medications have side effects that can cause Parkinson's-like symptoms, further complicating a diagnosis.

Research has shown that about 10 percent of patients suspected of having Parkinson's do not have it. That figure may be 15 or even 25 percent in practices that don't specialize in the condition, said Dr. Robert Hauser, director of the USF Health's Parkinson's Disease and Movement Disorders Center. End result: The proper diagnosis and treatment can be delayed for years. The delay is frustrating at best, and dangerous at worst.

In January the Food and Drug Administration approved a procedure called DaTscan from GE Healthcare, and it now is becoming more widely available. The procedure, which has been done in Europe for the past decade, uses an injected drug, Ioflupane I 123, and a type of brain imaging known as single photon emission computed tomography (SPECT) to look for dopamine, a brain chemical that Parkinson's patients lack. As the disease progresses, dopamine levels decline, and that's what the scan shows.

"A normal image looks like you have two fat commas in the brain," said Hauser, speaking of the part of the

brain where dopamine is concentrated. But because you lose dopamine neurons from the back forward, what happens is one of those commas looks more like a period," he explained."

Dr. Saleem Khamisani, a neurologist at St. Anthony's Hospital in St. Petersburg who specializes in Parkinson's, recently started offering the test. "DaTscan will help us make the diagnosis early and differentiate some other diseases that can be confused with Parkinson's," he said. Early diagnosis is important because there's evidence that at least one Parkinson's medication, Azilect, may not only reduce symptoms but may also slow progression of the disease.

"Normally when you have (obvious) symptoms, you have already lost 80 to 90 percent of cells that produce dopamine in the brain," Khamisani said. "You want to diagnose it at 30 percent and treat them earlier." By the time Vicky Greer had a DaTscan at Tampa General Hospital in December as part of a clinical trial, her dopamine level was 60 percent depleted. It was just last summer that the St. Petersburg teacher noticed she was extremely fatigued, had trouble walking and was developing a slight tremor in her right hand. Her family doctor dismissed the notion of Parkinson's, but when her symptoms worsened in the fall, she sought out Hauser.

"He looked at me and watched me walk and said he was about 98 percent sure that it was Parkinson's," recalls Greer.

The scan confirmed the diagnosis. "It was hard," said Greer, a reading teacher at Tomlinson Adult Learning Center.

"I'm an active, young 59-year-old. It has really impacted my lifestyle." Grim as the news was, Greer said it was a relief to have an explanation for her symptoms.

This article was forwarded by Steven Russell.

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Study suggests seeing a neurologist helps people with Parkinson's live longer

EurekAlert -

People with Parkinson's disease who go to a neurologist for their care are more likely to live longer, less likely to be placed in a nursing home and less likely to break a hip than people who go to a primary care physician, according to a study published in the August 10, 2011, online issue of *Neurology*[®], the medical journal of the American Academy of Neurology (AAN).

The study also found that women and minorities were less likely to see a neurologist than men and Caucasians, even after adjusting for factors such as age, socioeconomic status and other health conditions.

"If these findings are confirmed in future studies, they will have important policy implications," said James F. Burke, MD, of the University of Michigan in Ann Arbor and a member of the American Academy of Neurology, who wrote an editorial about the study. "Disparities in access to care should become a pressing priority if these limits to access are associated with worse outcomes. Policy changes could focus on improving access to neurologists or on improving the knowledge and care given by primary care physicians."

For the study, researchers examined the records of everyone on Medicare with a new diagnosis of Parkinson's disease who was seen in an outpatient clinic during 2002. Of the 138,000 people who were diagnosed with Parkinson's disease that year, 68 percent were seen by a neurologist from 2002 to 2005. Those seen by a neurologist were 20 percent less likely to die over a six-year period than those seen by a primary care physician. They were also 20 percent less likely to be placed in a nursing home and 14 percent less likely to have a broken hip. Women were 22 percent less likely to see a neurologist than men, and minorities were 17 percent less likely to see a neurologist than Caucasians.

Study author Allison Wright Willis, MD, of Washington University School of Medicine in St. Louis and a member of the American Academy of Neurology, said, "We need to understand how care

may affect people's health care outcomes to improve the quality of life for people with Parkinson's and also to minimize any avoidable health care costs."

Other studies have shown that the one year per-person direct cost of a hip fracture is up to \$26,000. "Of course, the benefit to people with Parkinson's disease and their families of avoiding a hip fracture or delaying the need for nursing home placement is immeasurable," she said.

Willis said there are several possible reasons why women and minorities may receive neurologist care less often than men and Caucasians. "Complicated types of Parkinson's may be more common in some groups," she said. "Women and their spouses may not request specialist care as often as men and their spouses do."

Burke noted that various limitations of the study could affect the results. For example, the study did not take into account the severity of the disease.

This article was forwarded by Steven Russell.

Brain PET scan

A brain positron emission tomography (PET) scan is an imaging test that uses a radioactive substance (called a tracer) to look for disease or injury in the brain.

Unlike magnetic resonance imaging (MRI) and computed tomography (CT) scans, which reveal the structure of the brain, a PET scan shows how the brain and its tissues are working.

How the Test is Performed

The health care provider will inject a small amount of a radioactive material into one of your veins, usually on the inside of the elbow. Or you may inhale the radioactive material as a gas. The substance travels through the blood and collects in the tissues of the brain.

You will be asked to wait nearby as the radioactive substance is absorbed by your body. This usually takes about 1 hour.

Then, you will lie down on a table that slides into a tunnel-shaped hole in the center of the PET scanner.

The PET machine detects energy given off by the radioactive substance and changes it into 3-dimensional pictures. The images are sent to a computer, where they are displayed on a monitor for the health care provider to read.

You must lie still during the PET scan so that the machine can produce clear images of your brain. You may be asked to read or name letters if your memory is being tested.

The test takes between 30 minutes and 2 hours.

How to Prepare for the Test

You must sign a consent form before having this test. You will be told not to eat anything for 4 - 6 hours before the PET scan, although you will be able to drink water.

Tell your doctor if you are pregnant or think you might be pregnant.

Also tell your doctor about any prescription and over-the-counter medicines that you are taking, because they may interfere with the test.

Be sure to mention if you have any allergies, or if you've had any recent imaging studies using injected dye (contrast).

People with diabetes who take insulin injections will need special preparation. Call the PET scan office the day before the study for instructions.

During the test, you may need to wear a hospital gown. Take off any jewelry, dentures, and other metal objects because they could affect the scan results.

How the Test Will Feel

You will feel a sharp prick when the needle with the radioactive substance is inserted into your vein. You shouldn't feel anything during the actual PET scan.

Why the Test is Performed

A PET scan can reveal the size, shape, and function of the brain, so your doctor can make sure it is working as well as it should. It is most often used when other tests, such as MRI scan or CT scan, do not provide enough information.

This test can be used to:

- Diagnose cancer

- Evaluate a patient with epilepsy who may need surgery

Help diagnose dementia if other tests and exams do not provide enough information

Several PET scans may be taken to determine how well that you're responding to treatment for cancer or another illness.

Normal Results

There are no problems detected in the size, shape, or function of the brain. There are no areas in which the radiotracer has abnormally collected.

Risks

The amount of radiation used in a PET scan is low. It is about the same amount of radiation as in most CT scans. Also, the radiation doesn't last for very long in your body.

However, women who are pregnant or are breastfeeding should let their doctor know before having this test. Infants and fetuses are more sensitive to the effects of radiation because their organs are still growing.

Before receiving the contrast, tell your health care provider if you take the diabetes medication metformin (Glucophage) because you may need to take extra precautions.

It is possible, although very unlikely, to have an allergic reaction to the radioactive tracer. Let your doctor know if you have ever had an allergic reaction to injected contrast dye. Some people have pain, redness, or swelling at the injection site.

Considerations

It is possible to have false results on a PET scan. Blood sugar or insulin levels may affect the test results in people with diabetes.

Most PET scans are now performed along with a CT scan. This combination scan is called a PET/CT.

Alternative Names

Brain nuclear medicine scan; Brain positron emission tomography.

<http://www.nlm.nih.gov/medlineplus/ency/article/007341.htm>

Parkinson's Disease: Tips for Caregivers

By Sandra Ray, Staff Writer, www.caregiver.org

The first noticeable symptom of Parkinson's is usually a slight tremor in the limbs. Over time, the patient will experience difficulty walking and may progress into a typical "Parkinson's Gait" – shuffling, head facing downward, and little or no swinging of the arms. Freezing in mid-stride is also a common feature. Other secondary symptoms related to Parkinson's include difficulty swallowing, small or cramped writing, loss of bowel control or constipation, dry skin and scalp, and even excess salivation.

Medication Management:

Keep medications in their original containers.

- Keep handy a list of medications that your loved one takes in case someone else needs to dispense medications for you.
- Take the list to each doctor appointment, especially if you are seeing a physician who isn't familiar with your situation.
- Consider using medication "mindes" for time of day or days of the week to keep a good system in place.
- Keep other family members and friends informed about the medication schedule, especially if you are the sole caregiver.

There are patient assistance programs available through most of the pharmaceutical companies. To find out if your medications are covered by these programs, visit www.rxassist.org or www.needymeds.com.

Lifestyle Changes:

Parkinson's disease may not require a dramatic change in your lifestyle overnight, but there will need to be some adjustments made, especially as the disease progresses.

Finding the right exercise program is important. Many people find that they are able to maintain a fairly active lifestyle, making minor accommodations in the beginning for Parkinson's.

It is important, however, to consider slowing down or limiting certain types of activities due to the disease and its progression.

Diet is especially important. If your loved one is overweight, now is an excellent time to begin managing weight loss. Losing weight can help your body adjust quicker to movement-related issues and can help muscles adjust to the extra demands of the disease. Your physician can suggest dietary changes that will provide the maximum health benefit and one that can be easily adopted by others in the household if this is a requirement.

If problems like swallowing do occur, changing the types of food in the diet may become critical. In addition, too much saliva can hinder swallowing, so limiting the foods that aggravate salivation may be helpful as well.

Traveling with Parkinson's:

Many people feel that Parkinson's disease limits their ability to travel and enjoy the retirement or later years. Instead, people with Parkinson's can still travel – they just need to make a few extra planning steps in order to make their trip enjoyable. Here are a few tips to consider:

- If you're flying, arrive at the airport earlier than usual.
- Double-check your medication to make sure that you have more than you'll need for the trip.
- If you can't bring extra medication, check to see if your pharmacy is available in the town where you'll be traveling.
- Keep emergency numbers stored in more than one place.
- Plan extra time on your vacation for rest.

A Note to Our Readers!

This newsletter is for informational purposes only. Readers are advised to consult a trained medical professional before acting on any of the information in this newsletter. The fact that a particular treatment, nutrient, herb, or supplement is discussed in this newsletter in connection with any illness or condition does not necessarily mean that it is safe and appropriate for everyone or that the editor or PPSG recommends its use for that illness or any condition.



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You are welcome to **drop by our board meetings and share ideas with us!** We meet on the **3rd Monday** of the month between **1:00 and 3:00 PM** at the Parkinson's Institute, at 675 Almanor Avenue, Sunnyvale, CA 94085. To confirm meeting dates and time, please call us at **408.542.5610**. If you are planning to attend, please call Charmaine Eng at 408.723.8116 (dial *82 before the number).



For current lists on exercise classes, and support group information/activity calendars, please log on to www.ppsg.org. These lists are maintained by **Steven Russell**.



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