



## Medical Director's Update:

Exploring Some Causes of Parkinsonism—

Will an influenza pandemic result in an epidemic of Parkinson's disease?

Thomas C. Hammond, MD

In 1817 James Parkinson, member of the Royal College of Surgeons wrote "An essay on the shaking palsy." In this publication he described accurately the major features that characterize what is now called Parkinson's disease (PD). Resting tremor, rigidity (stiffness of the muscles), akinesia (slowing of movements), and postural impairment (the four easily recalled by the mnemonic TRAP) were eloquently described as Parkinson presented illustrative case histories. In the current day, any patient who exhibits two of the four cardinal features outlined above is now said to have parkinsonism and more recently akinesia, or slowing of movement, has become a mandatory feature to diagnose PD.

Idiopathic PD is the most common cause for parkinsonism and is now known to be caused by loss of cells in the midbrain nucleus called substantia nigra (SN). When the patient shows the first sign of tremor or slowness, they have already lost about 70% of the pigmented neurons in the SN. Currently it is felt that a "first hit" causes cells to die off in the SN — perhaps a toxin such as pesticide exposure, or multiple head trauma such as boxing, interacts with the patient's underlying "genetic susceptibility" and a large number of SN cells die. With aging there is a slow decline in brain cells which is generally innocuous. However in the PD patients who suffered the "first hit" of cell loss they reach a 70% loss of SN cells that is critical for PD symptoms to appear.

What causes this loss of cells in the SN currently remains an enigma. James Parkinson speculated that there was a "swelling in the medullary column" (about two inches south of the SN!). He suggested treatment by leeches to "take blood" from the neck and application

of "vesicatories" to obtain "a purulent discharge" thereby draining pus for a cure. (These remedies were popular at that time!) Thus James Parkinson clearly was suggesting that infection may be playing a causative role in PD.

We now know that inflammation of blood vessels in the brain, or vascular disease causing strokes in the motor control areas, can cause parkinsonism, most often without tremor. There are a number of other rare causes of cell loss in the SN and motor control areas of the brain that result in degeneration of these cells and lead to conditions often referred to as "Parkinson's Disease Plus." These include progressive supranuclear palsy, multiple system atrophy, and primary autonomic failure (Shy-Drager syndrome).

Brain infections with viruses are referred to as encephalitis and these also can result in parkinsonism. The most dramatic and clear-cut example was the "Spanish flu" in 1918. This influenza type A virus is referred to as SC18 and was associated with a condition called encephalitis lethargica (Von Economo's encephalitis — VEE). Patients who had this viral encephalitis developed parkinsonism which was responsive to L-Dopa when the drug was developed in the 1960s. Almost five million people worldwide suffered from this condition. It was called "sleeping sickness" in the United States. One-third of the victims died from the disease and many others developed VEE related parkinsonism.

In the 1973 book by the New York Neurologist, Oliver Sacks, titled *Awakenings*, Sacks documents cases of VEE related Parkinsons patients who were treated with L-Dopa and "awoke" from their rigid, tremulous state. This was subsequently made into a movie starring Robin



## THE Parkinson's Source

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*Reminder:*

All material related to Parkinson's disease contained in this newsletter is solely for the information of the reader. It should not be used for treatment purposes, but rather for discussion with the patient's own physician. Specific articles reflect the opinion of the writer and are not necessarily the opinion of the Editor, the I&R Center, the Medical Director of the Center or the APDA.

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**National Young Onset PD**  
[www.youngparkinsons.org](http://www.youngparkinsons.org)



## Upcoming Events

### December 7, 2009 - Deerfield Beach

PARKINSON'S DISEASE UPDATE &  
RECOGNITION LUNCHEON

*Featuring:*

"Parkinson's Jeopardy" audience participation  
PD Update and Q&A - Thomas C. Hammond, MD

### January 27, 2010 - Deerfield Beach

PARKINSON'S 101 WORKSHOP  
Newly/Recently Diagnosed Workshop

### March 12, 2010 - Boca Raton

PARKINSON'S DISEASE SYMPOSIUM  
Boca Raton Marriott

### April 10, 2010 - Delray Beach

PICNIC & FUN WALK  
Annual Fundraiser for Parkinson's Research

**For more information call**  
**(954) 786-2305 or (800) 825-2732**

## Parkinson's Caregiver Respite Program

In home and adult day care respite assistance is now available  
to Chapter members in Broward and Palm Beach Counties.

To learn more about these programs contact  
the APDA Chapter at 800-825-2732.



## President's Message

Dear Members,

The South Florida Chapter would like to take a moment to remember Dr. Paul Maestroni, Director of Scientific/Medical Affairs from our national office.

We would like to thank his family for the years of service he provided to the Parkinson's Community throughout the United States as well as internationally.

This summer, Gigi Gilcrease, RN, MBA, and I attended the APDA Chapter Presidents & Coordinator Conference in Seattle, WA. Beside the wealth of knowledge we acquire at this meeting, networking with other Chapters and Coordinators is a huge benefit. Rather than reinvent the wheel, we share program and service initiatives. I felt very proud of the South Florida Chapter meeting many of the needs of our Parkinson's community with a variety of quality education programs, support groups and services, exercise, caregiver respite assistance and fundraising activities.

I look forward to seeing you at our upcoming

annual events: PD Update and Recognition Luncheon in December, Parkinson's Symposium in March and, to promote Parkinson's disease Awareness Month and raise funds for research, our Picnic and "Fun" Walk in April. If you are interested in volunteering to help with events, contact Gigi at 800-825-2732.

Our thoughts and prayers are with you and your families during these uncertain and tough economic times. However donations are vital in order for us to develop new and continue current services and programs. Please consider making a donation, in any amount, to the APDA South Florida Chapter.

My husband Jim and I understand what each of you are facing when dealing with Parkinson's, please keep in touch and remember American Parkinson Disease Association is here to "Ease the Burden — Find the Cure" for Parkinson's disease.

*Linda*

Linda Gilchrist  
Chapter President



***We wish  
all of you  
a safe and  
wonderful  
Holiday  
Season.***

*South Florida Chapter  
American Parkinson  
Disease Association*

*Continued from page 1*

### **Medical Director's Update:**

Williams and Robert DeNiro. The patients with VEE related parkinsonism differ from PD in that they only responded for a brief period of time to L-Dopa, then rapidly spiraled down into their frozen rigid state. Rarely have other viruses such as Western Equine, Eastern Equine and Japanese B encephalitis caused parkinsonism.

Some viruses are neurotropic. This means they are capable of infecting nerve cells or do so preferentially. Examples are herpes viruses such as herpes simplex virus 1 (HSV-1) which causes fever blisters and occasional encephalitis; herpes simplex virus 2 (HSV-2) which causes genital herpes and may cause meningitis or encephalitis; and Varicella Zoster (the chickenpox virus) which can not only cause chickenpox in childhood but lives on in an individual's nerve tissue through adulthood and causes re-infection in the form of shingles, or at times inflammation of the spinal cord or brain.

Some influenza strains are also neurotropic. The 1918 influenza pandemic occurred before the modern era of virology. However, post mortem examination of six patients with VEE parkinsonism was done in 1973 and revealed antigen for influenza A virus in brain tissue within the midbrain and motor control areas in the brain. These six patients with VEE parkinsonism were matched with six control patients with idiopathic PD, none of whom exhibited the influenza viral antigen in brain tissue. This finding clearly demonstrated that infection of brain tissue with this neurotropic influenza virus was a causal factor in the VEE parkinsonism.

In the past several years two worrisome strains of influenza have emerged. H5N1 is the Asian "bird flu" which is still restricted to Asia and still predominantly affecting the bird population with relatively rare human infections.

However, there have been 433 known bird flu human cases in Asia, 61% of these have been fatal. Elegant research done and published in the past few months by the Neurobiology and Virology Group at St. Jude's Children's Research Hospital in Memphis, Tennessee, examined the H5N1 virus closely. They infected mice with the Asian H5N1 virus and showed that it travels from the peripheral nervous system (via the mucous membranes in the nasal and throat cavity) into the central nervous system and causes inflammation in brain cells (encephalitis). Furthermore, the cells in the brain were found to be over-producing

alpha-synuclein which is a protein that aggregates in brain cells in PD patients.

Given these findings there is a strong likelihood that a bird flu pandemic would likely lead to a large number of new cases of encephalitis and post-encephalitic parkinsonism quite similar to the 1918 pandemic. Even if patients were not to exhibit parkinsonism immediately, this virus seems to be a causative agent producing a "first hit" to the SN cells causing a large number to die off and then setting the stage for early development of PD as the patient ages. Let us hope that this virus chooses to remain in the bird population.

The other worrisome virus is H1N1 (Swine flu) which is increasing in the number of cases in both the U.S. and worldwide and is felt to represent a pandemic influenza outbreak. Recent data on H1N1 in the U.S. reviewing the first 642 cases revealed a median age of patients affected is 20 years of age. 40% of the patients have been 10 years to 18 years and 35% have been 19 to 50. No one over the age of 51 has been hospitalized with H1N1. This Swine flu appears to be affecting younger persons and is unlikely to be a major factor affecting PD patients (about 1% of PD below the age of 50).

At this time, essentially all PD patients should get the seasonal influenza vaccine. Reactions to the vaccine are usually minor or none at all while influenza can be a severe and devastating illness for a PD patient. The H1N1 Swine flu vaccine (injection of dead viral antigen) is also a reasonable vaccination for most PD patients. Fortunately, so far H1N1 appears to be of low virulence in patients over the age of 50 and is not neurotropic so should not cause encephalitis or aggravation of Parkinson's disease.

**Please discuss these vaccinations with your primary doctor.**

In summary, viral infections can cause neural damage and the worrisome virus is the H5N1 bird flu. This virus could potentially lead into another "Spanish flu" pandemic such as that which occurred in 1918 with an increase in PD.

In the meanwhile, get your flu vaccine and keep up your exercise program. Regular exercise increases brain levels of neural growth factors that protect brain cells from injury such as infection.

*Sincerely,*

*THOMAS C. HAMMOND, M.D.*

*Medical Director*



Dear Friends,

I am saddened over the passing of Dr. Gianpaolo "Paul" Maestroni. For over twenty years, Paul was our Director of Scientific and Medical Affairs at the American Parkinson Disease Association (APDA) headquarters

in Staten Island, New York.

The exemplary high standards Dr. Maestroni set for his personal and professional accomplishments, carried through to his service with Parkinson's disease (PD). He selflessly devoted a large portion of his life, talent and spirit into developing programs and seeking research funds to help persons and families afflicted with the disease.

Paul was known worldwide. He helped raise Parkinson's disease awareness and made the APDA one of the largest grassroots organizations. He created the Information and Referral Center (I&R) concept whereby persons with PD, and their families, can now obtain information, education and support from healthcare professionals in 60 centers nationwide. He was instrumental in developing the World Parkinson Disease Organization involving 25 countries and in securing funding of \$30 Million for Parkinson's Research.

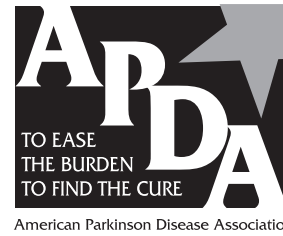
The Parkinson's Community has lost hero and a friend. He will be missed by all of us.

Our thoughts and prayers are with Paul's wife, Sophia and family.

*Gigi Gilcrease, RN, MBA  
Director & Coordinator*



*Faye Kern, I&R Coordinator, West Coast Florida is pictured here with Dr. Paul Maestroni in 2006. She had the honor of knowing Paul for 15 years. Faye states, "Paul was a friend of the coordinators and realized the importance of their work in the Parkinson's community." She added; "A smile placed on your heart by those who care is to be cherished."*



## Information & Referral Center

The American Parkinson Disease Association (APDA) has as its mission: "To Ease The Burden, To Find The Cure" for this neurological disorder affecting over one million Americans.

APDA focuses its energies on patient and family services, education, community awareness, and research. To accomplish this, APDA offers a comprehensive Information and Referral Center.

### TURN TO US...

For help answering questions and working through challenges. We offer:

- A telephone helpline
- Counseling and advocacy
- Referrals to community resources
- Support group network
- Caregiver respite — Palm Beach/Broward
- Regional symposium
- Newly diagnosed workshop

### ASK US...

For reliable information. This includes:

- Handbooks about the disease and daily living
- Newsletter: *The Parkinson's Source*
- Website announcements
- A library of books, DVDs, and other resources
- Community Education

### COUNT ON US...

For friendly and professional assistance you can trust. The Center has a:

- Nurse Coordinator and consulting neurologist  
Medical Director specializing in PD

### HELP US...

We need your help to continue these vital services through charitable donations to the South Florida Chapter.

### CONTACT US...

American Parkinson Disease Association  
Information & Referral Center  
201 E. Sample Road, Deerfield Beach, FL 33064  
(954) 786-2305 or (800) 825-2732  
[www.apdaflorida.org](http://www.apdaflorida.org)

# SUPPORT GROUP & EXERCISE CALENDAR • 1-800-825-2732

## SOUTH FLORIDA

### MIAMI-DADE COUNTY

#### Coral Gables

TEMPLE JUDIAH

5500 Granada Boulevard

2nd Thursday/month 11:00AM-12:30PM

Contact: Carol Goldman 305-476-8782

#### MIAMI VAHCS - Veterans Only

1201 NW 16th Street

7th Floor, Pain Clinic Psych Office

Room D707

Every Thursday 10:45AM

Contact: Paul Hartman, PhD 305-575-3215

### BROWARD COUNTY

#### Coral Springs

CORAL SPRINGS MEDICAL OFFICE

3100 Coral Hills Drive (next to hospital)

Support Group and Exercise

3rd Monday/month 2:00-3:30PM

Contact: APDA 800-825-2732

#### Davie

NOVA SOUTHEASTERN UNIVERSITY

University Park Plaza - Rm 515

3530 S University Drive

Every Wednesday 10:45-12:00NOON

Contact: Dr. Blodgett 954-262-5611

#### Deerfield Beach

NORTH BROWARD MEDICAL CENTER

201 E. Sample Road, Neuro Center

(off lobby)

Support Group and Exercise

2nd Tuesday/month 1:00-3:00PM

Contact: APDA 800-825-2732

#### Margate

NORTHWEST REGIONAL

MEDICAL CENTER

2801 N. State Road 7

Support Group and Exercise

1st Friday 1:00-3:00PM

Contact: Agnes Porzio 954-972-2221

### PALM BEACH COUNTY

#### Boynton Beach

"On Hold"

**NOTE:** Support Group day and time may change periodically.

For current updates on South Florida

Support Groups and Exercise

call the APDA Information

and Referral Center

at 1-800-825-2732.

#### Delray Beach

SOUTH COUNTY CIVIC CENTER

16700 Jog Road

Support Group and Exercise

1st Wednesday/month 2:00-4:00PM

CAREGIVER GROUP - CALL FOR DATES

Contact: APDA 800-825-2732

#### Jupiter

JUPITER TOWN COMPLEX

Activities Building, 210 Military Trail

Every Friday 1:00-3:00PM

Contact: Lottie Redlin 772-283-5693

#### Royal Palm Beach

CULTURAL CENTER

Royal Palm Beach Cultural Center

151 Civic Center Way

Support Group and Exercise

Monday and Wednesday 10:00-12:00

Contact: Mr./Mrs. Rodgers 561-791-9885

### EXERCISE ONLY

#### Boca Raton

Sugar Sand Park Field House

300 S. Military Trail

Monday 11:30AM-12:30PM

Wednesday 2:00PM-3:00PM

First class is free, just stop by the park

Contact APDA: 800-825-2732

#### Davie

Nova Southeastern University

Physical Therapy PD Exercise

Sanford L. Ziff Health Center

3200 S University Drive

Monday and Wednesday 12:30PM

Call: 954-262-4149

Speech Therapy PD Exercise

Wednesday 1:30-2:30PM

Call: Dr. DiCarlo 954-262-7726

### MARTIN COUNTY

#### Stuart

GRACE PLACE COMMUNITY CHURCH

1550 SE Salerno Road

Support Group

2nd Monday/month 1:00-3:30PM

Contact: Aileen Stiehle 772-286-3268

### ST. LUCIE COUNTY

#### Port St Lucie

HARBOR PLACE

3700 SE Jennings Road

3rd Tuesday/month 2:00-3:30PM

Contact: Cathy 772-201-6007 or

Laura 561-209-6124

## CENTRAL FLORIDA

#### Holly Hill

BISHOP'S GLEN RETIREMENT CENTER

900 LPGA Boulevard

4th Wednesday/month 2:00-3:30PM

Contact: Bruce Kozak 386-226-9000

#### Melbourne

SOUTH BREVARD PARKINSON'S

SUPPORT GROUP

Eau Galle Public Library

1521 Pineapple Avenue

4th Thursday/month 1:30PM

Contact: Lyndon Kirk 321-777-3590

#### Titusville

NORTH BREVARD PARKINSON'S

DISEASE AND CAREGIVERS

SUPPORT GROUP

c/o Parrish Medical Center

951 N. Washington Avenue

3rd Saturday/month 11:00AM

Contact: Mary McDowell 321-268-2363

#### Winter Park

FIRST UNITED METHODIST CHURCH

Wesleyan Building, Room 236

125 N. Interlachen Avenue

1st Friday/month 10:00am-12:00NOON

Contact: Dr. Lucy Braun 407-423-5311

## NORTHEAST FLORIDA

For information on the groups in cities

listed below, call: APDA Coordinator

Audrey Strongosky 904-953-7030

Deland

Orange City

Jacksonville

St. Augustine

Jacksonville - Young Onset

## WEST COAST FLORIDA

For information on the groups in cities

listed below, contact: APDA Coordinator

Faye Kern 727-328-6246

Avon Park

Orlando

Barrington

Palms of Largo

Bradenton

Pensacola

Clearwater

Sarasota

Englewood

Springhill

Fort Walton

St. Petersburg

Inverness

Sun City Center

Lady Lake

Tampa

Lakeland

West Pasco

Leesburg

Young Onset

North Port

Tampa Bay

Ocala

## Two Ways to Help APDA Go Green!

### 1. Update Our Mailing List:

Help us update our mailing list and your information by letting us know if this newsletter is reaching the wrong person or incorrect address.

### 2. Email Notices:

Receive newsletters, support group and other notifications by email instead of direct mail.

Please email your "primary" email to [apdasflorida@netzero.com](mailto:apdasflorida@netzero.com).

Or clip this section out of the newsletter and mail **changes only** to your information.

**YES!** I would like to receive newsletters, support group and other notifications by email.  
PLEASE PRINT CLEARLY

Name \_\_\_\_\_

Primary Email \_\_\_\_\_

## Making it Through the Tough Times: Building Resilience

*by Linda O'Connor, LCSW (excerpted from David Rintell, PhD)*

Getting a diagnosis of Parkinson's disease is a life changing event which starts people (both the person diagnosed as well as family members) on a journey full of challenges and uncertainty. But how you react to these challenges, how well you adapt to the changes and continue on with life can make all the difference in the world related to how you feel emotionally, how well you cope and the impact it has on your relationships. The quality of adapting well in the face of struggle is called resilience.

Resilience involves the ability to confront adversity and still find hope and meaning in life. It is having the capacity to "bounce back" from a difficult time feeling strengthened and more resourceful. Resilience is not a trait that people either have or don't have, rather it is a process involving behaviors, thoughts and actions that can be developed and strengthened. So the good news is that no matter what your age, your life circumstances or your PD symptoms, you can take steps to build your resilience so you can "weather" life's challenges and still remain in one piece.

Listed below are 10 ways to build resilience. You may already be doing some of these but it never hurts to add on additional strategies. In this uncertain world we live in we need all the help we can get!

- 1) **Make connections** — lots of research (and common sense) tells us that people who have some social support do better both emotionally and physically.
- 2) **Make achievable goals** — make them small and realistic. Figure out what you can change and what you need to let go of.

- 3) **Take action!** — act on your goals, it gives a sense of accomplishment and capability and that feels good.
- 4) **Locate your strengths** — how did you overcome challenges in the past? What skills did you use? Everyone has strengths, you just have to sometimes remind yourself.
- 5) **Express gratitude** — it reminds you that something is good and changes your focus.
- 6) **Maintain hope** — give yourself permission to be hopeful, hope is justified (there's lots of PD research underway).
- 7) **Keep things in perspective** — avoid blowing things out of proportion. Focus on what you can do instead of what you can't.
- 8) **Utilize your faith/spirituality** — having a connection to a community of faith, having a sense of something larger than yourself can bring comfort and peace.
- 9) **Give to others** — attend a support group, volunteer with the APDA Chapter, get involved with a community group; it's all good and changes your perspective.
- 10) **Humor works** — laugh at the silliness of life, find the humor in struggle, it really does lighten the load a bit. For more information on this topic go to: <http://helping.apa.org>.

*Linda O'Connor, LCSW is the APDA Coordinator at Cedars Sinai in Los Angeles, California.*

## Please Help Support APDA By Making An End of The Year Donation

Funding is crucial for Parkinson's research and local programs. Like most of you, economic times have greatly impacted charities. ***In order for us to be here for you tomorrow, we need your support today!***

Please make a tax deductible donation to the APDA South Florida Chapter by mailing the form below and including a check, money order, or credit card (Visa or MasterCard); or by calling (800) 825-2732; or going to our website at [www.apdaflorida.org](http://www.apdaflorida.org).

Please send your tax deductible donation payable to: **APDA South Florida Chapter, 201 East Sample Road, Deerfield Beach, FL 33064**  
 PLEASE PRINT CLEARLY

### Membership/Contribution Information

Name \_\_\_\_\_ Phone \_\_\_\_\_

Address \_\_\_\_\_ City \_\_\_\_\_ State \_\_\_\_\_ Zip \_\_\_\_\_

Enclosed is my check for:  \$1000  \$500  \$250  \$100  \$75  \$50  \$35 (membership)  Other \_\_\_\_\_

Include membership with my donation of \$50 or more. VISA or MasterCard # \_\_\_\_\_ Exp. Date \_\_\_\_\_

### Tribute Information

In Memory of  In Honor of  \_\_\_\_\_ Send Acknowledgement to \_\_\_\_\_

Address \_\_\_\_\_ City \_\_\_\_\_ State \_\_\_\_\_ Zip \_\_\_\_\_

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