



# THE PADRECC POST



## The Philadelphia VA Parkinson's Disease Research, Education and Clinical Center

Volume 2, Issue 1

Summer 2004

### Inside This Issue:

Speech and Swallowing Disturbances: The Facts	2
Presidential Trivia	3
An Overview of Dementia for Patients and Caregivers	4
The Other Faces of PD	5
Helpful Resources for Patients & Families	5
<u>Parkinsons:</u> Musical CD to Benefit PD Research	6
Important Tip	6
PADRECC Support Groups	7
Answers to Presidential Trivia	7



## Speech and Swallowing Patient Education Fair

The Philadelphia PADRECC held a Speech and Swallowing Patient Education Fair on Friday, May 14th, 2004. Julia Howard, MS CCC-SLP, Philadelphia VA's speech pathologist, provided valuable information on speech and swallowing disturbances in Parkinson's disease. Topics included common signs and symptoms as well as treatment strategies and options. Tables were also set up for veterans and caregivers to learn more about aspiration precautions, Lee Silverman Voice Therapy, Barium Swallow procedure, and different types and textures of food.

If you were unable to attend this program but would like a copy of Ms. Howard's presentation please contact the PADRECC at **215-823-5934**. Also, please turn to **page 2** for more information on speech and swallowing disturbances and pictures from the fair.



**Julia Howard, MS CCC-SLP presenting information on speech and swallowing disturbances in PD**

## Speech and Swallowing Disturbances: The Facts

### Speech Disturbances

- ♦ 75-100% of people with PD experience speech disturbances
- ♦ **Symptoms:** low volume, monotone, fast rate, rushes of speech, affects your respiration, voice, and articulation.
- ♦ **Treatment:** Lee Silverman Voice Treatment, compensatory speaking strategies, augmentative communication (ex. Picture boards), self awareness

### Swallowing Disturbances

- ♦ **Symptoms:** coughing, choking, throat clearing, gurgly voice while eating/drinking, "lump in throat", fevers, pneumonia (unexplainable), decreased appetite, holding food/liquids in mouth, heartburn
- ♦ **Risks:** pneumonia, malnutrition, dehydration, **DEATH**
- ♦ **Treatment:** medication management, compensatory strategies/swallow precautions (chin tuck, alternate liquids and solids, single sips, slow rate), consistency changes (thickening liquids, pureed/soft solids), exercises, electrical stimulation

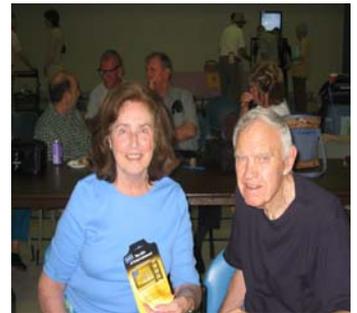
### When is it time for an evaluation?

- ♦ Whenever you experience symptoms, big or small, you should bring these to the attention of your doctor or nurse. Speech and swallowing symptoms can be subtle, but may represent larger problems. **Don't wait....Early Intervention is the Key!!**

### Resource Information

- ♦ **Julia Howard** is the Speech Therapist for the PADRECC and is available for consultation during your PADRECC visit.
- ♦ Your primary doctor or nurse may know of a speech pathologist they can refer you to.
- ♦ American Speech Language Hearing Association: 1-800-638-8255 or [www.Asha.org](http://www.Asha.org)
- ♦ **Lee Silverman Foundation:** [www.lsvt.org](http://www.lsvt.org)
- ♦ **The National Parkinson Foundation:** [www.parkinson.org](http://www.parkinson.org)

## Pictures from the Speech and Swallowing Fair



## Presidential Trivia



*The following are descriptions of a President of the United States. Please answer the questions below with the President's name who best fits the description. Answers can be found on **page 7** of the Newsletter.*

1. He was the Nation's 1st "Darkhorse" candidate for president and was a workaholic who drove himself ruthlessly. \_\_\_\_\_
2. A large, powerful man, he wore various sets of dentures but none were made of wood. He died of throat cancer. \_\_\_\_\_
3. He suffered from an eye disorder that caused him to cock his head to the left and close an eye. He was also the 1<sup>st</sup> bachelor president. \_\_\_\_\_
4. The 1<sup>st</sup> Quaker President who became the symbol for the Great Depression. \_\_\_\_\_
5. This former President along with his brother-in-law founded the Peace Corps. He was also 1 of 2 Presidents to be buried at Arlington National Cemetery. \_\_\_\_\_
6. The cornerstone of his administration's foreign policy was a call for human rights around the world. He is also a speed-reader and has been clocked at 2,000 words a minute with 95% comprehension \_\_\_\_\_
7. He was the 1<sup>st</sup> president to die in office and was also known as "Old Tippecanoe." \_\_\_\_\_
8. He was the shortest and skinniest president and was known as "master builder of the Constitution" and chief author of the Bill of Rights. \_\_\_\_\_
9. This president was assassinated while standing in line at the Pan American Exposition in Buffalo, NY \_\_\_\_\_
10. He was ranked by historians as one of the worst presidents, if not the worst. \_\_\_\_\_
11. He was the 1<sup>st</sup> president born an American citizen and was an impeccable dresser. \_\_\_\_\_
12. The Nation's tallest president who delivered the famous Emancipation Proclamation in 1863 \_\_\_\_\_
13. This president coined the phrase "We hold these truths to be self evident, that all men be created equal." \_\_\_\_\_
14. The only professional actor to become president not to mention the oldest one in history. \_\_\_\_\_
15. Contracted polio at age 39 and was an avid stamp collector. He coined the phrase "The only thing we have to fear is fear itself." \_\_\_\_\_
16. His hands shook with palsy and he died the same day as Thomas Jefferson. \_\_\_\_\_
17. The current President of the United States \_\_\_\_\_
18. His administration created the Department of Health, Education & Welfare. \_\_\_\_\_



# An Overview of Dementia for Patients and Caregivers

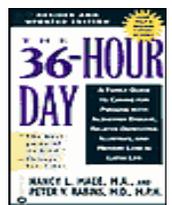
By: Gretchen Glenn, MSW, LSW

Dementia is a syndrome caused by a wide range of diseases that affect the brain such as PD. It has been estimated that as many as 50% of PD patients develop dementia at some point in the disease process. However, not every person diagnosed with PD will develop dementia. It afflicts both the young and the old and can be mild or rapidly progressive. The most common symptoms are a gradual loss of memory, problems with reasoning or judgment, disorientation, difficulty in learning, loss of language skills, and decline in the ability to perform everyday tasks. In addition, people with dementia also experience changes in their personalities and behavioral disturbances, such as agitation, anxiety, delusions, and hallucinations.

Dementia can be very disabling to both the patient and the caregiver. Like Parkinson's disease, the cause and progression of the disease varies from person to person and currently there is no cure. People with a dementing illness experience difficulties remembering things and their ability to understand, reason, and use good judgment may be impaired. A person with mild to moderate dementia may be able to perform normal activities; where as those with moderate to severe dementia may not be able to perform simple everyday tasks. Some are able to conceal their level of impairment and others deny that anything is wrong or place blame on others for their problems. Typically, people with memory impairment become upset when tasks that were once simple become difficult or impossible. It is important for caregivers and family members to remember that many of the behaviors displayed by the person with dementia are beyond his control and are not done out of anger or spite.

Caregivers of those with dementia tend to experience a mixture of feelings that can include frustration, anger, sadness and irritability. These feelings tend to fluctuate and depend on how well things are going on a day-to-day basis. It is important for caregivers to be well informed so that they are better equipped to address the problems they face while caring for a person with dementia. Caregivers also need to keep up on their *own* personal needs such as medical appointments and outings with friends and family. These activities are often neglected due to the caregiver's belief that they provide the best care and therefore, are reluctant to allow someone else to act in their absence. Caregivers should take advantage of the multiple community resources and support groups that provide information on respite services, assistance in the home, long term care issues and overall recognition and support for day-to-day care-giving efforts. Your clinician and/or social worker can provide you with assistance in locating and accessing these valuable resources that are often underused.

Most importantly, do not wait until a crisis occurs to access support services, be aware of them ahead of time so that you can utilize them when needed. Families should consider long term care issues such as Advance Directives, Power of Attorney, and possibility of nursing home placement in the early stages of dementia so that these issues can be discussed with the patient. Your clinician and/or social worker can assist you in exploring these options further. In addition, the book **The 36-Hour Day: A family guide to caring for persons with Alzheimer Disease, Related Dementing Illnesses, and memory loss in later life**, by: Nancy L. Mace, MA and Peter V. Rabins, MD, MPH is an excellent resource for those caring for someone with a dementing illness. It can be found in most bookstores and provides basic information about dementia, tips on daily care-giving tasks, long term care planning issues and coping techniques. The Alzheimer's Association (1-800-272-3900) is another good resource that provides information on AD and dementia as well as support group information and locations. The article on **page 5** of this newsletter, **The Other Faces of PD**, also provides a general description of the signs and symptoms of dementia.



# The Other Faces of Parkinson's Disease: Memory Impairment & PD

By: **Rebecca Martine, APRN, CS, BC**

Memory impairment is a common complication of Parkinson's disease, occurring in up to 50% of patients with PD. Symptoms can range from general memory decline to advanced dementia. It is important for patients, caregivers and family members to be aware of these potential changes and report all signs and symptoms to the clinician. Treatment options are available and can slow the rate of progression overtime.

## *Signs and Symptoms of Memory Impairment:*

- Poor attention skills or inability to concentrate (ie; becomes easily confused)
- Difficulty with problem-solving skills and everyday chores (ie; difficulty paying bills, cooking meals)
- Difficulty recalling information (ie; frequent difficulty remembering names or dates)
- Changes in language or speech (ie; difficulty finding and/or using appropriate words)
- Poor judgment skills (ie; wearing a sweater in the summer)
- Changes in mood or behavior (ie; frequent mood swings or unusual behavior)
- Poor sense of initiative (ie; refusals to participate in hobbies or activities)

*Neuropsychological testing is offered at the PADRECC by Dr. Paul Moberg. This testing provides a comprehensive assessment of one's memory and cognitive abilities. Please see your PADRECC clinician for more information.*

## Helpful Resources for Patients and Caregivers



### **American Parkinson Disease Association, Inc. (APDA):**

[www.parkinson.org](http://www.parkinson.org) (1-800-223-2732)

Was founded in 1961 with the mission to "ease the burden and find a cure" for Parkinson's disease.

The organization focuses its energies on research, patient support, education and raising public awareness of the disease.

### **Caregivers Are Really Essential (CARE):**

[www.pdcaregiver.org](http://www.pdcaregiver.org) This listserv web site is dedicated to caregivers and discusses the ups and downs of caring for someone with PD. The contributors are caregivers who have recorded their experiences to share with others.

### **Michael J. Fox Foundation for Parkinson's Research:**

[www.michaelfox.org](http://www.michaelfox.org) (212-509-0995)

The Michael J. Fox Foundation for Parkinson's Research is "dedicated to ensuring the development of a cure for PD" by providing grants that help guarantee that new and innovative research avenues are thoroughly funded and explored.

### **National Family Caregivers Association (NFCA):**

[www.nfcacares.org](http://www.nfcacares.org) (1-800-896-3650) This is a grassroots organization designed to educate, support, empower and speak out publicly for caregivers' needs.

### **Parkinson's Control:**

[www.parkinsonscontrol.com](http://www.parkinsonscontrol.com) This website is developed by medical experts and provides a wide range of information about PD, current treatment options and latest research.

### **People Living with Parkinson's (PLWP):**

[www.plwp.org](http://www.plwp.org) The mission of PLWP is to improve the quality of life of people living with PD by encouraging information sharing, mutual support and friendship within the PD community.



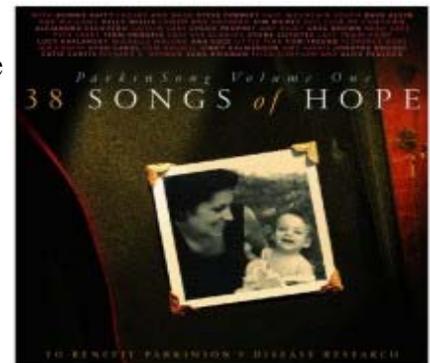
## **PARKINSONG: Musical CD to Benefit Parkinson's Disease Research**

**Parkinson, Vol. 1: 38 Songs of Hope** was recorded in honor of Selma Litowitz, a retired high school teacher from Lawrence, NJ who has been battling Parkinson's disease for over 10 years. In 2001, her children organized a concert in her honor at Lawrence High School, where she taught for 20 years. The concert featured uplifting and inspiring music and sold out almost instantly. Due to the concert's great success, Selma's children decided to organize another concert the following year which was hosted by legendary Philadelphia DJ, Pierre Robert. It was after this show that the **ParkinSong Foundation**, a nonprofit organization, was started by Selma's children with the goal of increasing awareness of Parkinson's disease.

As part of the ParkinSong Foundation, Selma's children, Rob Litowitz, Carol Golden and Debbie Frank assembled a tribute CD to their mother. **Parkinson, Vol. 1: 38 Songs of Hope** is a 2-CD compilation of songs by artists like **Terri Hendrix, Catie Curtis, Ana Egge, Grey Eye Glances, David Crosby** and **Graham Nash, Bonnie Raitt, Amy Ferris**, and many, many more. **Parkinson, Vol. 1: 38 Songs of Hope** has a broad range of musical talent and styles that is suited for all generations and more importantly, supports a great cause, Parkinson's disease research.

**Parkinson, Vol. 1: 38 Songs of Hope** can be purchased on-line at [www.parkinson.com](http://www.parkinson.com) and at Barnes and Nobles in the store and on-line at [www.bn.com](http://www.bn.com).

*Above information found at [www.parkinson.com](http://www.parkinson.com)*



## **Important Tip**

***Notify your local  
Emergency Medical Service (EMS)  
that you have Parkinson's Disease and sometimes  
have difficulty speaking. This will ensure that if  
there is an emergency and you dial 911, they will put  
your call at a high priority level even if you are  
unable to describe the emergency.***



## PADRECC Patient and Caregiver Support Groups



The PADRECC held its 1st support group on Wednesday, April 7th with an excellent turn out of veteran's and their caregivers. Support Groups are going to continue to be held the *1st Wednesday of the month* from *10:00am-11:30am in the Multi-Purpose Room (3rd Fl.)* and will be a combination of discussion and topic groups (please see below for a complete schedule). If you have any questions regarding the support groups please feel free to contact *Gretchen Glenn, Social Worker* or *Rebecca Martine, Clinical Nurse Specialist* at 215-823-5934.

### *Support Group Schedule*

<i>July 7th:</i>	<i>Gretchen Glenn, Social Worker:</i> <i>Community Resource Information</i>
<i>August 4th:</i>	<i>*Discussion Groups</i>
<i>September 1st:</i>	<i>Julia Howard:</i> <i>Speech &amp; Swallowing Issues in PD</i>
<i>October 6th:</i>	<i>*Discussion Groups</i>
<i>November 3rd:</i>	<i>Dr. Weintraub:</i> <i>Psychiatric Components of PD</i>
<i>December 1st:</i>	<i>Holiday Party</i>

\*Discussion groups will be divided into patient and caregiver sessions. Topics will be informal and chosen by the attendees.

\*\*The above topics and locations may change without notice if speakers and/or rooms become unavailable.

### Answers to Presidential Trivia Questions

- |                           |                           |
|---------------------------|---------------------------|
| 1. James K. Polk          | 10. Ulysses S. Grant      |
| 2. George Washington      | 11. Martin Van Buren      |
| 3. James Buchanan         | 12. Abraham Lincoln       |
| 4. Herbert Hoover         | 13. Thomas Jefferson      |
| 5. John F. Kennedy        | 14. Ronald Reagan         |
| 6. Jimmy Carter           | 15. Franklin D. Roosevelt |
| 7. William Henry Harrison | 16. John Adams            |
| 8. James Madison          | 17. George W. Bush        |
| 9. William McKinley       | 18. Dwight S. Eisenhower  |

*“There is no such thing in anyone’s life as an unimportant day.”*

**-Alexander Woollcott**  
American Author  
Found on:  
[www.inspirationpeak.com](http://www.inspirationpeak.com)

# What's New At the PADRECC

**Heidi Watson, RN** joined the PADRECC in April and will be providing patient care in the clinic as well as coordinating the DBS research study. Be sure to say "hello" to her at your next clinic visit!

Members of the Philadelphia VA PADRECC have recently completed writing a new National Parkinson's Foundation Handbook entitled: **Parkinson's Disease: Mind, Mood and Memory**. The Handbook should be published later this year. Thanks to all who contributed to the development of this Handbook.



## THE PADRECC POST

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