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### **PPS FATIGUE: HOW IT CAN CHANGE YOUR *MIND*** by Mavis J. Matheson, MD

One of the most frustrating late effects of polio for me was the awareness that I could not concentrate and a feeling that I wasn't thinking clearly anymore. For many of us who have compensated for our physical limitations through intellectual pursuits, this is a terrifying feeling . Is it not bad enough that our bodies are giving out? Must we undergo the indignity of losing our minds as well? Studies show that in spite of marked impairments of attention, polio survivors are within the high normal or superior range on measures of higher-level cognitive processes and IQ.

They also show that if we allow ourselves to become fatigued, we do lose our ability to focus our attention and to rapidly process complex information, requiring 23 to 67 percent more time to complete tasks requiring sustained attention and vigilance than did polio survivors with no fatigue or mild fatigue.

Polio survivors experience two kinds of fatigue. One is physical tiredness and decreased endurance. The other and often more distressing kind is "brain fatigue." Brain fatigue describes problems with attention, alertness and thinking. Between 70% and 96% of polio survivors reporting fatigue complained of problems with concentration (96%), memory (85%), attention (82%), word finding (80%), staying awake, and thinking clearly (70%). Tests indicate that an impairment of selective attention, related to damage as a result of polio, results

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## POLIO ECHO

2011

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## BOARD MEETINGS

All meetings are open to the public. Anyone wishing be on the agenda should notify the president, Brad Dowden, at (480) 987-2571 in advance.

Board Meetings are normally held on the third Tuesday of each month at the Disability Empowerment Center, which is located at 5025 E. Washington Street , Phoenix 85094. Meetings start at 11:30 am and conclude around 1:30 pm.

### 2011 MEETING & EVENT SCHEDULE

Tuesday—May 17 - Board Meeting at the DEC.

NO MEETINGS ARE CURRENTLY SCHEDULED FOR JUNE - AUGUST.

Tuesday, September 20—Board Meeting at the DEC.

Tuesday, October 18—Board Meeting and Special Event.

Saturday, October 22—Joint Meeting with Polio Epic in Casa Grande.

Tuesday, November 15—Board Meeting at the DEC.

Saturday, December 3—Holiday Luncheon and Annual Meeting at the Disability Empowerment Center.



We are sorry for the delay of this issue and any inconvenience it may have caused you. Tom has been ill with bronchitis as well as dealing with his radiation treatments. As a result I am pinch hitting for him and will try to get this issue out as soon as I can. J.Crawford

*(Continued from Page 1)*

in feelings of fatigue and cognitive problems.

The polio virus damages the anterior horn cells of the spinal cord, but that is not all it damages. It also damages parts of the brain stem.

Findings indicate that the polio virus consistently and often severely damages the brain areas known as the reticular activating system. These areas are responsible for activating the part of the brain involved in maintaining voluntary attention, memory, spontaneous interest, initiative and the capacity for effort and work, and for preventing feelings of fatigue. This is the area that keeps us awake and allows us to focus our attention.

Polio survivors report that they are most disabled by the visceral symptoms of fatigue. These are feelings of exhaustion, passivity, and an aversion to continued effort, that generate an avoidance of both mental and physical activity. Dr. R. L. Bruno suggests the existence of a fatigue generator in the brain. His findings suggest that there is a close relationship between impaired attention and fatigue. There would be survival value in a brain

mechanism that promotes rest when attention and information processing ability are impaired. An area of the brain, the basal ganglia, may generate mental and physical fatigue. When the reticular activating system is damaged, the fatigue generator takes over and produces problems with focusing attention and with physically moving without significant conscious effort. Damage caused by the polio virus chronically reduces the firing of the nerve cells in the reticular activating system. Rest or sleep would increase the firing of the brain activating system nerves, restore activation and once again allow motor behavior.

The damage would explain why polio survivors have difficulty concentrating after the original infection, but why are we developing problems thirty or forty years later? One theory is that the age-related loss of nerve cells combined with an already abnormally small number of nerve cells as a result of the original polio virus infection may impair the brain's activating system enough to produce impaired attention and fatigue as polio survivors reach mid-life.

The first step in treating the disorders of concentration, memory, attention, word finding, staying awake, and thinking clearly, is to deal with the fatigue. Energy conservation, work simplification and the proper provision of rest periods throughout the day are the treatments of choice in dealing with post-polio fatigue. Stress

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management is also critical in the treatment of post-polio fatigue. Dr. Bruno et al are currently studying the use of a medication, a post-synaptic dopamine receptor antagonist currently used in the treatment of Parkinson's Disease, in the treatment of post-polio individuals who do not respond to conservative treatments. They caution that there is a real danger that treatment with medications will allow polio survivors to resume their hyperactive type A lifestyles and further stress polio virus damaged "metabolically vulnerable" neurons in the brain stem and anterior horn.

As with any treatment strategy, we must try to find the most effective treatment that will do the least long-term damage while helping us to deal with our current problems. Certainly, reducing physical and emotional stresses in our lives and getting adequate rest makes sense for everyone, even polio survivors. The good news is, if you can get rested, you will find your ability to concentrate, pay attention, remember words, and stay awake will improve. You may even find that you can enjoy reading and thinking again!

*Reprinted from The Seagull, NC, October 2009; Reprinted from Second Time Around, Boca Area Post Polio Group, Boca Raton, FL, November 2010; Reprinted from The Polio Post, Ohio Spring 2011*

## Polio Echo Resource Directory

The Polio Echo Board of Directors is compiling a Resource Directory. We need your help. We would like to ask all members to send in names of individuals or organizations that have been helpful to you as a person aging with a disability. We would like to make the Resource Directory comprehensive, so it will include, but not limited to medical or disability resources. Let us know of services that you have found helpful, such as scooter repair and van modifications, handyman services, mobile dog groomers, etc. We want to include resources you have used to make your life easier. Be sure to ask your resource if it is okay to have them included in our Resource Directory. Please e-mail the complete contact information to Kathy Bollinger at [kbollinger3@cox.net](mailto:kbollinger3@cox.net)

## Ask Dr. Maynard.....

**Question:** Are there any nutritional issues that polio survivors should pay special attention to? Are there any particular dietary needs or concerns? Any supplements that are beneficial?

**Answer:** There are several important nutritional issues for people who had polio. No other issue is more important to good health than optimal nutrition, and no other is more controversial and little studied by good science.

The first issue is how to avoid excessive weight gain and obesity. Minimizing all refined sugars and grains is probably most important, particularly high fructose corn syrup which is now very widely used in processed foods and sodas. Portion control is also a central issue. Polio survivors are especially challenged to control weight

and avoid developing type 2 diabetes (insulin resistance) because of their reduced muscle mass and limitations to vigorous exercise. Muscle tissue is the most important user of sugar and insulin in the body, and when there is less muscle to use, it is harder to keep blood sugar levels stable.

A second important nutritional issue is avoiding excessive sodium intake because it can increase the risk of hypertension (high blood pressure). Polio survivors have a higher risk of hypertension, again because of decreased tolerance for aerobic exercise. Another special challenge is achieving healthy cholesterol levels and lipid profiles. It is more difficult to maintain high levels of good (HDL) cholesterol and low levels of bad (LDL) cholesterol without high levels of aerobic activity.

Additionally, a number of people, including polio survivors, cannot safely tolerate statin medications that are widely prescribed for cholesterol lowering. Many limit their intake of meat, dairy and eggs because of concerns about cholesterol, but this may leave them deficient in some essential fat-soluble vitamins only found in animal products, as well as low on essential amino acids. These amino acids and vitamins are critical to optimal muscle functioning, and polio survivors may be more sensitive to any relative deficiencies in these substances. Therefore, modest consistent intake of animal products is recommended with fish, white meats and grass-fed beef probably best. The last issue is prevention of deficiencies in various vitamins and minerals. Vi-

tamin D deficiency is very common today and contributes, along with low calcium intake/absorption, to the high incidence of osteoporosis in the United States. Less commonly known is that vitamin D deficiency can increase muscle and joint aches and pains, as well as lower energy levels - all common PPS symptoms. Vitamin D levels in the blood can now be readily measured and should be on survivors experiencing late effects of polio.

Adequate intake of B complex vitamins, especially vitamin B-1 (thiamine), vitamin B-6 (pyridoxine) and vitamin B-12/folic acid, are critical to nerve health and can be measured in the blood. Brewer's yeast and whole grains are excellent sources for insuring high levels of B vitamins, except B-12/folic acid, which must come from some meat intake. Fish is an excellent source of protein, the healthiest fats for a good lipid profile and a good source of vitamin D and vitamin B-12.

A high proportional intake of fresh vegetables and whole grains is recommended along with modest quantities of fruits and animal products. Organic foods should be considered since post-polio nerves may be more sensitive to the neurotoxic effects of pesticides.

*Reprinted from APPA News, Fall 2010*

## CHAPTER NEWS

**PHOENIX CHAPTER** (*Central Valley*) meets on the second Thursday of each month in the Mesquite Branch of the Phoenix Public Library in Paradise Valley Mall, 4525 Paradise Village Parkway North in Phoenix. The meetings begin at 11:00 am and conclude around 1:00 pm. The meeting room is near the entrance to the library.

The next meeting will be on May 12, 2011, on the subject of talking books.

The Central Phoenix will also meet on June 9, 2011. No program has been selected.

### **EAST VALLEY CHAPTER**

meets, and eats, at 1:00 pm on the third Wednesday of each month at selected restaurants throughout the east valley, which are designated in the newsletter and by electronic mail, if you have notified Jane Crawford to send reminders.

On May , 18, 2011 members will meet at Joe's Real BBQ at 301 N Gilbert Road in Gilbert.

On June 15, 2011, members will meet at Coco's Bakery Restaurant at 1882 West Baseline road in Mesa.

To make reservations, or get more information, contact Joan DeRenzis (480) 895-8238, or Jane Crawford, (480) 899-5857.

### **SCOTTSDALE CHAPTER**

meets on the first Thursday of each month, usually at the Scottsdale Public Library in the Gold Room.

Thursday, May 5, 2011, the group will meet from 11:30 to 1:30 p.m. at the Civic Center Library at 3839 N. Drinkwater Blvd. in

Scottsdale.

Thursday, June 2, 2011, at Olive Garden Restaurant, 3380 N. Scottsdale Road at 1:00 p.m.

Contact Carol Pranka at (480) 946-6669 for details.

## *IN FOND MEMORY OF BETTY JILL KJELLBERG*

By Tom Ringhofer

Betty Jill died on December 11, 2010 following a short battle with cancer.

She was a positive, effervescent personality and a magnetic over achiever.

Betty Jill had polio at the age of seven and I first met her when she became a member of our Arizona Wheelchair Pilots' Association.

Betty Jill was a highly educated woman with degrees from California State University—Los Angeles, Arizona State University and Embry-Riddle Aeronautical University.

She was Executive Director of the Arizona Psychological Association and the Association of Facilitators. She founded her company, Association Solutions LLC in 1998.

Betty Jill knew the freedom of flight as an aircraft pilot and was an inspiration to those of us in Polio Echo. God be with you always, beautiful lady.

Please take the time to complete the registration form below. If you cannot afford the membership fee, you can still receive the newsletter. We need everyone on our mailing list to send in their registration. Memberships are due in January for the current 2011 calendar year. If you have questions about membership status, contact the Treasurer, Roger Buel, at (602) 493-7242.

**POLIO ECHO MEMBERSHIP REGISTRATION & RENEWAL FORM**

Name: \_\_\_\_\_ Date \_\_\_\_\_

Address: \_\_\_\_\_ Zip: \_\_\_\_\_

Phone (\_\_\_\_\_)\_\_\_\_\_ - \_\_\_\_\_ Cell (\_\_\_\_\_)\_\_\_\_\_ - \_\_\_\_\_

E-mail address: \_\_\_\_\_@\_\_\_\_\_

Emergency Contact Name & Tel # : \_\_\_\_\_ ( ) \_\_\_\_\_

I am enclosing \$10.00 for my 2011 dues donation.

I am sending an additional donation in the amount of \$ \_\_\_\_\_

I am enclosing \$2.00; please send me a membership pin.

I am unable to pay membership dues at this time, but would like to be a member and receive the Polio Echo Newsletter by mail.

I do not wish to be a member, but am sending a (tax deductible) donation of \$ \_\_\_\_\_

Please remove my name from the Polio Echo Mailing list. (The Polio Echo News is available on our web site: ([www.polioecho.org](http://www.polioecho.org)))

Make checks payable to Polio Echo and send to:

Polio Echo, P.O. Box 61024, Phoenix, AZ 85082-1024

**KEEP US INFORMED**

If your Name, address, telephone number, or Internet address has changed, please up date your information with us. Either call Jane Crawford at (480) 899-5857, email her at [janwec94@q.com](mailto:janwec94@q.com), or use the website [www.polioecho.org](http://www.polioecho.org).

Annual contributions help to educate the public and health care community concerning polio. We respond to the needs of individuals who suffer from post-polio syndrome, through group meetings, educational programming, newsletters and website. Polio Echo is a 501(c)3 non-profit Arizona corporation. All contributions and voluntary dues are tax deductible.



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*Funding of this Newsletter is made possible through a grant from the Phoenix Chapter of MARCH OF DIMES*

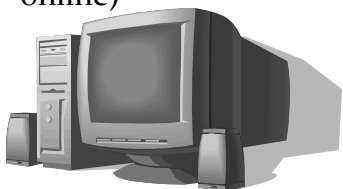
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Please address all correspondence to Tom Ringhofer, Polio Echo News, P.O. Box 61024, Phoenix, Arizona 85082.

**Polio Echo Website**

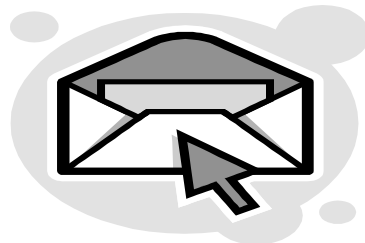
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**Polio Echo E-mail**

[polio\\_echo@polioecho.org](mailto:polio_echo@polioecho.org)



**Information:**

**(480) 987-2571**

If you have questions concerning projects or programs of the post-polio support group, please call our president Brad Dowden and leave a message. The person best able to serve you will call back.