

# First Coast Post Polio

March & April

Northeast Florida Chapter  
Jacksonville, Florida

2005  
Vol: 7 No.3

Happy Easter.



**Our Guest Speaker for  
April 21st Thursday**

**will be;**

**Catherine Mitchem**

**Physical Therapist & Nutritionist**

**Certified Medical Systems, I, INC.**

Also serving: Ocala (352) 237-4146

St. Augustine (904) 810-9747

**Please come and enjoy a great  
informative talk from  
Catherine on nutrition and  
physical therapy.**

***STOP!!! LOOK!!!  
We have moved...  
To Perkins at  
14471 Beach Blvd  
and San Pablo Rd  
From 9A and Beach  
Blvd go East to San  
Pablo Rd, just past San  
Pablo you will see the  
restaurant on your left  
with a huge American  
Flag. This restaurant  
has a private meeting  
room and I feel we will  
be happier with the  
accommodation there.***

**Please note our  
day has changed  
also to Thursday!  
Only availability.**



## Look at this Important DATE!!!

*All Florida Post Polio Association 'Managers in Ft. Lauderdale*

Dr. Bradley and Rotarians will be **Saturday, April 30, 2005**

12:30 am - 3pm at a location in West Fort Lauderdale near Sawgrass Mills shopping Center.. It's right off I-75 and 869 Expressway. If 1pm or noon would work better for you, please let us know and we will accommodate that.

### **Agenda:**

The opening of the University of Miami School of Medicine Post Polio Multidisciplinary Treatment, Education, and Research Center that will be initiated June 1, 2005.

Feedback for Dr. Bradley about what needs to be prioritized as we move forward with the PPS project.

Assistance from the Rotarians in supplying personal services, fundraising, and raising awareness for PPS. A caravan of Rotarians with a vehicle pulling an iron lung will come here in the first week in June on their way to Chicago to their bicentennial International Rotary Convention and making stops at 17 cities along the way. They plan to raise awareness for PPS and we will be coordinating an activity with them here in Miami. If they are coming through your city, you can get more details about their project and their goals.

Also our PPS group is working with the leaders of other US PPS groups to brainstorm and hopefully develop a National Post Polio Foundation. We are inviting all Florida Post Polio Support groups, so please forward to anyone that I've missed.

Please advise if you think you can make it so we can reserve the right size room. We are trying to restrict this to a smaller group and are thinking no more than 3-4 leaders from each PPS group, but we are flexible - depending on how many people respond

Look forward to hearing from you.

### **Barbara Gratzke**

2660 SE 7th Place, Homestead, FL 33033

(hm) 305-230-0687

President, Post Polio Assn. of South Florida

Board Member, International Post Polio Support Organization (IPPSO)

**Web Site:** <http://www.ippso-world.org>



**Ralph: The Home Assistant**

Debbie Hardy, Whittier, California



Speaker & Microphone



Do you ever wish you had a personal butler, valet or concierge at your beck and call? The reality is you may be able to purchase one in the form of an automated technology system for your home. The system, known as Ralph, is a voice-commanded control, monitoring and supervisory system. It uses voice recognition to take commands from the home's occupants and talks back to them with speech synthesis. For those who prefer not to use the voice command system, a pushbutton control is available. Ralph helps people live independently in their own homes by doing small things they cannot do for themselves.

The system was originally developed to help Don Holbert. Don, who is paralyzed below the waist (See Don's Story below.), unable to adjust the thermostat or open the drapes, thought his only options were to either sell his home or hire someone to stay with him. He was unhappy with these choices, so his friends came to the rescue and remodeled his house, making it more accessible for him.

One of those friends, Greg Corpier, a computer consultant and engineer, also decided to automate things in the house that needed to be done on a daily basis and created a "digital companion" that could talk as well as respond to verbal commands. Don named his companion "Ralph."

Ralph was installed in Don's home in 2001. Except for the monitor, keyboard, tiny speakers and motion detectors mounted on the walls, Ralph remains invisible and is multi-talented. He opens and closes drapes, blinds and doors, and controls lights, ceiling fans, and TV, VCR, DVD and stereo systems. Ralph can answer the door and telephone and can act as an answering machine. He reminds Don when to get up, take medication and eat. Ralph can make a shopping list, control thermostats for air conditioning and heating, and operate small appliances. He turns on a recirculator pump enabling Don to be able to walk into a dry shower on his crutches (lessening the chance of a slip and fall) and have instant warm water. Ralph

acts as a personal motion monitor and is able to call specific people for help if Don falls and is unable to get up. Ralph advises of weather conditions, reads the newspaper aloud, types and reads email, and acts as a home security system. He has given Don peace of mind by being a 24-hour-a-day personal assistant – always ready, willing and able to help.

Although this automated technology system was originally designed to help people with disabilities, it is available for purchase by anyone who would like to have such a system. Ralph can be customized for your individual needs and sized to fit any home from a cottage to a mansion. For more information, contact Greg Corpier (866-315-6967, greg@ralphmyfriend.com) or visit [www.ralphmyfriend.com](http://www.ralphmyfriend.com).

**Don's Story** ([donh1@swbell.net](mailto:donh1@swbell.net))

In 1949, shortly after my fifth birthday, I was diagnosed with polio. After spending 4½ months in the hospital, I returned home wearing braces on both legs and using crutches to help me walk.

I attended a special school in Kansas City, Missouri, for physically disabled students that offered both physical and occupational therapy as part of our regular school day.

At age 22, I married and we had three children. After 15 years, we divorced and I retained custody of the children. Though busy raising three children and working full-time, I managed to find time for a relationship and remarried. In 1981, my middle daughter was involved in athletics and I began volunteering with the Special Olympics. My volunteer service progressed from chaperon to coach to the state board to an employee as a director covering sixteen counties in Mid-Missouri.

In 2001, my wife became ill and died. I was alone and depressed. In addition to missing her love and companionship, I realized all of the little things my wife had done to make life easier for me. If it hadn't been for my family and friends, and the installation of a home-automated technology system known as Project Ralph, I might have given up.

In 2003, a woman on the Governors Council of Disabilities came to my home to assess the Ralph system. Later, I learned that in addition to checking out Ralph, she was also checking me out. A year later, we were married. She has made me feel alive again and, even though we both have limitations, we are very happy to have a new start at life together.



All Articles in this newsletter including those medically related are the opinions of the Editor or individuals contributing the article and are not an endorsement of the First Coast Post Polio News Group, Inc. To use articles from First Coast Post Polio News: please e-mail: [jfcask@comcast.net](mailto:jfcask@comcast.net) or call: (904) 333-3457.



### **DON'T WE LOOK HAPPY?**

A Look at the First Coast Post Polio Group. And what a great group we have. Not all of us could attend our last meeting but we are hopeful there will be more at our next meeting.

Thank you for coming;

(left to right): Dot Deceurs, Sue Bridges, Jessica Hoagic, Carl Cameron, Kathy Hutchinson, Betty Loyd, Eulie Nahm, Jean Van Meter, Joann Hadaway, Lynn Philips (not seen-behind Janice), Janice Askwith, and our famous mystery lady?

## **Unbelievably happy?**

U-M-led study of dialysis patients yields surprising findings about happiness among severely ill — and healthy — people

**ANN ARBOR, MI** - Despite what able-bodied healthy people might think, people with severe illnesses and disabilities don't wallow in misery and self-pity all the time.

In fact, a new study finds, such patients on the whole may be just as happy as those without major medical conditions.

The finding adds to the growing body of evidence that ill and disabled people adapt to their condition and show a resilience of spirit that many healthy people can't imagine. It's published in the new issue of the *Journal of Experimental Psychology: General* by a team led by University of Michigan Health System researchers.

The researchers made their surprising finding by having 49 pairs of dialysis patients and healthy people report their mood every few hours for a week, using a handheld personal digital assistant (PDA) such as a Palm. The patients had all been in dialysis for at least three months, visiting a hemodialysis center three or more times a week for hours at a time to have their blood cleaned because their kidneys had failed.

Lead author Jason Riis, a former U-M graduate student now at Princeton University, programmed the PDAs to beep randomly during each two-hour period of an entire week, and prompt participants to report their mood at those random moments by completing a quick series of ratings.

“The big advantage of using PDAs is that you can get representative snapshots of a person's experience, rather than just relying on their overall impressions of their lives,” says Riis, adding that several studies have shown such overall impressions to be biased in a variety of ways. “Our snapshots revealed that the patients were in good moods the vast majority of the time, and that their moods were not substantially worse than those of the healthy people.”

“This is further evidence that people adapt emotionally to serious adversity, such as end-stage kidney failure,” says senior author Peter Ubel, M.D., a U-M professor of internal medicine and psychology, and a staff physician at the VA Ann Arbor Healthcare System. “People who haven't experienced such adversity assume that it would destroy their happiness when in truth it probably would not.”

In fact, the researchers found that the healthy participants grossly underestimated the extent to which patients can adapt to dialysis. When asked to imagine that they were themselves dialysis patients, and to estimate the percentage of time that they would experience various positive and negative mood levels, the healthy participants assumed that they would be miserable.

(Continued on page 4)



They thought they would experience negative moods most of the time, and on average have moods that were much lower than what the real patients actually experienced.

Interestingly, the patients themselves seemed to underestimate their own adaptation. When asked to imagine the moods they would experience if they had never experienced kidney failure, the patients estimated that they would experience much better moods than those actually experienced by the healthy study participants.

Recent Press Releases:

The study involved healthy participants whose age, gender, race and education were similar to the patients. In all, 60 participants were white, 36 were black, and one was Hispanic.

The study does more than just give the first-ever glimpse into the hour-by-hour happiness of seriously ill and healthy people, Ubel notes. It may also help influence policy-level and personal decisions about treatments for serious illnesses.

For instance, someone who has been healthy but who is facing a decision about whether or not to have a colostomy, an amputation or a risky operation might worry that the procedure would make his or her life miserable. But in fact, it probably wouldn't.

That's not to say that a major health catastrophe doesn't change a person's life, nor that going on dialysis, losing a limb or using a wheelchair doesn't change a person's experience of life, Ubel says. It's also not to say that such a major change wouldn't come without periods of frustration and difficulty, risk of depression or effects on a person's social or economic situation.

But the evidence from the new study, and from studies before it, suggests that people who have gone through such changes tend to adapt their emotional response to their new life. In the words of some of Ubel's patients, "What use is there in complaining?"

"People are more resilient than they think they can be, and can get through things that they probably would have never thought they could," says Ubel. "The fact that people seem to be so poor at estimating the effect of illness on mood calls into question some of the ways we use such quality-of-life estimates in policy making and research."

In addition to recording the "snapshots" of mood, and the predictions of what life would be like in the other group's shoes, the researchers also had the patients and healthy controls recall the moods they had experienced during the week they had carried the PDA. While healthy people slightly underestimated their previous week's average mood, the patients were quite accurate in recalling theirs. The researchers speculate that the patients' recall accuracy may be involved in the adaptation process, but say that further research is needed on this area.

The researchers now hope to expand the use of moment-based well-being measures to assess people with a range of health conditions, including those associated with pain and mental illness, where the adaptation story may be quite different.

There was no difference between the 49 patients and the 49 healthy participants in the average hour-by-hour rating of their overall mood, which on the whole tended to be on the positive side. There was also no difference between the two groups in the average measures of specific momentary moods, such as "depressed," "pleased" or "worried/anxious." Even questions about pain, tiredness and overall life satisfaction showed no significant differences.

In addition to Ubel and Riis, the study team included George Loewenstein of Carnegie Mellon University, Jonathan Baron and Christopher Jepson of the University of Pennsylvania, and Angela Fagerlin of the University of Michigan. Ubel directs, and Fagerlin is a member of, the U-M Program for Improving Health Care Decisions, [www.pihcd.org](http://www.pihcd.org).

*Written by Kara Gavin*

This article "Unbelievably Happy" was provided by the University of Michigan Health System <[www.med.umich.edu](http://www.med.umich.edu)>

## Book Review - Breath: Life in the Rhythm of an Iron Lung

By Larry Kohout

**B**reath: Life in the Rhythm of an Iron Lung by Martha Mason is, as close as I can figure, the 30th polio memoir or biography that I have read. It is also one of the very best if not the best that I have ever read. I was not prepared for this. When I first heard of Martha Mason it was through one of those articles in the general press that I categorize as pity articles. You know the kind. Girl gets polio, lives 55 years in iron lung, what a hero! I was fully prepared to ignore the book until a friend of mine in Massachusetts gave it a rave. I felt I had to try it.

I knew something was up when immediately following the introduction Ms. Mason puts in a quote from The Talmud, "We do not see things as they are; we see things as we are." Well, I guess I have already admitted that. When you turn the page you get into the first part of the book that she has written in three parts. Quite cleverly, she does not start at the beginning but much later in her life at a point when her mother, who has been her caretaker, has entered a period of what I will refer to with apologies as senility. Ms. Mason never refers to it that way but quite beautifully and lovingly describes her mother and her condition.

It isn't until the beginning of part two that we go back to the beginning of her childhood, a childhood she shares with her brother, Gaston. And from there she weaves her story, their story, on through the remainder of grade school, high school, Gardner-Webb College in Boiling Springs North Carolina, and finally to graduate summa cum laude from Wake Forest College (then), in Winston-Salem, North Carolina.

I will freely admit that it doesn't take a great deal to move this old man to tears. Ms. Mason repeatedly moved me back and forth between tears and laughter and sometimes had me doing both at the same time. From early in her childhood her goal had been to write and those were the courses that she pursued throughout her educational career. While at Wake-Forest a Dr. Edgar E. Folk was one of her professors and mentors. In coaching her to add details and nuances to her writing he would often say to her, "Make me smell strawberries!" Martha, I smelled the strawberries.

Breath: Life in the Rhythm of an Iron Lung a memoir by Martha Mason is published by Down Home Press, P.O. Box 4126, Asheboro, North Carolina 27204 ISBN 1-878086-95-2, retail price \$24.95. Available from Barnes & Noble online for \$19.96. Available from Amazon.com online for \$17.47. I also found a couple of used copies available on Abebooks.com online. One was a cloth edition for \$10.60 and the others were first editions selling at higher than the retail price.

This information is the express views of Larry Kohout and not that of First Coast Post Polio Group, Inc.



### Our last meeting....

Thank you to Steve Hall a distributor of mangosteen juice and a special thank you to Teresa M Bernard, MD for her time and information given to us on her experience in taking mangosteen juice. Very informative and helpful. I drank the juice for six weeks and can honestly tell you I had more energy, Janice Askwith, Vice President.

**Brain Game for Rhyming Minds**

The rhyming two-word answers to the clues below all have to do with brains or “smarts”. For example, a headache is a “brain pain.”

Can you figure out the others?

1. Simple mind
2. Fast learner on the job
3. Tune stuck in your head
4. A healthy breakfast
5. What a teacher of critical thinking does
6. Person tired from trying to take in too much information
7. Smart folks in Madrid
8. What a neurology professor does
9. Chief genius
10. A crutch used to remember something

**Answers below**



**LOOK!  
NEW PLACE**

**Next Meeting:** April 21, 2005 on Thursday

**Place: Perkins**

At the corner of Beach Blvd and San Pablo Rd (go east on Beach past San Pablo Rd— Restaurant on left with huge American Flag)

**Phone:** (904) 333-3457

**Time:** 12:00 Noon -till....

Please come as we would love to meet all of you.

**Certified Medical Systems, I, INC.**

David Jacob  
2141 Lock Range Blvd #130  
Orange Park, Fl  
(904) 272-3022 or (800) 815-1211  
Scooters \* Wheelchairs \* Lifts \* Walkers  
Ramps \* Stairclimbers \* Elevators –Home & Auto  
Oxygen-Nebulizers-CPAP-BiPAP  
Complete Respiratory & Diabetic supplies  
**New onboard** \* Certified Respiratory Therapist  
*Catherine Mitchem*  
Also serving: Ocala (352) 237-4146  
St. Augustine (904) 810-9747

**NEEDED!!!!**

We are looking for a

- Program chairperson
- Recording Secretary.

Please won't you consider yourself for this very gratifying job?

**WE NEED YOU!**



**Jeri Gething, REALTOR®**

Cell: (904) 403-6888

Lady Realtor® on the move.....

If you're interested in buying or selling, call me and I'll make sure there are no unpleasant surprises.

21 years of real estate experience working for you.

Watson Realty Corp  
2490 Monument Road  
Jacksonville, FL 32225  
Jgething@yahoo.com



**Our Staff of Directors:**

President Kathy Hutchinson

Vice President / newsletter Janice Askwith

Treasurer Eulie Nahm

Program chairperson Needed

Recording Secretary Needed

*Sunshine committee* *Janice Askwith*

Board of Directors David Brynildson

Board of Directors Dr. Stuart Caplin

Board of Directors Joe Raker

Founder 1990 Sue Bridges

Contact: Editor First Coast Polio Support Group  
13119 Blackhawk Trail Court  
Jacksonville, Fl 32225  
(904) 220-3013

**Answers:** 1. Plain brain; 2. Brainy trainee; 3. Brain refrain; 4. Smart start; 5. Trains brains; 6. Brain drain; 7. Spain's brains; 8. Explains brains; 9. Main brain; 10. Brain cane