

POLIO DEJA VIEW

Central Virginia Post-Polio Support Group

August - September 2007

Carol T. Ranelli, Editor

visit our website at www.cvppsg.org

August 4th Meeting

2:00 pm at Children=s Hospital, 2924 Brook Road, Richmond

Our speaker will be **Amy H. Wenzel**, ANP, Medical Assistant
with Richmond Cardiology Associates

Amy will speak on cholesterol, diet and general cardiac health.

September 8th Meeting

PLEASE NOTE: This is the second Saturday, due to Labor Day

2:00 pm at Children=s Hospital, 2924 Brook Road, Richmond

General Discussion of questions, concerns, and the up-coming
Retreat in September.

******* 2007 Annual Retreat!! *******

Please make your reservations by August 31st for our annual Retreat.

All information about the weekend is in this issue, along with registration information. We have 30 members signed up already so join us for an informative and fun weekend!

FEMALE HEART ATTACKS

Did you know that women rarely have the same dramatic symptoms that men have when experiencing heart attack...you know, the sudden stabbing pain in the chest, the cold sweat, grabbing the chest & dropping to the floor that we see in the movies. Here is the story of one woman's experience with a heart attack.

"I had a completely unexpected heart attack at about 10:30 pm with NO prior exertion and NO prior emotional trauma that one would suspect might've brought it on. I was sitting all snugly & warm on a cold evening, with my purring cat in my lap, reading an interesting story my friend had sent me, and actually thinking, "A-A-h, this is the life, all cozy and warm in my soft, cushy Lazy Boy with my feet propped up." A moment later, I felt that awful sensation of indigestion, when you've been in a hurry and grabbed a bite of sandwich and washed it down with a dash of water, and that hurried bite seems to feel like you've swallowed a golf ball going down the esophagus in slow motion and it is most uncomfortable. You realize you shouldn't have gulped it down so fast and needed to chew it more thoroughly and this time drink a glass of water to hasten its progress down to the stomach. This was my initial sensation---the only trouble was that I hadn't taken a bite of anything since about 5:00 p.m.

"After that had seemed to subside, the next sensation was like little squeezing motions that seemed to be racing up my SPINE (hind-sight, it was probably my aorta spasming), gaining speed as they continued racing up and under my sternum (breast bone, where one presses rhythmically when administering CPR). This fascinating process continued on into my throat and branched out into both jaws.

"AHA!! NOW I stopped puzzling about what was happening--we all have read and/or heard about pain in the jaws being one of the signals of an MI happening, haven't we? I said aloud to myself and the cat, "Dear God, I think I'm having a heart attack!" I lowered the foot rest, dumping the cat from my lap, started to take a step and fell on the floor instead. I thought to myself "If this is a heart attack, I shouldn't be walking into the next room where the phone is or anywhere else.....but, on the other hand, if I don't, nobody will know that I need help, and if I wait any longer I may not be able to get up in moment."

"I pulled myself up with the arms of the chair, walked slowly into the next room and dialed the Paramedics... I told her I thought I was having a heart attack due to the pressure building under the sternum and radiating into my jaws. I didn't feel hysterical or afraid, just stating the facts. She said she was sending the Paramedics over immediately, asked if the front door was near to me, and if so, to unbolt the door and then lie down on the floor where they could see me when they came in.

"I then laid down on the floor as instructed and lost consciousness, as I don't remember the medics coming in, their examination, lifting me onto a gurney or getting me into their ambulance, or hearing the call they made to St. Jude ER on the way, but I did briefly awaken when we arrived and saw that the Cardiologist was already there in his surgical blues and cap, helping the medics pull my stretcher out of the ambulance. He was bending over me asking questions (probably something like "Have you taken any medications?") but I couldn't make my mind interpret what he was saying, or form an answer, and nodded off again, not waking up until the Cardiologist and partner had already threaded the teeny angiogram balloon up my femoral artery into the aorta and into my heart where they installed 2 side by side stents to

hold open my right coronary artery.

"I know it sounds like all my thinking and actions at home must have taken at least 20-30 minutes before calling the Paramedics, but actually it took perhaps 4-5 minutes before the call, and both the fire station and St. Jude are only minutes away from my home, and my Cardiologist was already to go to the OR in his scrubs and get going on restarting my heart (which had stopped somewhere between my arrival and the procedure) and installing the stents.

"Why have I written all of this to you with so much detail? Because I want all of you who are so important in my life to know what I learned first hand."

1. Be aware that something very different is happening in your body not the usual men's symptoms, but inexplicable things happening (until my sternum and jaws got into the act). It is said that many more women than men die of their first (and last) MI because they didn't know they were having one, and commonly mistake it as indigestion, take some Maalox or other anti-heartburn preparation, and go to bed, hoping they'll feel better in the morning when they wake up....which doesn't happen. My female friends, your symptoms might not be exactly like mine, so I advise you to call the Paramedics if ANYTHING is unpleasantly happening that you've not felt before. It is better to have a "false alarm" visitation than to risk your life guessing what it might be!

2. Note that I said "Call the Paramedics". Ladies, **TIME IS OF THE ESSENCE!**

Do NOT try to drive yourself to the ER--you're a hazard to others on the road, and so is your panicked husband who will be speeding and looking anxiously at what's happening with you instead of the road. Do NOT call your doctor--he doesn't know where you live and if it's at night you won't reach him anyway, and if it's daytime, his assistants (or answering service) will tell you to call the Paramedics. He doesn't carry the equipment in his car that you need to be saved! The Paramedics do, principally OXYGEN that you need ASAP. Your Dr. will be notified later.

3. Don't assume it couldn't be a heart attack because you have a normal cholesterol count. Research has discovered that a cholesterol elevated reading is rarely the cause of an MI (unless it's unbelievably high, and/or accompanied by high blood pressure.) MI's are usually caused by long-term stress and inflammation in the body, which dumps all sorts of deadly hormones into your system to sludge things up in there. Pain in the jaw can wake you from a sound sleep. Let's be careful and be aware. The more we know, the better chance we could survive...

Reprinted from Florida East Coast Post-Polio Support Group Newsletter, July-Aug., 2007

One of our long time members, Linda Myers, has been doing research on the iBOT "wheelchair" and wanted to share her findings with the group.

Advances in Assistive Technology – The INDEPENDENCE® iBOT® Mobility System
By Linda Myers

The INDEPENDENCE® iBOT® Mobility System is a major advancement in wheelchair technology and is unlike any wheelchair ever created. The iBOT® Mobility System has a combination of features that allow people with disabilities to: power across sand, gravel, grass and other uneven terrain; easily climb curbs up to 5”; climb stairs and steps; rise to an “eye-level” position; and hold a conversation, even when you are on the move.

Utilizing cutting edge technology that is easily accessible to many people with disabilities, users can operate the iBOT® Mobility System in five all-in-one functions, including:

- **4-Wheel** – traveling uneven terrain
- **Balance** – raising yourself to eye-level
- **Stair** – getting you from here to there
- **Standard** – proceeding with confidence
- **Remote** – taking your iBOT® with you

How does the iBOT® Mobility System work?

The iBOT® Mobility System contains patented iBALANCE® Technology, an integrated combination of sensor and software components and multiple computers that work in conjunction with gyroscopes. Gyroscopes are motion sensors that help maintain balance. When the gyroscopes sense movement, a signal is sent to the computers. The computers process the information and tell the motors how to move the wheels to maintain stability. This electronic balance system is custom-programmed to the user's center of gravity, to monitor and respond to subtle changes in motion. Reach forward to shake hands, and your iBOT® Mobility System moves with you. Lean back and it moves away as well. The iBOT® Mobility System constantly realigns and adjusts its wheel position and seat orientation to keep the user upright and stable at all times, even when driving up and down curbs or inclines. In addition, the iBOT® includes built-in triple redundant backup systems, as well as auditory and visual signals to provide even more safety and assurance.

Dean Kamen, the inventor of the Segway, created the iBOT® in 1995. The iBOT concept was developed, prototyped, and reviewed by focus groups and blue ribbon panels of disability users and experts in an attempt to solve multiple unmet needs of people with disabilities. The iBOT® Mobility System was first introduced on DATELINE NBC, June 30th, 1999. The iBOT® Mobility System underwent extensive clinical trials to ensure the safety of the product. FDA approval of the iBOT® System was granted in August 2003 and the first retail sales units were delivered later that year. Since that time, the iBOT® Mobility System has obtained favorable coverage decisions by a variety of insurers and companies including: the Veterans Health Administration, various state vocational rehabilitation departments and private payers. The efforts of Independence Technology have allowed scores of people with disabilities to obtain the unique, life changing iBOT® Mobility System. The company offers dedicated one-on-one reimbursement services throughout the process of obtaining an iBOT® Mobility System. A Reimbursement Counselor is assigned to your case and works with you to research options every step of the way.

The iBOT® is an exciting product to me because of the two unique features, the ability to climb stairs, and the ability to maintain a conversation at eye-level, even while moving. These capabilities have the potential to break through two of the biggest isolating barriers faced by the disabled. Being able to again visit the homes of friends and relatives who don't have accessible homes reopens a whole new freedom of movement for the disabled. However, in addition to the high cost of this power chair, there are two items that I've discovered thus far that could make me decide against the iBot. First, the automotive seat option is 28 ½” wide, which would prevent me from going through many standard doorways, particularly interior doorways, at the homes I'd like to visit. (The custom adaptive seat starts at 25”.) Secondly, the iBot does not have an accessory add-on plate and bolt that will allow it to be held in place in a vehicle with a lockdown box. It can only be held down via 4-way tie downs. This is a definite

“no-go” for me. The iBot Customer Care Center folks say they are continually looking into product improvements, and the tie down method is one of their most common user (or potential user) complaint.

Independence Technology is currently conducting test drive sessions across the US. Of interest to CVPPSG members and friends are the test drive sessions scheduled for the District of Columbia on either July 17th or August 19th, and in **Glen Allen, Virginia on September 19th**. For more information and to schedule a test drive, contact the company’s Customer Zone representatives thru the web site at <https://www.ibotnow.com/ibot/moreinfo.html>.

Most of the technical information about this technology is taken from the product’s website, <http://www.ibotnow.com/home.html>, with permission from Independence Technology, L.L.C., a Johnson & Johnson company. This article may not be reprinted without permission from Independence Technology, L.L.C..

Thoughts from members of Self-Appreciation and Self-Nurturing

- Taking joy in following a passion, doing artwork and hobbies that allow use of my hands rather than using legs that don't work so well anymore.
- Using more mental skills than physical skill such as reading and writing, work puzzles hand-held games.
- Acknowledging ones health and abilities
- Being one's own advocate with the medical profession
- Listening to trusted specialists
- Asking for help from the physically able
- Pacing oneself
- Putting oneself first now that the children are grown
- Hiring someone to do the housecleaning
- Moving to a one-level home with no steps or getting a stair lift
- Accepting family support, both emotional and physical
- Attending a support group
- Keeping up to date with the issues related to polio and post-polio syndrome

Because the speaker at our Annual Retreat, Dr. Lori Michener, is a shoulder specialist, I thought it was timely for us to think about our arms and shoulders and the abuse many of us put them through in the course of a day. Maybe by reading this article, you can think of a good question for Dr. Michener when you attend the Retreat.

Shoulder Concerns for People Experiencing Post-Polio

As polio survivors age, many experience problems in new areas of their body. One such area is the shoulder. Polio survivors who have weak legs have had to rely on their arms to assist with mobility related tasks such as pushing off the armrest of a chair when getting up or pulling on the railing when climbing a flight of stairs. Using crutches, canes and wheelchairs will also cause concerns after many years of using these aids. All of these arm compensations can increase the risk for symptoms of shoulder overuse. The symptoms can include pain, swelling, weakness and loss of function in one or both shoulders.

We hope to present information in this brief article about how to help polio survivors who are experiencing shoulder problems. Health care professionals are encouraged to learn about post polio to enable them to help overcome presenting problems without creating any new ones. One example: muscle overuse for patients experiencing post polio can permanently damage the overworked muscles.

Treatment approaches must be individualized and focus on minimizing or eliminating pain while maximizing function; and done without causing weakness to any area of the patient's body.

Common Causes of Shoulder Pain:

- Poor sitting posture – round shoulders, head forward, kyphosis of the thoracic spine, sacral sitting scoliosis
- Weak muscles that stabilize the shoulder blade and rotate the arm outward compared to the other shoulder muscles (i.e. weak external arm rotators and strong deltoids)
- New weakness or weakness of other muscles of the arms
- Trauma or injury (such as falling onto an outstretched arm, tearing tendons, brachial plexus injury, fracture)
- Excessive weight bearing on the arms, especially when muscles are fatigued (leaning heavily on an assistive device, numerous transfers and/or long term wheelchair pushing with arm fatigue)
- Poor or less than optimal transfer and/or wheelchair pushing techniques
- Excessive weight gain
- Sleep positioning directly on the shoulder
- Cervical spine or neck problems

Shoulder Problem Treatment Options:

Many approaches can be used to treat shoulder problems. Some examples of treatment are:

- Rest
- Cold Pack or Hot Pack
- Massage
- Ultrasound
- Aquatic Therapy
- Electric Stimulation
- Anti-inflammatory medicines or cortisone injections

- Pain Management at a Pain Clinic
- Modifications at home or work, adaptive devices or equipment, lifestyle changes
- Surgery

The most common treatment for shoulder problems begins with rest, ice and heat, and the use of anti-inflammatory medicines. If these conservative treatment options do not help, the doctor usually recommends cortisone injections to the painful area. After injections, the physician will often refer you to physical therapy for evaluation and treatment.

In physical therapy, there are several treatment techniques that can be combined to relieve the pain and increase the strength and use of the arm. Physical therapists may use exercise, stretching, heat, ultrasound (a deep heat), massage, electric stimulation (electrical current used to decrease pain or increase movement), water therapy or hands on techniques to help your shoulder problem.

The final option recommended by a doctor is usually surgery. Most doctors will try non-invasive options before recommending surgery.

The success of treatment lies with the patient and the healthcare provider working together so that the greatest benefit of the treatment goals can be reached.

It is very important **to listen to your body** for signs of tiredness, pain, unusual muscle twitching, inability to perform a task that you can normally do or the need for help with a task that you can usually do without help. **These are signs suggesting muscle fatigue or overuse and continuing activities that cause these signs could be harmful.** Each person needs to find a system that works best for them...**however, it is crucial to prevent fatigue because it many do irreversible harm to your muscles.**

References:

"Save Our Shoulders, a Guide for Polio Survivors". A complete download of this guide is available at www.einstein.edu/polioandmobility Rehabilitation Research and Training Center on Aging with a Disability, www.agingwithdisability.org/factsheets/shoulder_pain.htm Reprinted from PPASS News, March/April, 2006

Did you know?..... **RX** Information from Jenny

All types of grapefruit have the potential to interact with certain drugs. Various types of grapefruit juice (fresh, whole ,frozen) contain different concentrations of enzymes that can cause drug interactions. The potential to interact also depends on the patient's susceptibility, as we all express different levels of drug metabolizing enzymes. The take home message--- Avoid any form of grapefruit if you're taking medicines that could interact like: Diazepam, statins (Zocor, Lipitor, Mevacor), Viagra and blood pressure medicines such as Cardizem & Norvasc.

Any questions? Feel free to call Jenny Aveson at CVS/Pharmacy (804) 730-9498

We want to welcome our new pharmacist friend, Jenny Aveson to our newsletter. Jenny will be posting medical tips concerning taking drugs, drug interaction and other pharmacy issues in each issue. Thanks Jenny!!

Need-to-Know Numbers: Aim to reach these heart healthy numbers

TOTAL CHOLESTEROL less than 200 mg/dL

HDL ("good") CHOLESTEROL Women: 50mg/dL or higher Men: 40mg/dL or higher

LDL ("bad") CHOLESTEROL If you have a low overall risk of heart disease, strive for less than 100 mg/dL. If you have other heart risk factors, you may need to go even lower; talk with your doctor.

TRIGLYCERIDES Less than 150 mg/dL

BLOOD PRESSURE Less than 120/80 mmHg

FASTING BLOOD GLUCOSE Less than 100 mg/dL

For those of you who don't know....

At the June luncheon, there were some members who didn't realize that Bernie Haske, Mary Ann's husband and long time friend to our support group passed away in May of 2006. For we members who are regulars to the meetings....we really miss you Bernie!