POLIO DEJA VIEW

Central Virginia Post-Polio Support Group
www.cvppsg.org

April – May 2009

April 4th Meeting

Remember to come at 1:30 for refreshments and social time!!
Cookies provided – bring your own beverage.

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

We will have **The Woody Morris Memorial Brown Bag Auction** to benefit the social committee and help offset costs of our upcoming Retreat and social events.
(We are dedicating all future brown bag auctions in memory of our most ardent bidder, Woody Morris, who SO enjoyed these auctions and donated a lot of money to the cause.)
Please bring an item, white elephant, gag-gift or otherwise, in a brown bag with a short clue about the contents attached. Our favorite auctioneer, Dave VanAken, will preside. This is always a lot of fun for those attending!

May 2nd Meeting

******* 1:30 for Social Time *******

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

General Discussion or a Speaker to be Announced Later

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Mark your calendars for: June 6th, our annual June Luncheon
September 18-20, our Annual Retreat
More information in the next newsletter
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Mid-Month Lunch

Thursday, April 16th at 11:30 we will have lunch at
The Cheesecake Factory at Short Pump Town Center
Call Bev Lordi by April 13th at 569-4232 for a reservation

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Thursday, May 21st at 11:30 we will have lunch at
Capriccio's Italian Restaurant, 9127 West Broad St.
in TJMaxx Shopping Center (David's Bridal is there also)
Their website is: www.capricciosrestaurantva.com
We ate there after the Feb. meeting and everyone raved about it!
Call Bev Lordi by May 18th at 569-4232 for a reservation

It is with great sadness that our support group learned of the sudden passing of our dear member **Pat McGinnis** on February 27th.
Pat discovered our support group a few years ago and drove from her home in Virginia Beach to Richmond almost every month. She brought her wonderful humor and friendship with each visit.
Pat came to several annual Retreats and enjoyed the sharing of information and fun with people from our area and out of state.
As the drive became more uncomfortable for her, she came less often to monthly meetings, but still attended the Retreats and annual social gatherings.

Our group extends its sympathies to her family. She will be missed.

Credit Oversight!
In our October-November 2008 issue we used an article entitled " And By The Way…." which was from the Colorado Post-Polio Connections Newsletter.
I regret that I didn't give them credit for that article. Thank you Colorado Connections!
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If you would like to talk with someone about Post-Polio Syndrome, you are welcome to contact the above members. If you send an e-mail, please refer to APPS@ in the subject heading.

We would love to have any of our members write an article for our newsletter. It can be about your lifestyle adjustments, comments on post-polio or any subject, humorous or serious, that we may all benefit from. Please send articles for or comments about our newsletter, as well as changes, additions or deletions for the newsletter mailing list to:

Mary Ann Haske, Newsletter Editor, 2956 Hathaway Rd, Richmond, VA 23225
or contact me at: (804) 323-9453 or mahaske@hotmail.com

USING SUPPLEMENTS BEFORE AND AFTER SURGERY

People often don't realize the risks of using some supplements before or after surgery. Here are some risks everyone should be aware of.

BLEEDING: Gingko biloba is linked to several reports of surgical and post-surgical bleeding.

There are dozens of supplements that can POTENTIALLY increase bleeding...garlic, ginger, vitamin E, saw palmetto, policosanol, willow bark, and others.

SEDATION: Sedation from anesthesia and post-op meds might be increased by taking valerian, kava kava, L-tryptophan, etc.

BLOOD PRESSURE: Keep in mind that ephedra, bitter orange, guarana, and other stimulants can increase blood pressure. Ephedra is banned in the U.S. but people still get it online in all sorts of energy products.

SEROTONIN EFFECTS: St. John's wort is associated with vascular collapse (shock), which causes inadequate blood flow to the organs during anesthesia...possibly due to its effects on serotonin or certain metabolizing enzymes.

Be sure to tell your doctor about any supplements you take BEFORE having any kind of surgery. Also, be sure to stop taking most supplements two weeks before surgery...and do not restart them until the risk of bleeding is gone.

Various Types of Pain Defined

Pain:
The International Association for the Study of Pain describes pain as, "An unpleasant sensory and emotional experience associated with actual or potential tissue damage, or described in terms of such damage". Pain is a subjective condition which includes personal experiences and emotions. Therefore, no one patient with pain can be treated with exactly the same methods or medications as another patient.

Acute Pain: This usually has a sudden onset and a foreseeable end. It is most often associated with trauma or acute disease such as a broken limb or, for example, appendicitis.

Chronic Pain: This is usually described as pain which has lasted for 3 or more months. However, it also applies to pain which has lasted longer than the expected normal healing time.

<u>Pain terminologies and definitions</u> that you may have read about or heard from your doctor are listed below.

Allodynia: Pain caused by a stimulus which does not normally provoke pain. Eg. Lightly touching uninjured skin causing pain.

Analgesia: Absence of pain in response to stimulation which would normally be painful. Eg – Not feeling a pin prick to the skin.

Dysaesthesia: An unpleasant abnormal sensation, whether spontaneous or evoked.

Hyperaesthesia: An increased sensitivity to stimulation. Eg – A light touch is per-ceived as strong.

Hyperalgesia: An increased response to a stimulus which is normally painful. Eg – A pin prick is felt more painful than is normal.

Hyperpathia: A painful syndrome characterized by an abnormally painful reaction to a stimulus, especially a repetitive stimulus, as well as an increased threshold.

Hypoalgesia: Reduced feeling of pain to normally painful stimulus.

Hypoaesthesia: Decreased sensitivity to stimulation, excluding the special senses.

Causalgia: A syndrome of sustained burning pain, allodynia and hyperpathia after traumatic nerve lesion, often combined with vasomotor dysfunction.

Central Pain: Pain initiated or caused by a primary lesion or dysfunction in the central nervous system. (Brain and spinal cord).

Neuralgia: Pain in the distribution of a nerve or nerves.

Neuritis: Inflammation of a nerve or nerves.

Neuropathic pain: Pain initiated or caused by a primary lesion or dysfunction in the nervous system.

Neuropathy: A disturbance of function or pathological change in a nerve.
Mononeuropathy - in one nerve
Mono-neuropathy Multiplex - in several nerves
Polyneuropathy - diffuse and bilateral

Complex Regional Pain Syndrome I: CPRS I was formerly known as reflex sympathetic dystrophy, it consists of continuous pain (allodynia or hyperalgesia) in part of an extremity after a trauma. However the pain does not correspond to the distribution of a single peripheral nerve. The pain is worse with movement and associated with sympathetic hyperactivity.

Neuropathic Pain

Pain is often assumed to be caused by physical injuries such as a broken bone or skin cut and once the injury is healing the pain subsides and eventually disappears. However, nerves can also produce pain and this type of pain can be difficult to manage. It is called neuropathic pain.

Pain caused by nerve damage can be agonising and often fails to improve with time. It can originate from the peripheral and/or central nervous system. Neuropathic pain is often used as an umbrella term to include:

- Phantom limb pain
- Peripheral neuropathy
- Post herpetic neuralgia
- Trigeminal neuralgia
- Complex Regional Pain Syndrome (CRPS)

With neuropathic pain the nerves may be damaged or injured and they send incorrect pain messages to the brain. The cause is often difficult to discover. This sort of chronic pain may result from conditions such as Diabetes, Shingles, and

multiple Sclerosis or from injury, surgery or amputation. Although it can also occur without any of these factors.

Nerve pain is often described as:

- Shooting
- Stabbing
- Burning
- Searing

These pains may be accompanied with:

- Increased skin sensitivity
- Changes in skin temperature and colour
- Muscle weakness
- Loss of Feeling
- Swelling and stiffness in the affected joints

In some types of neuropathic pain the diagram shown below may help to establish the area of nerve damage or injury.

Phantom Limb Pain

Pain in a limb that no longer exists is a common phenomenon after amputation. For some people the phantom limb pain gets better without treatment but for others the management of this pain can be difficult. Phantom pain is more common after the loss of an arm or leg but can also occur after the removal of any body part such as an eye or breast.

To receive the correct treatment for your condition it is important for your doctor or specialist to determine whether you are experiencing phantom limb pain or stump pain.

Phantom limb pain: is pain that feels as if it is in the area of the lost limb.

Stump pain: is pain or discomfort felt at the site of amputation.

Phantom limb pain is an unfortunate term as it seems to imply that the pain is a psychological rather than a physical problem. In fact the pain may not have a psychological component at all. Although the longer pain continues it is more likely that physical and psychological influences are involved.

Contributing factors to phantom limb pain are thought to be:

- Nerve damage or injury
- Existing pain prior to amputation
- Neuroma, which is a growth containing nerve cells. This can form on the nerve endings in a stump after amputation.

If you are experiencing phantom limb pain you may benefit from a pain management programme.

Peripheral neuropathy

The peripheral nervous system includes nerves in the face, legs, arms, torso and some nerves in the skull. It often affects people with diabetes and auto-immune diseases. Certain vitamin deficiencies and alcoholism can also damage the peripheral nerves.

Symptoms will depend upon the cause of a persons' neuropathy and on which nerve or nerves are involved.

These can often begin gradually and are sometimes barely noticeable but for others the symptoms are constant and may be almost unbearable especially at night.

Symptoms may include:

- Pain
- Numbness
- Tingling
- Muscle weakness
- Burning
- Loss of feeling
- Sharp, stabbing pain
- Extreme sensitivity to touch
- Lack of coordination

If you experience any of these symptoms you should consult your doctor.

For others with a diagnosis but who have poor pain control a pain management program may be beneficial.

Post herpatic neuralgia

This type of nerve pain often happens after a viral infection such as shingles. The pain manifests itself as listed under neuropathic pain. Consult your doctor if you think that you have nerve damage or injury caused by a viral infection. If the pain persists you may benefit from a pain management pro-gramme or a review of your medications by a pain specialist.

Trigeminal neuralgia

This type of nerve pain affects the forehead, nose, cheeks, lips, teeth and jaw and can affect the most basic of daily activities such as eating, swallowing, teeth brushing and face washing.

The cause is not completely understood although it can occur when the trigeminal nerve becomes irritated or trapped causing pain to the face. Dental work has been identified as being the most common trigger for trigeminal neuralgia.

Symptoms include:

- Sharp, 'electric shock' type pain
- Dull ache
- Sensitivity to touch

If you have any of these symptoms you should consult your doctor who will advise you of the treatment options.

Complex Regional Pain Syndrome (CRPS)

This is a chronic pain condition. The key symptom of CRPS is continuous intense pain which may appear to be out of proportion to the severity of the injury. The pain commonly worsens with time.

CRPS I is often triggered by tissue injury but has no apparent nerve damage.

CRPS II has the same symptoms but is also associated with a nerve injury.

Symptoms include:

- Burning pain
- Increased skin sensitivity
- Changes in skin temperature
- Sweating and swelling of the affected area
- Changes in skin colour and texture
- Changes in nail and hair growth
- Decreased ability to move the affected body part
- Muscle spasm
- Reduced muscle tone
- Continuous pain

The cause of CRPS remains unknown and it is very difficult to diagnose. Diagnosis is usually achieved by ruling out other conditions.

There is no cure for CRPS but pain can be reduced or controlled by using a mixture of symptomatic pain manage-ment therapies. If you have been diagnosed with CRPS you and your doctor may decide that you could benefit from consulting a pain specialist. There are many treatment options available which can help you to gain control over this disabilitating pain.

Reprinted from San Joaquin CFIDS/ME/FMS Support Group, August, September 2008 newsletter and The Florida East Coast Post Polio Newsletter, Nov-Dec & Jan-Feb issues.

From Henry's Desk by Henry Holland

Falling Again and Again

At our regular Central Virginia Post Polio Support Group Meeting on March 7, 2009, we had a general discussion among the approximately twenty members present. The weather was unseasonably warm, but six days earlier we had had a 6 to 8 inch snow storm and many of us recounted some difficult times we have encountered with snow and ice. Some of our members lost electric power and this circumstance can lead to increased feelings of anxiety. We also talked about our dependence on others in stressful situations. Some of our members live alone and have increased vulnerability as a result. Among the members at this meeting twice as many of the polio survivors had sustained fractured bones from falls compared to the able bodied members present. In 1996 I wrote an article entitled "Falling." Seven years later in 2003 I wrote another similar article entitled "Falling Again." This article is a composite of both articles with some updates.

Some of us have vivid and unforgettable memories of falls we had in our youth because of the residual effects of polio, and others have equally memorable accounts of falls that we have had because of the effects of Post Polio Syndrome (PPS). An additional problem now is that we are older and probably do not fall as gracefully as we once did. Also, the risk is greater for injury because of weaker muscles, softer bones, and the same factors of aging that everyone experiences. Falling is no fun, but dealing with its reality may build character.

Some years ago, I made a list of all the falls that I could remember. Of course, the bad or spectacular falls are more easily recalled. My list came to about twenty-eight falls. The first occurred in 1950 in the halls of the Medical College of Virginia Hospital when I first learned to walk with two long leg braces and two crutches. Somehow, I lost my balance and fell backward like a small tree that had been cut at the base. My head hit the marble floor and I almost lost consciousness. However, I was picked up, and walked back to my bed. My most recent fall occurred in 2006 when I accidentally pushed against the forward switch on my power wheelchair while I was transferring from my bed to the chair. I was standing and the moving chair knocked me over. Fortunately with the help of my wife Brenda and one of my summoned patients nearby I was pulled up on the bed and could get back up. I was fortunate in that I did not sustain any injury. Some of my falls have produced considerable pain, swollen joints, large bruises, and anxiety. Pain is no fun, but dealing with it may build character.

For many of us the experience of terror occurs during that second or less when we realize that we have lost our balance and recovery of balance is impossible. To put it another way: "I have lost control and I am going to hit something for sure." A lot does depend on what we hit, and what part of our body hits first. I have fallen on marble, slate, wood, rugs, grass, dirt, concrete, snow, ice, and stairs. The part of the body that

usually hits first is any one of the four extremities (elbows, hands, knees, hips) or unfortunately the head or chin. During that split second of falling weightlessness, our autonomic nervous system kicks into the fright or flight mode. We cannot flee, thus, we have more of the fright mode. By the time we land, our hearts are racing, the respiratory rate is increased, and we are probably breaking into a sweat. If we did not sustain a serious injury, this extra adrenalin helps us get over the immediate effects of the fall. Of course, later, we are quite sore and fatigued, but grateful that nothing really bad happened. Fear is no fun, but dealing with it may build character.

Falls can result in serious injury or life threatening situations. About twenty years ago when I was leaving my office rather late one night, I fell on ice about midway between my office and my car. It was very cold. Because of the slippery ground, I was unable to get any traction, and could not get up. I was totally alone. I decided to crawl to my car. With my last source of energy, I was able to pull myself into the car, and get it started, and eventually I warmed up. This experience taught me about vulnerability, and having better options for help. Even with precautions, bad things can happen.

I am confident that each of you has experienced the reality, pain, fear and adversity of falling. There are many amazing stories that could be shared by all of our membership. Depending on each person's degree of physical handicap, our falls may have been more frequent and more dangerous. Decades ago, whatever the severity of the handicap, all of us were encouraged and motivated to get back on our feet, no matter what it may take. If we did not get back on our feet, then the world of the polio years was inaccessible. That world included schools, stores, houses of worship, some parks and many homes. I know that my experience included many falls, some more memorable than others. Like many PPSers, I have slowed down, am more cautious, and take all precautions to prevent falling. I began using a scooter on a part time basis in 1991. By 1996 I began using my scooter almost all of the time and in 2003 I acquired a power wheelchair. I use this same power wheelchair today. Also in 2002, I became totally ventilator dependent to prevent respiratory failure. I care a portable ventilator on my wheelchair. With these adaptations I have conserved my energy and reduced the risk of falling. No matter the precautions, falling and other types of accidents are a reality to all PPSers. We can always fall again.

Often I feel that my vulnerability is almost overwhelming or too frightening to think about, but I cannot escape reality. Sometimes I think of my faith as a source of strength. I think of the faith of the Apostle Paul and how he dealt with adversity. Just before his shipwreck described in Acts 27, Paul states in verses 22-24: "But now I beg you, take courage! Not one of you will lose your life; only the ship will be lost. For last night an angel of the God to whom I belong and whom I worship came to me and said, 'Don't be afraid, Paul!" While lying on the ground, concrete or whatever it may be I have never seen or heard an angel of the Lord, but I have felt the presence of loving souls, in essence saying, "Don't be afraid, Henry."

Many falls I will never forget. Turning over in a scooter or wheelchair, falling down a flight of steps, falling in the bathroom or shower, and falling in the comfort of your home can potentially be fatal. A head injury could lead to death. Fractures of major bones can lead to necessary surgery. The risk of surgery in polio-damaged limbs can increase the risk for clots. We are all older and do not recover as ably as in the past. The stress and shock of a fall can have an adverse effect on our cardio-pulmonary-vascular systems. Many PPSers take medication for hypertension and diuretics to reduce dependent edema. A sudden added stress on our bodies can increase the risk for stroke, heart attack, and clots. We could live in a vacuum and still there is no absolute safeguard against falling and other accidents.

Pain and fear are the expected results of a fall, even when no real damage is done. How do we go about coping with the possibility of falling and the resultant pain and fear? Do we simply deny the reality of this possibility? Do we allow fear to cause an obsessive concern about falling, resulting in even greater life restrictions? I think we have to accept the risks inherent in living with PPS just as we did with polio. I think we should adhere to practical and doable precautions. We probably should avoid being alone as much as possible. If we are alone we should have a cell phone on our person or a phone attached to our wheelchair or scooter. I think it is also wise to have a flashlight within close reach whenever one goes out at night or in case a power failure occurs at home. I would recommend that Post-Polio Support Groups discuss the risks of falling as a program topic at a meeting. Many experiences can be shared and good ideas can result from such a discussion. I am confident that each of you has experienced the reality, pain, fear, and adversity of falling. There are many amazing stories that could be shared by all.