

POLIO DEJA VIEW

Central Virginia Post-Polio Support Group

www.cvppsg.org

April - May 2006

Carol T. Ranelli, Editor

April 1st Meeting

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

Our speaker will be Deputy Jim McLaughlin, Hanover County Sheriff's Office.

A Crime Prevention Specialist will teach about safety in the home, while traveling, at work and on the computer. Learn how to remove the opportunity for becoming a victim and what to do if you suspect you are a victim of crime.

He will also address special tips for Post-Polio Living, such as unloading your scooter, shopping with your scooter at the mall and other valuable issues.

May 6th Meeting

2:00 pm at Children's Hospital

Our speaker will be Kay Hawkins, certified yoga teacher and therapist

She will present a Yoga Sampler....Have a little taste of what yoga has to offer: increased flexibility, more strength and ease in your body; techniques for improving breath capacity; techniques to better relax and de-stress. You won't have to get on the floor, but wear comfortable clothing and shoes. This yoga sampler will be centered on techniques done while standing and from a chair.

Kay Hawkins thinks of herself as a late bloomer....at age 50 she took her first yoga class. Now, at 65 she is twice certified as a yoga teacher and recently completed certification as a yoga therapist. Yoga therapists offer the tools of yoga to people with various challenges, from bad backs to long-term conditions.

Kay first became interested in working with these populations while working in Northern Virginia. There, she encountered many people whose limitations that prevented them from participating in regular yoga classes. She pioneered the concept of "gentle yoga" in her work for the Arlington County Recreation Department.

Assisting Kay will be Jacqueline Gooding, a Richmond-area yoga teacher.

Save These Dates !!!

June 3rd will be our **Annual Luncheon** and this year we are celebrating the Support Group's 20th Anniversary !!

The June-July newsletter will have a complete history of our support group and we would love to have all of our "longtime" members there.

We will have Buzz & Ned's Famous Barbeque catering our lunch with pork barbeque and barbequed chicken with all the fixin's for \$13 a person.

Also save September 22-24th for our **Annual Retreat** which will be held at the Holiday Inn Express Hotel & Suites in Ashland, VA, right off rt. 95 so it's convenient for everyone. We have reserved all the handicap accessible rooms and all rooms will be suites with sitting areas, microwaves, refrigerators, tv, coffee makers and hair dryers.

We will have the use of the heated indoor pool and hot tub all weekend. Again we will have our two massage therapists on Saturday .

The final cost will be **\$110 per person (double occupancy)** including meals for the whole weekend. We think this is a great value for the accommodations.

Our theme this year will be "**laughter is the best medicine**" and we are planning a lot of fun activities for the entire weekend with some "rest time" included.

This support group has come a long way in the past 20 years and we have accomplished so many things for our post-polio members and their families. Come help us celebrate the joy of being survivors with all our friends...and hopefully make some new friends during the weekend retreat.

Registration forms with all the information will be in the August-September newsletter. Remember, rooms are on a first-come- first-serve basis, so look at your calendar and send in your forms early.

INFLAMMATION and PPS

By Marcia Falconer, PhD

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Post-Polio Syndrome (PPS) has been a recognized condition for more than 25 years, with reports of similar symptoms going back to the 1800's. However, we still do not have a grasp of the underlying cause, or causes, of PPS!

We do not know how many polio survivors will develop PPS; estimates range from 20% to over 80%. We do not know why some polio survivors develop PPS and others do not. There is no diagnostic test and PPS remains a diagnosis arrived at after exclusion of other somewhat similar conditions. We do not understand why there is a lag time between recovery from the acute illness and development of symptoms severe enough to compromise the quality of life.

It seems there is very little that we do understand about PPS. However, if we can discover the underlying cause(s) of PPS; if we can find out what is happening at the cellular and even sub-cellular level, there is promise of being able to answer all of these perplexing issues. There is also promise of being able to treat and possibly even prevent the onset of many perhaps most, PPS symptoms.

Little research has been done on PPS, probably because polio survivors are a dying breed. After world wide eradication of polio, the 'lifespan' of PPS will be equal to that of the youngest living polio survivor. Or will it? Poliomyelitis continues to cause paralysis although now the virus causing the illness is not the polio virus but the West Nile Virus, or enterovirus 71, or one of several Coxsackie viruses.

The nerve damage caused by these viruses is virtually identical to that caused by the polio virus and therefore it is likely that PPS, perhaps by then called Post-Viral Syndrome, will continue to bring new limitations to survivors many years after they thought they had recovered. So it remains important to examine the underlying cause of new muscle weakness, central fatigue, pain, memory and word finding problems and other symptoms that accompany PPS.

Fortunately, current research in other areas holds great promise for explaining what is happening to so many polio survivors. The cause of virtually all PPS symptoms can be explained by one word: inflammation! Front line research in the fields of neurology, immunology, physiology and virology is coming together and the many pieces of the puzzle are being laid upon the table.

A good analogy is to think about a jig-saw puzzle. When you dump a 1000 piece puzzle out of the box, some pieces land right side up, others upside down. There is little hope of assembling the puzzle until you turn all the pieces right side up. The next step is to put all the straight edged pieces in a pile and then assemble the outer edge of the puzzle to give you a general outline. After this it is helpful to group pieces with similar patterns or colors together.

This is approximately where we are today in our understanding of how inflammation is related to almost all chronic diseases; PPS, MS, ALS, CFS, Parkinson's, irritable bowel syndrome, arteriosclerosis and many, many others. This also gives you some idea of how far we have to go until we have a complete picture! Let's look at the puzzle pieces that seem to belong to PPS.

Inflammation has two major causes; injury (including viral and bacterial infection, cuts, strains, operations, etc.) and psychological stress (including major events such as death of a relative, divorce, and job loss, but also including milder, repetitive stress that is encountered every day).

In a person with PPS, when the body suffers an injury, such as physically overdoing by climbing too many stairs, walking on uneven ground, etc. the first reaction is for the cells in the affected area to release a chemical messenger. This messenger, called a proinflammatory cytokine, tells specialized cells, whose job it is to protect you from invading organisms, to come to the site of the injury. At the same time the proinflammatory cytokines activate resident cells and cells that have migrated to the injury and all of them produce more proinflammatory cyto-kines setting up a cascade of events that will involve the entire body.

Two proinflammatory cytokines, interleu-kin-1 and Tumour Necrosis Factoralpha, are especially important in triggering an acute immune response, the body's first line of defense. The acute immune response involves developing a fever, fatigue, loss of appetite, sleepiness and other symptoms. It goes away within a few days. However, if the injury is repeated often – say if a person with PPS persists in exercising a stressed out muscle – then a chronic immune response will set in. The response to chronic stress involves the entire body including the brain and produces central fatigue, new muscle weakness, problems with short term memory and word finding, irritable bowel syndrome and other symptoms.

Recognize them? Indeed. These are the post-polio syndrome symptoms we are so familiar with. In an effort to keep this article shorter than a textbook on immunology, I have omitted the complex chain of events that takes place in the body between the original stress and the onset of PPS symptoms. There are many, many research papers that amply document what happens in the body after activation of the immune system by proinflammatory cytokines and that eventually results in symptoms identical to those of PPS.

Let's take a brief look at how proinflammatory cytokines may be the underlying cause of new muscle weakness. We begin with acute polio and the death of a large number of nerves whose job was to innervate muscles by telling the muscles to contract or relax and thereby allowing you to move a leg or an arm. If 60% of the nerves leading to a leg or arm died, the limb was paralyzed. When fewer nerves died the result was varying degrees of muscle weakness.

In many people, original paralysis or severe weakness eventually resolved; voluntary movement was restored and you could once again use your arm or leg. The body developed a neat trick to allow this to happen. The surviving nerves were able to send out 'neuronal sprouts' to attach to and innervate muscles that had been orphaned when the nerve originally attached to them died off. Thus the surviving nerves were able to activate not only the muscle that they always innervated, but also surrounding muscles creating something called a "motor unit".

This repair was essentially stable for many years. However 30 or more years after recovery from polio, many people begin experiencing new muscle weak-ness. Often the weakness is in the 'good' arm or leg. This may be due to the fact that the 'good' arm or leg was used more. Clearly something happened to the neuronal sprouts; either they no longer could maintain full time attachment to the

motor unit or else they may have died off completely. This caused the appearance of new muscle weakness. Once again, I've simplified this a bit – although the general picture is correct. But this is a description of *what* is happening, not an explanation of *why* it is happening.

Enter proinflammatory cytokines. Remember them? Researchers have well established that proinflammatory cytokines cause cells to release neurotoxic proteins. These neurotoxic proteins can damage or even kill neurons by a number of mechanisms including changing the outer membrane of the nerve cell resulting in cell death or increasing reactive oxygen inside the nerve cell which also leads to cell death. It is probable that the neuronal sprouts, that have served so well for so long, are more fragile and may be the first target of proinflammatory cytokines in the central nervous system.

A very important fact is that nerve death only occurs in an activated immune system. The next question is "Do people with PPS have an activated immune system?" The answer is YES! There have been a number of research papers indicating that polio survivors with PPS symptoms have an activated immune system while polio survivors who do not report PPS symptoms do not have an activated immune system [1].

A very recent research paper [2] looked at cytokines in people with PPS, polio survivors without PPS, people with multiple sclerosis (MS), a well known inflammatory neurological disease, and people who had no neurological problems. They found that people with PPS and MS have proinflammatory cytokines in their central nervous system while polio survivors who do not have PPS and people without neurological problems do NOT have proinflammatory cytokines in their central nervous system.

What might cause the presence of these proinflammatory cytokines in people with PPS? One hypothesis is the presence of very low levels of polio virus RNA hiding in nerve cells. This polio virus RNA is not capable of infecting you or other people, but is capable of triggering the production of proinflammatory cytokines and with that, an underlying state of chronic immune system activation.

Other researchers have demonstrated a clear connection between the presence of proinflammatory cytokines and central fatigue [3]. Psychological stress – the kind that doesn't involve overdoing physically – is perceived in the brain and the brain produces proinflammatory cytokines. This can cause profound fatigue, inability to concentrate and other symptoms [4].

Remember that 1000 piece jigsaw puzzle we have spread out on the table? We are now able to put together some of the same coloured pieces to make small pictures that are part of the larger picture. In the same way, we are piecing together what happens when a person with PPS experiences physical or psychological stress. We start to see small pictures and we can just begin to discern the larger picture coming together.

We are coming to the place where it may be possible to treat PPS symptoms using anti-inflammatory medications. A very exciting trial, using *intravenous immunoglobulin treatment*, is currently underway in Sweden. Preliminary trials of this treatment in people with PPS have yielded dramatic improvements in fatigue and muscle strength! [5,6]

Other treatments to reduce PPS symptoms may be based upon *traditional anti-inflammatory medicines* such as aspirin, ibuprofen, indomethacin and others.

All treatments would have to be done under the supervision of your doctor, but in the meantime, there are some things you can do that are known to minimize inflammation in the body – and with that you might have a reduction of PPS symptoms.

- *Meditation.* You might try meditation. Yes it works...if you do it consistently.
- *Exercise.* Appropriate exercise, under the guidance of a knowledgeable physiotherapist, will definitely lower inflammatory cytokine levels.
- *Pacing.* Pace yourself and don't overdo. This is easier said than done but if you understand that seriously overusing muscles will start the proinflammatory cascade of events and with that bring on or intensify PPS symptoms, perhaps you will be able to justify resting before you go too far.
- *Weight loss.* Adipose tissue – commonly known as fat – is also a producer of inflammatory cytokines. If you needed a good reason to lose weight, here it is.

Finally there are a few things you can try. *Drinking green tea* encourages weight loss and it has neuroprotective qualities. There are also reports that *undenatured whey protein* may be beneficial. These things are probably not as effective as direct medication to lower proinflammatory cytokine levels, but as we incorporate them into everyday life, they will bring positive benefits.

And let's keep working on that jigsaw puzzle!

References:

1. Dalakas, *Pro-inflammatory cytokines and motor neuron dysfunction: is there a connection in post-polio syndrome?* *J Neurolog Sci.* 205:5-8, 2002
2. Gonzalez et al. *Prior poliomyelitis-IvIg treatment reduces proinflammatory cytokine production.* *J Neuroimmunol.* 150:139-144, 2004.
3. Patarca, R. *Cytokines and chronic fatigue syndrome.* *Ann NY Acad Sci.* 933:185-200, 2001.
4. Black, PH. *Stress and the inflammatory response: a review of neurogenic inflammation.* *Brain, Behavior and Immunity* 16:622-653, 2002.
5. Farbu et al. *Intravenous immunoglobulin in postpolio syndrome.* *Tidsskr Nor Laegeforen.*124:2357-2358, 2004.
6. Gonzalez et al. *study in progress.*

Information about Dr. Marcia Falconer:

Now retired, Dr. Falconer led a laboratory doing research in virology and molecular biology at The Centre for Food and Animal Research, Agriculture Canada Ottawa, Ontario, from 1993 to 2000.

Educational background:

- Post-doctoral fellow in molecular biology at Massachusetts Institute of Technology (Center for Cancer Research), Cambridge, Mass. USA. 1990-1992.
- Ph.D. in neuronal cell biology from University of Ottawa, Ottawa, Ontario, Canada. 1990
- M.Sc. in cell biology from Carleton University, Ottawa, Ontario, Canada. 1985

Marcia was quarantined with polio at age 7 (1949). She had leg and arm weakness followed by complete recovery. She led an active life: swimming, ice-skating and cross country skiing. PPS symptoms first noticed in 1985, with fatigue and leg weakness becoming severe by 1996. PPS diagnosed in 1998.

I Could Give All to Time By Robert Frost:

To Time it never seems that he is brave
To set himself against the peaks of snow
To lay them level with the running wave,
Nor is he overjoyed when they lie low,
But only grave, contemplative and grave.
What now is inland shall be ocean isle,
Then eddies playing round a sunken reef

Like the curl at the corner of a smile;
And I could share Time's lack of joy or grief
At such a planetary change of style.
I could give all to Time except - except
What I myself have held. But why declare
The things forbidden that while the Customs slept
I have crossed to Safety with? For I am There
And what would I not part with I have kept.

From Henry's Desk: Lent and Crossing to Safety

By Henry Holland

For those of the Christian faith this essay may mean more, but perhaps some truth and wisdom will be reflected regardless of one's faith. We are currently in the season of Lent in the Christian calendar. Lent is a time for repentance and soul searching. A life with polio has most likely caused many of you to do considerable soul searching, both in the past and now in living with Post Polio Syndrome (PPS).

As an infectious disease, historical evidence would indicate that polio has been in existence for over five thousand years. However, over these many centuries, the literature on polio has been limited. In the last century there was more in the medical literature about polio as a result of the epidemics that began in the early part of the last century. With the development of the Salk and Sabin vaccines, the medical literature regarding polio quickly vanished. Now, with the reality of Post-Polio Syndrome (PPS), the literature, both medical, non-fiction and fiction have increased in the last decade. In my opinion, this literature has resulted for two reasons. One is due to PPS and the other is due to books that have been written by polio survivors and family members of polio survivors. In our support group's library, we have many of the medical books on PPS, but we do not have many of the non-medical books

Despite our knowledge of many of these books, polio still occurs in literature or the arts when I least expect it. Several years ago, I audited a course on Job at a local seminary. The course dealt with "Job in the Bible and Beyond" and how the story of Job has influenced the arts down through the centuries. On one evening, the professor (Dr. Sam Balentine of Union Theological Seminary in Richmond, VA), showed slides of art that best depicted the suffering of Job. One of the slides was a painting by Piero della Francesca in Arezzo Italy. The painting revealed a recently resurrected Jesus, half in and half out of the grave. There was still some of the look of death on Jesus' body. At this point, the professor read a passage from a novel, *Crossing to Safety* by Wallace Stegner.

"But I noticed that Sally stood a long time on her crutches in front of that painting propped temporarily against a frame of raw two-by-fours. She studied it soberly, with something like recognition or acknowledgment in her eyes, as if those who have been dead understand things that will never be understood by those who have only lived."

In the novel, Sally is a polio survivor who wears leg braces and uses crutches. She and her husband Larry become life long friends with Sid and Charity when both husbands were young college professors at the University of Wisconsin in the late 1930's. Both wives got pregnant at the same time. While vacationing in Vermont, Sally was stricken by polio. Years later, the two couples travel to Italy and the scene described above occurred. One interpretation offered by this scene is that many polio victims can identify with Job or the suffering of the crucified Jesus. Many polio survivors have risen to full lives despite the damage of polio. However, many can recall the fear and even horror of a near death experience. We may tend to forget that thousands of children died from acute polio, especially before the development of the iron lung. This disease has shaken thousands of families. Many of us do "understand things that will never be understood by those who have only lived."

I can identify with many interesting passages in this novel. Larry, Sally's husband, tells this story in the first person. Larry comments on the uncertainty of life with these words: "You can plan all you want to. You can lie in your morning bed and fill whole notebooks with schemes and intentions. But within a single afternoon, within hours or minutes, everything you plan and everything you have fought to make yourself can be undone as a slug is undone when salt is poured on him. And right up to the moment when you find yourself dissolving into foam you can still believe you are doing fine." This sounds a bit like the process of PPS. Many of us have "fought" to be contributors and not burdens to our individual worlds, only now to feel undone by the "salt" of PPS.

Again Larry speaks of the friendship that has developed over the years between his wife Sally and Charity. "The cant word these days is 'bonding.' I suppose some people see in a relationship like that signs of an unacknowledged lesbianism---the same people who probably speculate about the sex life of somebody like me, a perfectly healthy man with a crippled wife. I don't care how they speculate, or what their answers are. We live as we can, we do what we must, and not everything goes by either Freudian or Victorian patterns. What I am sure of is that friendship---not love, friendship---is as possible between women as between men, and that in either case it is often stronger for not having to cross sexual picket lines. Sexuality and mistrust often go together, and both are incompatible with amicitia."

Near the end of the novel, Larry writes of his observations upon living his adult life with his polio-disabled wife. "One of the peculiarities of polio is that its victims, once they have recovered from the virus and settled down to whatever muscular control it has left them, live a sort of charmed life. Crippled as they are, they are rarely ill, they are surprisingly tough and durable, they astonish their sound companions with their capacity to endure. But that is not forever. There comes a time in the life of every such patient when the whole system---muscles, organs, bones, joints---begins to fall apart all at once, like the wonderful one hoss-shay. Every polio patient is warned to expect that time, every polio family lives with the foretold doom waiting for it at some unknown but expected time in the future. One learns to live with it by turning away from it, by not looking. And yet on occasion one is aware of an intense, furtive watchfulness, and the victim, the doomed one, must surely have just as often the vulnerable sense of being watched."

In my mind, the above paragraph is describing PPS. The author of this novel, Wallace Stegner, lived from 1909 to 1993. *Crossing to Safety* was published in 1987, around the time PPS was being identified as an entity. Stegner has written many novels and wrote this one after fifty years of writing. I wonder how he knew so much about the character of polio. Perhaps, he had some personal experience with polio. In his career, Stegner won the Pulitzer Prize, the National Book Award, and O'Henry prizes. If you like a novel with deeper meaning I would recommend it to you.

Reference: *Crossing to Safety* by Wallace Stegner. Penguin Books. New York. 1987, pp. 274-275, 201, 288, 336