



March 2005

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Editorial

Are we just getting old –or what?? It seems like just a few of weeks since Blenda and I wrote the previous postbox. Things keep happening and we are compelled to keep you informed. Honestly, we enjoy writing post box stuff because you tell us you appreciate getting the information. Promise that you won't cry, when you read the "Puppy-love story"- Okay?

Since our last Postbox newsletter we elected a new executive; our president Carole Einfeld toured South Korea; new members have joined us; we had a capacity attendance at the Christmas banquet and we honored Joan McIver, the first president of the provincial body. March is Polio Awareness Month and a national campaign is underway to educate polio survivors and the general public about the effects of post-polio syndrome. Polio Canada's member-organizations all across Canada will be holding events to help raise awareness of post-polio syndrome – a medical condition that causes pain, weakness and fatigue.

Polio Regina continues to raise awareness through advertising our meetings in the Regina Leader Post and Regina Sun week-end editions; by taking part in the Saturday swim program; and by wearing our attractive Polio Regina Inc. T-shirts and sweat shirts.

Thank you to all of you who renewed your membership and for your additional financial contributions. Note that memberships are due the first of January each year.

As always; if you have a story to contribute to our Post Box publication, send it in! We love hearing from you!

F&B

Sales a great success

The Polio Regina Inc, sweat shirts and "T" shirts program received a tremendous response from our members with 30 items sold. Thanks to Murray Grant for his sales initiative (he even offered to give you "the shirt off his back") to complete a sale; and to Verna and Ross Copeland for handling the sales.

Executive Officers of Polio Regina Inc. 2005/2006

President:	Carole Einfeld
Vice-President:	Wilf Tiefenbach
Secretary:	Nora Schlosser
Treasurer:	Verna Copeland
Phone Co-Coordinator:	Pat Allonby
Convener:	Verna Copeland Carol Biberdorf to assist
Program Director:	R. H. "Doc" Bornholdt
Librarian/ Archivist:	Dr.Mavis Matheson, MD
Publicity/Post Box:	Blenda and Fred Ramsay

Thank You to Norm Desautels (past vice-president) and **Don Volpel** (Secretary for the last six years) for a job well done. We welcome **Nora Schlosser** (Secretary) and **Doc Bornholdt** (Program Director) in their new positions on our executive.

Polio Canada Liaison: Wilf Tiefenbach and
Carole Einfeld



Joan McIver: Life membership Award



An original organizer and the prime instigator and motivator of our Polio organization, Joan McIver is the proud recipient of our Polio Regina life membership award. President Carole Einfeld made the presentation.

Joan worked hard and diligently in assembling our organization on the provincial level.

She contracted polio during an epidemic in Winnipeg when she was two years, 10 months old.

“Treatment meant complete bed rest and tying my legs to the crib to prevent movement. This caused contractures of my unused muscles and I had many operations to cut the muscles to release the contractures, Joan recalls. By the age of four, I learned to walk using crutches and heavy steel braces to support my useless legs” she said.

After graduating from Business College at Caronport, Sask. her mother and Joan moved to Regina where she began a 38-year secretarial career, first in the provincial finance office for five years; then five years at the Wheat Pool. The remainder of her working time was with the provincial health department.

“During our first week in Regina, I saw an advertisement in the paper announcing an organizational meeting for a local branch of the provincial Handicapped Civilians’ Association (HCA), Joan recalls. “This was in 1948 just after the war when many clubs had formed to help returned disabled servicemen. There were no clubs for the civilian population such as polio survivors” she recalls.

Polio Regina Inc. members are proud of Joan’s work and involvement and congratulate her for this prestigious achievement.

From Korea With Love

Hi guys and dolls !

I am having such a great time in Korea. I can’t believe I am so far away from home! It is a beautiful country, with all the beautiful mountains, scenery and so many very nice people.



I actually feel at home and I don’t feel like a ‘foreigner’ at all. I love all the food! It’s so healthy but I am being stuffed more than I want to be. I want to lose weight, not gain! — even tho’ there is very little fat, too much of a good thing is not good (as we all know).

I went to Erin’s school (Erin attended school in Regina and lived at my home) where she teaches junior high. Her principal made such a big fuss over me; called a special meeting with all the teachers and, ordered tea for me.

He couldn’t speak English very well so Erin was his interpreter. He was amazed at her English language ability, because of course, he didn’t know how well some of his teachers could speak if they have studied abroad.

It is very difficult to work here if you are a rookie and especially if you have studied in another country. I think the other, more senior teachers, are quite envious of the younger ones who can actually speak the language they are suppose to be teaching.

The kids were wild about a Canadian being in their classroom and we had a ball !

The entire day was exhausting but so exciting. It was their last day of their semester and now they are on spring break. So Erin had a few days off before she has to go back to work on Friday and Saturday even tho’ there are no students to teach!

Yesterday we went to a Korean museum and it was SO interesting! I didn't want to leave but we had to continue on our way to explore some more. I was with Erin and her boyfriend. He is an excellent driver so I felt very comfortable. I have taken the subway once which is exactly like Vancouver's Sky-train--so fast!! It was freezing cold here with a wind similar to Winnipeg and Regina's so that was nothing to miss about home. I am definitely not homesick for winter! But of course, there is so much pollution here with 13,000,000 people around me.

We went to the border between North and South Korea and it was sort of unreal how the soldiers are posted with guns of course. We were told not to take pictures, but, sometimes, I am a 'tad bit' disobedient. I hope they turn out even if taken at a distance.

It is an extremely sad situation for the whole country because South Korea is so wealthy and North Korea is so poor. It is such beautiful country side. We had a good look through a telescope at North Korea from a tower.

I always seem to get really ill when I am up high and it took quite a few hours to feel better. We had stopped at a restaurant to have lunch before that (Erin, her Mom, and her Mom's best friend who drove, and me). It just about killed me to sit on a chair with no legs and I could barely get up.

There were very old ladies (much older than me) who can sit with their legs crossed very comfortably. The waitress brought many side dishes, (usually about 10) and a big pot which they cook in front of you. All the vegetables and liquid and (a live squid !) which I had to watch squirm to his death and then eat him!! Very chewy, but you all know, I can eat anything, and I was told it was good for my stamina, so if it is good for me, I will eat it!!! It was fresh from the sea.

I am already feeling sad about leaving Erin's home this Saturday for Daegu, where Rick's family is waiting patiently for me. I still have until the 26th of February in Seoul.

Tonight is Monday and there will be a Regina Reunion (in Seoul) which Jack is arranging. I have

no idea how many will be there or where we meet as of yet. I have appointments with students every day to try to meet their parents, and to get to their grads.

I still want to go to a Buddhist temple. The structures here are incredible. The apartments blew me away. I was told about them but you can't believe it until you see it. But they are so solidly built you feel like you are in a house. You never hear a thing from a neighbor, not a sound (even with my hearing aids in.)

It is very early right now. I have been awake since five am (which is two pm in Regina).

Everyone is sleeping except Erin's father who left for work about an hour ago. He is a construction worker and such a friendly guy!! Her mother and I are the best of friends even-tho' we cannot communicate (just body language and laughter).She loves me because I love her daughter like my own.

I will try to send this off to many of you as my emailing time is limited and because I am so busy or because I am exhausted! Hope all is well in Canada.

From beautiful Seoul, with love; Carole!

Thank you to Carole Einfeld for giving us this informative article.



Greetings to Wain Birch and Cindy Chamberlin from all the folks in Polio Regina Inc.

We wish you to know that we appreciate that you maintain the operations on behalf of the directors of the

Lorne & Evelyn Johnson Foundation and the directors of the **South Saskatchewan Community Foundation**. We are pleased to have framed this artwork, which is among pieces provided to your offices by Dawn Redmond-Bradley. Artwork framed by Fred Ramsay.

Swim for the healthy fun of it !



Swimming attendance has been great. We have had 10-12 taking part in the “Laugh & Splash” Swim program at the Wascana Rehabilitation Centre Saturday afternoons.

Swimmers taking part have been Jim & Pat Allonby,

Carol & Clarence Biberdorf, Grant Barrick, Carole Einfeld, Glenys Miekle, Murray Grant, Grace Lekivetz, Fred & Blenda Ramsay, Wilf Tiefenbach and Diane Weir-Wagg. We have lots of fun in the water and we usually go for coffee after the warm swim.

April 23 will be the last swim for this session. So, during the summer months, why not try the Adult Drop-In Program on the week ends. There is no need to pre-register. Drop-in swims will be open at the Sandra Schmirler Leisure Centre (call Tanya @ 777-7593) or the North West Leisure Centre (phone 777-7046) for more information. The Sandra Schmirler pool has a “lift chair” and the water is said to be the warmer of the two. The next registration for “Laugh & Splash” will take place in the fall so watch your mailbox for the City of Regina Fall/Winter programs.

Thank You!

Jim and Pat Allonby extend their thanks to Polio Regina for the cards and gift they received while in hospital. We are glad to hear they are recovering and we look forward to having them join us at our monthly meetings. Pat serves as the phone co-ordinator for Polio Regina.

A Puppy Love Story



A farmer had some puppies he needed to sell. He painted a sign advertising the four pups and set about nailing it to a post on the edge of his yard. As he was driving the last nail into the post, he felt a tug on his overalls. He looked down into the eyes of a little boy. “Mister,” he said, “I want to buy one of your puppies.”

“Well,” said the farmer, as he rubbed the sweat of the back of his neck, “These puppies come from fine parents and cost a good deal of money.” The boy dropped his head for a moment. Then reaching deep into his pocket, he pulled out a handful of change and held it up to the farmer. “I’ve got thirty-nine cents. Is that enough to take a look?”

“Sure,” said the farmer-and with that he let out a whistle: “Here, Dolly!” he called. Out from the doghouse and down the ramp ran Dolly followed by four little balls of fur. The little boy pressed his face against the chain link fence. His eyes danced with delight. As the dogs made their way to the fence, the little boy noticed something else stirring inside the doghouse. Slowly another little ball appeared; this one noticeably smaller.

Down the ramp it slid. Then in a somewhat awkward manner, the little pup began hobbling toward the others, doing its best to catch up.

“I want that one,” the little boy said pointing to the runt.

The farmer knelt down at the boy’s side and said, “Son, you don’t want that puppy. He will never be able to run and play with you like these other dogs would.”

With that the little boy stepped back from the fence, reached down, and began rolling up one leg of his trousers. In doing so he revealed a steel brace running down both sides of his leg attaching itself to a specially made shoe.

Looking back up at the farmer, he said, “You see sir, I don’t run too well myself, and he will need someone who understands.” With tears in his eyes, the farmer reached down and picked up the little pup. Holding it carefully he handed it to the little boy. “How much?” asked the little boy.

“No charge,” answered the farmer, “There’s no charge for love.”

Meetings and Important Dates:

Monthly meetings are held at the Wascana Rehabilitation Centre on the **LAST** Thursday of each month @ 7:00 pm with the exception of June, July, August and December.

2005 meetings will be held March 31; April 28; May 26; Sept. 29; Oct. 27; and Nov. 24.

Mark your calendars: Our summer picnic on will be held on **Saturday afternoon, June 11th** at the Rotary Senior Citizens Centre, 2004 Elphinstone St. Please note that we have changed the day to **Saturday** (instead of Sunday).

Christmas Banquet will be held at Westminster United Church, Saturday, Dec. 3.

Up-coming Conference - Post-Polio Health International Ninth International Conference will be held June 2-4, 2005 in St. Louis, Missouri. Check web site www.info@post-polio.org for more information.

Polio Regina took part in the Health Fair held last August, 2004 at the Regina Inn.



Carole Einfeld and Wilf Tiefenbach handed out information at our display and answered questions regarding Polio and Post Polio Syndrome.

*Speaking of farmers...*we received a new membership from **Doug Seierstad**, Box 129, Parkbeg, Sask. They are cattle ranchers. Doug had polio when he was five years old. In his letter Doug enclosed an advertisement for an electric boot and shoe dryer rack in which he stores and warms' his cowboy boots before he puts them on. His feet stay "toasty" warm for a long time.

The boot warmer is sold by your local Peavey Mart.

Electric Shoe/Boot Dryer
Safely removes perspiration, wetness and odour from any footwear overnight. Improve foot comfort and health while protecting your footwear investment. Ideal for leather, canvas, rubber, vinyl, cloth, plastic and all modern fabrics. (6-9-5089) Reg. 49.99

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Glove Drying Attachment (6-9-5102) 15.99

Save! \$10

The Grey Matters Senior Newsletter

(Winter 2005) had this information.

Saskatchewan Safety Council's Mature Driver Refresher Course is offered to:

- Gain more confidence behind the wheel
- Improve your awareness of traffic hazards
- Update yourself on traffic laws and new technology
- Identify and correct bad driving habits
- Voice your concerns in a friendly, relaxed environment

For more information on the courses or to register, please call the Saskatchewan Safety Council at (306) 757-3197.

Also effective January 1, 2005, all vehicles in Saskatchewan have been reclassified. Check with your SGI agent to see if you qualify for a rebate.

How I Spent Friday, February 18, 2005

Told by the renowned and celebrated: R.(robust) M.(magnificent), Murray Grant himself:

“It has been fun, taking part in television productions, beginning August 2003 at Taylor Field among extras in Episode 13, Season 1 of “Corner Gas” and twice again in summer 2004 episodes with short lines.



I’m cast as “an older man” and, there was a two day shoot for a Higgins Clark murder mystery “Cradle Will Fall.” I am the janitor who failed to see a beautiful woman in pain on the floor of the basement in the medical building.

Yesterday, a very bright, sunny and cold day — was different. This time, it was a big-screen production by a Hollywood company using locations in Regina and Moose Jaw for a romantic comedy, “Just Friends.”

Tuesday, Oct. 26th, 2004: I’m invited to an audition, and told within three days that I got the part. Only three words, perhaps a 30-minute job?

Wednesday, Feb. 16th, 2005: I get a call from Wardrobe in the Sound Stage building on College Avenue, fitted with clothing, even shoes, and given the full script for the entire show. It fills a big 3-ring binder: I looked pretty cute, I thought.

Thursday night, 17th An assistant director calls from Wakemaw Valley Park in Moose Jaw; I’m asked to be at the production trailers in the park before 9:30 a.m., and I’ll be outfitted by Wardrobe, taken in hand by Makeup and Hairdresser.

Friday, 18th: Only 35 minute drive from home to the Park. It’s a lovely area, with a variety of facilities provided by Rotary, Lions, Kiwanis etc. I drove over an old bridge that crosses the creek. On the frozen surface is a rink, a Second Unit camera crew and cast are shooting “Grade 3 Boys” playing hockey. AD Mike directs me to the food trailer for coffee and more. There is an 8-page Crew Document that lists all the info

for the day. It shows that Murray Grant is required on Set at 11:15 but a large passenger van takes me and others to the location before 10:15.

The location is a convenience store on the south side of Moose Jaw, a low-income area near the CPR railway main line. The owner is a cheerful man, standing to one side in his store for three days from sunrise to sunset. First day, the crew placed Christmas displays in every direction. They placed New Jersey lottery signs on shelves, and New Jersey newspapers on all the stands.

His store has a large adjoining room: a Laundromat with 24 machines, tables and chairs for background and cast actors, and tables with coffee, fruit drinks and food in abundance. Nobody touches anything in the store; a woman takes frequent Polaroid shots to be sure that Props remain in same positions, as used.

Outside the store, 20 extras have been directed to the store by Crew Security workers. All streets in four directions have been blocked. (Main Street in downtown Moose Jaw has been blocked for several days, as crews use the National Café for indoor and outdoor shoots.) The 20 extras have brought their own cars, and crew members place New Jersey plates on them. Outdoor scenes will be shot without a break until three p.m.

Temperature is a cold, but comfortable Minus 14 C -a bright and sunny day with no wind. Crews use giant white screens to reduce the bright light. Including the automobile drivers, there are 28 extras, three stand-ins, nine in the cast. Wardrobe provided me with thermal underwear. I’m glad I’m wearing it, since doors open and close often.

Now the principal production people come inside with the big camera equipment, mikes, lights, and more. They ask the set workers to reduce the Saskatchewan sunlight coming from the west windows. They use a big roll of grey plastic film. Some extras are brought into the store to be background shoppers. Ryan Reynolds is the star and he does some practice moves around the store. I’m the store owner so I can stand, watch and observe. After discussions of many details,

the camera begins to roll. Again, and again and again.

Finally, as 5 o'clock approaches, it's a Wrap. Everyone is satisfied. Ryan spoke his three words, and I spoke my three words. Crew chief tells everyone that it's lunch time, downtown Moose Jaw. I get a ride back to the Trailers and change my clothes. The Grade Three Boys continue to play hockey on the frozen river. I call Gen because we have booked a table for dinner at 5:30 in a Regina restaurant with five friends. I join them at 6:10 p.m.

As I left the convenience store in Moose Jaw, the owner said he'd be there first thing today (Saturday), ready for the crew to return his store to normal. I don't ask him what he is earning for the three days. In fact, I have no idea what I'm going to earn for my three words. Anyway, it was fun.

The End



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Regina, Saskatchewan
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Ivan Jorgensen
(306) 757-8051
Personalized Collector Plates
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Here's something pretty neat!

(We thank Jackie Ball for bringing this information to our attention.)



A Saskatchewan family from Ituna are manufacturing, selling and installing a very neat safety bathtub especially for people with disabilities.

At our last regular meeting we viewed a video to our group and we still have the tape for anyone who wants borrow it.

Safety Bath has been designed to allow easy access for people who are having difficulty getting in and out of a regular bath tub. If a person is capable of walking with a walker assist, they will not have trouble getting into this tub.

It has a built-in, non-slip surface on the floor and seat; a molded seat and back for maximum support and comfort; has a complete set of scald guard taps features and a pop-up drain valve with a built-in overflow system to prevent flooding. Safety Bath comes standard with a Hydro-therapy whirlpool system.

It is a replacement for a regular tub and no major renovations are required.

If you need more information, contact;
Safety Bath Inc, Box 53, Ituna, Sk. SOA 1N0.
Phone: (306) 795-3465 **OR** Liberty Lifestyles
(dealer) in Regina @ (306) 351-0212.

Post-Polio Syndrome and Inflammation

Marcia Falconer, PhD, (Speaker at the Polio Canada Workshop in 2003)

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 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 colours 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 will also give 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 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 cytokines setting up a cascade of events that will involve the entire body.

Two proinflammatory cytokines, Interleukin-1 and Tumour Necrosis Factor- α , 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. This response to chronic stress involves the entire body including the brain and it will produce 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 all the nerves leading to a leg or arm died, the limb was paralyzed.

However 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.

Thirty or more years after recovery from polio, many people begin experiencing new muscle weakness. 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 pro-inflammatory 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 Iv 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. You might try meditation. Yes it works... if you do it consistently. Appropriate exercise, under the guidance of a knowledgeable physiotherapist, will definitely lower inflammatory cytokine levels. 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.

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!

Thanks to Carole Einfeld for giving us this informative article .

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The TEN Commandments for Polio Survivors

Written by: Richard Bruno, PhD and Nancy Frick, PhD

(You may have read this before, but it's good to be reminded once again).

1. Listen to Yourself!

Polio survivors often turned themselves off from the neck down after they got polio. The first step in treating PPS is to listen to yourself: to what you feel, physically and emotionally, when you feel it and why. Our most powerful tool in treating PPS is the daily logs our patients keep that relate activities to their symptoms. However, polio survivors sometimes listen too much: to vitamin salesmen saying some herb or spice will “cure” PPS, to other polio survivors who warn that you will eventually have every possible PPS symptom, and to friends and family members (and the voices in your own head) saying you're lazy and that you must “use it or lose it.” Polio survivors need to listen to their own bodies, not to busybodies.

2. Activity is Not Exercise!

Polio survivors believe that if they walk around the block five times a day, spend an hour on the exercise bike and take extra trips up and down stairs, their muscle weakness will go away. The opposite is true: the more you overuse your muscles the more strength you lose. Muscles affected by polio lost at least 60% of their motor neurons; even limbs you thought were not affected by polio lost about 40%. Most disturbing is that polio survivors with new muscle weakness lose on average 7% of their motor neurons per year, while survivors with severe weakness can lose up to 50% per year! You need to substitute a “conserve it to preserve it” lifestyle for the “use it or lose it” philosophy. Stretching may help pain and non-fatiguing exercise for specific muscles can prevent you from losing the strength you have after you get a brace. But polio survivors need to work smarter, not harder.

3. Brake, Don't Break.

The follow-up study of our patients showed that taking two 15 minutes rest breaks per day – that's doing absolutely nothing for 15 minutes - was the single most effective treatment for PPS symptoms. Another study showed that polio survivors who paced activity — that is worked and then rested for an equal amount of time — could do 240 percent more work than if they pushed straight through. Our patients who took rest breaks, paced activities and conserved energy had up to 22% less pain, weakness and fatigue. But polio survivors who quit or refused therapy had 21 percent more fatigue and 76% more weakness. For polio survivors, slow and steady wins the race.

4. A Crutch is not a Crutch . . .

. . . and a brace is not a sign of failure or of “giving up.” You use three times less energy (and look better walking) using a

short leg brace on a weakened leg. Overworked muscles and joints hurt and nerves die after decades of doing too much work with too few motor neurons. So why not use a brace, cane, crutches (dare we say a wheelchair or a scooter) if they decrease your symptoms and make it possible to finally take that trip to Disney World? We know, you'll slow down and take care of yourself “when you're ready.” And you will use a wheelchair “when there's no other choice.” Well, you don't drive your car until it's out of gas. Why drive your body until it's out of neurons?

5. Just Say “No” to drugs, unless...

Five studies have failed to find that any drug that treat PPS. And there have been no studies showing that herbal remedies or magnets reduce symptoms. Polio survivors shouldn't think that they can run themselves ragged, apply a magnet or pop a pill, and their PPS will disappear. Pain, weakness and fatigue are not-so-subtle messages from your body telling you that damage is being done! Masking symptoms — with magnets or morphine — will not cure PPS. However, two studies have shown that polio survivors are twice as sensitive to pain as everyone else and usually need more pain medication for a longer time after surgery or an injury (see 10 below).

6. Sleep Right All Night.

The majority of polio survivors have disturbed sleep due to pain, anxiety or sleep disorders, such as sleep apnea (not breathing) or muscles twitching and jumping all over your body during the night. However, polio survivors are usually not aware that they stop breathing or twitch! You need a sleep study if you awaken at night with your heart pounding, anxiety, shortness of breath, choking, twitching, or awaken in the morning with a headache or not feeling rested. “Post-polio fatigue” may be due to a treatable sleep disorder.

7. Some Polio Survivors Like it Hot.

Polio survivors have cold and purple “polio feet” because the nerves that control the size of blood vessels were killed by the poliovirus. Actually, polio survivors, nerves and muscles function as if it's 20 degrees colder than the actual outside temperature! Cold is the second most commonly reported cause of muscle weakness and is the easiest to treat. Dress in layers and wear socks made of the silk-like plastic fiber polypropylene (sold as GORTEX or THINSULATE) that holds in your body heat.

8. Some Polio Survivors Like it Hot.

For once Mom was right. Many polio survivors eat a Type A diet: no breakfast, coffee for lunch and cold pizza for dinner. A recent study shows that the less protein polio survivors have at breakfast the more severe their fatigue and muscle weakness during the day. When our patients follow a hypoglycemia diet (have 16 grams of low-fat protein at breakfast and small, non-carbohydrate snacks throughout the day) they have a remarkable reduction in fatigue. Protein in the morning does stop your mid-day yawning.

9. Do Unto Yourself as You Have Been Doing For Others.

Many polio survivors were verbally abused, slapped or even beaten by therapists or family members when they had polio to “motivate” them to get up and walk. So polio survivors took control, becoming Type A super-achievers, “the best and the brightest,” doing everything for everyone except themselves. Many polio survivors do for others and don’t ask for help because they are afraid of being abused again. Isn’t it time that you got something back for all you’ve done for others? Accepting assistance is not the same as being dependent. Accepting assistance can keep you independent. But appearing “disabled,” “by not doing for others, asking for help or using a scooter, will be frightening. Remember: If you don’t feel guilty or anxious you are not taking care of yourself and managing your PPS.

10. Make Doctors Cooperate Before They Operate.

Polio survivors are easily anesthetized because the part of the brain that keeps them awake was damaged by the poliovirus. Polio survivors also stay anesthetized longer and can have breathing trouble with anesthesia. Even nerve blocks using local anesthetics can cause problems. All polio survivors should have lung function tests before having a general anesthetic. Your complete polio history and any new problems with breathing, sleeping and swallowing should be brought to the attention of your surgeon or dentist - and

especially your anesthesiologist long before you go under the knife. Polio survivors should NEVER have same-day surgery or outpatient tests (like an endoscopy) that require an anesthetic.

The Golden Rule for Polio Survivors:

If anything causes fatigue, weakness, or pain, Don’t Do It! (or do a lot less of it.) . . . and . . . The Golden Rule for Polio Survivors, Friends & Family: See no evil, hear no evil . . . and help only when asked.

Polio survivors have spent their lives trying to look and act “normal.” Using a brace they discarded 30 years ago and reducing their super-active daily schedule is both frightening and difficult for them to. So, friends and family need to be supportive of life-style changes and accept survivors, physical limitations and new assistive devices.

Most important, friends and family need to be willing to do the physical tasks a polio survivor should not do, but only when the polio survivor asks. Friends and family need to know everything about PPS but say nothing: neither gentle reminders nor well-meaning nagging will force survivors to use a new brace, sit while preparing dinner or rest between activities. Polio survivors must take responsibility for taking care of themselves and ask for help when they need it.

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