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Have a Great Summer



My Polio Story

This is the 17th My Polio Story in a series. The first was published in 2008. Diane Lemon was one of Polio Regina's founding members and has been an active participant at our meetings and a contributor to the Polio PostBox. Here is Diane's Polio Story.

In late August, 1957 I was a teenager of 15 years, helping my older sister Kay move from her house when I developed a sore back and neck accompanied with a severe headache. I had gone swimming a few weeks earlier which was probably the source of contact with the polio virus. The Sabin and Salk vaccine were available but my



father refused to allow me to be vaccinated since an aunt had died from a vaccination.

I was admitted to Indian Head hospital and then immediately transferred to the Isolation ward of the Regina General Hospital. I stayed there for one month. Lonely and feeling very much like a germ who was avoided by most staff, it was a difficult time. Physiotherapy was a very painful experience which consisted mainly of leg stretching. The next step was to be moved to a four bed adult ward. Many in my room were undergoing electro convulsive shock treatment and would have bizarre behaviour afterwards which was very scary. Visiting hours were from 2 to 3 o'clock only and coincided with Physiotherapy treatment which meant my parents could only visit on weekends. My wonderful treat each weekday was a visit from Auntie Laura who would be allowed to come to the ward 10 minutes before visiting hours started. Each day she brought the Leader Post, Seven Up, a donut treat and a small amount of Bridge Mix candy. To this day I am addicted to reading the Leader Post and Bridge Mix!! Unfortunately I cannot find good candy any more. Many of the nursing staff were quite abusive and rough when transferring me since my legs were completely paralyzed as well as my abdominal and back muscles. Because of this weakness I had to lie flat even to eat meals.

In those days back rubs were part of the protocol but mine consisted mainly of dousing me with rubbing alcohol twice daily and leaving me shivering in a

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My Polio Story continued

soaking wet hospital gown without much rubbing. After 3 months I was fitted with a back brace and allowed to sit up. I was moved to what was called Wascana Hospital then in November and allowed to return home at Xmas.

My father felt very responsible for me contracting polio so did a wonderful job of building exercise equipment and arising early each day to conduct assisted exercises with me before school as well as after school.

I was able to attend school on crutches. In one year I had made a good recovery. I was able to walk with no limp but could never run again. I have never had any resentment towards my father regarding my contracting polio. He thought he was acting in my best interests. In Grade 9 I had skipped our curling team at Regionals in Swift Current but after polio, curling was not possible. Curling was definitely in my blood so I became an avid fan, attending Canadian curling events and International events. The world curling championship was named the Silver Broom then.

It was wonderful to cheer on Canada at 16 world events which involved travelling to Scotland, Switzerland, Germany, Sweden, United States and parts of Canada. I was fortunate to be in Moncton, New Brunswick in 1980 to watch Rick Folk win the Worlds, the last time Saskatchewan achieved this award!!

Having been born and living all my life in the small Saskatchewan town of Sintaluta, I was aware only of



the standard professions of nursing (my oldest sister, Bette, took nursing), secretarial (my other older sister, Kay, took a secretarial course) and teaching.

I was excited to consider Physiotherapy since it had been so wonderful for me. The doctors at Wascana assured me that I had the strength and endurance to undertake the program. The closest university offering the program was Winnipeg so off went the small town prairie girl to the big city. It was a wonderful profession and I was so lucky to obtain a bursary which covered all costs. I even could come home once yearly on the bus for Xmas!! When I finished the program in December 1962 I had no debt.



I started as the Director of Physical Therapy for the South Saskatchewan Hospital Centre in 1973. This included being in charge of the Physio departments of Wascana,

The Plains and the Pasqua Hospitals. Prior to this I worked 10 years as Director of PT at the Regina General.

In 1978 as well as running the 3 Physio departments. I took on the additional role of Assistant Administrator at Wascana which meant I was also in charge of Speech Therapy, Occupational therapy, Prosthetics, Orthotics, Psychology, Recreation Therapy, Music Therapy, Social Work, Paediatrics and Exercise Therapy along with Physio. I continued in this role until 1990 when I became the director of Special Projects at Wascana Rehab Centre, a position I held until 1996.

Next I took on a position in Public Health where I opened and set up the Al RITCHIE Health Action Centre. After 11 years there I retired. In total I worked full time in Health Care for 44 years and 4 months.

In 1986 I saw an article in the Leader Post which had

been taken from the Edmonton Journal. It described a new syndrome "Post-Polio Syndrome" in which polio survivors were experiencing weakness decades after the acute episode. Dr. Feldman in Edmonton was holding clinics for diagnosis and treatment advice. I believe he travelled to Saskatchewan to conduct clinics and some from Saskatchewan travelled to Edmonton to see him.

I took a cane with me in 1989 when I traveled to the Orient but left it in my luggage since it was not needed.

In being proactive, I became a member of the Saskatchewan Association of Post Polio (SAPP) in approximately 1989. I do not have the date of the origin of the establishment of Polio Regina but was involved early on and with another Physio, Heather Flegg, conducted education sessions. I am sure some current members will know when it started. Soon after, I found difficulty climbing stairs and slowly developed increased weakness. About 2007 I needed a cane and in 2014 this moved to two. For any distance I use a walker.

For some time I was involved with Polio Regina. I took a hiatus due to being involved in many volunteer ventures. This included 26 years conducting education courses for the Saskatchewan Arthritis Society. I volunteered for the Saskatchewan and Canadian Physiotherapy associations serving on both Boards--The Canadian College of Health Leaders and the Saskatchewan Association of Health Service Executives, as well as serving as president for The Saskatchewan Gerontology Association. I also volunteer for the Al Ritchie Health Action Centre. This volunteer service occurred while I had a heavy workload and was raising a daughter.

Dr. Bruno says most polio survivors suffer from a Type A personality always trying to prove we are capable of doing whatever a "normal person" does.

Since I could only watch curling after polio, I dived literally into water sports. Swimming had always been a love of mine since Dad taught me to swim when I was three.

When I started work as a Physio in Regina I took all the Red Cross levels, Royal Life Saving up to Distinction, National Life Guard, and Scuba Diving and then fell in love with Synchronized Swimming.

I was involved with Synchro as a beginner swimmer, coach, board member, judge then in 1968 obtained certification as a Canadian National judge and International certification in 1989. This volunteer work took me to 3-4 swim meets across Canada yearly, plus gaining International status in 1989 meant travel yearly to countries such as Switzerland, Austria, Germany, Italy, Spain, Greece, Malaysia and United States. The highest meet at which I officiated was the Commonwealth Games in Kuala Lumpur, Malaysia.

I should have been designated to judge at the Summer Olympics in Beijing in 2008 but suddenly the male dominated International Synchro governing body moved the retirement age down to 65 from 68 so I missed out by ONE year. A huge disappointment!!

Travel is a passion of mine which I inherited from my father. I was very privileged to be asked by 2 different bosses to travel overseas to recruit Physiotherapists and Occupational Therapists. The countries I travelled to were Scotland, Sweden, Hong Kong, Australia and twice to London England.

My holiday travels have taken me on an African Safari in Tanzania and Kenya, the Galápagos Islands, Ireland, Singapore, Thailand, Japan, Taiwan, New Zealand, Australia, Panama, Columbia, Costa Rico, Russia, Hungary, Aruba, Jamaica, Germany, Austria, Holland, Finland, Denmark, Norway, Greece, England, Scotland, Dominican Republic, Chez Republic and Mexico. Up until 2 weeks ago my travel map indicated I have explored 34.18 % of the world however I have to update it to include provinces, counties and states to regain this percentage since the rules have changed.

One of the greatest gifts that has enriched my polio journey and has allowed me to still function as a contributing member of society is the support of my daughter, Kirsten. She has been there for me from the time she was a little girl. She knew instinctively how to help and friends often commented that she anticipated what I needed her to do for me before I asked whether it was running down stairs, lifting something, or other chores. I am forever grateful to her for the constant love and support.

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Diane was awarded the YWCA Woman of Distinction award in the Wellness category for all her volunteer work in Health in 1989. Later, in 1996 she was inducted into the Saskatchewan Sport Hall of Fame as a Builder, for her 43 years of volunteer contributions to synchronized swimming. She now fills her volunteer time with Kidsport Sask and the Alzheimer Society of Saskatchewan. Her daughter's 2 sons, age 12 and 14 are speed swimmers. Diane's son-in-law, Mike continues the aquatic family theme by playing water polo. After playing at a high level while attending University, he managed to bring together a team in Regina which in the early 90's won the National Championship!!

Message from the Vice-President and President



Wilf and I hope that whoever is reading this, doesn't really believe all we do is go away on holidays! That is simply not true! This was just a little trip for two

weeks added on to a six week holiday in Florida during the last week of January, February and a week in March. Truthfully, it is not my fault at all.

We have admired, smelled and touched so many beautiful flowers here, that it is hard to believe we are not that far from home, only 16 hours away. I do know that our flowering trees are in bloom at home. I just hope they are not finished blooming.

We have traveled over 15,000 kilometers since January 25th, that is a lot of sitting in a vehicle, but there is no other choice, as my ears simply won't let me fly. It is far too painful. There is no pill to take to ease that kind of pain.

We really had not felt the 'sting' of winter this year as Regina had one of the mildest winters ever, not really a good thing as no snow or moisture usually means more forest fires and that seems to be happening right

now. Our hearts go out to those who have lost their homes and everything they have worked for, from horrific forest fires in Fort MacMurray.

I am definitely wanting to come home and start the garden, first of all, and also lots of cleanup from the winter (that never came), which should have been done before we left but, to make a long story short, we never finished it.

It certainly has been a tough year on many of our Post-Polio members as many are suffering with added on illnesses, most likely due to having polio, and we sincerely pray for their recovery, so they can continue on with a happy life. As we age, we are all recognizing how short our time on Earth really is.

We are so grateful for so many things; the health that we do have, to be able to travel a bit, to keep up our home and garden. We are also very grateful for the professionals who studied about polio and who have helped us learn to 'conserve to preserve'. (Do I have that correct?) There is so much information now that never use to be and we can be grateful for that as well.

We can also be grateful for our post-polio friends from our province and other provinces, as well, and their input into their newsletters. Everybody's polio story is very different, yet so similar, that we all can empathize with each other.

We are so, so grateful for the executive for Polio Regina! Thanks for the hours of work from Ivan for putting a newsletter together and his dedication as secretary and David for his diligence and hard work as our Treasurer! Also many thanks to Peter for being our librarian and archivist! Good job, guys!

Where would we be, if not for the doctors who have taken the time to learn about the effects of polio? We are so grateful for the Rotary Clubs throughout the country helping eradicate this dreadful disease and hopefully it will be a thing in the past, that none of our posterity will have to suffer the consequences of polio.

Our Annual Spring 'Picnic' will be at Nicky's again on May 26th, 2016 at 5 p.m.

Wilf and I know that all of us have a lot to be grateful for and we wish you all the best of summers!

Warm wishes while feeling so grateful, with love from Carole and Wilf Tiefenbach

At The Meetings

November 2015 - Our annual Christmas party was held on November 26th at Nicky's Café. Diane Lemon talked about a story in the Reader's Digest. After the meeting we all enjoyed a turkey dinner with all the trimmings and were able to visit with fellow members after the meal.

March 2016 – This was our annual general meeting. Treasurer David Cotcher presented the annual financial statement for 2015 with comparative figures for 2014. Election of executive officers for 2016. The present executive was asked if they would continue for another year. They agreed to stay. There were no other nominations from the floor so the nominees were elected by acclamation.

The following are the Executive Officers of Polio Regina Inc. for 2016-2017:

President – Wilf Tiefenbach

Vice-President – Carole Tiefenbach

Secretary – Ivan Jorgensen

Treasurer – David Cotcher

Phone Co-ordinator – Carole Tiefenbach /
Blenda Ramsay

Archivist/Librarian/Web Master – Peter Huang

Post Box Editor – Ivan Jorgensen

Director – Blenda Ramsay

Correspondence: Ivan received an email from Wain Birch thanking us for keeping him informed. He also told us that he got married to Doreen O'Toole on February 20th. I sent him an email congratulating him from Polio Regina. David Cotcher talked about a letter that he received from Jean Gardner's family saying that she passed away December 28, 2015. Her obituary is printed later in this issue.

Open Forum: Diane Lemon led the Open Forum which was an open discussion with everyone talking about their winter and the health problems that they have had.

April 2016 – Location and times of future meetings – We decided to continue to hold the meetings at Nicky's Café. The fall meetings will be Thursday, September 29th and Thursday, October 27th, both at 3:30 p.m.

Open Forum: Since we are having some of our members moving into nursing homes and retirement residences, our open forum was a talk about what

assistance is available for choosing the right place, what facilities are available, home care, etc. We talked among ourselves about experiences we have had ourselves or with helping a loved one with these choices.

Jean was unable to attend our meetings but she sent in her membership and donation every year, and three years ago when she was 91 she included a note saying how much she appreciated receiving the newsletter.

Evelyn Jean Gardner (“Jean”)

Jean Gardner passed away Monday, December 28, 2015 in Kindersley at the age of 94. Jean was born at Grenfell, SK on February 19, 1921 to Robert and Emma Foster, the second eldest of 7 children. The Foster family learned at an early age to enjoy life, stretch a dollar and work hard. Jean loved to play ball, dance and visit with friends in her youth. She finished her grade 8 at Brown Hill School and then went to work full time as a “hired girl” working with various families over the years. She enjoyed playing practical jokes on people and always enjoyed a good joke (especially the off colour ones).



Jean married Albert Gardner in 1939, and they had four children together. In 1949 polio struck and Jean ended up having to use crutches for many years before being confined to a wheelchair fulltime. After she had polio, Jean started sewing professionally – doing alterations for the local clothing stores for many years as well as making clothes for people. She only retired completely from sewing after her 90th birthday. In 2000, she moved to Kindersley but made the trek to Grenfell and Indian Head twice a year to see everyone there.

Jean loved to play cards and visit with family and friends – many hours were filled with phone calls to her loved ones. She was always willing to provide a sympathetic ear and to help others in any way she could.

Jean is survived by her children - Ruth (Claire) Rein of Kamloops, B.C.; Wayne Gardner of Regina, SK; Pearl (Les) Elliott of Indian Head, SK, Debbie Perrin of Kindersley, SK; her daughter-in-law Lola Rogers of Indian Head, SK

Her grandchildren Dawn (Glen) Rein, Randy (Ann) Rein, Darrin Rein, Derek Rein; Shayne Gardner, Tracy (Tessa) Gardner, Pam (Phil) Vindevoghel; Darwin (Lisa) Elliott, Ora (Wayne) Blezy, Sheena (Calvin) Bostock, Marcie (Brad) Moore, Mike (Lindsay) Perrin, Greg (Amy) Perrin and 19 great grandchildren. She is also survived by 4 siblings – Madge Gardner, Winnipeg; Joyce Morrish, Calgary; Shirley Busch, Calgary and Gordon Foster, Edmonton.

Jean was predeceased by grandson Mitch Gardner, son-in-law Robert Perrin, her brothers Robert Foster and Donald Foster.

The following are excerpts from the Canadian Physiotherapy Association.

Preventing Falls

More than 1 in 3 elderly Canadians (ages 65 and older) fall each year. It's estimated that 50% of those who fall will suffer moderate to severe injuries such as sprains, hip fractures, or head traumas that can permanently reduce their mobility and independence.

Direct health care costs relating to falls among seniors in Canada are estimated at \$1 billion every year. More than 90% of incidents that result in injuries are predictable and preventable. Studies show that modifying the home and reducing hazards in the community can reduce the risk of falls by half. Impaired vision or mental functioning, along with medications are other risks.

Many seniors imprison themselves in their homes from a fear of falling. By doing this, they lose the physical benefits of normal activities and may compromise balance and muscle strength, putting themselves at even greater risk of falling at home. A targeted physiotherapy treatment program can maintain or regain strength, flexibility and endurance in a way that still feels safe and secure.

Exercise not only improves physical function, balance and muscle strength but also may reduce

falls, or the risk of falls, in older adults by improving cognitive function.

Tips to reduce the risk of falling:

Wear a good pair of lace-up shoes that will support your feet and provide necessary cushioning for your joints;

Avoid high heels, and open-toed sandals, which can cause you to trip;

Use aids for walking, balancing, hearing and seeing – view them as sources of strength to help you do things, not signs of weakness; remove reading glasses when walking;

Sit rather than stand while dressing;

When moving from lying to sitting, wait 10 seconds before rising. When moving from sitting to standing wait 10 seconds before moving away from a bed, chair or toilet;

Install handrails and grab-bars in the stairways and bathroom;

Make sure stairways are well lit. Install a night light at the top of the stairs;

Immediately wipe up any spills, especially on ceramic or linoleum floors;

Avoid taking unnecessary risks like standing on furniture. Instead, use a sturdy stepladder, or better yet, ask for help;

Plant both feet securely on the ground before getting out of the car;

Put everyday items on a shelf at eye level;

Manage medication properly;

Be mindful around pets. Feet can get caught in leashes, dogs can knock you down or you can trip over the sleeping or wandering pet.



The follow articles are a collection of articles that Dr. Richard Bruno has submitted to the Facebook group "The Post-Polio Coffee House" which is a forum for Polio Survivors. They are reprinted with Dr. Bruno's permission.

April 28, 2016

Physical Therapy and Post-Polio Sequelae (PPS)

By Shanti Chacko Molayal, PT, DPT

For almost ten years, I had the opportunity to work in a clinic that took a multi-disciplinary approach towards working with patients who have PPS. Although the clinic is no longer in existence, I wanted to share with you what physical therapy aimed to do in the clinic, what information was important for us to know about the patients we worked with, what PT's evaluated, and what our treatment interventions were.

GENERAL GOALS OF PPS PHYSICAL THERAPY

Our aims as PT's working with the PPS population were to:

- 1) Decrease symptoms of pain and weakness;
- 2) Teach activity modification and energy conservation techniques; and
- 3) Promote safety and efficiency with mobility and daily function.

GETTING TO KNOW YOU

Information from a patient with PPS that is helpful to have prior to a physical therapy evaluation would be the following:

- 1) The areas of your body or the physical functions that were originally impaired by Polio
- 2) If you had OR currently use a leg brace
- 3) If you use any adaptive equipment or assistive devices
- 4) If you have any new pain or muscle weakness
- 5) If you have frequent falls or balance issues
- 6) If you have difficulty walking or difficulty with stair negotiation
- 7) If you have difficulty with bed mobility and transfers
- 8) If you have difficulty performing self-care tasks such as dressing or bathing

9) If you have difficulty performing tasks inside or outside of the home

10) If you have decreased energy, endurance or have poor sleep quality

11) Your social history (i.e. work, retired, living situation)

12) Past and current medical/surgical history, test results and medications

PPS PHYSICAL THERAPY EVALUATION

After reviewing the "GETTING TO KNOW YOU" information with the patient, the PT would direct their evaluation towards what the patient's areas of limitation were.

Many times the PT Evaluation was a combination of both an orthopedic/neuromuscular evaluation and a functional evaluation because the patient would have joint or muscle pain along with a limitation in their ability to function or mobilize. The PT would assess the ability to stand and sit, the technique of getting in and out of bed, the ability to perform stairs safely, measure leg muscle circumference and leg length, test balance and upper and lower extremity muscle strength, and observe gait and posture.

PPS TREATMENT INTERVENTION

Based on the physical therapy evaluation and consideration of the patient's goals, the treatment plan could include (but not limited to) the areas of focus below:

1) Safety with Mobility: It's important to assess whether a patient needs an assistive device for mobilizing in the community or at home. This can be a wheel chair, chair lift, walker, or a forearm crutch amongst many other mobility devices. It can also come in the form of a lower extremity brace (orthosis). It's important for the therapist to assess muscle strength, fatigue levels, balance, fall history, pain, home environment, and the patient's support system when recommending the proper device or orthosis, to make mobilizing safe and efficient. With regards to leg braces, finding a licensed orthotist whom you can easily access and has experience in working with patients with neuromuscular conditions, is desirable.

2) Energy Conservation: A common issue amongst patients with PPS is fatigue. Some Polio survivors

also have respiratory impairments that cause shortness of breath with activity and even with rest. Doing activity logs where you can correlate possible relationships of shortness of breath, pain and fatigue with your everyday activity is an effective method of determining whether you need to eliminate or modify the performance of your daily tasks, use adaptive equipment, OR take more rest breaks throughout your day.

3) Pain Management: In addition to pain medications that your physician may prescribe, they may also refer you to a physical therapist to assist with pain that they suspect is from a musculoskeletal/neuromuscular source. If your pain stems from postural dysfunction, overuse or compensatory strategies secondary to longstanding weakness, PT's will educate you on proper posture and positioning with your static and dynamic activities. This can include (but not limited to) the use of lumbar cushions for sitting, cervical pillows for sleeping, or making your workstation more ergonomic.

If your pain is of an orthopedic nature, PT's can teach you non fatiguing flexibility and stabilization exercises to help restore or maintain function. Modalities such as ultrasound or heat can provide temporary relief and are primarily utilized as an adjunct to manual therapy or exercise. PT's may also choose to use manual therapy techniques such as joint and soft tissue mobilization, myofascial release, or gentle muscle energy techniques which can be helpful to address restricted mobility.

4) Functional Activity Training: Patients with PPS can have difficulty with getting in/out of bed, or standing up from lower surfaces or standing to cook amongst other limitations not mentioned here.

Physical therapy treatment may focus on safe techniques to perform those everyday tasks. Additionally

PT's may also recommend durable medical equipment and adaptive devices to make those tasks less painful, less effortful and most importantly SAFE for patients.

EXERCISE AND THE PPS POPULATION

Many of you may be wondering about aerobic or strengthening exercise in the PPS population. Since many of our patients came to the clinic being very

symptomatic with increased fatigue, newer pain and weakness, as well as having difficulty performing their daily activities, our recommendation was that they suspend aerobic or strengthening exercises during their time in our program. Our goal was to reduce the pain and overuse of weakened muscles and focus on conservation.

It would be my recommendation to review the latest research related to exercise prescription recommendations for the PPS population. However, if you feel more fatigue, more pain, or more weakness with exercise or any activity - LISTEN TO YOUR BODY and stop doing it!

LOOKING FOR A PHYSICAL THERAPIST?

I would recommend that you work with a therapist that has experience with orthopedic and neuromuscular conditions who can work with you 1 on 1. Obviously it would be a PLUS if they have experience with the PPS population OR can do the research to understand the pathophysiology of the polio virus, late onset problems, and treatment of the polio survivor. It would also be helpful if the PT has working relationships with the following: 1) a licensed orthotist if you are a candidate for a leg brace; and 2) an occupational therapist if you need to address limitations in activities of daily living performance or wheel chair management.

Posted May 12, 2016

Brain Cancer Treatment Given Breakthrough Status by FDA

A bold experiment to kill a vicious form of brain cancer has been granted breakthrough status by the Food and Drug Administration. Results in the earliest stage of testing have been so remarkable, the FDA wants to fast track the treatment to speed it to market.

The therapy uses the polio virus to attack glioblastoma.

One of those patients was a 20-year-old nursing student with headaches. In 2011 a doctor told her she had a glioblastoma tumor the size of a tennis ball and that she had months to live.

She had 98 percent of the tumor removed. Then in 2012, the doctors told her the cancer had come back.

With recurrent glioblastoma, there were no options except the one that had never been tried. She became the first volunteer for Duke University's experiment with the polio virus.

The virus is the creation of molecular biologist Matthias Gromeier. He re-engineered the virus, removing a key genetic sequence. The virus can't survive this way, so he repaired the damage with a harmless bit of cold virus. This new modified polio virus can't cause paralysis or death because it can't reproduce in normal cells. But it can reproduce in cancer cells, and in the process of replicating, it releases toxins that poison the cell. This process also awakens the immune system to the cancer it never noticed before.

"All human cancers, they develop a shield or shroud of protective measures that make them invisible to the immune system," Gromeier explained. "This is precisely what we try to reverse with our virus. So by infecting the tumor, we are actually removing this protective shield. And enabling the immune system to come in and attack."

It appears the polio starts the killing, but the immune system does most of the damage. The patient's tumor shrank for 21 months until it was gone. Three years after the infusion, something unimaginable had happened.

An MRI in August of 2014 showed no active cancer cells at all.

Excerpts from CBS 60 Minutes

<http://www.cbsnews.com/news/promising-duke-university-polio-brain-cancer-trial-given-breakthrough-status-60-minutes/>

Posted by Dr. Richard Bruno December 4, 2015

Inflammation is Not a Post-Polio Sequelae

A member's daughter, a nurse, asked a fascinating question: Do polio survivors have more inflammatory diseases (like rheumatoid arthritis), lupus and an elevated sedimentation rate, which is an indicator of inflammation. The answer to all three is no. What's more, inflammation does NOT cause PPS. Here is a summary about studies of markers of inflammation and muscle breakdown:

A Blood Test for Post-Polio Muscle Pain?

Dr. Richard L. Bruno

Q: Recently I had arm and chest pain. I went to the ER. The only abnormal blood tests showed high C-reactive protein and high creatine kinase. My blood pressure and cholesterol are normal, I have never smoked and I'm thin. My EKG showed that I hadn't had a heart attack. Could high CRP and high CK be related to PPS?

A. C-reactive protein is a blood marker for inflammation somewhere in the body. High CRP can be seen with type 2 diabetes, autoimmune diseases and cancers. Could inflammation somewhere in your body, as indicated by an elevated CRP, be related to PPS? Fifty consecutive patients evaluated at The Post-Polio Institute had CRP measured. The patients were on average 59 years old and 55% were women. Thirteen percent had an elevated CRP, 66% of whom were men. CRP was on average nearly three times the normal value. However, there was NO significant difference between those with high and normal CRP on self-ratings of daily fatigue, difficulty with self-care or ability to perform activities inside or outside of the home. So, there is no evidence that elevated CRP or inflammation are related to post-polio fatigue or difficulty in functioning.

Elevated CRP has been related to having a heart attack or stroke. The theory is that a bacterial or viral infection (although definitely not a poliovirus infection) somehow inflames plaque in arteries, causing it to break off and clog arteries. Our 1985 National Survey found no more heart disease or high blood pressure in polio survivors than in the general population. However, two studies found that 5% more male post-polio patients had abnormally elevated cholesterol as compared to the general population. In one of the studies, only 33% of those with high cholesterol had been given a cholesterol screening test by their own doctor and not even 25% were on cholesterol-lowering medications, like the statin drugs such as Lipitor and Pravachol. This is not good, since reducing "bad" cholesterol reduces heart attack risk and may increase survival even after having a first heart attack. But, as you know, statins can and do cause muscle pain and can cause muscle breakdown. So several may have to be tried before

finding one that helps and doesn't literally hurt (see CHOLESTEROL DRUG article in the POSTPOLIO LIBRARY <http://www.PostPolioInfo.com>).

CK AND STATINS

CK is an enzyme released when muscle is damaged. One half of one percent of anyone taking a statin develops muscle breakdown, which causes muscle pain (especially in the calves), muscle weakness and an increase in CK. Even without muscle breakdown or an elevated CK, many polio survivors report muscle pain or weakness when taking a statin, usually one of the older statins, like Lipitor.

But polio survivors can have an elevated CK without taking a statin. Two studies found that 40% of polio survivors had abnormally elevated CK, with men having significantly higher CK than did women. In one study, CK increased with the number of steps polio survivors walked in a day. In our fifty Post-Polio Institute patients, 21% had abnormally elevated CK levels (on average about 33% higher than normal) with men having higher CK than did women. But, as with CRP, there was NO significant difference between those with high and normal CK on self-ratings of daily fatigue, difficulty with self-care or the ability to perform activities inside or outside of the home.

However, an elevated CK may mean that polio survivors are making their muscles work too hard and are causing them to break down. So, neither CRP nor CK is related to fatigue or loss of functional abilities in polio survivors, but an elevated CK may be a warning of muscle overuse abuse.

Polio survivors need to have their cholesterol and CRP measured to assess heart disease risk. And, since an elevated CK indicates muscle breakdown -- either from taking a statin or from muscle overuse -- polio survivors should have CK measured before taking a statin. If you are worried about possible muscle weakness or breakdown with statins, ask your doctor about using newer cholesterol-lowering drugs, like Zetia and Zocor that seem less likely to cause pain, or older medications like slow-acting niacin or bile acid sequestrants.

Besides medication, polio survivors need to eat high fiber foods, reduce saturated fat, treat high blood pressure and stop smoking to keep their tickers ticking.

Posted by Dr. Richard Bruno December 15, 2015

We all know that STRESS is the #2 cause of PPS symptoms, after physical overuse and exercise. But here's another reason to reject distress -- especially around the holidays -- and to "de-stress" (Maureen McGovern's lovely recording of my "TWO BREATH TIME OUT" relaxation exercise costs only 1 cent at randomharvestbooks.com).

Stress in Older People Increases Risk for Pre-Alzheimer's Condition

Newswise — December 11, 2015—(BRONX, NY)—Feeling stressed out increases the likelihood that elderly people will develop mild cognitive impairment—often a prelude to full-blown Alzheimer's disease. In a new study, scientists at Albert Einstein College of Medicine and Montefiore Health System found that highly stressed participants were more than twice as likely to become impaired than those who were not. Because stress is treatable, the results suggest that detecting and treating stress in older people might help delay or even prevent the onset of Alzheimer's. The findings were published online today in *Alzheimer Disease & Associated Disorders*.

Each year, approximately 470,000 Americans are diagnosed with Alzheimer's dementia. Many of them first experience mild cognitive impairment—a pre-dementia condition that significantly increases the risk of developing Alzheimer's in the following months or years. This study looked at the connection between chronic stress and "amnesic mild cognitive impairment" (aMCI), the most common type of MCI, which is primarily characterized by memory loss.

"Our study provides strong evidence that perceived stress increases the likelihood that an older person will develop aMCI," said Richard Lipton, M.D., senior author of the study, vice chair of neurology at Einstein and Montefiore, and professor in the Saul R. Korey Department of Neurology and the Edwin S. Lowe Chair of Neurology at Einstein. "Fortunately, perceived stress is a modifiable risk factor for cognitive impairment, making it a potential target for treatment."

"Perceived stress reflects the daily hassles we all experience, as well as the way we appraise and cope with these events," said study first author, Mindy

Katz, M.P.H., senior associate in the Saul R. Korey Department of Neurology at Einstein. “Perceived stress can be altered by mindfulness-based stress reduction, cognitive-behavioral therapies and stress-reducing drugs. These interventions may postpone or even prevent an individual’s cognitive decline.”

The researchers studied data collected from 507 people enrolled in the Einstein Aging Study (EAS), a community-based cohort of older adults. Since 1993, the EAS has systematically recruited adults 70 and over who live in Bronx County, NY. Participants undergo annual assessments that include clinical evaluations, a neuropsychological battery of tests, psychosocial measures, medical history, assessments of daily-living activities and reports (by participants and those close to them) of memory and other cognitive complaints.

Starting in 2005, the EAS began assessing stress using the Perceived Stress Scale (PSS). This widely used 14-item measure of psychological stress was designed to be sensitive to chronic stress (due to ongoing life circumstances, possible future events and other causes) perceived over the previous month. PSS scores range from 0 to 56, with higher scores indicating greater perceived stress.

The diagnosis of aMCI was based on standardized clinical criteria including the results of recall tests and reports of forgetfulness from the participants or from others. All 507 enrollees were free of aMCI or dementia at their initial PSS assessment and subsequently underwent at least one annual follow-up evaluation. They were followed for an average of 3.6 years. Seventy-one of the 507 participants were diagnosed with aMCI during the study. The greater the participants’ stress level, the greater their risk for developing aMCI: for every 5 point increase in their PSS scores, their risk of developing aMCI increased by 30 percent. Similar results were obtained when participants were divided into five groups (quintiles) based on their PSS scores. Participants in the highest-stress quintile (high stress) were nearly 2.5 times more likely to develop aMCI than were people in the remaining four quintiles combined (low stress). When comparing the two groups, participants in the high-stress group were more likely to be female and have less education and higher levels of depression.

To confirm that stress was independently increasing risk for aMCI in this study, the researchers assessed whether depression—which increases the risk for stress as well as for cognitive impairment and Alzheimer’s disease—might have influenced the results. They found that depression did not significantly affect the relationship observed between stress and the onset of aMCI. Similarly, stress’s impact on cognitive status was unaffected if participants possessed at least one e4 allele of the APOE gene, which increases their risk for developing late-onset Alzheimer’s.

The study is titled “Influence of perceived stress on incident amnesic mild cognitive impairment: Results from the Einstein Aging Study.”

“Lexophile” is a word used to describe those that have a love for words, such as “you can tune a piano, but you can’t tuna fish”, or “to write with a broken pencil is pointless.”

- .. When fish are in schools, they sometimes take debate
- ... A thief who stole a calendar got twelve months
- .. When the smog lifts in Los Angeles U.C.L.A.
- .. The batteries were given out free of charge.
- .. A dentist and a manicurist married. They fought tooth and nail.
- .. A will is a dead giveaway.
- .. With her marriage, she got a new name and a dress.
- .. A boiled egg is hard to beat.
- .. When you’ve seen one shopping center you’ve seen a mall.
- .. Police were summoned to a daycare center where a three-year-old was resisting a rest.
- .. Did you hear about the fellow whose entire left side was cut off? He’s all right now.
- .. A bicycle can’t stand alone; it’s just two tired.
- .. When a clock is hungry it goes back four seconds.
- .. The guy who fell onto an upholstery machine is now fully recovered.
- .. He had a photographic memory which was never developed.
- .. When she saw her first strands of grey hair she thought she’d dye.
- .. Acupuncture is a jab well done. That’s the point of it.
- .. Those who get too big for their pants will be totally exposed in the end.

