

February, 2000

Editor: Fred Ramsay  
Phone: 543-6380

Polio Regina Incorporated

825 McDonald Street, Regina, Sask. S4N 2X5

## Editorial

The emphasis this year should be to reach out to the dozens of polio survivors who are out there and haven't yet joined our organization. There is some very helpful information available and unless it's being used, it doesn't serve a useful purpose.

As recently as two weeks ago, we had four people contact the editor requesting information about post polio syndrome. We sent them a package of information but there must more polio survivors who are not aware of our Polio Regina group and who could benefit from the information.

If you know of anyone who should get information about Post Polio supply us with their name and address or ask them to call us for information.

The computer Internet system has hundreds of web sites, which can be easily and economically visited. Just click on "Polio" and let your mouse do the rest.



### Financial Statement



Year ending December 1999

Bank Balance		
January 1999	\$ 1040.71	
Term deposit	<u>2116.64</u>	<u>3157.35</u>
Income		
Memberships	650.00	
Donations	1429.00	
Sponsors	50.00	
Xmas banquet (65 plates)	845.00	
Bank interest	<u>81.61</u>	
Outstanding cheque	145.00	
	<u>3200.61</u>	<u>6357.96</u>
Expenses		
Memorials	100.00	
Gift Certificate	50.00	
Corporation fee	10.00	
Plaques	115.62	
Postage	323.51	
Printing	350.30	
Photo & copying	76.55	
Social supplies & hall rental	401.27	
Xmas Banquet	994.54	
Cards & fruit baskets	245.86	
Stationery	93.12	
Xmas hamper donation	<u>145.00</u>	
1998 Outstanding cheque	50.00	
Bank Balance		
at Dec. 31, 1999	205.11	
Term deposit	<u>2197.08</u>	<u>6357.96</u>

prepared by Verna Copeland

## Suppliers of equipment

This is not a free endorsement advertisement. Polio survivors should know where they could get medical assistance equipment.

Here are some of the suppliers:

### Automobility Medical

1444-Lorne St, Regina, Ph. 781-9840

### Independent Living

1048 Winnipeg St. Regina, Ph. 352-2579

### Jolly's Vet and Surgical Supplies

120 Victoria Ave., Regina, Ph. 522-3833

### Medichair

3251 Saskatchewan Dr., Ph. 584-8456

### Nu-mobility

Regina, Ph. 757-2921

Saskatoon, Ph. 242-2266

### Prescriptions Plus

– Pasqua Hosp. Ph. 352-6309

– General Hosp. Ph. 565-8088

### Sask. Abilities Council

1118 Winnipeg St. Regina, 569-1262

### Special Needs Equip. Installation

Rian Tannahill, Ph. 731-2097

In addition you can get a variety of products department store, hardware and drugstores, mail order and Internet. Shop around and compare prices.

## Nominations for New Executive

When contacted, all members of the present executive agreed to serve another term in office. Never the less we must hold a nominating meeting to give others a chance to serve in office. So this meeting is an election meeting and your chance to volunteer your time and talents. All members in good standing are eligible.

The incumbent officers are:

President:	Norm Beliveau
Vice president:	Suzanne Lalonde
Treasurer:	Verna Copeland
Secretary:	Don Volpel
Programs:	Dr. Mavis Matheson
Phoning Chairperson:	Blenda Ramsay
Convenor:	Verna Copeland
Post Box editor:	Fred Ramsay

## E-mail addresses

Blenda and Fred have finally accepted Cyberspace as a fact of life. On February 11 we signed on. Gosh, what a challenge it is to keep up with the vast and fast space out there. But we will persevere.

If you are also on the Internet and wish to communicate with us and other members of Polio Regina, here is our E-mail address: [fbramsay@sk.sympatico.ca](mailto:fbramsay@sk.sympatico.ca)

If you want your website published send us an E-mail message.

## Birthdays

February-March

Feb. 2 Maurice Denzin  
Feb. 7 Jackie Ball  
Feb. 20 Barry Brown  
Mar. 14 Lloyd MacPherson  
Mar. 15 Carole Einfeld  
Mar. 17 Verna Copeland  
Mar. 17 Marion Vopel  
Mar. 17 Gen Grant  
Mar. 19 George Simpson  
Mar. 23 Dorothy Slater  
Mar. 25 Susie Quinn



## Anniversaries

Feb. 20 Don & Grace Lekivitz  
Mar. 31 Deryl & Susie Quinn



## *Meet Suzanne Lalonde*

Believe it or not, one of civilization's greatest treasures is a child. Yes, those noisy, rambunctious, nerve-racking, rascals that we send off to school for a well deserved few hours of rest.

Suzanne Lalonde, vice-president of Polio Regina, is one of the people to whom we send our kids. She is a teacher who loves her job and has had a lot of experience being around children.

Born and raised in Quebec, she was the fourth child in a family of 10 children. In 1947, at age three, she was struck down by polio. She spent 10 critical days in the Ste.-Justine hospital in Montreal. She recovered and returned home. However, in 1959, when the polio vaccination program was underway, she was informed that she didn't need to be vaccinated because she had already had polio.

Bad mistake. Within three weeks she was very sick again. She was taken to the hospital in Montreal again where she was diagnosed with Polio. She spent six months at the Pasteur Hospital where she exercised in water and the gymnasium. The polio had attacked her right leg.

Later she was able to return to school, wearing special shoes and a brace. When she finished elementary and high school, she pursued a career



in the teaching profession. She taught in Quebec for a few years, had an opportunity to teach in the Dominican Republic and Louisiana before coming to Saskatchewan. She taught in Saskatoon until she came to Regina a couple of years ago.

During various times in her career, she has visited Europe, China, Mexico, Guatemala and Las Antilles. She speaks fluently in three languages. Her mother tongue is French and she teaches in that language.

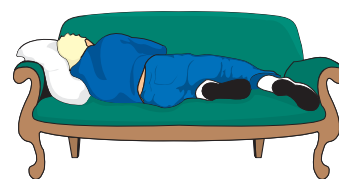
According to Suzanne "working with kids is the way to stay young. I love kids especially when they ask questions about everything. Their questions keep me mentally sharp."

### **Medical Terminology**

Artery – The study of paintings  
Barium – What you do when CPR fails  
Cesarean section – A district in Rome  
Colic – A sheep dog  
Coma – A punctuation mark  
Congenitol – Friendly  
Dilate – To live longer  
Fester – Quicker  
G.I. Serico – Baseball game between soldiers  
Grippe – A suitcase  
Hangnail – A coat hook

Medical staff – A doctor's cane  
Morbid – A higher offer  
Nitrate – Lower than the day rate  
Node – Was aware of  
Outpatient – A person who has fainted  
Post-operative – A letter carrier  
Protein – In favor of young people  
Secretion – Hiding anything  
Serology – Study of English knighthood  
Tablet – A small table  
Tumor – An extra pair  
Urine – opposite of you're out  
Varicous veins – Veins very close together

# *P.P.S. And Abnormal Movements in Sleep*



*Dr. Richard L. Bruno  
The Post-Polio Institute, Englewood, New Jersey USA*

Nearly two-thirds of polio survivors report Abnormal Movements in Sleep (AMS), with 52% reporting that their sleep is disturbed by AMS. Sleep studies were performed in seven polio survivors to objectively document AMS.

Two patients demonstrated Generalized Random Myoclonus (GRM), brief contractions and even ballistic movements of the arms and legs, slow repeated grasping movements of the hands, slow flexion of the arms and contraction of the shoulder and pectoral muscles.

Two other patients demonstrated Periodic Movements in Sleep (PMS) with muscle contractions and ballistic movements of the legs, two had PMS plus Restless Leg Syndrome (RLS) and one had sleep starts involving only contraction of the arm muscles.

AMS occurred in Stage II sleep in all patients, in Stage I in some, and could significantly disturb sleep architecture even though patients were totally unaware of muscle contractions. Poliovirus-induced damage to the spinal cord and brain is presented as a possible cause of AMS. The diagnosis of post-polio fatigue, evaluation AMS and management of AMS using benzodiazepines or dopamimetic agents is described.

Despite numerous late-onset symptoms reported by polio survivors (fatigue, muscle weakness, pain, cold intolerance, swallowing and breathing difficulties) one symptom was totally unexpected: abnormal movements in sleep (AMS). As early as 1984 our post-polio patients

were reporting muscle contractions as they fell asleep.

The 1985 National Post Polio Survey included two questions about AMS: “Do your muscles twitch or jump as you fall asleep ? and ”Is your sleep disturbed by muscle twitching?” It was surprising that 63% of the 676 respondents reported that their muscles did twitch and jump during sleep and that 52% (one third of the entire sample) said that twitching disturbed their sleep.

These percentages are markedly high as compared to the incidence of AMS in the general population. In one survey only 29% of those without neurological disease, who were at least 50 years old, reported AMS, versus 63% of surveyed polio survivors who were 52 years old on average.)

In another survey only 34% of those older than 64 reported AMS, slightly more than half the incidence of AMS in the younger post-polio sample. Given the apparent increased prevalence of AMS in polio survivors, and with daytime fatigue the most commonly reported Post-Polio Sequelae (PPS), we were interested in objectively documenting AMS, relating them to possible disturbances in sleep architecture and identifying an effective treatment for AMS.

## **METHODS**

**Subjects.** Seven polio survivors were referred for sleep studies to a sleep disorder centre. This was a sample of convenience, in that the subjects

were patients presenting with PPS who themselves knew (three patients) or whose bedmates knew (four patients) that AMS were occurring. Patients were on average 54 years old, 44 years post acute polio which occurred at age 10. The patients had had AMS for a mean of eight years which was on average 35 years of post acute polio.

Patients reported moderate-to-severe difficulty sleeping at night and moderate-to-severe daytime fatigue that did not respond to the treatments of choice for post-polio fatigue (i.e., pacing of activities, daytime rest periods, energy conservation and use of appropriate assistive devices). In addition to fatigue, patients reported an average of two limbs having late-onset muscle weakness.

## **PROCEDURE**

Patients underwent a standard polysomnographic evaluation with EEG and facial EMG recorded for sleep staging. Blood oxygen saturation, measured using a finger pulse oxymeter, chest and abdominal wall excursion and nasal air temperature were also recorded; video monitoring of sleep was also performed. Surface EMG was recorded from patients' legs as well as from limbs in which AMS were reported.

## **RESULTS**

Four types of AMS were seen: Two patients presented with what has been called Generalized Random Myoclonus (GRM). Two patients had Periodic Movements in Sleep (PMS), two had PMS plus Restless Leg Syndrome (RLS) and one had Sleep Starts (also called "hypnagogic massive myoclonic jerks").

Generalized Random Myoclonus. GRM was seen in two patients. One had bulbar polio with little or no arm or leg involvement acutely, while the

other has been diplegic since polio but had no bulbar or respiratory symptoms acutely. These patients had random contractions of muscles throughout their bodies. One had such violent contractions of the trunk muscles that she was pulled into the fetal position during the night. This patient had been very aware of GRM for about 10 years.

However, the other patient had been completely unaware of GRM until her husband noticed them.

Random, rapid muscle contractions were noted in all four limbs, jaw and pectoral muscles, in addition to slow repeated grasping movements of the hands, slow flexion of the arms and movement of the shoulders. The presence of bilateral toe flexion was notable since the patient's right leg has always been totally paralyzed except for a minimal ability to flex her toes; the toes of her right foot contracted numerous times during the night.

In both patients, GRM occurred during Stage II sleep; the latter patient also had GRM in Stage I. The patient with violent trunk flexion had muscle contractions, causing a severe disturbance of sleep architecture, only during the first third of the night. She also had a few episodes of obstructive apnea that were not related to the muscle contractions but did disturb her sleep. She was prescribed clonazepam, 0.5 mg B.I.D., which eliminated her GRM. The other patient had GRM throughout the night but had no disturbance of sleep architecture and was not treated pharmacologically.

## **PERIODIC MOVEMENTS IN SLEEP**

Two patients demonstrated PMS with contractions only of the leg muscles of which neither patient was aware. Both had limb and respiratory involvement with the acute polio and had PMS during Stage II sleep with one patient also having muscle contractions during Stage I. The former patient had nearly continuous EMG

activity in his legs throughout the night and had a severe disturbance of sleep architecture.

He also had some central episodes of apnea early in the night as he was falling asleep that did not disturb his sleep. The latter patient had PMS occurring only during the first half of the night, which caused no disturbance of sleep architecture. However, he had frequent hypopneas, which did severely disturb his sleep. Both patients were prescribed lorazepam, 1.0 mg H.S., which eliminated the PMS.

### **PMS PLUS RESTLESS LEG SYNDROME**

Two patients had PMS plus Restless Legs Syndrome. RLS is characterized by the subjective feeling that the legs must be moved. This feeling increases during the evening, often preventing sleep onset because patients feel as if they must get up and walk. The patients with PMS plus RLS had been very little affected by the acute polio, one having no polio residual and the other having one leg weakened. PMS were seen in both legs and occurred during Stage II in both patients and during Stage I in one patient.

One patient's leg muscle contractions were so violent that she was propelled one to two inches off the surface of the bed. Although her PMS occurred only during the first half of the night, her sleep was severely disturbed and she was very aware that she had had PMS for about five years. She was prescribed L-dopa/carbidopa (Sinemet) 200/50 mg, ½ tablet B.I.D., and clonazepam, 0.5 mg H.S. and at 3 am, which reduced the RLS and PMS by about 80% and allowed her to have a restful nights sleep. The other patient did not know he had PMS, which were continuous throughout the night and did moderately disturb his sleep architecture. He was prescribed L-dopa/carbidopa, 200/50 mg H.S., which eliminated his RLS and PMS.

### **SLEEP START.**

One patient was diagnosed as having a Sleep Start, her arms ballistically abducting as she began to fall asleep. She was very mildly affected by the acute polio and had no AMS in the legs, even in the leg in which she reported new muscle weakness. The patient's sleep was markedly disturbed since her arms would move as she started to fall asleep and prevent sleep onset. She was prescribed alprazolam, 0.125 mg H.S., which eliminated her AMS.

### **DISCUSSION**

Sleep studies in this sampling of post-polio patients objectively documented three different types of AMS. Whether other types or combinations of AMS occur in polio survivors cannot be determined from this study, nor can this study or the 1985 National Post-Polio Survey state the actual incidence of AMS in polio survivors, since neither sample was random or population-based. However, the objective documentation of AMS in these post-polio patients, and the Post-Polio Survey finding that 63% of polio survivors reported muscle "twitching or jumping" as they fell asleep, suggest that AMS may in some way be related to the pathophysiology of the original poliovirus infection.

A detailed report of this study can be obtained by contacting Dr. Bruno at his clinic or by visiting the website listed below. Set your browser to:

<http://members.aol.com/ppsend/pps.html> or  
Dr. Richard L. Bruno  
The Post-Polio Institute,  
Englewood Hospital and Medical Center  
Englewood, New Jersey USA  
(201) 894-3724 1-877-767-9875  
PPSENG@AOL.COM

# *Cold Intolerance and “Polio Feet”*



*Condensed from the Handbook on the Late Effects of Poliomyelitis.  
St. Louis: Gazette International Networking Institute, 1999.*

Polio survivors are extremely sensitive to changes in temperature. At merely cool temperatures, most polio survivors report that their feet have always been cold to the touch, their skin a purplish color. However, as polio survivors have aged, 50% report “intolerance to cold” and that their limbs have become more sensitive to pain as the temperature decreases (Owen, 1985).

Cold was reported to cause muscle weakness in 62% of polio survivors, muscle pain in 60%, and fatigue in 39%. (Bruno & Frick, 1987). When polio survivors were cooled in the laboratory from 86o F to 68o F, motor nerves functioned as if they were at 50o F and polio survivors lost 75% of their hand muscle strength. (Bruno, et al., 1985a) But, although polio survivors are twice as sensitive to pain as those without polio, no increase in pain sensitivity was found at lower temperatures.

## **Why ?**

The reason polio survivors have such trouble with cold is that the parts of the central nervous system that should control body temperature were damaged by the poliovirus. In the brain the hypothalamus (the “automatic computer” that controls the inner bodily environment) was damaged by the poliovirus, including the body’s “thermostat” and the brain area that tells your blood vessels to constrict. (Bodian, 1949) In the spinal cord, the nerves that carry the message from the brain that tells the capillaries in the skin to contract when it’s cold were also killed by the poliovirus. (Bodian, 1949)

Thus, polio survivors are unable to stop warm blood from flowing to the surface of the skin as the outside temperature drops. This allows loss of heat from the blood near the surface of the skin and causes the limbs to cool. When the limbs cool, arteries carrying blood to the skin and veins that should carry blood out

of the skin narrow passively as they get cold, trapping blue venous blood in the capillaries and causing the feet to look blue and to become even colder.

The cold skin chills the motor nerves, causing them to conduct more slowly and to be less efficient in making muscles contract. The cold also chills tendons and ligaments (like putting a rubber band in the freezer) making movement of weak muscles more difficult. As polio survivors know, it takes hours under an electric blanket or a long, hot bath to warm cold legs and regain strength.

## **Caution**

However, when polio survivors take a hot bath, blood vessels do exactly the opposite of what they do in the cold. Polio feet and legs become bright red as arteries and veins relax and blood rushes to the skin. Then, when polio survivors stand to get out of the tub, they can feel dizzy or even faint as blood pools in their legs and causes their blood pressure to drop (see Bruno, 1997). The pooling of blood in the feet also explains why polio survivors’ feet swell, swelling that increases as they get older. And polio survivors’ easily losing body heat explains why they have an increase in symptoms, especially cold-induced muscle pain, as the seasons change.

Polio survivors need to dress as if it were 20o F colder than the outside temperature. They need to dress in layers and wear heat-retaining socks or undergarments made of polypropylene (marketed as Gortex or Thinsulate) that should be put on immediately after showering when the skin is warm. Polio survivors need to remind doctors that EMGs or nerve conduction tests must be performed in a room that is at least 75o F to prevent false abnormal readings and that a heated blanket is necessary in the recovery room after polio survivors have surgery (Bruno, 1996).

## Newsworthy items:

**Regina Polio members** express sincere condolences to **Ross & Verna Copeland** as they mourn the death of Verna's brother, Norman Shaw who passed away last month.

We also offer sincere condolence to **Suzanne Lalonde** as she mourns the death of her mother who passed away recently in Quebec.

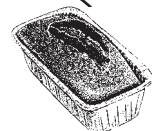
**Get Well Greetings** are extended to Carol McClintock who had foot surgery at the end of January. We hope it won't be too long before you are back on your feet and able to join us at our meetings.

**Received a Thank You card from Barry Brown** for a fruit basket sent by Polio Regina folks.

**A letter has been received** from Irene Vollman of Balgonie thanking us for the newsletter which she enjoys receiving. She is keeping well through exercise and massages, but is not able to come out to our get-togethers. She says "Good Luck" to all members in the year 2000! It was great to hear from you.

**Muriel-Lindsay Ewing** of Regina is our newest member of year 2000! Welcome to our group Muriel!

### Recipe for Bread Strata



Butter four slices of bread and place (butter side up) in a buttered glass dish or pan, Cover with some grated cheddar cheese. Place 4 more slices of bread (butter side up) over the cheese. Mix four eggs slightly. Add 2 2/3 cup milk. Beat in some prepared mustard, grated onion and any other cooked vegetable you may have handy. Adding some ham is also good. Pour mixture over the bread slices and let set overnight in fridge or for a couple of hours so that the egg mixture soaks into the bread. Bake 350 degrees for about an hour.

**Note:** You may use old bread, wiener buns, hamburger buns or old doughnuts.

### Your Invited

If you wish to learn more about Post Polio Syndrome, join us. Our Polio Regina group meets at 7 pm on the last Thursday of the month at Wascana Rehabilitation Centre. Wheelchair access is gained from underground parking. **Next Meeting is Thursday, March 30, 2000.**

### MEMBERSHIP APPLICATION

POLIO REGINA Inc.

Name \_\_\_\_\_

Active ( ) if you had polio      Associate ( )      New ( )      Renewal ( )

Address \_\_\_\_\_

Postal Code \_\_\_\_\_

Phone: \_\_\_\_\_

Annual membership fee: (Jan.- Dec.)

\$10 Single; \$15 family      \$ \_\_\_\_\_

My donation to Polio Regina Inc.: \*\$ \_\_\_\_\_

Total      \$ \_\_\_\_\_

(If you require sponsorship for your fee, inform our membership chairman)

Please make cheque payable to: **Polio Regina Inc.** and mail this application form and cheque to:

Polio Regina Inc. 825 McDonald St. Regina, Sk. S4N 2X5

\* (Official receipt of donation for income tax purposes will be mailed.)