

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.)



Editors: Blenda &
 Fred Ramsay
 Phone: 543-6380

June 2003

Polio Regina Incorporated

fbramsay@sk.sympatico.ca
 825 McDonald Street, Regina, Sask. S4N 2X5

What a great year we are having; and its only half spent! We are excited about the “new” people who have joined; the vibrancy of new information coming from Polio Canada and the calls we receive from people who are polio survivors and have been totally unaware about why they are feeling so exhausted and lethargic from day to day. Polio Regina hasn’t got all the answers but the information we disperse “is helping a lot”- many have said.



The presentations by our own Dr. Mavis Matheson, MD, are priceless as we can ascertain from the riveted attention she gets when she explains the intricate details of Post Polio Syndrome. When she talks; the gang listens.

Now its summer time and time to kick back to enjoy the incredible country we live in. Go ahead. Indulge yourself.

F&B

Carole has agreed to attend!

Polio Canada Training Conference: We are happy that Carole Einfeld of Polio Regina will be attending the Training Conference at St. Catherines, Ont. on August 25-28 .We look forward to hearing all about it when she returns. Thank you, Carole! We know you will bring back new ideas to share with Polio Regina.

HERE'S THE PROBLEM: Either you have to buy two pairs of shoes to get a proper fit, (expensive if you're buying good quality shoes), or you're walking around with ill-fitting shoes.

HERE'S THE SOLUTION: A registry of people who have the opposite foot size problem to yourself. For example, if you wear a size 10 on the left, and a size 9 on the right, you need to find someone who wears a size 10 on the right, and a size 9 on the left. Now all you have to do is search the registry, be sure to add yourself too!

Soles Mates - sponsored by Bio Ped:

<http://www.bioped.com/solemates.html>

Kimberley Dowds

Peer Support and Conductive Education Services Manager, Ontario March of Dimes, 10 Overlea Blvd. Toronto, ON M4H 1A4.

Ph. 416-425-3463 ext. 286 416-425-1920 FAX Toll Free: 1-800-263-3463

Gazette International Networking Institute (GINI) has changed its name to Post-Polio Health International and has developed a new membership structure. Post-Polio Health International will continue to respond to the needs of ventilator users through its affiliate, International Ventilator Users Network.

The new name, Post-Polio Health International, clearly focuses on living with the late effects of polio and reaffirms an ongoing interest in international issues. Post-Polio Health International is meant to project the broadest meaning of "health," encompassing the physical, emotional, social, psychological, and spiritual aspects of individuals' lives.

The new membership structure is designed to strengthen Post-Polio Health International's ability to advocate for its constituents. Current newsletter subscribers are automatically members of Post-Polio Health International and/or its affiliate International Ventilator Users Network.

Not already a subscriber? Check out <http://www.post-polio.org/order.html> to become a member today.

Meet and greet: Ivan and Judy Jorgensen



On June 3, 2003, Ivan Jorgensen, Manager of Printing Services, was honoured at a retirement celebration at the University of Regina after completing 38 years of service. The event was a come-and-go gathering attended by approximately 200 co-workers—complete with a huge cake and chocolate covered strawberries. His wife Judy, who is also an employee at U of R, was at his side. Fred and Blenda Ramsay represented Polio Regina Inc.

Ivan was born in 1946 and raised on a farm a couple of miles south of Redvers, Sk. He had Polio when he was 18 months old, so he doesn't remember being ill.

"The disease left the muscles in my left leg weak and I was unable to stand on my toes on my left foot," Ivan recalls.

He worked on the farm, participated in sports and other activities like the rest of the kids, and didn't know any different. The only time it really bothered him was when he walked on soft ground like summer-fallow or a freshly tilled garden. "I always wore boots, which even back then weren't in vogue when all the other kids wore canvas running shoes", he said

His mother took him to lots of different doctors to see if there was anything that could be done about his leg. "We finally found a doctor in Winnipeg, Dr. Deacon, who said that he could operate to correct some of my problems, but he couldn't do it until I was 11 years old. I think I was only about eight at the time. Dr. Deacon had also had Polio. He wore a brace from his hip to his shoe and he walked with great difficulty."

But sleep inertia isn't napping's only detrimental effect. If you get too much sleep during the day you can have trouble falling asleep or staying asleep at night. Lack of night time sleep makes you more fatigued during the day, can make you want to nap longer and gives you even more trouble sleeping at night. So, before you start napping you have to make sure you're sleeping well at night and don't have the breathing problems or muscle twitching that disturb sleep in half of polio survivors (see PPS Forum, May 2002). You also need to give your body the amount of night time sleep it needs. Don't expect to feel rested if your body needs nine hours of sleep and you give it only six.

If your sleep is good enough and long enough and you still have daytime fatigue, napping is an option. Before you lie down to nap set an alarm for forty minutes so you'll sleep for only thirty minutes. Although research has shown that a thirty-minute nap is good for pilots and older folk who didn't have polio, thirty minutes may be too short a nap for polio survivors who have brain fatigue. If you need a longer nap increase your sleep time by fifteen minutes a day. But don't nap longer than ninety minutes, which is when dream sleep starts. Also, never nap after 5:00 pm (which includes dozing in front of the TV after dinner) because you'll make falling asleep at bedtime and staying asleep more difficult.

Remember that naps are only one part of your fatigue management program.

You also need to pace activities, take a fifteen-minute rest break in the morning, in the afternoon and after lunch. One of these breaks could be substituted with a nap. (Remember that the Americans with Disabilities Act permits rest breaks and even naps as reasonable accommodations in the workplace.) Some days you may not need a nap and can just rest. Or you may plan naps for every Saturday and Sunday. However, long weekend naps aren't substitutes for too little sleep during the week.

Whether you rest or nap during the day it is important that you keep a consistent daily schedule, including on weekends, with specific times to go to sleep, to wake up, and to take your rest breaks or nap. This schedule will train your brain when it should be sleeping and should be awake so that you can manage your fatigue in the cockpit...or wherever you work.

Co-ordinator in the Systems Department at the University of Regina Library. She has worked at the University since 1969. It has been wonderful being able to go to work together and understand each other's work," Ivan said.

In 1979 Ivan became manager of the print shop and is officially retiring at the end of June 2003.

"The University has grown substantially in the time Judy and I have been there. It became the University of Regina in 1974. When I started, there were only two buildings on the new campus, now there are 20 with 3 more under construction. The enrolment was 2,000 students, now it is 11,000. There was only my boss and I in the print shop now there is a staff of 13. The technology has also changed a great deal. When I started we had one copier that did about 15,000 copies a year, now we have 80 copiers that do a total of over 20,000,000 copies a year. When I started we didn't even have an adding machine in our department, now everyone has a computer on their desk." Ivan said.

"We have been printing the Polio Post Box and its predecessor since 1992 at U of R Printing Services and we have enjoyed working with the people from Polio Regina, especially Fred and Blenda Ramsay who always have interesting stories to tell." (Dr. Elisabeth Brandt, an original member of our Polio group, originally contacted the Printing Services department for our printing needs).

"I have been fortunate not to have any symptoms of Post Polio Syndrome, only the wear and tear that comes with age. After I retire, I plan to spend more time in my garden, which is my hobby and my passion. I also plan to occasionally go back to the farm to help out my brothers."

Polio Regina members congratulate the couple and extend our sincere thanks for a job well done.

survivors, health care professionals and inform the public. She asked us for any in-put we might have and she went away with lots of ideas from us.

By January 2003 I started to receive new details and we were to see if our members would like to become part of the new Network. A vote was taken at our Feb. Meeting. Members agreed to join. A Memorandum of Understanding was signed and we were included with all the other provinces across Canada who wanted to join. I was asked and agreed to handle the duties.

I have taken part in several Tele-Conferences since as well as kept everyone informed about what has been happening. We spent the month of March working on our Awareness Month, which proved worthwhile as we had many new polio survivors call and want information.

Most of these people asked to be put on the Registry so they will now be receiving information from Polio Canada. As well, we mailed out about 38 information packages to several of these people.

During that month we sent out press releases to all the weekly newspapers in Southern Saskatchewan and made arrangements for the media to interview some of us. A display was set-up at the Regina Science Centre.

We will need a liaison to participate in the future. I suggest that whoever attends the Training session in August, will take this on. Most of the work has been done. Good luck to whomever steps in.

You Are Invited

A special “Sing-Along” afternoon will be held Wed, June 25 (1:30-3:30 pm) at Christ Lutheran Church, 4825 Dewdney Ave. featuring “B J” Hughes of Watertown, New York at the piano. Invite your family and friends for a fun afternoon of singing. Everyone is welcome.



There is parking behind the church and we have an elevator. Refreshments will be served.



Birthday Invitation

You are invited to come and celebrate with the Copelands on the occasion of Ross’s 80th birthday, July 6 from 2-4 pm at Westminster Church, 3025 -13th Ave. Verna tells us there’s an elevator in the building and you can park in the church parking lot or across the street in the Holy Rosary parking lot. Use the Cameron Street access.

Gifts are graciously declined.

Come and help us give Ross the royal bumps!

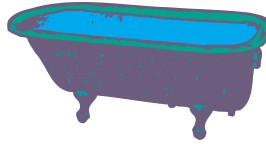
News about this and that

Our annual summer picnic will be held on the afternoon of June 22 at the Rotary Senior Centre, 15th & McTavish St. (next to the Neil Balkwill Centre). Our next regular meeting will be held on September 25 at the Wascana Rehab Centre at 7:00 pm. Please note that we do not meet over the summer months of July and August.

Special Needs Tub Lift

(Dancing on the slippery rim !!!)

For most people taking a bath is so simple you don't give it a second thought. Just turn on the water, undress and jump in, right?



Wrong; -if you are a disabled person. Taking a bath can become a monumental balancing act that should be in the repertoire of *Cirque du Soleil*, who perform awesome aerial and aquatic acts in Las Vegas.

Even with non-slip hand bars and non-slip flooring it's a tricky touch-and-go procedure. One wrong manoeuvre and you could be in trouble. That was the dilemma at our house for many years.

Finally we had enough hassle and called for help.

Our first call was to **Rian Tannahill**, a special needs consultant who provided us with brochures about barrier-free lifts. Rian supplies and installs great stuff: (electric hoists; tracked slings, grab bars etc.) but not quite what we needed.

We visited hardware and plumbing suppliers but the folks there sell only what they have on hand otherwise you are into 'special order' categories that translates into bigger bucks. The "wonderful world of internet" gave us some help, but not exactly what we needed. So we spent a fair amount of research trying to locate a suitable product.

We also drew diagrams on how we would build an "extension" to our cramped 1960's bathroom to add a new walk-in shower stall. New plumbing and re-wiring would be involved.

So, back to the drawing board and shopping routine.

Our first stop was to talk with **Peter Hillcoff**, proprietor of Automobility Medical on Lorne Street in Regina. Even before Peter arrived we saw exactly what we needed! A battery-operated bath lift which fits into a tub. It was perfect for our needs and definitely a case of "love at first sight".

The bath lift is relatively light-weight, portable so that if you are on a trip it fits easily into the vehicle.

Please update your records accordingly: GINI is now Post-Polio Health International.

Post-Polio Health International (PHI) 4207 Lindell Blvd #110, Saint Louis, MO 63108

info@post-polio.org www.post-polio.org 314-534-0475 314-534-5070 fax

Message from the South Saskatchewan Community Foundation:

"A gift today for tomorrow" is a most appropriate description of the South Saskatchewan Community Foundation. In a nutshell, the community foundation is one of the fastest-growing and most dynamic networks dedicated to building and strengthening communities in Canada.

What does it do ? Basically it pools charitable gifts of many donors into permanent, income-earning endowment funds to benefit local communities.

Using the interest earned from these funds, grants are used to fund a wide range of local initiatives for health, education, social services, culture and environment. Donors can choose to support their hometown broadly or designate a favourite cause or charity.

Get more information by contacting Wain Birch at Regina, 751-4756.



“When I turned 11, we were off to Winnipeg to see Dr. Deacon. By that time my left leg was almost two inches shorter than my right leg. I had two operations to correct the way I walked on my left foot. Then I had an operation where they put staples into the bone over the growth rings on my right knee. The staples were ¾” long and ¾” deep. They stopped my right leg from growing so my left leg could catch up. The problem was that I was quite active and the staples kept coming out so I had to have them replaced three times. I had my last operation when I was 16. If I wouldn’t of had the staples put in, my left leg would probably have been four inches shorter than my right leg and I would have had to wear a built-up shoe or my spine would be crooked” Ivan said.

“My mother promised me that if I went through with all the operations I would be able to wear running shoes. I did get a pair of running shoes after I was 16 but by that time it wasn’t such a big deal. My left foot is still smaller than my right foot. I used to buy two pair of shoes to get one pair that would fit. Now I have a shoemaker who makes me custom-built shoes that fit my feet and have steel shanks and supports to help me walk better,” Ivan said.

“I am very thankful to my parents – my mother for being so persistent and my father for paying for it all. There was no Medicare back then. After my first operation, I stayed in the hospital for a whole month. I wasn’t sick after the first week, but they kept me until my next operation. Nowadays for the same operation a person would be in the hospital for three days, maximum. We were farmers and by no means rich so it was quite a financial burden on my parents.”

Ivan graduated from Redvers High School in 1965 and after harvest was finished, he, and a friend went to the big city of Regina to get jobs. He got a job at the print shop at the University of Saskatchewan, Regina Campus and his friend got a job at the new Woolco store. Ivan worked at the University for two years then quit and went to the Southern Alberta Institute of Technology where he received a Diploma in Graphic Arts Administration. He worked at a graphic trade shop in Calgary for a short time then came back to the University in Regina in the fall of 1969.

“I met Judy Romanuik who worked in the University Library and we started to date. We were married in 1976. Judy was born and raised in Regina. She is a Systems

First British Conference: “Neither Lazy Nor Crazy”

Subject: The truth about the cause and treatment of myalgic encephalomyelitis and post-polio sequelae

Date: July 12th 2003 12:00 pm until 5:30 pm,
the Oakengates Theatre, Telford, Shropshire

Speakers: Prof. Richard L. Bruno, HD. Ph.D

Chairperson, international post-polio task force
Director, the post-polio institute and fatigue management programs
Englewood (new jersey) hospital and medical center U.S.A.

Dr. Elizabeth G. Dowsett, M.B, Ch.B., Dip. Bact.

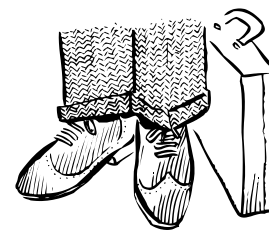
One of the UK’s foremost experts on ME who has carried out research in this field for over four decades.

Contacts: slawrence@onetel.net.uk petercr@sagainternet.co.uk

Thanks, Mark!

We received a lengthy article from Mark Burrell of Swift Current about the explosive dangers of using a cellular phone while fuelling a vehicle. There have apparently been gasoline fires and explosions resulting when a person uses a cell phone. Mobile phones that light up when switched on or, when they ring, release enough energy to provide a spark for ignition. Mobile phones should not be used at filling stations, or when fuelling lawn mowers, boat, etc.

ODD SHOE Sizes info from Kim Dowds - Polio Canada



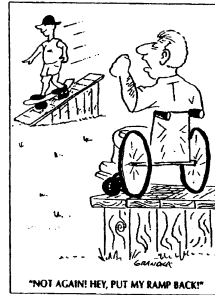
It has been a long time since I’ve mentioned Sole Mates on any of the forums - years probably.

We had a request today for information and I thought I would pass this information on Sole Mates to all of you as well as it is a great service!!

Hints from Dr. Richard Bruno:

How to keep a healthy level of insanity:

1. At lunchtime, sit in your parked car with sunglasses on, and point a hair dryer at passing cars. See if they slow down.
2. Page yourself over the intercom. Don't disguise your voice.
3. Every time someone asks you to do something, ask if they want fries with that order.
4. Put your garbage can on your desk and label it "IN".
5. Put decaf in the coffee maker for three weeks. Once everyone has gotten over his or her caffeine addictions, switch to espresso.
6. Finish all your sentences with "In accordance with the prophecy..."
7. Don't use any punctuation.
8. As often as possible, skip rather than walk.
9. Ask people what sex they are. Laugh hysterically after they answer.
10. Specify that your drive-through order is "to go."
11. Sing along at the opera.
12. Go to a poetry recital and ask why the poems don't rhyme.
13. Put mosquito netting around your work area. Play a tape of jungle sounds all day.
14. Five days in advance, tell your friends you can't attend their party because you are not in the mood.
15. Have your co-workers address you by your wrestling name, Rock Hard.
16. When the money comes out of the ATM, scream: "I won! I won! Third time this week!"
17. When leaving the zoo, start running towards the parking lot, yelling, "Run for your lives!!! They're loose!!!"
18. Tell your children over dinner: Due to the economy, we are going to have to let one of you go."



TIPS AND TECHNIQUES FOR TREATING PPS

by Dr. Richard L. Bruno



I get more fatigued as the week goes on and my ability to concentrate gets worse and worse. When the weekend comes I just have to nap. I sleep for three hours on Saturday and feel better. I nap for two hours on Sunday but afterward my brain feels sluggish and I often have a headache. I then have trouble falling asleep Sunday night and feel even sleepier on Monday in spite of the naps. What am I doing wrong?

You have discovered the pleasures and problems of napping. Rest periods and naps can be very helpful, even lifesaving. NASA studied daytime rests periods in those for whom fatigue, trouble concentrating and falling asleep can be deadly: pilots. Fatigued flight crews who took brief hourly breaks had improved alertness. These breaks were similar to the two, fifteen minutes breaks that work so well in reducing fatigue in Post-Polio Institute patients.

NASA also studied the effect of what they dubbed "Power Naps." Pilots took a planned 40-minute rest period during which they slept for about thirty minutes. After the nap pilots had increased alertness and performance and relief from what was described as "significant sleepiness." The same benefit was found in a study of healthy elderly folk: A thirty-minute nap at 1:00 PM significantly reduced afternoon sleepiness and fatigue.

But with napping, as with so many other aspects of life, there can be too much of a good thing. Long naps can actually be detrimental, causing the problems that you have described: grogginess, headaches and a "sluggish" brain after awakening. These symptoms have been given the wonderful name "sleep inertia" (from physical inertia: "a body at rest tends to stay at rest"). NASA scientists found that deep sleep begins about thirty minutes into a nap. When deep sleep begins your brain shuts down and it is more likely to feel "inert" when you wake it up. That's why researchers recommend thirty minutes as the ideal nap length: If you prevent yourself from going into deep sleep, there's no groggy brain and no sleep inertia.

Our calendar year is from Jan. 1 to Dec. 31. Thank you to those who have sent in your memberships and for the donations we have received. This is appreciated and helps with printing and mailing costs of our Newsletter.

Speaking of Newsletters, **Polio Canada** is working on the first Edition of their Newsletter so look for it in your mailbox next month. Anyone who has joined the Registry will receive a free copy. If you have not joined the Registry, you may do so by calling Polio Canada, at 1-800-480-5903. For your information the Polio Canada web site is www.poliocanada.com.

We are always looking for articles to put in the Post Box, so if you have any news or articles you would like published, give the editors a call at 543-6380. We enjoy receiving calls or letters from our members anytime.

Thank You to Dr. Mavis Matheson for her presentation at our May meeting. Mavis “walked” us through Chapter three of Dr. Bruno’s “Polio Paradox” book. Your little pictures and examples on the overhead helped us to better understand what the Polio virus did to our bodies and why we need to preserve what motor neurons we have left. We have invited Mavis for another book report in the fall.

Reminder – We have a number of books and articles about polio in our library so if you would like to do some summer reading, give our librarian Mavis a call at 586-5094.

We welcome these new Members:

Linda Degelman from Raymore, Leon Panachuk, Moose Jaw, Harold Robert Johnson, Nokomis, Isabelle Eaglesham, Weyburn, Muriel Neilson, Swift Current; and from Regina we have Joan Patterson, Gerry Freeland, Nora Schlosser and Art & Marg Petrovitch. A warm welcome to all!



We wish **Lloyd MacPherson** a speedy recovery after his “holiday” in hospital. We are glad to hear he is back home with Inge taking good care of him.

New addresses:

Dorothy Slater is #406-3651 Albert St. Regina, S4S 0A3

Jim McKechnie has moved to 430 Pioneer Dr., Regina S4T 2L8.

Don't forget to give us your new address if you are moving. Send to Fred Ramsay, 4334 England Rd., Regina, Sk. S4R 4N9.

Polio Canada Up-date

*Blenda Ramsay, Liaison for Polio Canada
and Polio Regina Inc.*



Last August, 2002, I had a phone call from the Ontario March of Dimes office in Toronto asking me if it would be possible to have a meeting with Kim Dowds. Kim was travelling across the Western Provinces trying to meet with as many of the polio groups as possible. I didn't really know what this was all about, but agreed to invite some of our members to come and meet her.

I was told she would be in Regina on the afternoon of Aug. 26.

The day arrived and I believe we had 17 of our members meet in our back yard. She explained that she was hoping to set up a National Polio Network right across Canada and invited us to be part of it. The Network promised to provide a strong voice to influence policy changes and encourage full access to health care services. As well the National Network would share information about our groups and she mentioned that if Polio Regina joined, we would be able to receive one or two free newsletters per year. They also hoped to set up a Registry of polio survivors. Belonging to the Network would help to bring Awareness and educate polio