

Christmas dinner highlights

A full house, a fantastic turkey dinner, great entertainment and lots of prizes pretty well describes our annual Polio Regina Christmas banquet. The 65 people who attended enjoyed the fantastic puppet show put on by the Westhill Baptist church puppeteers.

There was a lot of detailed work required in putting the banquet together and Polio



Regina members extend special thanks to Ross and Verna Copeland and various members of the executive. Make plans now to attend and help with the organizing next year. It's a big assignment for only three or four people.

(ps: Joyce Wellings, Regina & Fred won the big prizes !)



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Happy New Year!

When planning this issue of Post Box we realized there were a lot of things happening in Polio Regina. We held our Christmas dinner, sent flowers, fruit baskets and cards to several members and made personal contact with members and received greetings from other Polio groups. Some of that information is in this edition of Post Box.

The inter-net (click on *Polio*) has a wealth of information that our archivist/librarian, Dr. Mavis Matheson has submitted to us. We've also had letters, telephone calls and e-mail notes from our readers. We love it !
Enjoy the Postbox; We write it for you !

Meet and Greet: Bud & Hilda Findlay

When Hilda Findlay was a toddler in 1925, she contracted Polio (it was called infantile paralysis then) a rare, virtually unknown disease. She was paralyzed on the whole left side of her body for several months but the disease gradually disappeared and she was able to function normally.



Q. When will the PPS documentary appear?

A. Well, filming is just beginning. Should be on the air in the US late this year.

Q. So this year there will be The Polio Paradox, The Post-Polio Letter and a documentary on PPS?

A. All of these events may finally allow awareness of PPS to reach critical mass. To insure that end, the International Post-Polio Task Force is asking the United Nations, Parliaments throughout the world, the US Congress and each state and provincial legislature to declare 2002 “The Year of the Polio Survivor.” The IPTF members in 25 countries are asking every polio survivors to write their legislators, MPs, prime ministers, presidents and governors and ask that 2002 be “The Year of the Polio Survivor.”

Q. These are incredibly ambitious goal. It’s as if you’re trying to treat 20 million patients.

A. Well, that’s how I feel, not to mention the 10 million people with CFS and ME. But we can’t treat everyone at The Post-Polio Institute. We can only evaluate or treat less than 200 polio survivors a year.

Polio survivors need to take treatment into their own hands and teach interested doctors how to help them.

The goal of educating every polio survivor and doctor may be ambitious but it is do-able with the help of the media, governments throughout the world and polio survivors by mailing The Post-Polio Letter to their doctors. But all of this must happen now. Since research has shown that motor neurons are actually dying in polio survivors who have increasing muscle weakness, polio survivors have no time to waste!

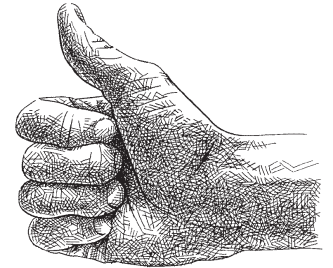
The Polio Paradox was published in June 2002 by Warner and can be purchased at Chapters book store or borrow a copy from our library. Talk to Dr. Mavis.

To register call the Playline at 777-7529 (City of Regina) or register at North West Leisure Centre, Sandra Schmirler Leisure Centre or the Lawson Sportsplex Centre.

Just a reminder: Here are some great benefits from joining the Canadian Paraplegic Association (Saskatchewan) Inc.

- Vehicle Registration Rebate Program
- SaskTel Mobility Cellular Phone Benefits
- Lottie V.M. Teale Scholarship/Bursary

Contact Regina Branch Office
210-4401 Albert St., Regina.
Phone (306) 584-0101.



Thanks

Sincere thanks to Leo Ell of the Rotary International Regina Club for lending us video tapes about their massive “Polio Plus” eradication program in the world.

Our members were keenly interested in the Rotary International global project, as we, being victims of Poliomyelitis which attacked our bodies years ago, are presently under-going various levels of Post Polio Syndrome.

The specter of PPS inflicts various forms of suffering among those who had the original disease. On-going medical research is reaching higher levels of activity with no cure in sight.

We congratulate and extend our best wishes to Rotary International in the monumental task to totally eradicate Polio in the world. It’s an outstanding accomplishment. We are making arrangements to obtain copies of the video tapes for member distribution through our library.

Q. Is your latest research included in the book?

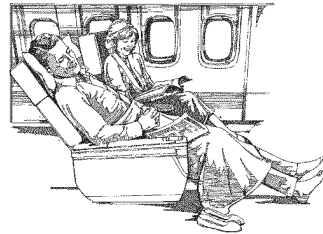
A. Yes. There's a whole chapter on our laboratory study and the 1998 International Post-Polio Survey showing that polio survivors are functionally hypoglycemic and what to do about it. Included throughout is information from the 2000 International Post-Polio Survey showing that polio survivors are exquisitely sensitive to anesthetic and have trouble breathing and waking — can even have severe vomiting and pain — after surgery. There are the first published results of The Post-Polio Institute's ongoing Treatment Outcome Study showing that those who become less Type A, who learn to take care of themselves, get better quickly and stay better — and those who don't do everything they can to treat their PPS get worse. And we report the first findings from the 2001 International CFS/ME (Chronic Fatigue Syndrome/Myalgic Encephalomyelitis) Survey.

Q. Why is Chronic Fatigue Syndrome and ME in a book on polio and PPS?

A. Because there are amazing historical connections and physical parallels between polio and CFS/ME. There is a nearly 70-year history of chronic fatigue outbreaks occurring at the same time as polio epidemics. Between 1934 and 1954 — the year the polio vaccine was developed — nine CFS/ME outbreaks occurred either at the same time as polio epidemics or affected the staff at polio hospitals. In fact, the first documented CFS/ME outbreak was in 1934, sickening the staff of the Los Angeles County polio hospital. The 2001 International CFS/ME Survey showed that 20% of baby-boomers — those who were kids before the development of the polio vaccine — who are now diagnosed with CFS/ME may have had a mild case of “non-paralytic” polio in the 1940s or 1950s and now actually have PPS, not CFS or ME.

Q. And what are the physical parallels between polio and CFS/ME.?

A. Our research has shown that polio survivors with fatigue have lesions of the brain on MRI, attention deficits on neuropsychologic testing, reduced levels of brain activating hormones and brain wave slowing. This evidence of damage to the brain stem neurons that activate the brain — the “brain activating system” — that keeps the brain awake and focuses attention — is identical to abnormalities seen in patients with CFS. So we think brain activating system damage is the cause of fatigue in both polio survivors and those with CFS/ME, even if the CFS/ME patients are not baby boomers.



Holidays:

Grace Lekivetz is planning a little winter holiday with family members to Mexico. We are all jealous!

We also understand that **John and Zenny Burton** are spending the winter in Arizona.

Speaking of holidays, the Ramsays are looking forward to a summer visit from long time friend, Barrie (BJ) Hughes of Watertown, New York. BJ has offered to do some entertainment for us when he is here in June and we are hoping this may be arranged at the **Wascana Rehabilitation Centre**.

BJ goes to Senior homes and does a “Sing-Along” party with them. He tells us he did 58 “gigs” during the month of December. He is a super piano player and he brings music and laughter to all his “gigs”. He calls seniors “recycled teenagers”. How would you feel about attending this function??? We will keep you posted when details are confirmed.

Conserving Energy: *Your key to better health*

It takes time and effort in order to use energy conservation to your greatest advantage. It is important to have the right attitude. There are times for different kinds of tasks to be done, and other times when you have to be willing to do a job less thoroughly than usual in order to have the energy to spend on your family or friends.

Try to accept the things you can't change and minimize the frustrations you face. Don't expect the impossible because even with a good plan, there will be setbacks. Work-simplification is an important tool to use in reaching your daily and long-term goals in life.

Remember: *using your energy to best advantage* will allow you to do more and better.

The name ‘Teddy’ was attached to the Steiff bears and the world’s love affair with teddy bears began. When Margarete died in 1909 her company was exporting hundreds of thousands of bears and it still produces them.

Source: Post-Polio Network (New South Wales Inc. Newsletter #48)
<http://www.post-polionetwork.org.au/news/ppn48.html>

Letter describes USA polio survival

Don Volpel, secretary, gave us a letter from Catherine Moore Shipman, a friend of the family living in Leesville Louisiana. The letter outlines Catherine’s contact with Polio when she was five years old and the struggles she had in getting assistance for her disability. Her story is somewhat parallel to our conditions in Canada.

We thank Don for sending it to us.

Please let us know if you would like any special items or announcements to put in the Post Box. Have a great day! - Fred & Blenda

For Sale: One second-hand 3-wheel scooter. Phone Kathy Yakubecke @ 789-6383 for all the details.

Thanks to Barry & Betty Williams for the slide presentation about Australia shown at our November meeting.

Reminder about Plaque card from City Hall

Regina City Hall issues special parking permits for \$5.00 per month to anyone who owns a Disability plaque card. Take your Disabled Parking plaque card to the front desk and they will give you a special parking permit to use when parking in a metered zone. This gives you to free parking for three hours.

neurons’ protein supply increases and you are able to use your muscles again. But every time you drain your motor neurons, we think you are doing damage that eventually causes permanent weakness as the drained neurons die.

Think of what would happen to your car battery if you left the headlights on every night. You get up the first morning and your battery is dead. You jump-start the car and drive off.

The next night you leave the lights on, jump-start the battery again, and drive away. But after about a week the battery will no longer take a charge and you won’t be driving anywhere!

Canadian PPS researcher Alan McComas, found that polio survivors who are getting weaker over time lose 7% of their motor neurons per year, that’s 7% on top of the 50% they have already lost! Prevent transient weakness —and permanent weakness — by resting before your muscles become weak, let alone become completely lame. Remember: you can replace your car’s battery but you can’t replace your motor neurons!

Read Dr. Bruno’s new book: “**The Polio Paradox; Uncovering the hidden history of polio to understand and treat “post-polio syndrome” and chronic fatigue**”, published by Warner books. (aol keyword polio paradox.) E-mail questions to Dr. Bruno at polioparadox@aol.com

Dr. Mavis Matheson has a copy of the book available for loan from our library.

Upcoming Meetings:

Our regular meetings are always held on the last Thursday of the month at 7 pm in Salon A & B on second floor of the Wascana Hospital.

So, the next meeting dates are: February 27; March 27; April 24 and May 29.

The June meeting is our annual barbecue and that date will be announced later.

Now it seems the original polio has returned in the form of Post Polio Syndrome. Hilda has difficulties walking even for short distances. Her aching muscles throughout her left side are barely able to support her and she uses supportive devices to assist her if her husband Bud isn't readily available.

For several years Hilda and Bud have been involved in Yoga exercising for three or four times a week and have found the exercises help to stimulate their muscles. They purchased video tapes several years ago. She is also on a drug plan to help alleviate her aches and pain.

Hilda was born and raised on a farm near Southey, 50 kilometres north of Regina, where she attended school and married Bud Findlay in 1944, a grain and livestock farmer from the Semans district, 50 kilometres north of Southey.

Bud's dad homesteaded the original Findlay farm and it is now farmed by their son, Lyle. Bud still enjoys helping out on the farm during the busy times.

For the last 26 years, Bud and Hilda have spent their winter months at Hemet, Calif., living in a comfortable 5th wheel trailer. One of the reasons they go south is because of Hilda's intolerance to cold weather, another frequent detrimental affect of post polio syndrome. This winter they have decided to stay home in Regina for the first time in 26 years.

Bud and Hilda have been members of Polio Regina for about 12 years and are getting the benefit from our information and the personal contact with other Polio Regina members.

Our next meeting (February 28) is our annual meeting and election of officers. All positions are up for election.

The Laugh & Splash Swimming will resume at Wascana Rehabilitation Centre pool on February 8 to April 12, from 2-4 pm. Cost is only \$20 for 10 weeks for an individual with a disability and *free* for family members and assistants. The pool water is 33C and a life-guard and a qualified assistant are available to help if you need assistance getting in and out of the pool.

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 \$ _____

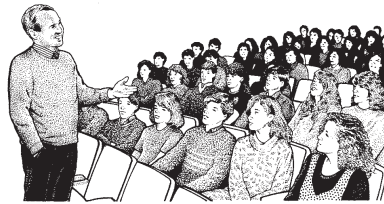
(If you require sponsorship for your fee, inform our membership chairman)

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.)

Manitoba Plans Symposium

On May 30-31, 2003 (Thursday & Friday) has been selected as the date for a major Post Polio symposium sponsored by the good folks of Post-Polio Network (Manitoba) Inc.



Details include Dr. Julie K. Silver MD of Harvard as keynote speaker. Advance registration forms are available by contacting Post-Polio Network (Manitoba) Inc., 2nd floor-825 Sherbrook St., Winnipeg, Man. R3A 1M5. Phone 204-775-8791. Attendance fee is \$25. (*Should we consider sending a delegation to attend ?*)

Alberta Busy

As usual the two Alberta support groups enjoyed a good year filled with activity. Edmonton's Wild Rose Polio Support Group's annual report reflected activities ranging from head-to-head meetings with political big-wigs to fund-raising at public displays and malls. The Southern Alberta group was equally full of activity.

B.C. Busy, busy

British Columbia's PPASS, located in Victoria and linked with five area groups, is involved in everything imaginable in their quest to solve the Post-Polio Syndrome challenge. Surveys and reports on members, contact with doctors and other practitioners, is all part of finding a cure for post-polio syndrome.

Condolences

Our condolences to the family of **Thomas Robert King** who died on January 04, 2003 at the age of 85. He is survived by his wife Ann Marie King (Buckley) and family Marilyn Morton, James King, June Domokos, Donna King and Dianne Harmon and his 10 grandchildren and three great-grandchildren. Mr. King was a long time member of Polio Regina Inc. Thank you for the memorial donations from the King family members.

So we treat CFS/ME patients the same as polio survivors with fatigue, applying "The Golden Rule: *If anything causes fatigue, weakness or pain DON'T DO IT!*" (Or do much less of it.)

Q. How do you fit all this information in one book? Is it 1,000 pages long?

A. No, it's 368 pages — with figures! And it's not written in scientific jargon. My goal was to present all of this information in clear terms, making it easy to understand, interesting — even fun to read.

Q. You must have succeeded. Those who've read *The Polio Paradox* —including polio survivor authors like Mia Farrow and Arthur C. Clarke — have praised the book.

A. I very much appreciate their kind words. But the proof of the writing will be in the reading, if the book can inform and empower the world's 20 million polio survivors, helping them to understand polio, the cause of PPS and take treatment and management into their own hands.

I am so grateful to Mia Farrow and her son, Thaddeus — who is also a polio survivor — for helping to get PPS information out. Mia and Thaddeus are the co-chairpersons of the International Post-Polio Task Force's Post-Polio Letter Campaign.

Q. What is The Post-Polio Letter?

A. The Post-Polio Letter is a one page description of the cause and treatment of PPS, giving a web address — postpolioinfo.com — where polio survivors and their doctors can go to get more information. The Post-Polio Letter ask everyone who reads it to make a copy and send it to their doctors. In this way every doctor in the world could learn about PPS. The UN has also agreed to partner with the International Post-Polio Task Force and provide information about PPS as part of its polio eradication education program, including when Mia speaks about vaccination.

Q. Where will The Post-Polio Letter appear?

A. It will appear first in the March issues of *New Mobility* magazine in the US and in Canada's *Total Access* magazine, on disability web sites and in post-polio support group newsletters. We are also asking newspapers and magazines throughout the world to run *The Post-Polio Letter*, including newspapers owned by Scripps Howard, the company that is doing the TV documentary on PPS.

TIPS AND TECHNIQUES FOR TREATING PPS

*Dr. Richard L. Bruno
Chairperson of the International Post-Polio Task Force and Director
of The Post-Polio Institute and International Centre for Post-Polio
Education and Research at Englewood (NJ) Hospital and Medical Center.*

“If the accepted theory of post-polio muscle weakness is that our motor neurons are dying, why do I improve with rest after having a period of severe weakness when I overdo?”

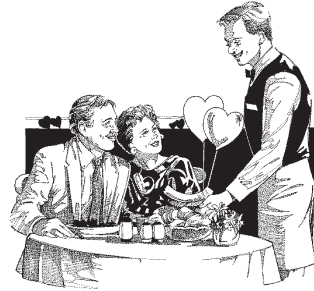
“Even though I can become completely lame, the loss is temporary if I rest up for a day or a week.”

You are describing a symptom that PPS researchers have totally ignored: “transient weakness.” We call it “Holiday Syndrome.” Polio survivors complain that their muscles become significantly weaker in December, as they do too much Christmas shopping, but strength returns in January after they rest.

Something dangerous is happening to cause the transient weakness of “Holiday Syndrome.” Remember that the poliovirus killed off at least 50% of your motor neurons. The neurons that weren’t killed were damaged by the poliovirus but were able to sprout — send out extra “telephone lines” — to talk to the muscle fibers that were orphaned when their motor neurons died.

After polio you were left with less than half of your motor neurons—neurons that not only are over-sprouted, but also have cell bodies that are smaller than normal, have damaged protein-making “factories,” and have been severely overworked for the past 50 years.

When you experience transient weakness we think you have overloaded your neurons’ protein-making factories and drained their reserves. After you rest, the



The Doctor With 30 Million Patients



*An interview with Dr. Richard Bruno
Director, Post-Polio Rehabilitation and Research
Service, the Kessler Institute for Rehabilitation,
New Jersey*

Written by Vicki McKenna
*Excerpt from A Balanced Way Of Living Newsletter 4
April 2002*

*Editor’s note: In the last edition of Postbox we published
the first half of this interview with Dr. Bruno.*

Q. There are chapters on the development of the Type A post-polio personality and there is a long chapter on dealing with the psychological issues surrounding PPS (Post Polio Syndrome). What are the other chapters about?

A. The book begins with the recognition of PPS 20 years ago, then goes back to the first reported case of PPS in 1875...

Q. 1875?

A. Yup. It’s not like PPS is new. There were 100 cases described in medical journals before 1980! This is why it makes me furious that doctors today say they “don’t believe” that PPS is real, as if polio survivors are members of some bizarre religious cult and their symptoms are the result of demonic possession. PPS is old news; it’s just news nobody wanted to hear. I describe the reasons some people and not others got polio, the damage the poliovirus did inside polio survivors’ bodies — both obvious and hidden — and how that damage so many years ago set the stage for new symptoms. There are separate chapters on the cause and treatment of new muscle weakness and pain, and I explain why polio survivors are twice as sensitive to pain as those who didn’t have polio. There are chapters on brain fatigue; on polio survivors’ sleep problems, caused by their unique muscle twitching and breathing problems; why polio survivors are so cold; the new swallowing and belly problems we’ve found that cause low blood pressure and fatigue. Of course, a huge chapter describing in detail The Post-Polio Institute evaluation and treatment program.

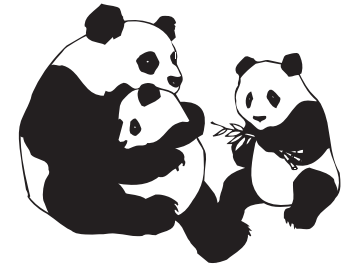
Don V's Witticism

1. Don't sweat the petty things and don't pet the sweaty things.
2. One tequila, two tequila, three tequila, floor.
3. Atheism is a non-prophet organization.
4. If man evolved from monkeys and apes, why do we still have monkeys and apes?
5. The main reason Santa is so jolly is because he knows where all the bad girls live.
6. I went to a bookstore and asked the saleswoman, "Where's the self-help section?" She said if she told me, it would defeat the purpose.
7. What if there were no hypothetical questions?
8. If a man is standing in the middle of the forest speaking and there is no woman around to hear him is he still wrong?
9. If someone with multiple personalities threatens to kill himself, is it considered a hostage situation?
10. Is there another word for synonym?
11. Isn't it a bit unnerving that doctors call what they do "practice"?
12. Where do forest rangers go to "get away from it all" ?
13. What do you do when you see an endangered animal eating an endangered plant?
14. If a parsley farmer is sued, can they garnish his wages?
15. Would a fly without wings be called a walk?
16. Why lock gas station bathrooms? Are they afraid someone will clean them?
17. If a turtle doesn't have a shell, is he homeless or naked?
18. Why don't sheep shrink when it rains?
19. Can vegetarians eat animal crackers?
20. If the police arrest a mime, do they tell him he has the right to remain silent?

Did you know . . .

Polio survivor invented teddy bears !

Margarete Steiff was born in Germany in 1847. She contracted polio when she was two and used a wheelchair for the rest of her life. After attending school, where the janitor carried her up stairs, she took sewing lessons and opened a dress shop in her parents' home.



This grew to several shops. Margarete began using scraps left over from sewing to make toys. These were so successful that she abandoned dressmaking and with her brother opened the Steiff Toy Company. The building was wheelchair accessible with long sloping ramps and wide spaces.

By the 20th century according to an article in *Mainstream Magazine* (12/95) the name 'Steiff' on a stuffed animal or doll was comparable to the word 'sterling' on silver. Margarete wanted to create a stuffed toy animal that would compete with dolls in popularity. The animal had to one appeal to both sexes and be able to dressed liked a doll. After a visit to the zoo her brother suggested a bear.

Their factory manufactured a toy bear made of *wool plush and cotton fabric called mohair to give the bear a furry, cuddly appearance. Wooden discs were placed at the neck, shoulders, and hips to allow the bear to be posed in different positions. Shoe buttons were used for eyes and silk thread for nose, mouth and claws.*

The first bear was exhibited at the Leipzig Toy Fair but there was only one order. This was from a New York department store that placed a large order for 3000 bears.

When the bears arrived in the US Theodore (Teddy) Roosevelt was the popular president who loved hunting. On a recent hunting trip he had shot nothing so his aides put a bear cub in his path. Roosevelt refused to shoot the bear. The picture of him with the cub captured Americans' imagination.