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Polio Regina Incorporated

Happy Thanksgiving



My Polio Story

The following is our new president's Polio Story. Wilf has been a member of Polio Regina for about 10 years.

Wilf Tiefenbach



I was born on March 15th, 1947 in Regina, Sk. My family moved to Cardston, Alberta, my mother's birthplace, in the summer of 1947. About July, 1950, we moved back to Balgonie to farm my father's parent's farm. In 1952, I contracted polio. I don't remember how long I was hospitalized, but, after I was released from hospital, we moved into Regina in the winter of 1953. I, then, could be closer for the March of Dimes bus to pick me up, to go to Wascana Rehab for treatment on my leg. My left leg was very deformed from the polio.

My remembrance of being in the hospital was not pleasant. I kicked and screamed when the nurse took me in, but I didn't win the battle. I started school a bit late, but soon caught up.

I found it very difficult being different from other kids and not being able to run. I always wanted to be able to run and was never able to. I had surgery during the summer months, age 7, so I wouldn't miss school. I had pins put in my ankle and was fitted with a brace. From the age of 5 until 13 years of age, the March of Dimes bus would pick me up at school to go to Wascana. I hated it so much as it was terribly embarrassing.

At age 13, I had my second surgery during Christmas holidays. I still wore the brace at that time. Spring of that year found me playing fastball. I couldn't run, but I sure got a handle on pitching.

Upon entering high school, my brace squeaked when I walked down the hallway in school, so I threw the dam thing away. I continued playing baseball until 35 years of age, when my shoulder started to wear out. I must mention that I grew up in the North end of Regina, and because of my disability and my inability to run; I got into various scraps with other guys.

I was the oldest of 10 children. We always had food to eat, but never in abundance.

I started working at the age of 15 on a farm for 3 weeks, and then also helped my uncle paint his house for 2 weeks. The following year I started working for Roantree Plumbing and Heating for the summer months. I did 2 more summers after that. At age 18, I started my apprenticeship in the sheet metal trade, working in the construction industry. This work has been my way of life until this present day. I have worked on many buildings in Regina and surrounding areas, during the past 45 years. I started my own company, Marathon Mechanical in 1993. I have 3

IN THIS ISSUE

My Polio Story	1
Greetings from the President	2
At the Meeting	2
Survey - Polio Regina Metings	3
Polio and Post-Polio Related Web Sites	4
Fragments of Poliovirus in PPS Patients	4
Cholesterol Drugs and Muscle Problems	5
You are Invited	7
Membership Application	7
Spring Picnic	8

Continued on Page 2

My Polio Story - Continued

children from a previous marriage.

I have been very blessed to have accomplished all that I have done, having had that dreaded polio. Every year now, due to post-polio, it has been a bit more difficult in keeping my balance and walking in general.

My lovely wife, Carole, and I plan on doing some more travelling and enjoying many happy retirement years in the near future.

By the way, I now have to wear a brace for the last 8 years and I wear it every day, squeak or no squeak, I wear it!

The best thing about having polio is joining the polio support group and meeting Carole, who also had polio in 1952, and having that loving support from someone who understands what it is all about.

Greetings from the President

By Wilf Tiefenbach

Welcome back everyone. I certainly hope all had a great 'wet' summer! Here we are into a quick autumn with frost already. My sympathies go out to all the farmers suffering from this devastating weather.

Summer started out on a bright note. I was contemplating retirement! After 45 years in the sheet metal business, I was ready to shut her down. Somehow that just didn't happen and am now just as busy as ever back at the same old job. Pretty soon, though, I will retire for sure.

I supposedly retired on June 1st, took a few days off, broke my leg on June 5th, and somehow, just gradually, I was back at work with my crutches and broken leg.

How it happened, I will never know. I have fallen off ladders at work, also scaffolds, always pretty fortunate that nothing serious happened. Lady Luck finally gave up on me on June 5th. I had accidentally stepped to reach a stepping stone in the back yard, missed the stepping stone, heard something crack, couldn't get up, sent my dear wife, Carole, to London Drugs for a pair of crutches so I could get around a bit and they have been my companions for the summer months.

Plans for summer travelling went down the drain, but there is always next year. Since we were unable to travel, I slowly started going into work again.

I hope you all had a better summer than I did, physically. We did end up going to 4 weddings, a trip to Winnipeg to pick up the grandchildren, and drive them back again, Cirque du Soleil, another Rory Allen show, and just recently, Andy Kim, who put on an excellent concert, for an old guy! It was an awesome evening as Carole and I were celebrating our 2nd wedding anniversary the next day. Andy Kim kissed Carole on the cheek and then he signed the CD she had purchased that night. Great evening, for sure! Our annual picnic was held at Mavis Matheson's home again and everyone had a very enjoyable evening. We also held a meeting that night which turned out to be an excellent time to hold a meeting as there are many more members at that picnic than at our normal meetings. Ivan passed out survey papers to try to see if we can increase our attendance at meetings. Only 19 people responded and that will be mentioned at our next meeting. I do believe these social events, our annual picnic and the Christmas party, are so very important for our support group.

Please let our executive know if you have any questions.

Lest we forget about winter around the corner, maybe we will have a toasty warm fall and we can forget about our wet cool summer.

At the Meeting

Our annual spring picnic and May meeting was held at the home of Dr. Mavis Matheson. A motion was moved to "Amend the Constitution of Polio Regina Inc. Article 8(a) to read: A quorum of five members must be present before business is conducted." The motion was carried.

A survey requesting members' opinion on how we could increase attendance at meetings was distributed along with the Polio PostBox to everyone who attended the meeting. The survey was also mailed along with the Polio PostBox to the people on our mailing list. (The results of the survey are included on page 3.)

Survey - Polio Regina Meetings

The number of people that attend our Polio Regina meetings has been declining over the past few years. We would like to know what you think could be changed to increase attendance at our meetings. The following is a short questionnaire that we would like you to complete and return to: Ivan Jorgensen, 3344 Baneberry Drive, Regina, SK S4V 2V2.

1. How often do you attend meetings? Almost every meeting -10, 3 or 4 a year -2, 1 or 2 a year -2, Only Spring Picnic and or Christmas Party -1, Never -4
2. Is the time of meetings (7:00 p.m.) convenient for you? Yes -14, No -4, (Prefer 7:30 -1)
3. When would you like to meet? During the day -5, In the evening -9, Either -4
4. Is the day (the last Thursday of the month) convenient for you? Yes -18, No -1
5. Would you rather meet on the weekend? Yes -0, No -17, Undecided 1
6. Is the location (Wascana Rehabilitation Centre) convenient for you? Yes -18, No -1
7. Do you need assistance getting to and from meetings (rides)? Yes -2, No -15, Sometimes -2
8. Would you like to have more information at the meetings? Yes -11, No -4, Undecided -2
9. What topics are you interested in? Health -4, Aids to Independent Living -5, Research -1, Reports from Conventions -1, Anything -3, PPS Treatment -2, Problem Solving -1, Aging -1, Financial assistance for equipment or house renovations, travel, exercise, diet, spots for handicapped people -1
10. What would you like to see? (Check all that apply) Speakers -17, Videos -13, Forums -8
11. Do we need a social director? Yes -7, No -5, Undecided -3
12. Should we be paying our guest speakers? Yes -7, No -4, Undecided -4, Travel, Expenses or Gifts -2
13. Should we have refreshments such as coffee, tea or juice at our meetings? Yes -11, No -7, Undecided -1
14. Should we have snacks like fruit or pastry at our meetings? Yes -4, No -13, Undecided -1
15. Would you be willing to submit an article to the Polio PostBox? Yes -8, No -7, Maybe -1
16. Do you have access to the internet? Yes -12, No -6

17. Do you think that Polio Regina still serves a useful purpose? Yes -17, No -0, Unsure -2
18. If you are unable to attend meetings, how can Polio Regina help you?
Send reports and information from meetings.
Different day. There should be a notice mentioned at meeting prior to "Due Date" to pay fees.
Continue newsletter – could be sent by email.
More information about meetings.

The Survey on Polio Regina Meetings - Some Observations

62 surveys were distributed. There were 18 people in attendance at the May meeting where it was distributed. 44 surveys were mailed out along with the May issue of the Polio PostBox. A total of 19 surveys were returned. This works out to about 30% that were returned. Some of the surveys were given to couples who would have only filled out one survey.

Most respondents were satisfied with the time and location of the meetings.

Most respondents would like to have more information at the meetings like speakers, videos and forums. Some of the subjects that people are interested in are: Health, Aids to Independent Living, PPS Treatments, Reports from Conventions, Problem Solving, Aging, Financial Assistance for Equipment or House Renovations, Travel, Exercise, Diet, Spots for Handicapped People. There is a feeling that the meetings need to have more exchange of information and experiences among its members. We need to get back to being a "Support Group".

The question "Do we need a social director?" was probably misleading. It should probably have been "Should we have a program director." We seem to be doing fine with our social activities but are falling short on the programming for our meetings.

Many people thought that whether we should pay for speakers depended on the quality of the speaker. Paying expenses and giving a gift were also mentioned.

Most people thought we should have refreshments such as coffee, tea or juice but some thought it was too much of a bother. Most people didn't think snacks were necessary.

12 respondents said they had access to the internet.

Most people still think that Polio Regina serves a useful purpose; two were not sure.

Polio and Post-Polio Syndrome Related Web Sites

For those of you who have access to the internet, the following are some web sites that have information related to Polio and Post-Polio Syndrome:

<http://nonprofits.accesscomm.ca/polio/> This is our “Polio Regina” web site. It contains information on Post-Polio Syndrome as well as archives of all the issues of the Polio PostBox newsletter.

<http://www.marchofdimes.ca/polio> This is the web site for Polio Canada which also contains the PoliO’Canada newsletter.

<http://www.poliotoday.org> This is a web site by the Salk Institute for Biological Studies. It contains lots of information on Post-Polio Syndrome but it also features video testimonials from polio survivors who share recollections of their personal battles with polio.

<http://poliosask.org> This is the web site for the Saskatchewan Awareness of Post-Polio Society Inc.

<http://www.post-polio.org> This is the web site for Post-Polio Health International. It contains all kinds of information as well as the Post-Polio Health newsletter.

<http://www.ppsmanager.com> This is the web site for the Southern California PPS Manager newsletter.

<http://www.postpolio.org> This is the Florida East Coast Post-Polio Support Group newsletter.

These are just some of the web sites that are available. If you Google “Post-Polio or Polio” you will find hundreds of web sites that contain information on Post-Polio. Keep in mind that consumer health information on the internet can’t replace the knowledge and expertise of a health professional. Always consult with your doctor or medical practitioner about any questions concerning your health.

P.S. I have set up Polio Regina as a “Group” on PolioToday.org. This will allow us to share information with our group in a manner similar to Facebook but it will be more Polio focused. If you wish to join, send me your email address and I will send you an invitation to join. I would like to get everybody’s email address so I can make a list of addresses so I can send out information related to Polio Regina. I will not share the list with anyone other than Polio Regina people. My email address is ivan.jorgensen@sasktel.net

FINAL REPORT: Persisting Noninfectious Genome Fragments of Poliovirus in PPS Patients

Antonio Toniolo, MD; Andreina Baj, MD; Giuseppe Maccari, MS - Laboratory of Medical Microbiology and Virology, Department of Clinical and Biological Sciences, University of Insubria Medical Center, Varese, Italy & Laura Bertolasi, MD; Salvatore Monaco, MD - Department of Neurological Sciences, University of Verona Medical School, Verona, Italy

Correspondence to; antonio.toniolo@uninsubria.it

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Dr. Toniolo’s team submitted an Interim report that is posted online at: www.post-polio.org/res/

Purpose of the grant: The funds our team received from The Research Fund of Post-Polio Health International helped us continue our ongoing research of identifying poliovirus (PV) genome fragments in the survivors of polio. Our goal also is to clarify whether the presence of fragments is related to the symptoms of post-polio syndrome (PPS).

Recent findings: Using molecular tests and cell lines expressing polio-virus receptors, PV genome fragments and low-level infectivity have been detected in CSF (cerebral spinal fluid) and peripheral blood leukocytes of 52 out of 63 patients (82 percent) diagnosed with PPS (median age, 58 yrs; range 46 to 81 yrs; median time from acute paralytic poliomyelitis, 55 yrs).

Using these same methods, PV genome fragments could be detected in only one of 58 control subjects (blood donors, n =26; family members of PPS patients, n =21; adult pathologic controls with neurologic conditions other than PPS, n =11).

In a few PPS patients undergoing surgical procedures, PV genome fragments have been detected also in primary cultures of skeletal muscle, peripheral nerve and duodenal mucosa cells.

The amounts of PV genome fragments were extremely low in all patients. This made the detailed analysis of these fragments extremely difficult. When dealing with other viral infections, it is common to “sequence” the

genome of the virus isolated from the patient (i.e., to express the composition of its genome as a sequence of nucleotides). The sequence of the viral isolate is then compared to genome sequences of reference strains of the same species in order to identify potential unique properties of the isolate. In the case of PPS, sequences of genomic PV fragments must be compared to those of the three wild-type PVs.

So far, we have only been able to obtain partial sequences of some genomic fragments (the so-called 5'UTR, VP1, and 3D^{pol} regions). However, the limited data obtained have been sufficient to indicate that the majority of patients (70 percent) were carrying genome fragments belonging to PV type-1, 16 percent to PV-2, and 4 percent to PV-3 (some fragments remain to be identified). Partial sequences also showed that the genome fragments detected in PPS patients contained extensive mutations as compared to wild-type PVs. Tests in cultured cells exposed to PV genome fragments showed that these fragments contained some residual biological activity, such as low production of PV capsid proteins and induction of some pro-inflammatory cytokines.

Conclusions: The data indicate that low-level PV activity can persist for decades in most polio survivors. The results, however, *do not* provide a pathogenetic link of PV persistence with the development of PPS. Through collaboration with other virology laboratories, we now hope to characterize in detail the mutated PV strains obtained from PPS patients in order to understand their possible contribution to pathogenetic events.

Subsequently, we will use *in vitro* assays to test the activity of novel antiviral compounds against the mutated and persisting PV strains. The hope is to find drugs capable of eradicating viral genome fragments from the body of PPS patients.

UPDATE on Post-Polio Health International's Research Fund:

The money invested in the fund is on the rebound with a current value of \$550,000

PHI received six Phase 1 applications (or its next award to be given in late 2010. The submissions, from Brazil, Israel, United States and Sweden), will be reviewed by an expert panel, which includes polio survivors; to determine which applicants will be asked to submit Phase 2 requirements.

Murphy's Lesser Known Laws

*Flashlight: A metal tube used to store dead batteries.
A fine is a tax for doing wrong. A tax is a fine for doing well.*

New Knowledge about Cholesterol Drugs and Muscle Problems

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Edward A. Bollenbach is a retired professor of microbiology and chemistry at Northwestern Connecticut Community College. He earned BA and MA degrees in biology from State University of New York at New Paltz. He holds National Science Foundation Certificates for NSF courses in cryptogamic botany, holistic health and origins of life. He contracted polio in 1954 and is now experiencing post-polio syndrome.

Statin drugs are one of the great health breakthroughs of the 20th century, dramatically lowering cholesterol and helping to prevent heart attacks and strokes. Taken by millions of people, statins are one of the most effective and widely prescribed medications ever. But they're not risk free. The most common problem reported is muscle pain. PHI asked polio survivor Edward A. Bollenbach, a retired professor of microbiology and chemistry, to explain why this occurs and to discuss how it may relate to post-polio people.

PHI: *What is this new knowledge about muscle problems, and which cholesterol drugs are involved?*

EB: There have been studies at Harvard and Beth Israel in Boston with statins, such as Lipitor and Crestor, which were published last year. This work points at a single chemical, normally produced along with cholesterol, as the lynchpin in the development of new muscle problems.

PHI: *So you are saying that when cholesterol is normally formed in the body this chemical is formed with it?*

EB: Yes, and when drugs like Lipitor, Zocor, Crestor, Mevacor (1), among others, are used, they slow the speed of cholesterol formation, and the amount of cholesterol in the blood and muscles decreases. Geranylgeranyl pyrophosphate, the chemical responsible for preventing muscle problems, also decreases, and it does not function as it normally does. This decrease is very likely the cause of muscle-related problems.

PHI: *What happens to the muscle to make it sore from the decreased amount of chemical?*

EB: Apparently there is a gene which becomes active in the muscles of the body if there is a decrease in the

normal function of the chemical mentioned above. The gene produces a substance which stops muscles from rebuilding themselves after use so muscles cannot repair normal wear and tear. But remember, this happens to a small minority of patients.

PHI: *How can this new knowledge help polio survivors?*

EB: There are different forms of this gene, so one form may be more damaging than others. Soon we may be able to test for which version of the gene is present. Also, work is now underway to determine exactly what happens to the chemical that is decreased, which results in the activation of the atrophy gene, called atrogen, and so named because it results in muscle atrophy.

PHI: *Are there any other developments on this subject?*

EB: In 1997, the New England Journal of Medicine reported that 60 percent of people who develop muscle problems from statins have a double copy of another gene we can designate as C. So, if you inherited a C gene from your mother and a C gene from your father, you will be CC. If you have neither C but two of an alternative gene, your chance of developing muscle problems is very low.

PHI: *Between the atrogen gene and the C gene how does this change the picture for people experiencing the late effects of polio?*

EB: First of all, muscle problems seem to be controlled by genetic factors, so whether you are a polio survivor may not be likely to have much of an effect on whether you develop increased problems from statins. It seems we may all be in the same boat. Secondly, it is very possible that in the near future we will develop interventions to make the probability of muscle side effects extremely unlikely for everyone even though such effects are already infrequent. When they do occur, they are usually transitory.

PHI: *Are there any other practical issues that we should be aware of to reduce the chance of muscle damage due to statin drugs?*

EB: I think physicians should probably, if they do not already, take into account other medications that a patient is using when prescribing a statin drug.

PHI: *Why is that?*

EB: Because Lipitor, for example, is broken down in the liver by a different chemical than Crestor or some of the other statins. Other medications are also broken

down in the liver by other chemicals. If medications, like the heart drug amiodarone or the hypertension drugs called calcium channel blockers, are taken together with a particular statin like Lipitor, the chemical that breaks down both drugs is the same, so the statin will not be broken down as quickly and will increase in the blood. This may cause muscle soreness.

PHI: *Are there other medications to watch out for?*

EB: Some medication interactions are stronger than others. One particularly powerful interaction is with anti-fungal drugs called azoles. Using them while using statins can increase the amount of statin in the blood significantly and increase the probability of muscle problems.

PHI: *Can you summarize the essence of what you just described?*

EB: Sure, since there are several different statins that use different liver decomposition chemicals, patients should use a statin that is processed by a chemical that is not being used by another medication they are taking.

PHI: *It seems a lot can be done to lessen the likelihood of problems with statins. Is there anything else we should know?*

EB: One principle is that low doses of statins rarely cause problems and that muscle problems increase as the dose of statin increases. So it is prudent to make diet and lifestyle changes and use low doses of statin rather than continue to eat lots of cholesterol-generating fatty foods and rely on a big dose of a statin to reach your cholesterol target.

(1) Lipitor, Zocor, Crestor and Mevacor are the trade names of statin drugs produced by Pfizer, Merck & Co. and AstraZeneca.

Get Well Message

We are sorry to report that two of our members, Don Lekivetz and Ross Copeland have spent some time in the hospital recently. Our thoughts and prayers are with their families at this time. I am sure Grace and Verna would enjoy hearing from any of you at any time so why not give them a call.

You Are Invited

Polio Regina is inviting people who have had poliomyelitis and are now experiencing new symptoms such as fatigue, muscle weakness and cold intolerance, to join our self-help support group to learn how they can cope with post polio syndrome. Spouses and partners of polio survivors are also welcome. Polio Regina Inc. was formed to help people from southern Saskatchewan.

Our Objectives:

- To develop, promote and increase awareness of Post Polio Syndrome.
- To disseminate information concerning research and treatment pertaining to Post Polio Syndrome.
- To provide support to survivors of polio, other than financial aid.

Where to meet

Our Polio Regina group meets at 7:00 p.m. on the last Thursday of the month at room H203 at the Wascana Rehabilitation Centre 2180-23rd. Ave., Regina, SK.

Enter the main doors of the Wascana Rehabilitation Centre and turn left and take the elevator that is across from



the information desk. Push button “2” (not 2R) on the elevator. When you leave the elevator turn left and go past the information desk, through a recreation area, past the pool table to room H203 which is the first meeting room. Our group should be in there. There are no meetings in June, July, August or November. We usually have our Spring Picnic in May at a private residence and our Christmas Party in December at a restaurant.

Web Site:

Check out our website for more information on Polio Regina and links to other useful related information at:

<http://nonprofits.accesscomm.ca/polio/>

or you can just Google **Polio Regina**.

Our email address is: polio@accesscomm.ca

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.)

Spring Picnic 2010

Our annual spring picnic was enjoyed by everyone with lots of great food and conversation. Due to the rain it was held inside but there was plenty of room and everyone was comfortable. Thank you to Mavis and Adam for hosting us in your lovely home and thank you to Carole and Wilf for getting the food and setting everything up.

