

Thank you for the letters and memberships we received lately -.

- **Mark & Joyce Burrell** (Swift Current) sent in their membership and told us that they have both had health problems but are recovering and hoping for a better year ahead.

- **Clarence Biberdorf, Ed Schindler and Doc Bornholdt** have been in hospital but are now recovering at home.

- **Elaine Schrader** of Weyburn called us for information on PPS. She sent in a family membership and commented:

“I am astounded at how the effects of PPS mirrors our health condition”.

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.)



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Spring 2006

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Message from Carole Einfeld

President, Polio Regina Inc.



I must start off with an apology to all of our members who receive this newsletter:

I have been president of Polio Regina Inc. for two years and as of now, have not

had a report in before the deadline to our favorite editor-in-chief, Fred Ramsay and his superb co-pilot and beautiful assistant, Blenda. She is also his wife. Fred, Blenda and Polio Regina members, I am so sorry...I have no excuses. It is total procrastination on my part—and I'm working on it!

Yes, my life is very busy, having between three and six Asian students living with me at all times; but that is still no excuse! Everyone has busy lives!

It has been truly an honour to be the President of one of the best support groups across Canada and for that, I thank each and every one of you for participating in our group! Without you, there is no group, and that's a reality.

Together, we can accomplish so much more by helping each other and also those members who are unable to attend our monthly meetings.

Thank you to members of the Executive who volunteer many hours of their time to help make our organization run smoothly. A big "Thank You" to our Treasurer, Verna Copeland (and husband Ross) for keeping our finances in order as well as for the many hours spent organizing our social events like our

One of our Polio Regina members, Georgina Heselton has been very busy with **DisAbled Women's Network (DAWN)** and with human rights and equality issues in general. In June 2005 she received the Saskatchewan Centennial Leadership Award from her peers in DAWN. She is the Provincial Chairperson of DAWN. In October, Deb Higgins, Minister of Labour and Minister Responsible for the Status of Women nominated Georgina for the Saskatchewan Centennial Medal that was presented to her by the Lieutenant Governor, Lynda Haverstock. She also received the Citation Rose from lite92fm Radio and Unique Florists for her volunteer work. She tells us there is still so much to do in advancing human rights and equality, so whenever she is asked to speak on those issues, she gladly accepts. We might add that she is involved in many international projects in Nicaragua and visited there last May/June. Georgina is married to Allan and they have two sons. **Congratulations Georgina** from your friends in Polio Regina and may your good works continue!

(Editors note: Blenda met Georgina in 1953 when they were polio patients at the Regina General Hospital (B Flat) and have remained good friends ever since).

“Maintaining an Independent and Healthy Lifestyle”

is the theme of the BC Symposium to be held in Richmond March 30-April 2, 2006. It will be presented by the Post Polio Awareness and Support Society of British Columbia. There will be several workshops to choose from and special speakers include **Dr. Rubin Feldman**, physiatrist, retired Director of the Post-Polio Clinic at the University of Alberta; **Dr. Marcia Falconer** PhD – Virologist from Ottawa and **Ken Craig**, PhD, Department of Psychology, UBC. Congratulations to the organizers of this big undertaking and we wish them all the best! We are happy that two of our members, Carole Einfeld and Wilf Tiefenbach will be attending and look forward to their report when they return.

In the Fall 2005 edition of Regina Qu'Appelle Health News we see a picture of Dr. Adam Gruszczynski, (member of Polio Regina) Family Physician offering guidance to second year resident, Dr. Budimka Oroz as she examines a patient. The Regina Qu'Appelle health region is in partnership with the University of Saskatchewan to train medical residents.

As members of Polio Regina Inc., we want you to tell us the kind of information you need to know and we will research the information and send it on to you.

We have very accessible web sites to access for polio information. Please feel free to contact these web sites.

Polio Regina: <http://nonprofits.accesscomm.ca/polio/index.htm>)

Polio Canada: www.poliocanada.com)

There is a lot of good information out there for us to use. Let us use it!!

Our Archivist and Librarian, Mavis Matheson, has done a superb job, also, obtaining excellent information and also attending previous conferences for her own benefit, which, in turn benefits us all. Thank you, Mavis.

Our Vice president, Wilf Tiefenbach, and I are gearing up for a great Polio Conference in Richmond, B.C. on March 30th—April 4th. We will have a report on that conference next newsletter! Promise!

I can smell those flowers in Vancouver already!! Take care and have your naps if you need them!!

Warm regards, Carole Einfeld, President, Polio Regina Inc.

“Our Own Woman in Motion”



Ruth Adelia accepts achievement award from President Carole Einfeld

In her own quiet way, Ruth Adelia most certainly deserves our profound thanks for the leadership skills she provided to Polio Regina Inc. in which she served for several years as our Secretary. At our Christmas gathering, Ruth was awarded a life membership in Regina Polio Inc.

Her long confinement in a wheel-chair hasn't dissuaded her passion for travel and physical activity. She has traveled to Alaska, Europe, British Isles, Israel, Tokyo, Hong Kong, Taiwan, Manila, Athens, Portugal, Spain, Hawaii, USA and Canada.

We do ourselves no favors when asked, “Can you get up a flight of stairs?” In just saying “Yes” without adding, “but I go up one step at a time pulling myself up each stair with my arms, and for the last year or so have had to stop halfway and rest, but five years ago I was able to walk up and down normally and carry items.”

Polio survivors are notorious for being strong willed, determined and not requiring help to do even quite heavy tasks. Unfortunately we are also highly skilled in not “seeing? OR wanting to “see” that we now need some help, human and/or aids and assistive devices. We expected that we might have to change the way we lived our lives when we got old – about 90 – but not in our 40’s, 50’s and 60’s.

Polio survivors have a variety of muscle weaknesses in a variety of areas. There is no set pattern – a nightmare for health professionals. We will demonstrate a few of the changes that we have noticed in how we go about our lives. If the way you do an action of daily living has changed in the last few years then there has to be a reason or a number of reasons for this.

We know that making notes is a good idea so we don’t forget anything, but arriving with pages of them and articles off the internet is more likely to set up a barrier than be helpful.

Appointment times are limited – there will probably not be time to discuss more than a couple of issues. To help you remember dates and medical facts it is an excellent idea to make up a large file on yourself containing anything you consider relevant, including newspaper items, certificates, a couple of photographs, covering:

1. Medical History
2. Work History
3. Physical Ability before current problems (include sports, exercise, hobbies, crafts, housework, etc.)
4. Problems with diagnosis, assessment, treatment, employer’s understanding of your new problem, welfare applications, etc.
5. Current problems.

Good Home Safety Advice

It seems that a polio survivor’s worst fear is falling and sustaining physical injury. It happens so quickly and always without warning.

At our October monthly meeting Debora Peterson, a member of the Canadian Red Cross, spoke to our members about the dangers of falling and offered numerous safety practices to prevent falls.

Just being aware of the danger was paramount on her prevention list of frequent common targets. She listed six potential “tripper-uppers” at the entrance of your home; six others in the bathroom; five in the bedroom and four more in living room; eight in the halls and stairways and at least four in the kitchen.

In her presentation Debora proposed a comprehensive check-list for fall-proofing a residence using basic corrective actions such as replacing burned-out light bulbs keeping hand-rails sturdy and clearing a sidewalk when required. For more information contact the Canadian Red Cross or the Saskatchewan Safety Council @ (306) 721-1600.



At our last meeting in November, we talked about medications and what to do when visiting your doctor. Here are some of the suggestions we discussed:

1. Make a list of your medications and carry it with you.
 - Get a list from your pharmacist. (It’s best to use only one pharmacy.)
 - Ask your doctor for a list of your medications.
 - List your meds on your computer and print off copies.
 - Write your meds out on a recipe card.
 - Put your allergies in **red**.
 - Include everything you are taking (prescription, over the counter, herbals and vitamins).
 - Include the names of all your doctors.
 - Put in a two or three word note of what each medication is for.
2. If you have any serious health problems get and wear a [medical alert bracelet](#), watch or necklace.

Christmas banquet. Thank you to Wilf Tiefenbach, Vice President and Liaison to Polio Canada; thank you to Nora Schlosser, our capable Secretary; and to Pat Allonby and her Phoning Committee of Carol Biberdorf, Grace Lekivetz and Isabelle Hitchie for keeping our members informed about all our meetings and social events. Congratulations for jobs well done!

One of our members, Zenny Burton, suggested at a meeting, that we should have an open forum near the end of each meeting. Her plan worked out very well, with all members having an input into the subject of that particular evening. It had been something I thought would have been a good idea years ago, (but I was too timid to say anything, because after all, we *ARE* a support group) but Zenny had the fortitude to bring it up at a meeting and it has been well received! Well done, Zenny!

Polio Regina's 'March Awareness' goes on every month of the year! Thanks to our own Murray "Corner Gas" Grant, who diligently worked with the Leader Post and the weekly, Community Sun, our advertisement for Polio Regina is located in some part of the paper so very often! This is all done FREE of charge! How great is that?? Kudos to Murray! You are so appreciated...

Blenda & Fred receive many calls from these newspapers ads and they both deserve much credit for answering their phone, talking with the person interested in the ad, and putting together an information package to send on to the person.

That is a huge responsibility and for that we are ever so grateful. They also spend hours of their time and patience putting together this newsletter, which is not an easy job when people don't submit any articles.

In the future let's make their job a little easier by brain storming and getting something off to our editors!! They are doing their best and we can help!

It's a natural for Fred; he's a professional writer; Blenda is a highly skilled secretary and Murray Grant is an accredited Canadian publicist. The fourth, and most essential ingredient in this boiling soup is you, Dear Reader- so jump in with your with comments and suggestions. (First take your boots off, Eh!!)

Fred and Blenda's new book entitled "Hit the Road Again, Fred" has been launched



Wow ! What an emotional rush! Signing "author" autographs; receiving congratulations from friends and total strangers and hearing praise about a job well done –are salient extra thrills of being the authors of a book.

Hosting an "author book signing" is definitely the "pan-ultimate of self-emulation !"

I think most of our members know that some of the proceeds garnered from the sales of the book will be donated to Polio Regina Inc. For more information on the book call Blenda or Fred (306) 543-6380.

Lifeline – Personal Response and Support Services. Who needs Lifeline? Lifeline is for you if you can answer "yes" to any of the following: You are home alone on a frequent basis; you are at risk for falls; you use adaptive devices to assist you with walking; you are managing a medical condition. Lifeline makes it safe to be home alone. For about \$1 a day, you can have a direct line to a safe, independent life. For more information get in touch with Terri Berglund, Program Manager, Lifeline Regina Qu'Appelle, 112-2001 Cornwall Street, Regina, S4P 3X9 or call 1-(306) 751-2561.

A Handy Little Invention

We receive newsletters from the Saskatchewan Parkinson's Disease Foundation and in their recent Newsletter featured an article on a little tool called "Handybar". I was interested because I have trouble getting in and out of a vehicle and I thought our members might want to check out at www.handybar.com/index.html



Insert the Handybar® into the U-shaped striker plate located on the driver and passenger-side door frames of the vehicle.

Ruth retired after nearly 31 years of service in the provincial government. In 1968 she was involved in setting up a Wheelchair Sports Branch in Regina and became provincial president and a board member for many years. She has served as secretary/treasurer for Polio Regina. Best of all she was an active participant in the sports events and particularly loved target practice with her .22-calibre rifle (with real bullets). Now the members use pellet guns.

For many years, she served on the executive of the **Voice of the Handicapped** and in 1978, her group initiated a housing project for the physically disabled which is now known as Huston Heights. She says it's the most accessible apartment she has ever lived in. She served on the board for five years and is active on the tenants committee.

She has also been involved in **DAWN** (DisAbled Women's Network) Saskatchewan; Disabled Transportation Committee; the Canadian Paraplegic Association and the Canadian Diabetes Association.

Who exactly is Ruth Adelia? She was born and raised in the Climax district of southwest Saskatchewan where her parents farmed. The family consisted of seven children, six girls and one boy. Her dad died in 1946 and her mother continued to farm and raised her family.

In July, 1952 Ruth was afflicted with polio and for the next five years she resided at the Red Cross Wing of the Regina General Hospital. There she underwent therapy for her legs and arms; and while recuperating, she obtained a high-school education.

Because there were no suitable "accessible" business colleges in Regina, Ruth moved to Saskatoon to take a secretarial course. When she graduated, she was terrified at the prospect of not getting a job, but a few days following graduation, she was called to work by the Provincial Municipal Affairs Department in Regina. She worked for the government until her retirement.

Polio Regina members proudly salute Ruth for her excellent service to the people of Saskatchewan. *(excerpts have been taken from an earlier edition of Post Box).*

We can be better prepared if we write notes on what we want to discuss at the appointment. We can look at the file and take out the relevant information. Now look at your notes again as if you were the health professional at the appointment. If you were doing the report at the end of the appointment, what facts would you write down.

Health professionals have a variety of ways of running their appointments and we cannot dictate how the appointment will go. We can, however, set the scene with a "Good morning, Dr. X, thank you for seeing me about my" "I have made a few notes so that I don't forget anything and thought you might like a copy for your records."

Remember the health professional is seeing you as you are now, they do not know what you were capable of five, ten, twenty or more years ago. They may think Polio and go back to the short lecture they were given at College and assume you have been as you are now since your polio.

What is important is the change in how you do actions of daily living. Why have you changed the way you do this action? (Unquote)

They suggest that you write your own report or write up information on a separate sheet of paper making short notes. Try to show a series of changes for some actions and then grade them, starting with the action that shows the highest level of change. The two or three actions that show the biggest change are the ones to demonstrate. It is also a good idea to list the names of the drugs you are taking, the strength and the amount you take each day.

BANGLADESH

Polio vaccinations to be resumed - Bangladesh will vaccinate nearly 18 million children against polio beginning next month, health officials said, after recently detecting the first case of the disease in nearly six years. Children under five years old will be vaccinated during three nationwide immunization days.

3. Keep healthy with a good diet.
4. Sort your pills for each day into a pill sorter or separate containers.
 - Old photo film canisters work well.
 - There are various pill sorter systems at pharmacies.
5. For travel
 - Carry a small day pack or a back pack (some come with wheels).
 - Always carry your medication list.
 - Keep your medications with you.
 - Carry prescriptions and other medications in their original bottles.
 - Sort them into daily system when you reach your destination.
6. Put a dot of bright nail polish on the two spots on medication bottles for easy alignment for opening.

Here is something else to know when purchasing drugs. Each time you receive a prescription there are dispensing fees added to the total. You can call your pharmacy and ask what they charge for dispensing fees. Here are some of the places in Regina we have checked and found out the following: Super Store, London Drugs, Easy Foods, Costco and Wal-Mart charge \$4.98; Zellers and The Bay charge \$4.99; Safeways charge \$6.99 while Shoppers Drugs and Sherwood Food Store charge \$8.21. The lowest we found was Sobeys (north end) and they charge \$3.48. Most of these outlets have free delivery.

News from Post-Polio Health International's St. Louis.

The following information was presented at the Ninth International Conference on Post -Polio Health and Ventilator-Assisted Living, June 2-5, 2005 in St. Louis. We thank Florida East Coast Post-Polio Support Group for the following article printed in the January/February issue of their Newsletter.

“How Self Assessment Can Help You Obtain Better Care from Health Professionals”.

Mary Kinane, BA, PGCE, Chair; Hilary Hallam, FIST, Founder, Secretary and Newsletter Editor; Denise Carlyle, BA, MA, PhD, LRAM, Treasurer, Lincolnshire Post-Polio Network, U.K.

“The most reported problem to our Network, not only from the U.K., but from around the world, is that the assessment that has taken place did not find evidence of the symptoms / level of symptoms being reported.

Polio Survivors often spend months, sometimes years, putting off going to a doctor to find out why they are experiencing pain, fatigue and functional decline. To then be told that there is nothing or little wrong with them causes considerable stress. Each negative appointment causes frustration, anger and more stress that makes our medical condition worse.

Again and again, through lack of knowledge about polio, they tell us that they had what must have been a mild case of polio because they recovered so well and managed so much in their lives. Regardless of level of recovery they are so proud of their achievements. Then comes the but... But, after a fall, an operation, an accident, a period of huge stress, something changed because from then on the harder they pushed the worse they got. If their lives are changing so much why are they having such a hard time getting medical help?

So why is this happening? We have highlighted eight possible reasons that we believe should be taken into consideration.

1. Not enough facts about Polio and its late effects are being taught in Medical Schools.
2. Interpretation of facts in medical articles.
3. Diagnoses were made using test results, physical examination and clinical observation of the weakest part of the body.
4. The extent of recovery from Polio is often not realized.
5. There are no tests for PPS. It is a diagnosis of exclusion.
6. The way we present our symptoms.
7. The way questions are asked, and the way we answer.
8. Manual Muscle Testing – validity and reliability.



We will then show how self assessment can provide us with more information so that we can answer questions more accurately and ensure that the picture in the health professionals mind matches ours.