

**Accessible Taxicab Review**

Regina City Council is asking for input from the Advisory Committee on Access as it reviews accessible taxicab service in Regina and to determine particularly if customers are able to get service when needed

To share your experiences related to accessible taxicabs, please contact Janice Solomon at the City of Regina: Fax: 777-7549 Mailing Address: City of Regina, Community Services Department, Box 1790 Regina SK S4P 3C8. E Mail: jsolomon@cityregina.com

**You can also call Mavis Matheson at 586-5094.** She represents Polio Regina on the Access committee. Your comments would be appreciated by as soon as possible. Please call 777-7549 for more information. Do your stuff today.

In case you are wondering what happening to information about Birthday and Anniversary dates it’s because Blenda has misplaced her calendar book so all that information is gone. Sorry!

Bouquets go to our faithful telephone callers, Grace Lekivetz, Jim Hipfner, and Carol Biberdorf for another year of keeping our members informed about events and meetings in our organization. You do a great job! Thank you.

**Carole Einfeld, Pat Birchall and Blenda Ramsay** spent a busy morning with Jayne Whyte talking about issues concerning disabled women. Jayne was asked by the Women’s Secretariat to talk to a number of Saskatchewan women about issues that concern them and their information needs. We hope that our input will help increase understanding of women with disabilities.

We are happy to report that **Clarence and Carol Biberdorf** have moved and are getting settled in their new home at #101 - 1130 Radway St. Clarence and Carol, let us know when your house warming party is happening and we’ll all come!

**Swimming:** Some of our group have been enjoying the Wascana Rehab pool every Saturday afternoon. We would like to have more people join us so if this is something you would be interested in, please come on Saturday afternoons between 2-4 pm and check it out. The City of Regina is offering a summer session in July and August if we have enough people interested. It only costs \$10 per session. See Murray Grant’s center-page color story in this issue.

**Next Meeting** will be on April 25th and we hope to have a Pharmacist as our guest speaker.



March 2002

Editors: Blenda &  
Fred Ramsay  
Phone: 543-6380

Polio Regina Incorporated 825 McDonald Street, Regina, Sask. S4N 2X5

**Editors’ Comments:**

There’s lots of good stuff in this post box and it’s always a pleasure for Blenda and I to write it. First of all we have house-keeping duties to report on.

We have a full slate of members nominated for the executive and we need your approval. A ballot form will be circulated at the meeting today.

Read the report on the presentation by Donna Dobrowolsky, our member from Craik on an upcoming event in Saskatoon and a province-wide celebration in 2005 that will recognize the Polio epidemic as a very significant influence in Saskatchewan.

With this post box we are also separately circulating an excellent feature story “Polio Still Stalks”. Get an extra copy for your doctor.

Thanks to Murray Grant for his feature story and pictures about swimming.

Thanks to those who bought my book “Hit the Road, Fred !”  
(Note: When my stock runs out, there ain’t no more !)

**Don Volpel Becomes Life Member**

As it is with all Polio Survivors, Don Volpel of Regina has not allowed Polio to rule his life and succeeded where many co-workers have failed.

Don had polio in June 1952.

museum, Janet would be most interested.

The story is the title for four exhibits planned by the Saskatchewan Western Development Museum in celebration of our province’s centennial. New permanent exhibits will be created at Moose Jaw, North Battleford, Saskatoon and Yorkton.

Celebration is an important ingredient in the vision of these exhibits. The exhibits will present provincial milestones, benchmarks and achievements to celebrate the indomitable spirit of Saskatchewan’s people. They will highlight events, accomplishments and individuals significant to the history of our province in a unique and captivating context. They will engage, entertain and educate Museum visitors, fostering pride in Saskatchewan, its people and their dreams.

The story will present 100 years of history through authentic voices of prairie people and through authentic artifacts collected over the past 50 years. A museum is distinguished from other places of learning by its use of three-dimensional objects, the “real things,” to tell stories and to illustrate history.

**Saskatchewan cares for its own The health care story**

Saskatchewan has a long tradition of caring for the sick and less fortunate. The hardships faced by its people during the early years of the 20th century—isolation, disease, epidemics and lack of access to medical care spurred many compassionate individuals to action.

From the farm women’s leaders who campaigned for improvement in rural housing and health, to the Saskatchewan Anti-Tuberculosis Commission who pioneered the testing of school children for the disease, to the provision of free treatment for cancer patients, to the implementation of Medicare, Saskatchewan has become a leader on the world stage in providing quality treatment at no charge to all residents. In the 21st century, amid declining rural population and skyrocketing health care costs, health care concerns remain a top priority for Saskatchewan people.

**The health story includes:**

1. The roots of free medical care for Saskatchewan people leading toward what we now know as Medicare, a first in North America; although there are few artifacts that relate to this story we propose to collect other available resources.
2. The air ambulance story, another North American first; collection contains two air ambulances; Investigations are to make CF-SAM and CF-KIY in the aviation gallery viewable from within the 2005 exhibit where the air ambulance story will be told; film footage of CF-SAM is available.
3. The fight against tuberculosis; Saskatchewan’s leading role in the survey, treatment and prevention of tuberculosis led by the Saskatchewan Anti-Tuberculosis League. We hope to

**Elections-**

As chairman of the nominating committee, I move the acceptance of this report on behalf of the members of the committee: Carol Biberdorf, Jim Hipfner, and Norm Beliveau. At this time you may nominate any member in good standing to serve on the executive providing you first obtain the consent of the person you wish to nominate.  
*Fred Ramsay*

**Proposed candidates for Polio Regina Inc. executive.**

- President - Norm Beliveau
- Vice-President - Evelyn St.Denis
- Secretary - Don Volpel
- Treasurer and Social Convenor - Verna Copeland and Inge MacPherson (Convenor)
- Program Co-ordinator - Carole Einfeld
- Telephone Co-ordinator - Blenda Ramsay
- Post Box Editor - Fred Ramsay

We particularly thank Dr. Mavis Matheson for her guidance since the inception of Polio Regina Inc and her decision to continue being our source of technical information. Mavis has also agreed to represent us at the City of Regina Access Committee.

Thank you to George Simpson for his service as Vice-president and thanks to all of you for your support of your executive.

**Tips And Techniques For Treating PPS**

Dr. Richard L. Bruno  
International Centre for Post-Polio Education and Research  
Englewood Hospital and Medical Center, Englewood, New Jersey U.S.A. 07631  
Phone: 201 - 894-3724 Toll Free: 1-877-POST-POLIO  
PPSENG@AOL.COM

“I am angry and desperate again this year” writes a reader. “My company has changed HMOs again. I am trying to find a doctor who treats PPS. And again the

## Presentation by Donna Dobrowolsky, Craik

At our last meeting, president Norm Beliveau introduced our guest speaker Donna Dobrowolsky from Craik. Donna is a member of both Polio Regina Inc. and Saskatchewan Awareness of Post Polio. She gave us information about SAPP's annual meeting at the Abilities Council, 1410 Kilburn Ave., Saskatoon on April 19 & 20th, 2002 and invited us to attend and hear their guest speaker, Karen Kennedy of West Park Polio Clinic in Toronto. Cost for the day is \$10.00, which includes lunch.



Karen Kennedy has prepared a presentation/workshop that will cover emotional wellness. The first session will deal with *Setting the Stage for Wellness* followed by *Permission Giving*. The workshops will be interactive and she will have information handouts. She will also be available Friday evening to discuss local support groups.

### Who is Karen Kennedy?

Karen is a registered medical social worker who for the past nine years, has worked in the Post-Polio Clinic at West Park Healthcare Centre in Toronto, Ontario. West Park Healthcare Centre is a regional rehabilitation center and offers rehabilitation, complex continuing care and long-term care services. The Centre's Post-Polio Clinic provides comprehensive, trans-disciplinary team evaluation for approximately 300 clients per year. As a member of the Post-Polio Clinic team, Karen provides assessment, counselling, education, management recommendations and referral for individuals and families of those who have previously contracted poliomyelitis. Karen holds a Masters of Social Work degree from the University of Toronto.

Karen also enjoys the opportunity to interact with individuals in groups, encouraging people of all ages along in their journey of adjustment to Polio and its "recent" or "late effects". Karen has published various articles on topics such as family adjustment, new polio related challenges, the impact of earlier polio memories on present coping etc.

Karen will offer two workshops that will focus on constructive approaches for individuals, family members and friends, to help promote emotional wellness, health and balance individually and in relationships that have been impacted by the late effects of polio.

Many individuals have acted upon healthy choices in their ongoing adjustment to living with effects of new or chronic pain, weakness and fatigue. At the same time, there are often opportunities to make a "good thing better". For others there may be personal or relational signals that indicate the need for ongoing, purposeful adjustment and change.

can no longer work. The EU ministers have agreed to place these items on their November 2002, meeting agenda.

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" and September 2002, "Polio Survivors Month." You can help by writing to your President or Prime Minister, your Governor and to your state/provincial and federal legislators (see below).

Please join us and help make 2002 "The Year of the Polio Survivor" and make the IPTF motto a reality: "Every child vaccinated. Every survivor - and doctor — educated."

Here is a sample letter:

Dear Polio Survivors and Other Friends:

Polio survivors are no longer poster children. We are accomplished adults who are being disabled by the unexpected symptoms of Post-Polio Sequelae overwhelming fatigue, muscle weakness, muscle and joint pain, sleep disorders, heightened sensitivity to anaesthesia, cold and pain, and difficulty swallowing and breathing — that occur about 35 years after the poliovirus attack.

There are 20 million polio survivors throughout the world, nearly 2 million in North America and over 3 million in Europe. About 70% who had paralytic polio and 40% who had "non-paralytic" polio are experiencing Post Polio Syndrome (PPS). Yet many polio survivors and most doctors do not know PPS exist, let alone know how to treat them and deal with polio survivors' special medical needs.

Would you please ask your post-polio support group newsletters and local newspapers to print the post-polio letter beginning in March 2002, and the post-polio letter public service announcement (PSA) in the following months. The text of the post-polio letter follows. Please set your browser to: <http://www.postpolioinfo.com> and click on Post-Polio Letter for a print-ready version with photographs.

“I remember waking up one morning and I couldn’t talk, swallow or move. My mom and dad took me to our family doctor and within 15 minutes of observing me, they had me in the isolation ward at the Regina General Hospital” Don recalls. His speech and swallowing continued to deteriorate, as did his mobility. He remained for three weeks in isolation then transferred to the Red Cross wing for a couple of months.



*Don Volpel holding  
Granddaughter Abbey Roach*

“I went from wheelchair to braces and crutches and finally to no support at all” he recalls. Then he spent five years in speech therapy at the Wascana Rehab Centre.

Don chuckles as he recalls that his faithful farm dog went daily to the grid road to wait for him to return. It was a long four months after his Polio attack before Don was able to go home.

Don was able to complete one year of university education then worked for 32 years with the federal government. He retired (1995) as Chief of Purchasing for Supply and Services for all Saskatchewan. His last assignment was the modification of the retail concession area at the Regina airport.

“I am now busy working at Chalet Manufacturing, a firm which manufactures commercial and residential kitchen cabinets”.

Don and Marian will be celebrating their 37th year of marriage. They have four children (Janet, Douglas, Susan and Catherine) and four grandchildren. They also have two dogs and three cats.

Polio Regina members congratulate you Don and Marian.

assemble a portable x-ray unit used in testing for TB.

4. Development of Cobalt-60 treatment for cancer; a Saskatoon team led by Dr. H. Johns pioneered the development of what is commonly known as the cobalt bomb, a radiation therapy for treating cancerous tumours

5. The polio epidemic in Saskatchewan; the impact of the disease on otherwise healthy people, especially children; Saskatchewan’s contributions were the early provision of free health care for victims and families, the ground-breaking Sabin oral polio vaccine trial in Prince Albert in 1961 and the unique province-wide vaccination program of 1962-63.

The major artifacts for this module, an Emerson iron lung, is a symbol of the devastation caused by this disease; at the same time it represents the hope for treatment.

A research paper on polio in Saskatchewan will illustrate this topic with audio clips from polio survivors describing living in an iron lung and polio treatment in Saskatchewan. We are also looking for donations of related artifacts such as crutches, braces or boots for our collection and exhibition, as well as photographs, documents, and other support material that will help people today imagine how polio affected our people.

The World Health Organization estimates that there may be as many as 50,000 post-polio syndrome sufferers in Canada. The number is undoubtedly larger than that. (After 1957, the Department of Health collected statistics only of those paralysed by polio. It is now becoming clear that many people who were infected by the poliovirus, but did not suffer paralysis, are becoming affected by PPS.)

The Western Development Museum polio exhibit of 2005 will be very timely as a new public awareness of polio and the devastation of its long-lasting effects.

### **News About This and That:**

Thank you for sending in your memberships and for the donations we have received. Remember that memberships help cover the cost of postage and issuing the Post Box and other information for prospective members. By the way if you know of anyone who had Polio and is not a member give us their name(s) and we will call and invite them to join or send them information.

New Parking information: The City of Regina will issue a disabled driver with a parking permit for \$5 per month per vehicle that allows parking at any meter for up to three hours. The advantage to you is that you don’t have to plug a meter and if you shop downtown on a regular basis, this is a gold mine for you.

For full details contact the City of Regina Municipal Engineering Department at (306) 777-7241.



doctors I find don't know how to treat PPS, know nothing about PPS or say they don't believe in it. When is someone going to educate doctors that PPS is real?"

Bruno: We have been trying to educate doctors for 20 years! There have been articles in all the major medical journals—including the Journal of the American Medical Association and New England Journal of Medicine—which leave no doubt that PPS are real. There is no excuse for doctors not to know about PPS. There is certainly no excuse for them to say they “don't believe” in PPS, as if it were a matter of religious faith.

But much is being done to educate doctors and polio survivors this year, since 2002 is the 50th anniversary of America's most devastating polio epidemic that affected 58,000 people in 1952. The International Post-Polio Task Force (IPTF) is working on many fronts:

- In 2002, the US Social Security Commissioner has agreed to expand the regulation — the POMS for “The Late Effects of Poliomyelitis” —that allows polio survivors to get SSDI; to educate local SSA adjudicators nationwide about the POMS and PPS; and to write a Ruling for Administrative Law Judges to stop inappropriate denials of benefits, thanks to the efforts of NJ Congressman Steve Rothman.
- In 2002, UNICEF will partner with the International Post-Polio Task Force and provide information about PPS as part of its polio eradication education program. In March 2002, polio survivors Mia Farrow and her 13 year old son Thaddeus will co-chair the post-polio letter Campaign the post-polio letter is a one page summary about the cause and treatment of PPS that is appearing in magazines, newspapers and on websites throughout the world. You can help by asking your post-polio support group newsletter and local newspaper to print the post-polio letter and the Public Service Announcement.
- In April 2002, Scripps Howard will begin filming the first documentary on PPS which will air on US television in the Fall.
- In September 2002, the IPTF will present the first David Bodian Memorial Awards to the “Unsung Heroes” of PPS throughout the world.
- In November 2001, the IPTF requested that European Health Ministers discuss their governments' providing information about PPS to health professionals and polio survivors, their national health services providing treatment for polio survivors to prevent them from becoming disabled, and providing disability benefits to polio survivors who

“Your power lies in the choices you make every day, on your own behalf. If you react out of habit or fixed attitudes, you may not be using your choices wisely to create wellness in your life. To create wellness, you must expand your focus beyond mere physical health.”

*(American Holistic Health Association 1997).*

### **Permission giving & nurturing emotional wellness**

This workshop addresses the healing influence that personal, emotional permission giving can have in lives and family relationships touched by polio. Personal permission-giving means allowing one to acknowledge reality, to accept one's needs, and to take the steps to initiate purposeful change. It is key to making changes related to the late effects of polio or any chronic health condition.

Permission-giving requires self-awareness and encourages people to think about new ways they can take responsibility for their health and the quality of their lives. It offers a compassionate frame for making decisions to accommodate new weakness, pain, fatigue and or breathing problems.

The workshop content will move from personal permission giving to constructive approaches for individuals, family members and friends to help promote emotional wellness, intimacy, and balance in relationships.

### **Setting the stage for wellness**

This creative session will involve presentation mixed with discussion, music and visual arts. Karen will share ideas for creating “mini wellness retreats” in one's daily routine and lifestyle. Participants will be encouraged to develop a realistic plan to further personal wellness. Participants will also be welcome to share insights and strategies that they have gathered over the years.

Everyone is invited to attend. Contact Blenda for registration forms that must be sent in by the middle of April.

### **“Winning the Prairie Gamble” The Saskatchewan Story 1905-2005**

The second topic Donna Dobrowolsky touched on was information on a major project being planned for Saskatchewan's 100th anniversary in 2005. The project is called “Winning the Prairie Gamble: The Saskatchewan Story 1905-2005. The museums are searching for artefacts such as crutches, artificial limbs, Emerson iron lung etc. or any symbols of the devastation caused by polio. Janet Mackenzie, Project Manager, Western Development Museum, Saskatoon is looking for anything that would tell the polio story.

No doubt we'll be hearing lots more about this project in the future. In the mean time, if you have any iron lung experiences, Sister Kenny treatments, or any articles to put in the

