

onslaught by the poliovirus, but to also recover and function again.

Finally, we need to ask what it was about having polio that caused polio survivors to push themselves “beyond the competence of their damaged bodies,” and how that pushing caused them to develop new symptoms.

*Editors Note: Polio Regina Inc. purchased four copies of “The Polio Paradox” for circulation to our members. Rather than wait for a copy to become available, it would be worthwhile to purchase your own copy. The book sells for \$36.95 (Cdn) plus taxes and we bought ours at Chapters.*

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## 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.)



April 2003

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## Polio Awareness Month A Huge Success

The month of March was designated as “Polio Awareness Month” throughout Canada and our members of Polio Regina Inc. swung into action on several fronts. We are grateful for the involvement by our members.

We are overjoyed that our publicity efforts were rewarded by an influx of nine new members and requests for PPS information from 27 people from various areas of Saskatchewan. We sent out news releases to the major news media and to 35 weekly newspapers in south Saskatchewan. Our efforts were rewarded with prominent articles in the newspapers and two television interviews.

*Viewing our Polio Awareness display is polio member Grace Lekivetz discussing the contents of our display with a tour guide at the Saskatchewan Science Centre.*



Remember: *Taking fewer medications is better.*

It is no solution to use drugs and continue to abuse your joints, overuse your muscles. It is your responsibility to be informed about your medications so that you can monitor the side effects.

When certain drugs are taken for a long time you can develop a tolerance so that larger and larger doses are needed.

Physical dependency, addiction can develop from taking certain drugs, especially narcotic analgesics.

## Twenty Million More

*An excerpt from "The Polio Paradox" Richard L. Bruno, H.D., Ph.D.*

The story of polio and the facts about the cause, treatment, and management of Post Polio Syndrome need to reach every polio survivor and every doctor, because twenty million polio survivors across the globe need their new symptoms to be believed and need help in treating them.

But there are thirty million more individuals throughout the world who have disabling conditions and can also benefit from polio survivors' painful experiences and our new knowledge about the late effects of polio.

There are clear parallels dating from as far back as 1935 between polio and what in the 1980s came to be called chronic fatigue' syndrome (CFS). These parallels can help us understand, treat, and manage CFS as well as fibromyalgia—both conditions affecting millions of people worldwide in which doctors also choose not to believe.

Twenty million more individuals with a variety of disabilities—cerebral palsy, spina bifida, Guillain-Barre syndrome, and spinal cord injury—are also experiencing fatigue, muscle weakness, and pain in mid-life, and seeing their abilities ebb away. They too have much to learn from polio survivors' experiences.

So come and meet some of the world's twenty million polio survivors, listen to their stories, and learn the important lessons they are eager to teach.

Whether you had polio, have chronic fatigue syndrome, fibromyalgia, or are suffering the slings and arrows of aging with any disability, the lessons polio

Furthermore, because of local privacy laws, none of the groups will be able to submit their membership lists without approval from their individual members. Therefore, we encourage our members to give permission to register their name. This will be a strictly confidential list accessible only by Kim Dowds, Manager, Peer Support Services and Conductive Education or Peggy Mann, Secretary, Peer Support Services.



If your name is on the list you will receive newsletters and other information free of charge.

If you have not been contacted, call us (Blenda & Fred Ramsay) at (306) 543-6380 at Regina and we will put your name on the list. You may also write directly to Polio Canada if you would like an information package sent to your doctor. Address is: Polio Canada, National Polio Survivors Network, 10 Overlea Boulevard, Toronto, ON M4H 1A4.

**Most of the groups** across Canada have been working on the Polio Awareness month and future plans are to hold a training session in August at St. Catherines, Ont. More about that later.

In summary, the four advantages of being a member of the National are:

- Polio Survivors Registry:
- Healthcare Professionals Registry:
- Education and Information:
- Support Groups contact

convince parents to have their children immunized. A critical part of the global effort, this 'social mobilization' draws on the entire society to promote polio eradication.

In **Nigeria**, young men play soccer with their hands, propelling themselves on rough skateboards. Polio robbed them of their ability to walk forever.

**Sudan:** A child is vaccinated in the village of Agepic in Rumbek county. Vaccinators and polio surveillance teams rely on UN relief flights to access remote southern parts of this vast, sparsely populated country.

**Pakistan:** During the country's November NIDs, mothers wait their turn for their babies to be vaccinated in a village in the southern Thar Desert region.

The crippling virus has disabled nearly 20 million people living today. But the world is poised to ensure that not one more person ever suffers such a fate.

Since its creation in 1988, the Global Polio Eradication Initiative has helped cut the global toll of polio paralysis from an estimated 350,000 to fewer than 500 in 2001. Thanks to the hard work of millions of volunteers, the commitment of governments everywhere and the dedication of international partners, nearly four million people have been spared crippling lifelong disability.

Very soon we will live in a polio-free world. The Initiative demonstrates how much can be achieved when the world pulls together to help all its citizens.

This Website, featuring the work of renowned Brazilian photojournalist Sebastião Salgado, tells the epic story of how this disease is being eradicated. Take a peak! There are several dozen pages dealing with this subject. It's a very humbling experience. <http://www.endofpolio.org/countries/partone.html>

### What you should know about taking drugs

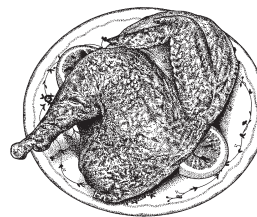
A guide for Polio survivors prepared by J.M. Walker, PhD, PT and A.M. Whelan, Pharm D Published by Ontario March of Dimes, Toronto, Ontario

### Why You Should Be Informed:

A survey in 1994 revealed that 57% of respondents, polio survivors, were over 60 years of age and 27% were over 70 years. Medications (drugs), may be by

## Upcoming Events:

**Polio Regina** continues to meet on the **last** Thursday of each month at 7:00 pm at Wascana Rehabilitation Centre, 2<sup>nd</sup> floor, Salon A & B. Guest speaker at the April meeting is Dawn Suchoboki from the Industrial Rotary Club in Regina. Next Meeting: Polio Regina will meet on Thursday, May 29.



**Our Annual Summer Picnic** will be held Sunday, June 22 at the Rotary Senior Centre 15<sup>th</sup> & McTavish St. (next to the Neil Balkwill Centre) from 1:30-5:00 pm. Would you like to have Kentucky Fried Chicken again? Whatever we have will be served about 4:00 pm and please bring a salad **OR** a dessert to share.

## For Sale

**Motorola Cell Phone** Model DPC650 - with manual, 2 batteries - 1 - Ni-Cd1 - Ni-Mh CellTek Rapid Charger/conditioner Model DP-905 with car adapter for mobile charging. Auto charging cord for use or quick charge. This unit provides excellent provincial coverage (with SaskTel)  
Complete - \$100. Phone - Ollie - 543-2752



**Also for sale:** Electric stair-climbing unit. Good condition. Call Fred, the editor for more info.

During that time I became interested in airplanes and often visited a small private airfield owned by Hank Troh. I met another fellow there (Doug Parrot), and we decided to start an agricultural spraying company spraying different types of crops in eastern Oregon and South Dakota. We owned a very old Stearman bi-wing aircraft. "Snoopy" had nothing on us!

After a few years, I decided to work at some major airlines at the Seattle-Tacoma airport. It was during that time that I moved to Bellevue, Wash., where my luck really turned for the better. I met Shirley, my dear wife.

Both of our children were born in Washington, and they each have two sons. This makes Shirley and I four-time grandparents. We are very proud of our kids.

We lived for a few years in Port Angeles Wash., and at that time in my life, I really felt badly that I hadn't finished high school, so I enrolled at the local community college, and completed the requirements for this diploma. I had a terrible time with algebra.

In 1969, my parents, who were still farming, wanted to retire so we purchased some additional farmland and Shirley, the kids and I started a 30-year farming career. We retired about seven years ago.

Looks like I've come full circle, but the best part is still to come. During my farming years, I served for years as a Rural councillor and Reeve for the R.M. of Lajord; Chairman of the Wascana Conservation and Development area authority, Director on the province-wide Conservation and Development area authority Association, School board chairman and Sask. Wheat Pool director.

Over the years we have made several trips: two to Hawaii; three to Cuba (love those Cuban people) seven weeks to seven different countries of Europe, and in 2001, we travelled to the Gold Coast of Australia. We also travel regularly to the USA to visit Shirley's relatives.

I haven't taken much time to develop hobbies but we both love music and the theatre. I may try golf this summer. Well, Fred, that's about it.

Thanks for asking. -Norman

**You Are Invited:** A special complimentary "**Sing-along**" afternoon will be held June 25 at Christ Lutheran Church featuring **B J Hughes** of Watertown, New York at the piano. BJ has been friend of the Ramsay family's for many years and will visit us on his way through to Calgary where he will be attending the 100<sup>th</sup> Anniversary of his High School.



While in Regina, BJ has offered to put on a "free" afternoon of fun, songs and maybe even have a couple jokes to make you smile.

BJ performs at dozens of "gigs" each year entertaining at seniors' centres throughout New York State and in the Ottawa area where he once resided. The party will include the "Silver Threads Seniors Group" from Christ Lutheran; Polio Regina and anyone who loves to sing the good old songs of yesteryear is welcome to join us. It will be held upstairs in the Education Centre at Christ Lutheran Church, 4825 Dewdney Ave; **2-4 pm on Wednesday, June 25**. There is plenty of parking behind the church and we do have an elevator. Refreshments will be served. Come and bring your friends.

Since then we had umpteen phone calls for information and have sent information packages to people who contacted us.

Our most successful recruiting method is for you, as a member of Polio Regina, to call someone that you know had polio and invite him or her to join our organization. Call today. You will be doing your friend a great favour.

**We thank Val Lyons and her group** (Norm Beliveau, Norm Desautels, and Inge & Lloyd MacPherson) for helping at the display at the Saskatchewan Science Centre during the month of March. It was a miserably stormy month, but attendance was very good- sort of. Special thanks to the Saskatchewan Science Centre folks for inviting us to “kick-off” the Polio Awareness activities at their facilities. Special thanks to John Snell for inviting us and arranging the displays.

### **Here’s a brief up-date on what has been happening with Polio Canada:**

Our nation-wide website: [www.poliocanada.com](http://www.poliocanada.com) is up and running and gathering new information as it becomes available.

The National Network is funded by a grant from Health Canada. The grant requires the provincial groups who are interested to sign up and show we agree to be part of the network. Nothing is changed for our Polio Regina Inc. organizational structure.

The National Polio Registry is growing by leaps and bounds. Special thanks to Dr. Mavis Matheson for phoning people to get permission to put their name on the National Polio Registry. Due to privacy laws, your name will be listed **only** with your permission and **only** a polio survivor’s name will be listed.

survivors have learned—about their bodies and their minds, about disability, society, and the way medicine is practiced—must be applied to everyone. Only then can we all survive and thrive in this new century as polio survivors learned to survive and thrive in the last century.

More than a hundred years of observation had taught that years after the polio attack:

- Polio survivors experience weakness, either transient or permanent, both in muscles obviously affected by polio and in those that had apparently been unaffected.
- Polio survivors experience excessive fatigue, an inability to concentrate, drowsiness, and sometimes, severe attacks of sleepiness.
- Polio survivors’ limbs are abnormally sensitive to cold.
- Polio survivors do become weaker over time, but are not developing the progressive and fatal disease ALS.
- Polio survivors who are highly motivated, who push themselves “beyond the competence” of their polio-damaged bodies, are most likely to develop new symptoms.

What wasn’t known in 1981? It wasn’t why polio survivors were experiencing new symptoms.

Were they developing a new motor neuron disease, a progressive atrophy?

Was slight damage to poliovirus-infected somehow “flaring up” to cause weakness in muscles that had apparently been unaffected by polio?

Were oversprouted motor neurons breaking apart because they were unable to nourish and activate their extra sprouts?

Worst of all, could poliovirus lie dormant in the body and somehow become reactivated to cause new symptoms decades after the original poliovirus infection?

We needed answers to all these questions if we are to understand what was happening and just what we had to do to treat their new symptoms.

To begin to answer these questions we need to understand what the poliovirus did inside the body and how it was able to enter, damage, and kill neurons.

We also need to know how infected neurons were able, not only to survive an

## Thanks!

At our March membership meeting attended by 45 people we had quite a few first-time attendees and it was very timely to have Dr. Mavis Matheson as our speaker. Mavis spoke about the basic causes and effects of Post-Polio Syndrome and her personal experiences with PPS. She referenced a fair amount of information from “**The Polio Paradox**” written by Dr. Richard Bruno. Our thanks to Mavis for her excellent presentation.

**Thank you** also to the Thomas King family members who designated memorial donations to our association. All donations to Polio Regina are used to provide services for you as members. Services such as the costs of printing and mailing our Postbox booklet and other general information for members comes from donations.

We are now able to offer a **disability taxi service** for people unable to attend our meetings because of transportation problems. Call Verna Copeland at 781-1314 for information about this new service.

### We welcome these new members who joined Polio Regina this past month:

Brenda Brough, Sharon Jensen, Elaine Logan, Ella McEwen, Jim McKechnie, Jim Stachan (Oxbow), LaVaughn Strohan (past member has returned), Frances Walkington, (Balcarres), and Wilfred Tiefenbach.

### Your Executive for 2003

Norm Beliveau:	President
Norm Desautels:	Vice President
Don Volpel:	Secretary
Verna Copeland:	Treasurer
Inge MacPherson:	Convenor
Carole Einfeld:	Program Director
Blenda Ramsay:	Phone Co-ordinator
Dr. Mavis Matheson:	Archivist and Librarian
Fred Ramsay:	Postbox Editor.

prescription, or Over-The-Counter (OTC). As a polio survivor you should become an informed user of drugs because:

- The drug effect may enhance post polio symptoms while influencing the primary condition. Fatigue, muscle weakness, muscle irritability (cramps), ability to cough & clear secretions, anxiety feelings may be increased so that your performance decreases.
- With increasing age the potential for interaction between drugs increases and these effects are often more severe.
- With increasing age individuals are more likely to be taking or be prescribed medications for a variety of conditions, such as hypertension, diabetes, arthritis, insomnia, indigestion, constipation ... the list can go on and on.

### Who is at greater risk?

- Individuals with respiratory muscle weakness or paralysis
- Individuals with weakness of the muscles of swallowing
- Individuals diagnosed with Post-Polio Sequelae (Post-Polio Syndrome)
- Older individuals (over 65 yrs)

You may have experienced a ‘full recovery’, Grade 5, Manual Muscle Test of involved muscles and were unaware of any involvement of your respiratory muscles, however, research has shown that these so-called ‘normal’ muscles are not necessarily normal and may be supplied by only 60% of the usual number of spinal nerve cells.

### What you should do

- Change your lifestyle before resorting to use of an OTC drug or requesting a prescription.
- Always inform your doctor(s) about which drugs you are currently taking regularly, prescription & OTC drugs.
- Ask your doctor about potential side effects, particularly those that may increase or cause:  
Fatigue  
Respiratory depression muscle weakness  
Dizziness and/or drowsiness which may impede your balance and cause falls  
increase depression thus changing your perception of pain, making it seem worse  
insomnia, sleeplessness, will increase - fatigue  
Vaso-constriction, may increase cold intolerance

## Polio forgotten but not gone

People think Polio and polio survivors are gone. Polio may be forgotten but it is not gone. There are estimated to be approximately 20 million polio survivors throughout the world.

Post Polio Sequelae (PPS) are the unexpected and often disabling symptoms such as overwhelming fatigue, muscle weakness, muscle and joint pain, sleep disorders, heightened sensitivity to anaesthesia, cold and pain and difficulty swallowing and breathing – that occur in 75% of paralytic and 40% of non-paralytic survivors approximately 35 years after the polio virus attack.

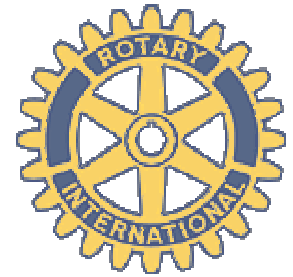
Research has shown that PPS are caused by neurons failing and dying that were damaged by polio and have been overworked for 50 years. Polio survivors whose muscle weakness goes untreated can lose 7% of their remaining motor neurons each year.

But neurons need not die, says Dr. Richard Bruno. PPS can be treated and even prevented through simple therapies.

**Conserve your energy; walk less and rest more; use needed assistive devices such as braces, crutches, wheelchairs, scooters and walkers and/or whatever is easiest and appropriate for you. Exercise carefully and not strenuously or vigorously.**

## The Rotary Connection

Blenda Ramsay had an interview with Dawn Suchoboki who represented a Regina Rotary International Club asking us to assist in promoting Rotary awareness month. Some of our members volunteered to sit at information displays in malls. The discussions are at very preliminary stages but you will be kept posted on this project. Rotary International has been doing a spectacular job in world-wide eradication of the Polio virus.



Here's a sample of the Polio Eradication project:

### Gleanings from the internet

In **India**, a child drags herself across an orphanage floor, her knees raw with open sores. Children disabled by polio and other diseases participate in occupational and physio-therapies, attend school, and learn vocational skills at the Amar Jyoti Rehabilitation and Research Centre in New Delhi. The centre was established in 1981

In the **Democratic Republic of Congo**, an elderly man earns a pittance hauling goods on his wheelchair – the only work he has ever had.

### Global campaign to eradicate Polio.

A health worker calls out to communities along the banks of the Congo River to bring their children to be immunized. He is also watching for children in passing canoes. The three-day national campaign aims to immunize all children under five. Throughout the country, warring factions have agreed to cease-fires for the duration of vaccination campaigns.



**Somalia:** Singers and musicians like these help motivate health workers and



Photo by Murray Grant

**Congratulations to president Norm and Bernice Beliveau, the recipients of our honorary life membership in Polio Regina Inc. It's our private "hall of fame." Norm is serving his fourth consecutive term as president. Presenting the award to Norm is Don Volpel, last year's winner. Previous winners include, Ross & Verna Copeland, Dr. Mavis Matheson, Jackie and Keith Ball, Lloyd & Inge MacPherson, Maurice & Virginia Denzin and Fred and Blenda Ramsay.**



A replica of "the iron lung" on display at the science centre.



One of our regular member meetings in progress. Join us !  
Photo by Murray Grant

## Meet and Greet Norm and Shirley Desautels



Hello Fred: Seems like the minute one is born and the feet hit the ground, one travels through life with such speed, that it makes you wonder what happened ?

In my case, life began at the Grey Nuns Hospital, (now Pasqua) on Feb. 17, 1934. I was brought home to a farm near Riceton, Sask. in a model "T" Ford. Relatives and neighbors celebrated the arrival of this fat baby with lots of hair (believe it or not) with good wishes and drinks of home brew, which had been allowed to age 20 minutes-so I'm told.

As you can imagine, my parents Leon and Rose Desautels were very poor in those depression years, but with hard work and perseverance they managed to do quite well. I was blessed with the best mother and dad one could hope for.

My elementary school years began with the first grade in a one-room schoolhouse near our farm, at Sedley, and ended at a boarding school in Moose Jaw.

It was during those Moose Jaw school years that I contracted polio and I subsequently spent about a month in the Regina General Hospital isolation unit. Anyone who had polio can remember those Sister Kenny "hot" treatments. I think I lost 40 pounds that month and I've always considered myself very fortunate for having survived it as well as I did.

My first few years of high school were spent at Scott Collegiate in Regina and, when an opportunity presented itself to move to Portland Oregon and work, I didn't hesitate. I worked in a plywood factory, making very good money for the time. At age 18, I thought the world was my oyster.