

When you are coming to terms with new symptoms, it is important to know that you are not alone. The most important aspect of Polio Canada® is our member groups, which organize local meetings and seminars, as well as provide information, support and encouragement. Please contact the local support group leader nearest you.

Polio Canada® Support Groups in Canada

Post-Polio Awareness and Support Society
of British Columbia
#2-2630 Ross Lane
Victoria, BC V8T 5L5
Tel: 250-477-8244
Fax: 250-477-8287
E-mail: ppass@ppass.bc.ca
www.ppass.bc.ca

Southern Alberta Post Polio
Support Society
Reny de Jong
#7 - 11 St. NE
Calgary, AB T2E 4Z2
Tel: 403-265-5041
Fax: 403-265-0162
E-mail: sappss@shaw.ca

Wildrose Polio Support Society
Pat Laird
c/o CPA (Alberta)
305 Hys Centre
11010 - 101 St.
Edmonton, AB T5H 4B9
Tel: 780-992-0969
E-mail: wpss_edm@hotmail.com

Saskatchewan Awareness of
Post Polio
Ron Johnson
2310 Louise Avenue
Saskatoon, SK S7J 2C7
Tel: 306-343-0225
E-mail: msjohnson@sasktel.net
www.sfn.saskatoon.sk.ca/health/polio/index.html

Polio Regina Inc.
Carole Einfeld
4264 Wascana Ridge
Regina, SK S4V 2T2
Tel: 306-761-1020
E-mail: bubbiecarole@accesscomm.ca

Post Polio Network (Manitoba) Inc.
c/o SMD Self-Help Clearinghouse
825 Sherbrook St.
Winnipeg, MB R3A 1M5
Tel: 204-772-6979

Post-Polio Program
Ontario March of Dimes
10 Overlea Blvd.
Toronto, ON M4H 1A4
Tel: 1-800-263-3463 or 416-425-3463
Fax: 416-425-1920
E-mail: polio@dimes.on.ca
www.dimes.on.ca

Association Polio Quebec
CP 1030 Succ. B
Montreal, QC H3B 3K5
Tel: 1-800-263-1969 or 514-866-1969
E-mail: polioquebec@hotmail.com
www.polioquebec.org

Polio New Brunswick
Peter Heffernan
268 Montreal Ave.
St. John, NB E2M 3K6
Tel: 560-635-8932
E-mail: peterhef@nbnet.nb.ca

Polio Northern New Brunswick
Claudia Godin
Bathurst, NB
Tel: 506-548-1919
E-mail: cgg1@nbnet.nb.ca

Polio Newfoundland
Carolyn Few
Tel: 709-739-4299
E-mail: cfew@nfd.com

Polio PEI
Steven Pate
47 Westwood Crescent
Charlottetown, PE C1A 8X4
Tel: 902-566-4518
E-mail: sdpate@islandtelecom.com

Polio Survivors Group
c/o NWT Council of
Persons with Disabilities
Doreen Baptiste
5014 47th Street
Yellowknife, NT X1A 1M1
Tel: 867-873-8230
E-mail: dbaptiste@nt.sympatico.ca



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Views expressed herein do not necessarily represent the official policies of Health Canada.

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PolioO'Canada

National Polio Survivors Network

Welcome to Polio Canada! Canada's National Polio Survivors Network

I am so excited to bring you the first issue of *PolioO'Canada* - the official newsletter of Polio Canada®, the National Polio Survivors Network.

Over the last two years, representatives from polio survivor groups and associations across Canada have been working hard to create this new program.

Since its launch in March, 2003, Polio Canada® and its National Polio Survivors Network has been working hard to increase awareness of post-polio syndrome (PPS) in Canada. The organization has especially worked hard to put people in touch with the support they need.

Right now, I'm proud to report that many Polio Canada® member support groups and associations are in place throughout the country. With the strength of polio survivors, Polio Canada® and its member groups, we will become the

leading service provider of education, information and peer support to polio survivors across Canada.

This newsletter is just one of the many services offered by our organization (Please see page 2 for a complete list of Polio Canada®'s services).

In each issue of *PolioO'Canada*, we will bring you the most up-to-date information on the late effects of polio and post-polio syndrome, including news on member organization activities, upcoming events and conferences. *PolioO'Canada* is here for you! Together we have "Polio Power!"

Elizabeth Lounsbury

Elizabeth Lounsbury
Chair
Polio Canada®

160,000 Canadians Had Polio and Most Don't Even Know It!

Anyone who has been dealing with mysterious medical issues involving fatigue, weakness and pain should talk with family and friends about their childhood, and in particular, they should be asking about polio.

It is estimated that there are approximately 160,000 Canadians in Canada who have survived polio; however, most never even knew they had the disease. Today, ironically, some of those same survivors are dealing with the disease's late effects – and they don't even know it.

In the 1980s, medical science confirmed that many survivors of polio will develop post-polio syndrome (PPS) later in life, a

condition with symptoms that include weakness, fatigue, breathing and swallowing problems and muscle atrophy. In fact, it is estimated that up to 50 to 70 per cent of polio survivors may experience the disabling effects of PPS 25 to 45 years after their initial recovery from polio. But many survivors – not knowing that they had polio in the first place – are unable to provide the vital medical history information to their doctors in order to get the proper medical assessment and treatment they need.

Many Canadians who are suffering from fatigue, weakness and pain should be

Continued on page 2...

Help Us Help Others!

Your donation to Polio Canada® will help us continue to provide education and support to polio survivors everywhere.

Here is my T2E 422 to Polio Canada® of: \$25 \$50 \$100 \$250 I prefer to give \$ _____

Mr. Mrs. Ms. Miss

Name: _____

Address: _____

City: _____ Prov: _____ Postal Code: _____

E-mail address: _____

My cheque is enclosed OR Please charge my: VISA MasterCard American Express

Card No. _____ Expiry Date (mm/yy): _____

Name on card: _____ Signature: _____



Send form with donation to:
Polio Canada®
10 Overlea Blvd., Toronto, ON M4H 1A4
Charitable No. (BN) 879585214RR0001

Thank you for your support!

PolioO'Canada is produced by
POLIO CANADA National Polio Survivors Network

The information contained in this newsletter is a compilation of resource materials from sources in Canada and the U.S. It is not intended as medical advice or as a substitute for individual consultation with your own physician or health care provider. If you have any questions or concerns about this information please contact us at:

1-800-480-5903 www.polioCanada.com

1-800-480-5903

www.polioCanada.com

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asking their family members if they remember polio being in their neighbourhood during their childhood. Post-polio syndrome may be the cause of the difficulties they are experiencing today.

"If your sibling, friend, cousin or kid down the street had polio, and you were exposed to them, it is possible that you also contracted polio," says **Marcia Falconer**, PhD, virologist and researcher into post-polio syndrome. "It may be that your family wasn't even aware that you had had polio, as the symptoms of very mild polio cases can be similar to the flu."

Often polio survivors are misdiagnosed with chronic fatigue

syndrome, fibromyalgia or depression. "I was told for years that it was all in my head," says **Elizabeth Lounsbury**, a polio survivor and now chair of Polio Canada® and its National Polio Survivors Network.



If you suspect that your symptoms could be caused by a forgotten or missed childhood case of polio, call 1-800-480-5903 or visit the Polio Canada® Web site

at www.poliocanada.com for a free information package.

Polio Canada® is Here for You.
Through five main services, Polio Canada® supports and informs the community and health care professionals.

POLIO SURVIVORS REGISTRY

Polio survivors who join the Polio Survivors Registry receive a comprehensive information package on post-polio syndrome, a free subscription to our newsletter, local chapter newsletters and bulletins on news and events.

HEALTH CARE PROFESSIONALS REGISTRY

Educating the health care community is a very important part of Polio Canada®. You can request that we send an information package to your doctor and other health care professionals.

EDUCATION AND INFORMATION

Education is the core function of Polio Canada®. In addition to distributing information to people who join the registry, we also offer resources on the late effects of polio and post-polio syndrome.

SUPPORT GROUPS

When you are coming to terms with new symptoms, it is important to know that you are not alone. Polio Canada® organizes support groups, local meetings and seminars, providing information, support and encouragement. Contact us to find a support group in your area. There you will find other polio survivors who are ready to answer many of your questions and share their personal experiences.

CONFERENCES

Polio Canada® and its member groups organize conferences, seminars and workshops on the late effects of polio and post-polio syndrome.

Is Your Health Care Provider Informed?

The need to educate and inform all health care professionals about post-polio syndrome is vital to effective treatment for polio survivors. Polio Canada® offers free educational packages for polio survivors, as well as for health care professionals.

Often you think of your doctor and specialist when you think of health care – but what about your nurse, therapist, dentist, pharmacist, or caregiver? They, too, need to be informed about post-polio syndrome.

Contact Polio Canada® at www.poliocanada.com or 1-800-480-5903 and order a customized educational kit for all your health care providers.



Polio Canada® Grows

Thanks to funding received from Health Canada's Population Health Fund, Polio Canada® has been able to provide assistance, support and leadership in the formation of new polio survivor support groups in: the North West Territories, Newfoundland and two new groups in Saint John and Bathurst, New Brunswick.

"It is so much easier to deal with post-polio syndrome when you have others to talk to who are going through the same thing," says **Claudia Godin**, chair of the newly formed Polio Northern New Brunswick (Bathurst). "Together we can do so much to educate health care professionals and advocate for service; we are so fortunate to have the assistance of Polio Canada® in starting this group."

If you would like to start a support group in your area, contact

Kim Dowds – manager, Polio Canada® at info@poliocanada.com or 1-800-480-5903.



"It is so much easier to deal with post-polio syndrome when you have others to talk to..."

Claudia Godin, Chair of Polio Northern New Brunswick

MARCH Polio Awareness Month

In March 2003, the first national Polio Awareness Month was launched in Canada by Polio Canada®. Working together, polio survivor support groups across the country held events and seminars throughout the month of March to raise awareness of the new challenges faced by polio survivors.

"Polio is not a dinosaur disease!" says **Ron Johnson**, president of Saskatchewan Awareness of Post-Polio Society. "We're going to make sure that health care professionals listen and understand post-polio."

Mall displays, raffles, parade floats, public educational seminars, volunteers delivering brochures and books on post-polio syndrome to medical centres and hospitals made the Polio Awareness Month a huge success.

March is fast approaching! You can be part of Polio Awareness Month, 2004. There are estimated to be 160,000 polio survivors in Canada today – they need information and education about post-polio syndrome NOW! Help us help them! Contact your local Polio Canada® support group or Awareness Team at 1-800-480-5903 to find out how you can be involved in the next Polio Awareness Month.



LEADERSHIP TRAINING Polio Canada® Conference 2003

COMMENTS and REPORT
Stewart Valin, Polio Quebec

This past summer, the leaders of Canada's post-polio support groups came together for a four-day conference that shed some new light on the forgotten disease.

From Aug. 24 to 27, Canada's polio experts, including 50 polio survivors, were at Brock University to attend the first Polio Canada® Leadership Training Conference.

The conference, which was led by **Kim Dowds**, Manager of Polio Canada®, established new levels of motivation and determination that will eventually improve the state of local and Canadian post-polio matters.

In fact, several presentations were given by various experts in the field that left everyone in attendance with new ideas and a shared vision on how to tackle polio-related issues locally and nationally.

Dr. Marcia Falconer (virologist) gave two such presentations.

First, she presented an informed account of the poliomyelitis virus, the medical manifestations of its strains and possible or probable causes of post-polio syndrome. Then, Dr. Falconer discussed some results (to be published) from a survey of polio survivors concerning post-polio syndrome.

Gaile Lacy (BC PPASS) presented the main features of a swim exercise program featuring Ai-Chi postures. Gaile talked about how delegates could initiate a similar program in their regions. The benefits and risks of water exercises were discussed.



Canada's polio survivors and leaders came together in August to discuss post-polio issues.

There were many interactive workshops with different topics, however, the main focus of each workshop was "How can we improve support for polio survivors and increase awareness of post-polio syndrome?"

WORKSHOP TOPICS INCLUDED:

Awareness Month 2004

Groups came up with many innovative ideas, including spokespeople, public displays, group talks, and involving the media. They also discussed the use of promotional materials such as brochures, bumper stickers, T-shirts with logos and slogans, and other visible devices to get the polio message to the public.

Engaging membership

This workshop led to ideas about new activities that different support groups may want to try to incorporate in order to prevent their groups from growing stale. The suggestions included: holiday party, corn roast, beach party, nature stroll, camping, day cruise, shopping expedition, outdoor concert and cinema.

Maintaining volunteers

Corey Berry, an Ontario March of Dimes speaker, presented methods for maintaining an active volunteer pool. Keeping volunteering fun was the most important suggestion for retaining members. She recommended the importance of keeping a positive environment by avoiding problematic actions such as inappropriate gossip, calling upon unwilling volunteers, and overwork.

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Workshop topics continued from page 3.

Strategic planning

The group agreed that post-polio syndrome will continue to exert its influence on the community, and as the community ages, new concerns such as osteoporosis, arthritis, and loss of independence — associated with the aging process — will require attention. Regional organizations should actively seek to include and engage families and other interested people as active members in the polio support system.

The Polio Ambassador Program and Initiative: PAPI

PAPI was probably the best concept presented at the conference by **Kim Dowds**. PAPI is a network of volunteers living the polio vision twenty-four hours a day, seven days a week. Polio ambassadors will be trained to promote the need for further vaccinations against polio and the realities of polio and post-polio syndrome through public awareness events. Regional, provincial and national organizations will train the ambassadors, providing them with the materials and support needed to bring the polio vision to the community. The ultimate objectives would be to elevate public awareness about post-polio syndrome and inform polio survivors about the support networks available. Polio Canada® has expressed a willingness to coordinate the ambassador program whereby they would establish a national registry of ambassadors, make media materials available and establish an ambassador recognition program.

Conference Conclusion

In all, the Leadership Training Conference was very successful in generating information, ideas, and motivation relevant to improving support for polio survivors and raising awareness of post-polio syndrome. Leaders were successful in generating enthusiasm for a new program to support and recognize Polio ambassadors.



Conference participants cheer for polio power!

Did You Know? You May Already Have Polio Canada® in Your Pocket!

In 2001, the Royal Canadian Mint marked the International Year of the Volunteer with a special commemorative dime. The dime used the image of the Marching Mothers® who had marched door-to-door in the 50s collecting dimes to raise money for a polio cure.

Today, the Marching Mothers® image has been incorporated into the Polio Canada® logo and represents our history as well as the solidarity of polio survivors working together across Canada to raise awareness of a new foe — post-polio syndrome.



Volunteers Needed

Are you bilingual in English and French? Do you have access to a computer to send and receive e-mails? Volunteer translators are needed to translate articles on post-polio syndrome from English into French. If you have some time available to translate, please contact Peggy Mann at Polio Canada® info@poliocanada.com or 1-800-480-5903.