

# PoliO'Canada



n 2007, Post-Polio Health International launched its international "We're Still Here" campaign to give voice to the millions of polio survivors around the world. Polio Canada® has embraced the theme of "We're Still Here" and remains committed to educating people across the country about polio and its late effects in the form of post-polio syndrome. Too many Canadians believe that polio is safely in the past - merely a part of Canadian history - a forgotten disease. But for the thousands of Canadians who survived polio, it is anything

but forgotten. Polio is a very real and pervasive part of their daily lives as they deal with post-polio syndrome.

Elizabeth Lounsbury, Polio Canada® Chair and Mike Fogarty, Health Promotion Coordinator will be members of the 2009 Wellness Camp Committee at the upcoming Post-Polio Health International Conference (see page 5 to learn more). For the first time, both Mike and Elizabeth attended the 18th Annual

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## **Survivors Speak:**

## Polio around the world, Victor Furangi's Story

ictor Furangi is a trained doctor who came to Canada as a refugee from the Sudan close to four years ago. He is currently volunteering with March of Dimes in the Polio Canada® program while

he studies to become re-certified as a general practitioner in this country. Victor is also a polio survivor.

Victor does not remember his polio experiences as he was little more than an infant when he contracted the virus. Much of what he knows

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Victor Furangi

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## Note from the Chair, Elizabeth Lounsbury



As Chair, I welcome every opportunity to represent Polio Canada®, spread the message about the wonderful work we do and reach out to

polio survivors from around the world.

On Sunday, April 13th, 2008, Mike Fogarty, Health Promotion Coordinator and I attended the 18th Annual Polio Network of New Jersey Conference. The conference was very informative and I am so pleased to have the opportunity to report on the many interesting things we learned. Mike and I were able to connect with polio survivors and post-polio groups from around the world and let them know about the important work Polio Canada® is doing.

The conference featured a number of topics dealing with health and wellness

for survivors living with post-polio syndrome. There were sessions on learning how to nurture your spirit as well as your body. I was quite interested in guest speaker, Dr. Fredrick Maynard MD, a specialist in physical medicine and rehabilitation from Upper Peninsula Rehab Medicine Associates, Marquette Michigan Medical Center who spoke on the role of exercise for people with PPS. He suggested that people with PPS should take it slowly when they exercise and focus on building strength and flexibility, using their own body weight. Those with spinal stenosis need to be more cautious, as this is a common condition for people with post-polio syndrome. He also recommended swimming as a form of gentle exercise and counselled eating more protein.

Mike and I also met Joan Headley – the Executive Director, Post-Polio Health International to discuss the Post-Polio

Health International conference, taking place this year between October 12-18, 2008. Once again the theme is "We're Still Here". Polio Canada® has embraced the message of "We're Still Here" as a year-round initiative, with media releases, website updates and our Polio Canada® newsletters. We are also supporting peer support groups across the country.

We want to hear from you. Please send us any information you think might be helpful to polio survivors, share your personal polio story with us or let us know what your group is doing to help people living with post-polio syndrome. Together, we can remind Canada and the world, that "We're Still Here".

All the best.

Elizabeth Louisbury

Elizabeth Lounsbury

## March of Dimes to Benefit from Judge's Memoirs

he Honourable Justice George Ferguson has published his memoirs, "Who Am I To Judge?", reflecting on his Toronto upbringing, his years recovering from the devastating effects of polio, his legal career and appointment to the Superior Court of Justice of Ontario. In his retirement years he continued to flourish and he never forgot the charity he helped create, Ontario March of Dimes.

Contracting polio at fourteen, Justice Ferguson was left with permanent physical disabilities, but they did not diminish his spirit. Ferguson went on to have a lengthy and distinguished career in law, a long and happy marriage to his wife Diana that produced three children Steve, Mike and Didi and an involvement with March of Dimes that has spanned over 50 years and continues today.

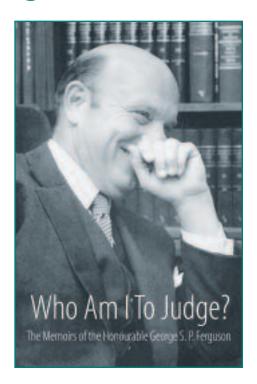
Given Justice Fergusons' significant

accomplishments, March of Dimes established an award in his honour over a decade ago, known as the Judge George Ferguson Award for Full Participation and Equality, which recognizes truly distinguished contributions to the lives of people with disabilities, such as the adoption of Human Rights legislation, or the creation of barrier-free communities.

Proceeds from the sale of Justice Ferguson's autobiography will benefit Polio Canada<sup>®</sup>.

The I60 page volume, "Who Am ITo Judge" is available for purchase from the March of Dimes Web site at a cost of \$25.00 per book which includes GST and shipping.

To purchase the book please e-mail fundraising@marchofdimes.ca or call 1-800-263-3463.



www.poliocanada.com

## How Massage Therapy Might Help You

assage therapy is becoming more integrated in mainstream healthcare, and can be an important and beneficial part of a healthy lifestyle. Massage improves circulation; promotes the release of endorphins – the "feel-good" hormones that help manage pain, and acts directly on the muscular, nervous, circulatory and lymphatic (immune) systems. With so many health benefits it is worthwhile to explore massage therapy as part of any rehabilitation and recovery program.

Ruby Fletcher, a polio survivor who lives in Fredericton, New Brunswick, has been receiving regular massage therapy for over two years and speaks passionately about its benefits.

As a child, Ruby contracted bulbar polio, initially resulting in total body paralysis. She has since recovered much of her mobility and uses an electric scooter. Ruby strongly believes that regular massage therapy is improving her circulation, warming up her muscles faster, helping to maintain her mobility – all essential to her independence.



Ruby attends sessions at a local massage therapy school and recommends it as a great addition to any polio survivors' healthy lifestyle.

Consult with your healthcare provider before beginning any massage therapy program.

To obtain an information package on postpolio syndrome for your healthcare provider or massage therapist, please contact Polio Canada by calling I-800-480-5903, e-mailing info@poliocanada.com or mailing:

Polio Canada®,

a program of March of Dimes Canada 10 Overlea Boulevard Toronto, ON M4H 1A4

### Massage treatments can help:

• Relieve or prevent physical dysfunction and pain

Certain types of massage are specifically recommended for sore muscles to improve function.

• Relax tight and tense muscles

Tight muscles can lead to poor posture, and muscle strain overall.

### Improve circulation, recovery time and immunity

The movements of massage cause blood to flush in and out of muscles and joints. This flushing process – enhancing circulation in the affected areas – can, in some cases, aid recovery time from injuries.

• Provide relaxation and stress relief

Source: www.massage the rapy 101.com

### **Consider Complimentary Therapies**

he adoption of alternative or complimentary therapies for chronic disease management is gaining in popularity with many polio survivors to help improve well-being and to better manage their condition.

Many polio survivors experiencing postpolio syndrome search for alternative methods of healing. In addition, there is great enthusiasm from complimentary therapy practitioners to help people living with post-polio syndrome. Practitioners such as registered massage therapists (RMT), doctors of naturopathic medicine (ND), and nutritionists realize the potential of their fields to help polio survivors better manage their symptoms and help to live a happier, healthier life.

In Canada there is a decreasing number of traditional healthcare professionals with knowledge of and experience with postpolio syndrome. Polio Canada is continually providing educational resources to healthcare providers and recently has increased its partnership base with various complimentary therapy practitioners to help provide resources to polio survivors.

### www.poliocanada.com

# Polio From Down Under: The Churchill Fellowship Study Tour

he Polio Network, located in Victoria, Australia, recently sent two representatives, Mary-Ann Liethof and Jill Pickering, to tour North America from April 20 to May 31, 2008. The purpose of their tour was to learn more about the polio and post-polio community in North America, share resources and discuss a future vision for polio survivors across the globe.

Their trip began in Los Angeles, where Jill and Mary-Ann met with support group members before moving onto various medical and rehabilitation centres. From California the tour moved to St. Louis, Missouri where they met representatives from Post-Polio Health International. Other stops included

Warm Springs, Georgia where the women attended the Roosevelt Warm Springs Institute for Rehabilitation. The US tour was rounded out in Washington, Pennsylvania and New York. From there they had three Canadian stops: Toronto, Ottawa, and Montreal.

At their Toronto stop, Mary-Ann and Jill were met by Elizabeth Lounsbury, Polio Canada Chair, Jan Nichols, Toronto/Peel Post-Polio Chapter Chair, and Sheila Casemore, the Manager of Group Development and Support for March of Dimes Canada/Polio Canada. Their focus was the future of resources for polio survivors in Australia and Canada and what can be done for polio survivors globally.

The Polio Canada representatives were able to provide support and information toward the upcoming development of The Polio Network in Australia, using the existing framework of connected support groups. They also discussed the established communication links between the US, Canada, Australia, Britain and Europe and exploring the creation of a Polio World, whose purpose would be to coordinate worldwide awareness campaigns and offer support through a united voice.

It was a great opportunity for Polio Canada to strengthen its connections internationally, share resources and to continue its development of resource provision to polio survivors and health-care professionals.

### Take Some Time for Yourself!

arch of Dimes, through its Recreation and Integration Services program, provides opportunities to increase social and recreational experiences.

We will be offering a number of accessible vacations and out-trips

over the coming months, including a holiday to Las Vegas, an Alaskan cruise and numerous day trips.

If you are interested in learning more about the trips please contact Abbey Royle at 1-800-263-3463 ext. 7251 or e-mail recreation@marchofdimes.ca.



### We're Still Here Continued from Page I

Polio Network of New Jersey Conference to connect with post-polio groups from around the world and help raise awareness of post-polio syndrome (see page 2 for conference highlights).

It is vital that we not relegate polio to Canada's past. We must continue to

educate the public about post-polio syndrome and provide the peer support services that link polio survivors together, allow them to draw strength from each other – and most importantly, spread the word, that "We're Still Here."

We want to hear from you. You can call 1-800-480-5903, or e-mail us at info@poliocanada.com or mail:

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a program of March of Dimes Canada 10 Overlea Blvd. Toronto, ON M4H 1A4

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### Victor Furangi's Story Continued from Page 1

of his childhood battle with polio has been told to him by his mother. She said that shortly after he started walking, he became seriously ill resulting in paralysis and a lengthy hospital stay. At the time there was no effective medical care in the Sudan so his mother took on the role of doctor and physiotherapist — working with the young Victor to help him regain his movement and allowing him to walk again. As the result of her efforts, Victor was able to participate in sports, playing soccer, riding his bicycle and engaging in all community activities.

"Unless someone was paying close attention to my physical condition, they would not have been able to notice that my right side is markedly weaker than my left," says Victor.

In the Sudan, people with disabilities are placed in one of two categories – they are either made to do the same things as everyone else, regardless of their challenges or limitations, or they are seen as completely without use. Victor was in the former – forced to complete mandatory military training, a time he describes as, "terrible."

Since arriving in Canada Victor has seen

a remarkable difference in what it is like to be a Canadian living with a disability. "In Canada," he says. "There is a place for everyone – there is something for everyone to do."

"For years as a polio survivor I was still expected to be the same as everyone else – but here they recognize your limits and that there is still a place to belong," he continues.

Victor is using his medical expertise as a volunteer with Polio Canada® and is researching the latest information and treatments of post-polio syndrome. He has come to learn how PPS has influenced his life, including his lengthy recovery from a severe hernia in his back that he suffered three years ago. He was once again temporarily paralyzed in both his legs and required months of physiotherapy to heal. Victor believes the hernia was the result of favouring his left side for so many years. He now recognizes the impact of PPS-related fatigue and knows he needs to better manage his energy levels.

Victor hopes to not only help educate polio survivors about PPS, but also the medical and healthcare fields. He

knows firsthand the lack of knowledge in the medical community about PPS and how to best mitigate its symptoms. He would also like to help improve the condition of polio survivors in the Sudan, many of whom have no access to assistive devices and are forced to crawl to get around.

Victor credits March of Dimes for welcoming him and helping him to better understand his condition and how to manage it. "Everyone at March of Dimes has been so warm and trusting," he says. "They have really helped me feel like I belong."

To share your story in an upcoming issue of Polio Canada, please contact Mike Fogarty, Coordinator, Education and Health Promotion by calling 1-800-263-3463 ext. 7212 or e-mailing mfogarty@marchofdimes.ca. He can also be mailed at:

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# Post-Polio Health International's 10th International Conference April 23-25, 2009

Elizabeth Lounsbury, Polio Canada® Chair and Mike Fogarty, Health Promotion Coordinator are members of the 2009 Wellness Camp Committee, which is organizing the Post Polio Wellness Camp for 2009. The Wellness Camp is being held at Camp Dream, located at the Roosevelt Warm Springs Institute for Rehabilitation in Warm Springs, Georgia. The Wellness Camp will precede

Post-Polio Health International's 10th International Conference being held April 23-25, 2009.

For more information about the Wellness Camp and the conference, please visit our website at www.poliocanada.com or e-mail info@poliocanada.com or call 1-800-480-5903.

hen 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

#214 - 10114 McDonald Park Road, Sydney, BC V8L 5X8

Tel: 250-655-8849 Fax: 250-655-8859 E-mail: ppass@ppass.bc.ca www.ppass.bc.ca

## Wildrose Polio Support Society

Edmonton

Tel: 780-428-8842 E-mail: wpss@polioalberta.ca www.polioalberta.ca

## Southern Alberta Post Polio Support Society Calgary

Contact: Vern Hamm, President Email: dvhamm@shaw.ca

#### Lethbridge and Area

Contact: Juanita Takahashi, President

Tel: 403-329-9453 www.polioalberta.ca

## Saskatchewan Awareness of Post Polio

Contact: Ron Johnson Tel: 306-343-0225

E-mail: rnsjohnson@sasktel.net www.geocities.com/sapponline

### Polio Regina Inc.

Contact: Carole Einfeld Tel: 306-761-1020

Email: twilf\_ecarole@hotmail.com

### Post Polio Network (Manitoba) Inc.

Contact: Cathy Grabowecky

Tel: 204-975-3037 Toll-free: 1-866-282-8041 Fax: 204-975-3027

#### **Polio Ontario**

Over 15 groups throughout Ontario

Tel: I-888-540-6666

or 416-425-3463, ext. 7207 E-mail: polio@marchofdimes.ca

### **Association Polio Quebec**

Toll free: I-877-765-4672

Tel: 514-489-1143

E-mail:

associationpolioquebec@bellnet.ca www.polioquebec.org

#### **Polio New Brunswick**

268 Montreal Ave. Saint John, NB E2M 3K6

Contact: Peter Hefferman

Tel: 506-635-8932

E-mail: peterhef@nbnet.nb.ca

## **Polio Northern New Brunswick** *Bathurst. NB*

Contact: Claudia Godin

Tel: 506-548-1919

E-mail: sunrayfifty@yahoo.com

### **Polio PEI**

Contact: Stephen Pate Tel: 902-566-4518

E-mail: stephen pate@hotmail.com

You are not alone. Join Polio Canada® now!	Please complete the following information:		
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E-mail address:			
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