



Survivors Speak: Catherine Bell

The history of polio is still being written as global eradication efforts continue and it becomes possible there may be a polio-free world within the next five years. However, polio survivors still have a story to tell, one they are determined doesn't get lost to history. Kingston, Ontario resident and March of Dimes Canada Board Member and monthly donor, Catherine Bell, shares her story to help educate survivors, and to highlight the benefits of giving back.

Catherine contracted polio in 1953 when she was two years old. The polio vaccine would be discovered just two years later. Catherine had to re-learn to walk, and had a number of surgeries before she turned seventeen. Despite this, Catherine was an exceptional student, and studied fashion design at Ryerson in Toronto, eventually working as head fashion designer at Parkhurst, a sweater manufacturer.

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Catherine Bell

Sleep and Post-Polio Syndrome

Sleep is invaluable and a restorative state that is essential for every human being. However, there are various physical factors that can disrupt our sleep; ones we can control and ones we cannot. With post-polio syndrome (PPS), restless or poor sleep can be directly linked to respiratory issues. Treatment can improve both quality of life and prognosis. There are various respiratory problems seen in people with PPS which may be due to one or more of the following:

- respiratory muscle weakness
- bulbar impairment which may affect control of the upper airway or the respiratory cycle. If the upper airway is affected, there may be obstructive sleep apnea
- skeletal deformity - scoliosis or chest wall stiffness.
- other pathology - e.g. chronic obstructive pulmonary disease (COPD), asthma, obesity
- aspiration - if swallowing is affected

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Elizabeth Lounsbury

Note from the Chair, Elizabeth Lounsbury

Why is Polio Still Important? - Polio Awareness Campaign

I developed polio in London, Ontario when I was eight years old. Years later, I started volunteering with Ontario March of Dimes, now March of Dimes Canada and have been a volunteer for over 25 years.

I became involved with March of Dimes because I was desperately looking for answer to what was causing my new pain, weakness and fatigue. My life changed when I attended a conference called “Polio: A Second Challenge”, held in Toronto, Ontario, and sponsored by March of Dimes, and I learned I had post-polio syndrome.

This inspired me to chair the Sudbury Post-Polio Support Group for 11 years. Presently I chair Polio Canada and sit on the Board of March of Dimes Canada, and Polio Health International St Louis, Missouri. I have attended Post-Polio Conferences in St. Louis, Missouri, Toronto, Vancouver, Newark, New Jersey and Warm Springs, Georgia. I participate annually in the Leadership in Volunteer Education (L.I.V.E.) conference, sponsored by March of Dimes Canada.

I continually advocate for better awareness of polio and how devastating it is not only to those who have the virus, but also to their families.

I want to see every child inoculated. This is important even in the western world. Polio is only a flight away. I remind all parents about the devastation of polio — and that it lasts for the rest of your life. Post-polio syndrome robs adults of their freedom. They will live with pain, new muscle weakness and unbelievable fatigue.

Many survivors like me have had to return to the assistive devices, i.e. wheelchairs and braces; that we fought so hard to throw away as children. The best way to keep the memory alive is to join our campaign. If you are a survivor, a family member or a concerned citizen, get the word out about polio and WHY it is still important today!

According to the World Health Organization, polio immunization saves three million lives and prevents 750,000 disabilities worldwide each year, making it ‘the single greatest public health achievement of all time.’ *

In 1951, March of Dimes Canada was founded to raise funds for a vaccine to end the scourge of polio — and our advocacy continues today. October is Polio and Post-Polio Awareness Month. March of Dimes Canada and I are starting a social media campaign to remind people that polio survivors are still here. As a polio advocate, we hope you can help us answer the question: “Why is polio still important?”

To do this, we are encouraging people (in 25 words or less) to write your answer in black marker on a whiteboard or white bristol board. If you could send a picture to March of Dimes Canada (via email at info@marchofdimes.ca) of you holding your answer, we can post to our social media accounts; letting people know the lifelong consequences of polio — we will do this throughout the year.

We are still here! Share your stories with us.

Elizabeth Lounsbury
Chair, Post-Polio Canada

*Source: Canadian Public Health Association - Online 2014

Survivors Speak: Catherine Bell (continued from page 1)

After 14 years at Parkhurst, Catherine began to experience new troubling symptoms of fatigue and weakness. She was only 36 years old, but was having difficulty with mobility, often falling, and tiring out after walking even short distances. She was to discover she was now dealing with the late effects of the polio virus in the form of post-polio syndrome.

Little understood by most doctors, in the 1980's medical researchers confirmed that many survivors of polio would 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 percent of polio survivors may experience the disabling effects of post-polio syndrome 25 to 45 years after their initial recovery from polio. There are approximately 125,000 Canadian polio survivors.

Concerned, Catherine contacted March of Dimes Canada, where she learned about post-polio syndrome and began to attend the Toronto post-polio support group. Soon after, one of the members told her about an electrical therapeutic study funded by the charity.

The therapy proved very helpful, and Catherine, who had been using an electric scooter or cane, was once again able to walk unaided. She moved to Kingston, Ontario shortly after receiving her therapy, and began working, first as a professor at St. Lawrence College, then opening her own image consulting business, Prime Impressions. She is one of only 13 certified Image Consultants in Canada, has been running her business for over 20 years and is a published author.

“Electric stimulation therapy, which I still use today, restored so much of the strength I lost 25 years ago. I feel that I have conquered polio – twice,” says Catherine. Looking to give back and reach out to fellow survivors, Catherine first began volunteering with the Kingston post-polio support group and for the past seven years, has been a Board Member of March of Dimes Canada.

“March of Dimes Canada has so many different ways to support people living with disabilities to become more independent,” says Catherine.

“I am so thankful for what March of Dimes did for me and what I was able to do in my life. If it wasn't for March of Dimes, I would not be able to be active and run my business. So by donating, and volunteering, I am able to give back, the way they gave to me,” she continues. “I am naturally a person who cares for others, I always want to help. In fact, my mother is 90 years old and still helping people too! So, working with and supporting March of Dimes Canada is a natural fit. Together, we are helping people remain independent, maintain their dignity and have hope. We make such a positive impact on people's lives,” says Catherine.

To learn more about Post-Polio Canada, a program of March of Dimes Canada, please visit our website at www.marchofdimes.ca/polio

Sleep and Post-Polio Syndrome (continued from page 1)



Symptoms may be subtle or unnoticed. Breathlessness may not be a symptom in patients with limited mobility. Possible symptoms are:

- sleep disruption, eventually leading to insomnia, daytime sleepiness or fatigue.
- morning headaches, irritability, poor concentration, anxiety or depression.
- abnormal sleep movements, nocturnal confusion, vivid dreams.

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(Sleep and Post-Polio Syndrome continued...)

- breathlessness which may be positional.
- Weak cough and chest infections.

There are various ways to help manage the symptoms and issues that post-polio syndrome and respiratory issues have on our sleep.

- **Avoid smoking**
 - Nicotine can be a stimulant like caffeine and can lead to temporary alertness. It can leave you wide awake and boost your metabolism into action, not to mention the detrimental effects it has on lung tissue
- **Avoid sedatives and alcohol**
 - Alcohol is a sedative, but it can disrupt the sleep cycle and prevent entering the third or fourth stage of deep sleep. It should be avoided if you have

a sleep issue and at a minimum, limited to earlier in the evening rather than close to bedtime

- **Avoid caffeine**
 - Caffeine increases your state of alertness and people who drink too much are less likely to sleep well than those who do not. Herbal teas are a good replacement

Other suggestions for a good sleep include:

- use postural support if needed
- maintain an optimal weight and practice good nutrition.
- get prompt treatment of chest infections
- try chest expansion exercises
- consider various assistive breathing devices



Stroke Recovery Burlington



Gary Fletcher and Mary Gordon

Walk 'n' Roll 2014 — A Great Success!

The sixth annual Walk 'n' Roll, held the weekend of May 2–4, 2014, was by far one of our biggest successes when it comes to media and group participation! We had media at almost all of our locations, and raised just over \$35,000 to support our peer support and community engagement programs.

The Walk 'n' Roll, is an annual fundraiser that allows people with physical disabilities to get out and be active in their communities, support vital programs, and improve their health and fitness. Volunteers and participants from

March of Dimes Canada stroke, polio, and acquired brain injury support groups, and residents of our supportive living homes, walked or rolled through local shopping malls to raise awareness and funds for our programs and services.

Thank you to the 20 groups who came out to 15 different locations to raise awareness and funds — we look forward to your feedback about how we can make this event even bigger in 2015!

March of Dimes Canada – Declaration on the Value of Immunization

A hundred years ago, infectious disease was the leading cause worldwide of all premature deaths. Today, in Canada, due to publicly-funded vaccination campaigns, it accounts for less than 5%. March of Dimes Canada has historically been a strong advocate for the power of immunization and continues to be today.

In the 30s, 40s and early 50s — poliomyelitis (polio) or — infantile paralysis was a dreaded household word across the western world. “Thecrippler,” as it was often known, was a threat to young and old and could lead to death or lifelong disability. Fear of polio spread like wildfire — especially during the summer months. Pools were shut down, children were kept inside, and the polio wards in hospitals were teaming with individuals in iron lungs or quarantined in hospital beds.

The funds collected door to door by the Marching Mothers made the dream of a polio vaccination a reality. March of Dimes was established in Canada in 1951 specifically as a result of the scourge of polio, with the goal of raising funds to contribute to the research into a preventative vaccine. By 1955, Doctor Jonas Salk had successfully developed a vaccine and it was rushed to be manufactured at a variety of laboratories including Connaught Laboratories (now Sanofi Pasteur) in Toronto, Canada.

The introduction of a preventive vaccine against polio, and with it, immunization programs across Canada have significantly reduced the incidence of polio. The last indigenous case of wild poliovirus was in 1977, and in 1994, Canada was certified as being free of wild poliovirus by the World Health Organization (WHO). More recent cases of paralytic polio in Canada have been associated with importations of wild poliovirus from countries where polio remains endemic, namely — Pakistan, Afghanistan and Nigeria.

99% of those at risk in the developing world have been inoculated — thanks to policy developed by the World Health Organization, resulting in a push for vaccination in polio endemic nations. India, a country long considered to be the hardest place to eradicate polio, was taken off the polio endemic list in January 2012 after being a whole year without a single case of polio. It was certified polio-free in January 2014 after three years without a reported case of wild polio virus.

These modern day statistics are a testament to the power of immunization and how crucial it is that we take advantage of accessible, affordable vaccination programs. While new cases of polio are historically low — only 89 cases reported year to date—the threat of infection remains high.

Unfortunately, these diseases are never truly eliminated and risk returning, as we are seeing in their re-emergence in other parts of the world. In May, the WHO declared a “State of Emergency” due to reported cases of polio in previously controlled areas (i.e. Syria and Cameroon). The Public Health Agency of Canada is cautioning travelers to stay up to date with their vaccinations and make sure everyone receives a booster before traveling to places where the polio virus is endemic or cases have been recently reported.

March of Dimes Canada is well aware of the importance of prevention and the truth to the adage ‘an ounce of prevention is worth a pound of cure’. There is no cure for polio. We have spent over 60 years providing services and support for polio survivors, including those who have experienced the late effects of polio (post-polio syndrome) many years after the initial onset.

For this reason, MODC strongly supports the Public Health Agency of Canada’s position on immunization and vaccines. We encourage all Canadians to get immunized and ensure that their immunizations are up to date. We also want to remind Canadians that there are individuals at higher risk of infection such as small children, the elderly, people with chronic health conditions, and travelers to countries where infectious diseases such as polio continue to be endemic, and they need protection. Immunization is safe and the most effective way to ensure that children and communities remain free of serious diseases.

IMPORTANT NOTE:

When you are coming to terms with new symptoms, it is important to know that you are not alone. The most important aspect of Post-Polio Canada is our member groups, who organize local meetings and seminars, in addition to providing information, support and encouragement. Please contact the local support group leader nearest you.

POST-POLIO CANADA SUPPORT GROUPS IN CANADA

Southern Alberta Post Polio Support Society

7-11 St. NE
Calgary, AB T2E 4Z2
Contact: Esther Hendricks
Tel: 403-813-9583
Fax: 403-281-1939
calgary@sappss.com
www.sappss.com

Wildrose Polio Support Society

132 Warwick Road NW
Edmonton, AB T5X 4P8
Contact: Glyn Smith
Tel: 780-428-8842
Fax: 780-475-7968
wpss@polioalberta.ca
www.polioalberta.ca

Lethbridge & Area

2722-7A Ave. North
Lethbridge, AB T1H 1A4
Contact: Juanita Takahashi
Tel: 403-329-9453
lethbridge@sappss.com

Saskatchewan Awareness of Post-Polio

2310 Louise Ave.
Saskatoon, SK S7J 2C7
Contact: Ron Johnson
Tel: 306-477-7002
Fax: 306-373-2665
sapp1@sk.sympatico.ca
www.geocities.com/sapponline

Polio Regina

825 McDonald St.
Regina, SK S4N 2X5
Contact: Carole Tiefenbach
Tel: 306-761-1020
twilf.escarole3@gmail.com
www.nonprofits.accesscomm.ca/polio

Post Polio Network (Manitoba) Inc.

c/o SMD Self-Help Clearing House
Suite 204, 825 Sherbrook St.
Winnipeg, MB R3A 1M5
Contact: Charlene Craig
Tel: 204-975-3037
postpolionetwork@shaw.ca
www.postpolionetwork.ca

Polio Ontario

Over 15 groups throughout Ontario
Tel: 1-800-480-5903
or 416-425-3463 ext. 7209
polio@marchofdimes.ca
www.marchofdimes.ca/polio

Polio PEI

47 Westwood Crescent
Charlottetown, PE C1A 8X4
Contact: Stephen Pate
Tel: 902-566-4518
stephen_pate@hotmail.com

Association Polio Quebec

3500 Decarie Blvd., Suite 219A
Montreal, QC H4A 3J5
Contact: Florence Copigneaux
Toll Free: 877-765-4572
Tel: 514-489-1143
Fax: 514-489-7678
association@polioquebec.org
www.polioquebec.org

Polio Northern New Brunswick Bathurst, NB

Contact: Claudia LeBlanc
Tel: 506-548-1919
sunrayfifty@yahoo.com

Polio New Brunswick

268 Montreal Ave.
St. John, NB E2M 3K6
Contact: Peter Heffernan
Tel: 506-635-8932
peterhef@nbnet.nb.ca
www.polioCanada.com

YOU ARE NOT ALONE. JOIN POST-POLIO CANADA NOW!

Mr. Mrs. Miss Ms. Are you a: Polio Survivor Healthcare Professional Family/Friend Other

Name: _____ E-mail Address: _____

Address: _____ City: _____ Province: _____ Postal Code: _____

Your donation to Post-Polio Canada will help us continue to provide education and support.

Here is my tax-receiptable donation to Post-Polio Canada of: \$250 \$100 \$50 \$25 I prefer to give \$ _____

Yes, I have left a gift in my will to March of Dimes Canada.

I would like more information on making a gift in my will to March of Dimes Canada.

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: **Post-Polio Canada® - March of Dimes Canada, 10 Overlea Blvd., Toronto, ON M4H 1A4**

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www.marchofdimes.ca | 1-800-263-3463

 Text the word SUPPORT from your mobile phone to 45678 to donate \$10.