



Survivors Speak: Carol Coiffe

The history of polio is still being written as global eradication efforts continue and it becomes possible that 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. Toronto, Ontario resident Carol Coiffe shares her story to help educate survivors about the impact of post-polio syndrome (PPS).

Like many people, Carol contracted polio while out swimming over her summer holidays. She was at a birthday party at Balsam Lake near the Kawarthas in Ontario. She remembers coming home and feeling sick, with chills but also a fever, and attributed it to eating too much at the party. After a few days of getting progressively worse, and being unable to get out of bed, polio was suspected.



Carol Coiffe with her grandson

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Polio Still Exists

On November 4, 2014, a room full of post-polio survivors and their caregivers had the opportunity to listen to two amazing speakers at the March of Dimes Canada L.I.V.E (Leadership in Volunteer Education) Conference in Toronto. Azra Rafiq a Community Educator at the International Maternal & Child Health Foundation, and her husband Dr. Muhammad Rafiq Khanani a past professor of Microbiology and Public Health Director at Dow University of Health Sciences in Pakistan.

Dr. Muhammad Rafiq Khanani and Azra Rafiq are passionate and strong advocates who believe that immunization is key to prevent infectious diseases like polio. The theme was evident in their presentation, which focused on India and Pakistan.

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Elizabeth Lounsbury

Note from the Chair, Elizabeth Lounsbury

When I am asked to think, I retire to my recliner in our sunroom. I like to sit and look out over the lake trying to unlock this thinker of mine. Today I see beauty, a white field of sparkling crystals. On the other side of the lake are pine trees clothed in white brilliance. So clean! The thought that comes to mind is that winter is such a beautiful season. I don't dare utter this sentiment around here or I hear things like: You don't have to shovel. You only drive when it is nice. Do I hear a smidgen of jealousy?

Then the comment that literally stops me in my tracks. You know you hate winter, you can't go anywhere on your own. Your wheelchair bogs down in the first three feet. That shuts me up in hurry. My wheelchair is a centre wheel

drive and does not like snow. So with this thought in mind I do look forward to the snowless season.

Not only do I need someone to go with me to help the chair plow through the snow, but when I get to where I am going, I have six very mucky wheels. This embarrasses me to no end. I believe if someone could invent a tire cleaner that could be installed just inside office doors they would become rich very quickly. Anyone know an inventor?

Recently I flew to Ottawa to attend a meeting with Sylvia Davies of March of Dimes Canada, and the ladies from the National ME/FM Action Network, to discuss how Post-Polio Canada and the Action Network can work together. We have support groups that they can benefit from our services. As our polio survivors age there are less people able to attend support group meetings. Again and again, I hear: can we enlarge our membership? Fibromyalgia has very similar symptoms. I was attending a group meeting one afternoon and it occurred to me to ask members what they thought. The vote was a unanimous YES. I would love to hear your opinion. **Please email me at elounsbury@marchofdimes.ca**

Elizabeth Lounsbury
Chair, Post-Polio Canada

Survivors Speak: Carol Coiffe (continued from page 1)

She was taken to Riverdale Hospital in Toronto and placed in an iron lung ventilator. She can't remember how long she spent in the hospital, but recalled that it felt like forever; how hard it was to see her mother upset and the loneliness. Carol was eventually moved to Thistletown where she spent two years rehabilitating.

Carol's entire body was affected, and while her left side mostly recovered, she had permanent weakness on her right side, including her face. Because of this weakness, she developed severe scoliosis and required three surgeries and many body casts. The first surgery took place before she was 12-years-old followed by the second one after a

fall, breaking her back at fifteen-years-old. This was one of the more difficult times in Carol's life as she had just started attending high school for the first time as previous education was self-taught and home schooling. Her final surgery at 26-years-old was experimental and badly needed as Carol's health deteriorated due to once again worsened scoliosis; this major operation proved to be very successful.

Carol does have some fond memories from her time recovering from polio. She needed to use a ruler to keep her hand straight when re-learning how to write, and says to this day her handwriting is like calligraphy. But like many

young polio survivors, she didn't want to feel different. At 16-years-old, she 'threw away her crutches', and pretended she didn't have a disability.

Carol did live a full exciting life, getting married, having two children, working for years with the Government of Ontario and volunteering.

In the early 1980s, a car accident forced her onto long-term disability. She never fully recovered, and didn't initially make the connection to polio. She thought perhaps it was stress, or over-exercising. It was when she learned about post-polio syndrome (PPS) from March of Dimes Canada that she realized the true reason for her slow recovery. At first she was reticent to accept that she was living with post-polio, finding it too scary, but quickly became a strong advocate for raising awareness, attending seminars, conferences and support group meetings with March of Dimes. She continues to volunteer, and it's allowed her to meet people from all over the province.

PPS has taken a toll on her strength, and Carol now uses a power wheelchair, but doesn't let it stop her from living her life to the fullest.

Carol says that the resilience needed to fight polio also gave her the tools she needed for life, and shaped who she became - and still is today. She was able to pass this on to her children, and now her grandson. She signs off all her emails, 'Resilient Carol'.

"I can truly say today that I am blessed in all aspects of my life. I believe in living large; and spending time with family, friends, and always learning and growing. I try to live my most balanced life that is full of love. I would say that is my greatest achievement, and polio has been a part of it," says Carol.

We want to hear from you. To share your story, please email polio@marchofdimes.ca and we will include it in an upcoming newsletter or on our website.

Polio Still Exists (continued from page 1)



Dr. Muhammad Rafiq Khanani and Azra Rafiq at the L.I.V.E. Conference, November, 2014

Azra was a paediatrician in Pakistan who worked closely with children with AFP (Acute Flaccid Paralysis) and assisted parents with preventative pediatric programs. As a health promoter, she focused on educating families in South Asian communities on preventable diseases and the importance of immunizations.

Both presenters focused on the number of children and adults who are still contracting the polio virus in underdeveloped countries. Many polio survivors are now dealing with postpolio syndrome and the ambiguous nature that post-polio presents. Education and financial resources are needed to help under-developed countries beat the war on infectious diseases. Anti-polio campaigns and strong advocates for immunizations can help eradicate polio. Azra continues to help educate young mothers and families at the International Maternal & Child Health Foundation in Mississauga, Ontario. She continues to have a special interest in promoting the benefits of breast feeding, child health and educating families on preventable diseases.

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 "Advocate, educate and stay strong" - Dr. Muhammad Rafiq Khanani
 E-mail: imchfontario@imchf.org Website: <http://ontario.imchf.org>

Depression: How to Spot and Prevent It by Hugo Mobility (www.hugoanywhere.ca)

Depression is very common, especially in older adults, but it is a treatable medical condition.

Research tells us that people may be more prone to depression if they are dealing with a serious illness, have trouble getting around or have lost their independence. We also know that some medications, as well as drinking alcohol, can cause depression.

How do you know if it's depression?

We all feel down sometimes, and when we go through big changes, it's even expected. Depression is different. Its symptoms go far beyond grief and usually last a lot longer.

If you or someone you care about experiences these symptoms for several weeks, it's a good idea to speak with a health care provider. Here are the signs to be aware of:

- Feelings of hopelessness and/or pessimism
- Feelings of guilt, worthlessness and/or helplessness
- Irritability, restlessness
- Loss of interest in activities or hobbies once pleasurable
- Fatigue and decreased energy
- Difficulty concentrating, remembering details and making decisions
- Insomnia, early-morning wakefulness, or excessive sleeping
- Overeating or appetite loss

- Thoughts of suicide, suicide attempts
- Persistent aches or pains, headaches, cramps, or digestive problems that do not get better, even with treatment

So what can you do to help alleviate depression?

In addition to speaking with a healthcare professional about medication and therapy, try to actively incorporate healthy habits into your daily routine. For more inspiration:

- Exercise because it produces happy hormones
- Connect with others, go to the community center
- Get enough sleep, it's restorative and healing
- Maintain a healthy diet
- Participate in activities you enjoy
- Try the calming practice of meditation
- Volunteer your time, you're needed!
- Take care of a pet
- Learn a new skill, sign up for an art class
- Create opportunities to laugh

Depression may not be preventable, but detecting it early and getting help can make a huge difference. And you deserve to feel your best.

Centres for Disease Control and Prevention "Depression is Not a Normal Part of Growing Older" <http://www.cdc.gov/aging/mentalhealth/depression.htm>

Helpguide.org "Depression in Older Adults & the Elderly"

Art and Vaccinations



Photo Credit
GMB Akash:
Crossing the Waterways in Bangladesh

The Art of Saving a Life is an initiative of the Bill and Melinda Gates Foundation and features a collection of stories about how vaccines change history, and continue to save lives around the world.

These stories are told by more than 30 world-renowned artists, including photographers, painters, musicians

and more, with the goal of highlighting both the benefits and importance of inoculation. Combining artistry and inspiration, the project beautifully weaves together the idea that art can help save a life.

For more information and to see the artists' work, please visit www.artofsavingalife.com.

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 a local shopping mall, to raise awareness and funds for our programs and services.

Thank you to the 20 groups that 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!

Our next "Walk 'n' Roll" is scheduled for May 1-3, 2015. For more information, or to set up your own fundraiser, **please call Gemma Woticky, Education and Health Promoter at 1-800-263-3463 ext. 7207.**

March of Dimes Canada Launches New E-Store

Shop and do good! March of Dimes Canada's new retail initiative can be found at www.mod-estore.com. The site offers a variety of products great for everyday use like apparel, water bottles, flashlights, and more specialty items, including adaptive clothing, "smart" stands for your phone or tablet, and even a gumball machine for your

home. Many of these products can help make life a little easier, and include items developed by March of Dimes Canada's DesignAbility® program.

A portion of proceeds benefits March of Dimes' programs and services. **For more information, please email Dennis Ullman at dullman@marchofdimes.ca.**

OPEN UP A FUTURE OF POSSIBILITIES.

Make March of Dimes part of your legacy today.



Charitable Registration Number: 10788 3928 RR0001

EACH YEAR,
WE EMPOWER
50,000 PEOPLE 
to lead
MORE INDEPENDENT LIVES

Since 1951, March of Dimes has improved the lives of Canadians living with disabilities.

Please consider a gift in your will.

For a **FREE** copy of My Personal Organizer, a handy estate planning tool, call today.



March of Dimes Planned Giving Department

10 Overlea Boulevard, Toronto ON M4H 1A4 | 416-425-3463 | 1-800-263-3463 ext. 7338
E-mail: plannedgiving@marchofdimes.ca | www.marchofdimes.ca/PlannedGiving

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