

PoliO'Canada



Fall / Winter 2016

Survivors Speak: Joan Toone

I contracted polio in 1951 at the age of 7. The little girl we played with got polio and quickly died. A short time later, my eldest brother was paralyzed from his neck down in a few hours and he was rushed to hospital. My parents were distraught and, while I didn't understand polio, I knew it was something bad and I was afraid. Then, one morning, I could not move my left side. I was paralyzed. It was polio and again my parents made that terrible journey to the hospital. Because we were in isolation, our parents couldn't visit us. Some looked in the windows and waved, but I was in the extended polio unit on the second floor so I didn't even have that small comfort.

I was fortunate. I walked again, and polio became part of my past. I was married with two young children when I began to trip and fall. Orthopedic surgeons performed five operations to help me walk and balance, but other symptoms presented themselves - extreme fatigue, intense cold sensitivity, and aching muscles and joints.



Joan Toone

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October is Polio and Post-Polio Awareness Month

This year we are partnering with I Boost Immunity and we need your help to get the word out! This website asks you to answer a series of polio or vaccine related questions. For each question you get right a vaccine (polio) is donated to a child in need worldwide. Please keep your eyes open for the link and information. In addition, we shall be showcasing a series of survivor stories on video on our website and their website. Please share and get the word out about Polio and Post-Polio Syndrome nationwide!



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Note from the chair, Elizabeth Lounsbury

It's hard to believe that 2016 is coming to an end. This year has been a remarkable one in the fight against polio. Nigeria was about to receive its polio free certificate from the WHO when 2 children were paralyzed with the wild polio virus, so the challenge in Nigeria begins again!

For me, September included a trip to the first ever Australasia-Pacific Post-Polio Conference. Polio survivors from all over the world came together with caregivers, health care providers, and researchers to share stories and best practices, exchange information, and discuss the consequences of polio.

This was a great chance for everyone are affected by polio, personally or professionally, to collaborate on the shared goal of eradicating this debilitating disease and making life fuller for polio survivors of all ages. I look forward to many more conferences in the future.

March of Dimes Canada and the University of Toronto have been collaborating on a research program into the present needs of people aging with PPS. The objective is to come up with a questionnaire that will be circulated throughout Canada, the USA and possibly Australia. It has been surprising to find out the biggest need of the majority of people surveyed is still professional education.

Just as exciting is World Polio Day, which we'll celebrate on October 24th. I encourage you all to reach out to other polio survivors, tell your stories, and let the world know that, we are still here.

As more and more parents become wary of vaccines, it is crucial that we use opportunities like the Australasia-Pacific Post-highlight the benefits of immunization. Vaccinating saves lives, and protects long-term health. No child should have to live with the after effects of Polio.

This is our last newsletter of the year, so I'd like to wish everyone a wonderful holiday season. Enjoy yourselves, and we'll see you in 2017.

Survivors Speak: Joan Toone (continued from Page 1)

What was going on? Doctors had no explanation and ignored my questions about whether these strangely familiar symptoms might be connected to polio. Eventually, I was diagnosed with Post-Polio Syndrome (PPS). It was a relief because, quite frankly, I thought I was imagining my symptoms.

In 1988, I heard about the Post-Polio Awareness and Support Society of British Columbia (PPASS BC). My husband and I attended a conference in Vancouver,

and the first thing we heard was a request to TURN UP THE HEAT. I knew I was in the right place! Nine years later, I became President of PPASS and served until 2000. After a break, I became President once again in 2007 and remain in the role today.

PPASS BC has provided crucial information about ways to combat PPS but, most importantly, it assured me that I wasn't alone. It was helpful to speak with others who understood PPS. I became determined to use

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Survivor Speak: Joan Toone (continued from page 2)

PPASS BC to reach out to anyone with PPS with care, information and assistance. We now work with BC CDC and Immunize BC, and make presentations to Rotary Clubs in Canada and the USA. We've attended 4 International conferences, and presented at three of them. We exchange newsletters and information with polio groups all over the world. I'm extremely proud to be President of this fantastic organization that existed since 1986 and has over 400 members.

I've always admired March of Dimes Canada's work. Polio Canada was formed by MODC in the early 2000s, and we've worked together since then. Brent Page of MODC came to Vancouver and we've met several times to discuss how our organizations can help others. An example: we're active with Barrier Free BC. Brent is a great MODC representative and eager to help us with outreach and community education.

I want to tell those who've lived through polio, and are now facing PPS, that they aren't alone and there is help. There are people who do understand your struggle. There is information available for you and your doctors to help with your unique problems. We can also provide information to spouses, families, and friends so they can understand polio and it aftereffects.

I'm also a Rotarian and I speak to groups about the awesome work of Rotary International to end polio. There are only two countries in which the wild polio virus is still endemic, but very soon all children will be safe from this terrible disease. I'm certain I speak for PPASS BC, Polio Canada, the March of Dimes Canada, and polio survivors everywhere when I say we eagerly await that day.

A Profound Sense of Gratitude and a Desire to Help Others: Feruze Mitrovica's Story



Feruze Mitrovica (1926 – 2015)

"Her quality of life was improved beyond measure," recalls Dervish, Feruze Mitrovica's son and caregiver. "There isn't enough that I could say to convey our deepest appreciation for the March of Dimes Canada."

Feruze had lived in the same house for over 40 years, but having osteoarthritis and dementia was

making it increasingly difficult for her to live independently. Dervish and his brother Jerry worried that the impact of moving out would be devastating.

A solution presented itself when an occupational therapist put the brothers in touch with March of Dimes Canada. After an assessment by Sandy Faugh, a design counselor in our London office, a grant was provided under the Home & Vehicle Modification Program for a stair lift. Sandy said "Once it was installed everyone was very happy and everything went very smoothly."

Thanks to the assistance of March of Dimes Canada, Feruze was able to continue living at home, comforted by the familiar surroundings and close to her family, until she passed away in July of 2015. To show his appreciation, Dervish is making March of Dimes Canada a beneficiary in his Will. In his words: "I am doing this out of a profound sense of gratitude and a desire to help others."



Little Activities with Big Health Rewards

By Michael Izzo, Airgo Mobility

Being active doesn't need to be complex. Studies show there are significant health benefits associated with simple activities like sitting outside, taking a walk, being neighbourly, and helping out a friend.

Soak up Sunlight

Sunlight is a natural mood booster. Your body needs to soak in natural sunlight in order to produce enough Vitamin D to sustain a healthy immune system and strong bones. Vitamin D plays an important role in the functioning of the adrenal gland, which dispenses hormones like dopamine and adrenaline to help the body cope with stress. Letting your skin come into contact with direct sunlight helps stave off chronic fatigue and depression.

Vitamin D is understood to regulate nearly every tissue in your body, and it even plays a role in calcium metabolism and neuromuscular and immune system function. Vitamin D helps prevent bone density loss, lowering the risks of fractures and developing osteoporosis. Since most Vitamin D deficiency is caused by lack of exposure to natural sunlight, spending time in the sun is a worthwhile activity!

Help a Neighbhour or Friend

Give somebody a hand any way you can. It doesn't have to be physically arduous to be beneficial. Whether you're keeping someone company or helping them with errands, shopping or household chores, studies reveal you're raising your life expectancy.

Research shows that generosity lowers the risk of dying for people who went through traumatic life events. The mental and physical health benefits of helping others cancels out the higher risk of death associated with the experience of the stressful event.

Go for a Walk



Walking is a low-impact one-size-fits-all form of fitness with many health benefits. It elevates the mood, lowers bad cholesterol and raises the good cholesterol. It's just as good for the heart as heavier-impact jogging or running, safer than other types of exercise, and because it's adaptable to almost any ability level, almost anyone can do it.

People that have trouble with balance and endurance can gain a lot of mileage using the correct walking aid properly, such as a cane, folding walker or rolling walker. Take a walk outside in the sunshine and invite a friend that can use the company, and you've tripled the benefits instantaneously!

Coping with a Chronic Condition (Summarized from Harvard Health Publication - Harvard Medical School)

Anyone living with a chronic condition like post-polio syndrome knows how exhausting it can be. But you aren't helpless. There are things you can do to improve your quality of life, and find the support you need. Here are some suggestions:

Step 1

Learn and educate yourself. The more you know about your condition, the better equipped you'll be to understand what's happening and why. Direct questions to your doctor or nurse not Google. Ask them to refer you to trusted sources of medical information. If your doctor is not agreeable start looking for a new doctor.

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Coping with a Chronic Condition (summarized from Harvard Health Publication - Harvard Medical School) (continued from page 4)

Step 2

Take responsibility for your care, and don't leave everything to your doctor. One way to do this is to listen to your body and track its changes. Home monitoring lets you spot potentially harmful changes before they bloom into real trouble.

Step 3

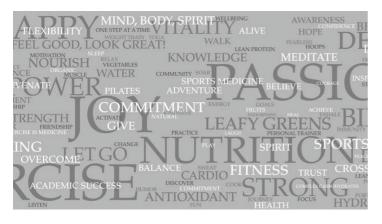
Build a team. Doctors don't have all the answers. Seek out all experts; physiatrist, physiotherapists, nutritionists, speech and language pathologists, occupational therapists, nurses and other health care practitioners.

Step 4

Coordinate your care. In an ideal world, the specialists you see for your heart, your diabetes, and your arthritis would talk with each other every now and then about your medical care. In the real world, this doesn't usually happen. A primary care physician can put the pieces together to make sure your treatments are good for the whole you.

Step 5

Make a healthy investment in yourself. Part of the treatment for almost any chronic condition involves lifestyle changes. Investing the time and energy to make healthy changes usually pays handsome dividends, ranging from feeling better to living longer. Taking into consideration always the limitations of each individual and designing appropriate programs based on means.



Step 6

Make it a family affair. The lifestyle changes you make to ease a chronic condition are good for almost everyone. Instead of going it alone, invite family members or friends to join in.

Step 7

Manage your medications. Remembering to take one pill a day is tough; managing 10 or more is daunting. Knowing about the drugs you take — why you take them, how best to take them, and what problems to watch out for — is as important as learning about your condition.

Step 8

Beware of depression. Dark, dreary moods plague a third or more of people with chronic diseases. Depression can keep you from taking important medications, seeing your doctor when you need to, or pursuing healthy habits. Do let your doctor know if you think you're depressed or heading in that direction.

Step 9

Reach out. Medical professionals aren't always the best reservoir for information about what it's like to recover or live with a chronic condition. To get the real scoop, look for a support group in your area and talk with people who have been through what you are facing.

Step 10

Plan for end-of-life decisions. If the diagnosis of a chronic condition, or life with one, has you thinking about death, channel those thoughts to the kind of care you want at the end of your life. Spelling out whether you want the most aggressive care until the very end, or whether you'd prefer hospice care and a do-not-resuscitate order, can save you and your loved ones a lot of confusion and anguish later on.

Source: http://www.health.harvard.edu/staying-healthy/10-steps-for-coping-with-a-chronic-condition

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

Association Polio Quebec

3500 Decarie Blvd., Suite 219A Montreal, QC H4A 3J5

Contact:

Roxanne Gauvreau Toll Free: 1-877-765-4672 Fax: 514-489-7678 association@polioquebec.org www.polioquebec.org

Post-Polio Network (Manitoba) Inc.

c/o SMD Self-Help Clearing House Suite 204, 825 Sherbrook St. Winnipeg, MB R3A 1M5 Contact: Cheryl Currie Tel: 204–975–3037 postpolionetwork@qmail.com

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 New Brunswick

268 Montreal Ave. St. John, NB E2M 3K6 Contact: Peter Heffernan

peterhef@nbnet.nb.ca www.poliocanada.com

Polio Northern New Brunswick

Bathurst, NB Contact: Claudia LeBlanc sunrayfifty@yahoo.com

Polio Regina

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

nonprofits.accesscomm.ca/polio

Polio PEI

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

Alberta

There are three support groups in Alberta

Calgary

Esther Handricks: 407, 217, 05

Esther Hendricks: 403-813-9583

Edmonton

Glyn Smith: 780-428-8842

Lethbridge

Terry Prince: 403–752–4667 www.polioalberta.ca

Post-Polio Awareness and Support Society of British Colombia 102-9975 4th St.

Sidney, BC V8L 2Z8 Contact: Joan Toone Tel: 250-655-6471 Fax: 250-655-8859 jtoone@ppassbc.com www.ppassbc.ca

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

☐ Mr. ☐ Mrs. ☐ Miss ☐ Ms. Are you a:	☐ Polio Survivor	☐ Healthcare Professiona	l □ Family/Friend □ Othe	
Name:	E-mail Address:			
Address:	City:	Province:	Postal Code:	
Your donation to Post-Polio Canada will hel	p us continue to p	provide education and supp	ort.	
Here is my tax-receiptable donation to Post-Polio Canada of: ☐ \$250 ☐ \$100 ☐ \$50 ☐ \$25 ☐ I prefer to give \$ _				
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□ I would like more information on making a gift in my will to March of Dimes Canada.				
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Name on Card:		Signature:		
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