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**1-800-480-5903**



## A Survivor's Story: Ontario's new Lieutenant Governor, The Honourable David C. Onley

**M**arch of Dimes was thrilled when it was announced on July 10, 2007 that David Onley would be the 28th Lieutenant Governor of Ontario — the first with a disability.

The Honourable David Onley has had a twenty-two year career in broadcasting and was one of Canada's first on-air personalities with a visible disability. He has published a bestselling novel, *Shuttle: A Shattering Novel of Disaster in Space*, and in 2005 was appointed Chair of the Accessibility Standards Advisory Council to the Minister of Community and Social Services.

At age three, His Honour contracted polio and now uses a scooter, leg braces and a cane. Installed on September 5, 2007, he has renewed his commitment to improving accessibility for people with disabilities as part of his mandate over the next five years as the Queen's representative in the province.

His Honour graciously took time out of his busy schedule to sit down with Polio Canada and discuss his long history with March of Dimes, post-polio syndrome and how all people with disabilities can actively promote reasonable accommodation and accessibility in their communities.

**Q: You contracted polio when you were three years old. Do you remember anything of that time and what was the impact on you and your family?**

I contracted polio on Labour Day of 1953 when I was three years, three months old. No, I don't remember anything from that time — I have only heard stories, mostly from my mum, but from my dad as well. But my mum was really the oral historian of the family.



*Lieutenant Governor of Ontario, The Honourable David C. Onley*

My sister Elaine was eighteen months old at the time, so it was a really busy time for the family. At the time we were living in Midland,

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## How massage therapy might help you

**M**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.

Fredericton, New Brunswick resident Ruby Fletcher, a polio survivor, 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 post-polio syndrome for your healthcare provider or massage therapist, please contact Polio Canada by calling 1-800-480-5903, e-mailing [info@poliocanda.com](mailto:info@poliocanda.com) or mailing:*

**Polio Canada,**  
*a program of March of Dimes Canada  
10 Overlea Blvd.  
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 immune system function** – 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.massagetherapy101.com](http://www.massagetherapy101.com)

## Polio Awareness Month Campaigns

**E**very March during Polio Awareness Month, support groups from across the country get involved in their communities to increase awareness of polio, post-polio syndrome and the positive impact of peer support groups.

Events are held across Canada that educate the public and provide support for polio survivors and those who might have survived polio but don't know it — and may now be experiencing post-polio syndrome. More importantly, Polio Awareness Month events help spread the message of “conserve it to preserve it” — helping to mitigate post-polio symptoms.

“We have many new Canadians who

had polio in their country of birth and have since immigrated to Canada — and it is these people I really worry about the very most. They need to know what can happen to them in later years,” says Elizabeth Lounsbury, Polio Canada Chair.

“I often wonder if I had known about post-polio syndrome earlier if I would have ever ended up in my wheelchair — I could have conserved my energy better,” she continues.

Some of the more popular events held include mall displays, presentations with entertainment; a city proclamation; Polio Awareness Month information packages given to local community centres, hospitals, and various healthcare locations; an

interview in the local paper about polio, post-polio syndrome and the local support group and more.

“I don't believe there is a right or wrong way to raise awareness,” says Mike Fogarty, Coordinator of Education and Health Promotion for Polio Canada. “The important thing is that people do something in their community no matter how big or small, because every little bit counts.”

*For a list of activities across Canada or to learn how your group can participate, please contact Polio Canada by calling 1-800-480-5903 or e-mailing [info@poliocanada.com](mailto:info@poliocanada.com)*

# Survivors Speak

## Post-polio and health recovery through Tai Chi Carol Rankmore shares her experience

**E**xercise has never been my thing. On the first gym class of each school year I timidly handed the teacher my annual note from the family doctor, a note which explained that the muscles of my right leg had atrophied due to poliomyelitis as a child and that I was to be excused from physical education classes. To my undisguised relief, this note was never questioned although it was sometimes met with thinly disguised disapproval.

In my fifties after my diagnosis, I read the research on post-polio symptoms along with the various recommendations for managing the condition. There was one piece of advice I knew I'd have no trouble with — do not exercise to the point of fatigue. As I now wore a brace on my foot, used a cane heavily, and had frequent falls from either losing my balance or dragging my right foot, I didn't even consider exercise. To my dismay, however, my muscle strength, balance and endurance diminished steadily for several years.

Ten months ago, my friend and I heard about Health Recovery classes offered through the local branch of the Taoist Tai Chi Society of Canada. (My friend was struggling to recover use of her muscles paralyzed from a stroke.) Neither one of us thought we would be able to do any of the exercises but we decided to watch a class having always seen the Tai Chi movements as graceful and pleasing to the eye. The instructors were extremely welcoming, explaining to us that we would start from where we were physically, that we would rest when we needed to, and that we would progress at our own speed. Several of the participants in the class encouraged us by telling us how far they had come. We decided to start attending the



*Carol Rankmore*

Health Recovery classes. The only benefit I thought I might gain would be a little more ease of movement.

After a few months I found out more about the workings (and non-workings) of my legs than I had ever known. I had never before zeroed in on the muscles and joints of the polio-affected leg — instead I had always just blanketed its condition with the remark “My right leg is weak.” As I attempted to do the basic health recovery exercises, I found out that the right leg avoided working, that certain parts such as my hip and ankle joints seemed rusted in place, and that my right leg veered off to the side when I tried to bend it straight over my foot. I also discovered, however, that I could slowly but successfully nudge a muscle in the direction that I wanted it to go or gradually loosen a rigid joint. Sometimes the initial nudging was all

in my mind (“having the intention” of a movement) but for the first time my right leg was being asked to contribute to the body's support, to move, to push, to straighten. Its efforts were pretty minimal but I was fascinated by the idea of challenging the muscles and interested in the process of accomplishing this.

When I started the classes, my lack of balance was a real problem, so I worked with one hand on the bar. This freed me to attempt the move without worrying about falling. If I needed to, I could have done the exercises from a chair. Standing and moving so that the body is balanced can be learned. After a few months I realized that I no longer needed the bar and that my “daily life” falls due to over-balancing had stopped. I also had learned to stand in a balanced way, distributing the pressure evenly on both feet thus allowing me to stand for a longer time.

After several months of health recovery classes, I realized that my strength had been building. I can always judge my muscle strength and endurance by how far I can walk in a mall - that used to be one of my favourite activities — which I had had to give up with the onset of post-polio syndrome. To Ikea and Square One I now shouted, “Carol is back!”

I then did something which I had thought would be physically beyond my reach: I signed up for beginner classes in which I would learn the 108 graceful movements which comprise the Tai Chi set. I now attend both health recovery and continuing classes as often as I can in my busy life, constantly working on improving my Tai Chi moves and my health.

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## The Honourable David C. Onley

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Ontario, which is about 100 miles north of Toronto and my parents quickly realized that I would be requiring therapy and maybe surgery — so that necessitated some four years later a move to Toronto, and that is where the family has lived ever since.

Obviously, the times were different, this was before the Salk vaccine had been introduced, and it was an obvious huge upheaval for the family. These were in the days before OHIP, but my father was a prudent man and he had taken out some very extensive family health insurance — private health insurance. And that was a huge, huge factor in my family being able to cope with it.

And the rest of it, well, what can one say, a family member becomes sick, you do what you have to do, and that is certainly what they did. I had a tremendously supportive family network, not only of my mother and father, but extended family of grandparents, so it was a supportive extended family network at that time.

**Q: Moving forward to your adult years — when did you first start noticing the signs of post-polio syndrome and has it had a big impact on your life?**

Oh, there is no question at all, I had polio when I was three, but I remember clearly — clearly — the first sense that something was different, not just in terms of my disability, but in terms of the fatigue, I remember it in grade eight. I remember just being tired, and thinking, I shouldn't be tired, but I am tired. By virtue of four successful surgeries, in 1959 and 1963, and by aggressive therapy and just to the extent to which the disease hit me, it affected my arms and legs, but not my torso or neck — I had really recovered to a very real extent. I was a very active

kid — to the point where I didn't use long-leg braces from seven or eight years old until I was twelve and my height and weight overtook my muscle power necessitating using them again. This whole time — I didn't perceive myself as being disabled. And it wasn't until getting into my late twenties and early thirties that I started to realize that this fatigue that I had been feeling actually had something to do with my condition, and that it wasn't psychological.

**Q: Did you have a healthcare provider at the time who told you about post-polio syndrome?**

No, it was reading articles in the newspapers, the very first articles about post-polio fatigue — and this really led to me establishing much closer contact with March of Dimes. March of Dimes had been instrumental in helping my parents when I was young as a support network source and later on in terms of providing financing for a trip to the United States for some experimental therapy. As information about post-polio syndrome and fatigue was coming out through March of Dimes, I re-established the connection which I have maintained ever since. I was on-air at the time with City TV in the mid-eighties when the first real flood of information started coming forward.

I remember speaking to a family doctor, not my main family doctor, and asking him about my fatigue and saying, "well after all, I have polio." And he corrected me saying, "No, you had polio." Like — you had a broken arm, trying to tell me that polio had nothing to do with what I was feeling, when I knew intuitively that it did.

**Q: What do you do to help mitigate your fatigue and preserve your energy?**

I often say to people that my physical

limitations are a factor of my life, but the real limiting factor, much more so than the disability, is the fatigue — that is the real disability. The actual disability, I can measure that, I use a cane, I use braces, I use a scooter, but the on-going disability is the fatigue aspect.

Once you realize that there is a real physiological explanation for what you are feeling, it becomes much easier to say, no, I am going to put my feet up and become a movie aficionado if that is what it takes. And I have gotten to the point of differentiating when I can get in my La-Z-Boy chair, the one with the vibrating and heating part — which I strongly recommend, and just relax, and when I have to say no, its lights off, television off, I am sacking out for an hour.

Whatever it takes to get the patience to understand as survivors, because that is what we are, survivors — anyone who is an adult who has gone through polio and overcome it, really is a survivor. So anything that gives you the psychological tools to let you know that is OK to put your feet up — and that you don't have to explain it, you don't have to rationalize it — it is just the way it is. It is no different from someone who is diabetic needing an insulin shot. A diabetic doesn't emotionally wrench themselves for needing insulin, beating themselves up daily for it, it is totally acceptable. Somehow, as polio survivors, we need to get to that same point. We need to be able to say, "It is called fatigue, it is a legitimate part of the condition of post-polio syndrome, and here is the legitimate response."

**Q: Switching tracks for a minute. It could be said that the overall theme of your career has been accessibility, and certainly your mandate as Lieutenant Governor includes reasonable**

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**accommodation and accessibility for all people with disabilities. What impact will this have in particular for polio survivors and how can they be part of the movement?**

That's a very good question. The role of Lieutenant Governor is different from a politician, in that politicians are the one who promote and enunciate programs and policies and with a stroke of a pen can change the amount of money or commitment to any given project. The Lieutenant Governor on the other hand has very different responsibilities, not the least of which is to encourage and warn the government in terms of overall initiatives. What I hope to do in terms of promoting accessibility is by touring the province of Ontario to show that while yes I use long-leg braces and yes I use an electric scooter to get around — that reasonable accommodation is not some societal burden. Rather, reasonable accommodation and modification just makes good business sense.

There is a significant percentage of the population that has, both visible and

invisible disabilities and there is an aging baby boomer population and their parents who are living longer and healthier, but who need special assistance. Crashing in from the other side is a pending labour shortage. Unless we make a concerted effort to ensure that we have an inclusive, accessible society we are going to be running into some very serious, societal problems — including companies without enough employees. So in that sense, accessibility is not just a civil right, but it is right — and it just makes good business sense. A business that doesn't make reasonable accommodations and modifications will simply be losing business and those who make the extra efforts will be financially rewarded.

In terms of what the people can do themselves, continue to encourage government, continue to patronize businesses and stores that make the effort and give them your feedback — thank them. Let them know you are shopping here because of what they provide.

**Q: Is there any message you would like to send to polio survivors and readers of Polio Canada?**

We have come a long, long way over the last twenty years in sensitizing people to the idea that the fatigue related to polio is a real condition. It is not imaginary, it is not an excuse — an excuse is something you need to apologize for — it is just simply a reality. And the wise thing to do is to make the best of the situation by recognizing what your limitations are. We have to get to the point, and I encourage people to get to the point, to recognize the fatigue aspect in the same way you recognize the physical limitation. Polio survivors are the prototypical “type A” personalities, who are driven, who have been given the message of fighting their way through, go for it, be independent. This is why we have all succeeded. Having overcome polio is a success, so we need to remind ourselves that each and everyone of us who has fought through this condition that we have earned the right to relax. It is not a privilege — it is a right! Be good to yourselves, take care of yourselves.

### Carol Rankmore *Continued from Page 3*

The Taoist Tai Chi® Internal Arts and Methods movement is focused on health - health of the whole body and, in addition, calmness of the mind.

Progress through small steps, individual not group improvement, non-stop encouragement, and a genuine belief in the benefits of this whole body exercise provide an atmosphere and a space where persons with conditions such

as post-polio, parkinson's disease, MS, stroke, or arthritis, to name just a few, can improve their physical health.

The old aphorism “slow but steady” was never more appropriate.

### **We Want to Hear from You!**

Polio Canada is dedicated to preserving the memories of polio survivors, their families and those who cared for them. The history of polio is still being written as global eradication efforts continue, but many already have a story to tell. Men and women who survived polio long ago have unique tales of their personal experiences with a disease that has affected millions worldwide.

We encourage you to send your story to us at: 10 Overlea Blvd., Toronto, ON M4H 1A4, or by e-mail at: [info@poliocanada.com](mailto:info@poliocanada.com). We will add your story to our Web site – and you may be featured in the next issue of **PoliO'Canada!**



**W**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,  
Sidney, BC V8L 5X8  
Tel: 250-655-8849  
Fax: 250-655-8859  
E-mail: ppass@ppass.bc.ca  
[www.ppass.bc.ca](http://www.ppass.bc.ca)

### Southern Alberta Post Polio Support Society Calgary

Toll Free: 1-866-265-5049  
Vern Hamm, President

### Lethbridge and Area

Contact: Juanita Takahashi, President  
Tel: 403-329-9453  
[www.polioalberta.ca](http://www.polioalberta.ca)

### Wildrose Polio Support Society Edmonton

Tel: 780-428-8842  
E-mail: [wpss@polioalberta.ca](mailto:wpss@polioalberta.ca)  
[www.polioalberta.ca](http://www.polioalberta.ca)

### Saskatchewan Awareness of Post Polio

Contact: Ron Johnson  
Tel: 306-343-0225  
E-mail: [rnsjohnson@sasktel.net](mailto:rnsjohnson@sasktel.net)  
[www.geocities.com/sapponline](http://www.geocities.com/sapponline)

### Polio Regina Inc.

Contact: Carole Einfeld  
Tel: 306-761-1020  
Email: [polio@accesscomm.ca](mailto:polio@accesscomm.ca)

### Post Polio Network (Manitoba) Inc.

Tel: 204-975-3037

### Polio Ontario

Over 15 groups throughout Ontario  
Tel: 1-800-480-5903  
or 416-425-3463, ext. 7207  
E-mail: [polio@dimes.on.ca](mailto:polio@dimes.on.ca)

### Association Polio Quebec

Toll free: 1-877-765-4672  
Tel: 514-489-1143  
E-mail:  
[associationpolioquebec@bellnet.ca](mailto:associationpolioquebec@bellnet.ca)  
[www.polioquebec.org](http://www.polioquebec.org)

### Polio New Brunswick

268 Montreal Ave.  
St. John, NB E2M 3K6  
Contact: Peter Hefferman  
Tel: 506-635-8932  
E-mail: [peterhef@nbnet.nb.ca](mailto:peterhef@nbnet.nb.ca)

### Polio Northern New Brunswick Bathurst, NB

Contact: Claudia Godin  
Tel: 506-548-1919  
E-mail: [sunrayifty@yahoo.com](mailto:sunrayifty@yahoo.com)

### Polio PEI

Contact: Stephen Pate  
Tel: 902-566-4518  
E-mail: [stephen\\_pate@hotmail.com](mailto:stephen_pate@hotmail.com)

## You are not alone. Join Polio Canada® now!

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### Please complete the following information:

Are you a:  polio survivor  family/friend  
 healthcare professional  other: \_\_\_\_\_

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

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