



## Survivors Speak:

**Patti Idenouye**

“Life gives you challenges – it’s up to you what you make of them.” This was the message of Patti Idenouye’s grandfather. Like so many polio survivors, Patti was raised to be strong, smile in the face of adversity, and feel she could accomplish anything as long as she put her mind to it. She believes these lessons shaped her life as a healthcare professional, wife, mother – and now grandmother.

Patti was just a baby, only six months old, when she contracted polio in 1949. She remembers nothing of her time in the hospital, including subsequent surgeries and has only fuzzy memories of swimming in the pool at Sick Kids Hospital in Toronto, likely as part of her rehab.

As a result of polio, Patti grew up with a wasted calf muscle in her right leg, a drop foot and her right leg was approximately an inch shorter than her left.



Patti during a recent trip to Kurdistan.

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## Post-Polio Canada

To more accurately reflect the mission of the program, we have changed our name to Post-Polio Canada. The new name more clearly demonstrate the goals of the program - educating polio survivors (PPS), families and healthcare professionals about post-polio syndrome, and providing support to our peer groups across the country.

As always, we will strive to learn and disseminate the latest information about PPS and support Canada’s approximately 125,000 polio survivors as best we can.

For more information, please contact Post-Polio Canada by calling toll-free at 1-800-263-3463 or e-mailing [polio@marchofdimes.ca](mailto:polio@marchofdimes.ca) ■

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## Note from the Chair, Elizabeth Lounsbury



Once again Happy Anniversary March of Dimes Canada. Sixty years! This year our theme for Post-Polio Canada along with the US and many other countries around the world is, "WE ARE STILL HERE".

March of Dimes Canada realizes we are still here and that polio survivors and other people with disabilities still need support. March of Dimes applied for and received a grant from the Ontario Trillium Foundation that allowed many polio survivors and stroke survivors to attend the Festival of International Conferences on Caregiving, Disability, Aging and Technology, (FICCDAT) held in

Toronto in early June. It was a great opportunity for those of us that attended to meet other survivors from around the world to learn together about aging with a disability and for our caregivers to learn about supports that are available to them.

The highlight of the conference for me was the evening jointly sponsored by Post-Polio Health International and Polio Canada. The time we spent together with other survivors from Canada, the US and India. No matter where you are or where you are from when polio survivors get together it is always the same, you are among friends and all have similar needs.

Speaking about polio friends, I have met so many that have become life long friends. Jan Nichols, Audrey King both from Toronto, Joan Headley from St. Louis, Missouri and I spent the day following FICCDAT together on the Toronto Island. We toured the entire island from one end to

the other on our four wheels. We laughed until we cried, and then laughed some more. That is a day that has gone into the memory bank as one never to forget.

We made many memories that day such as lunch together in a beautiful garden. We viewed the wonderful flower gardens and enjoyed stepping back into the 1950's on Ward Island. It was awe-inspiring. The homes and gardens were in most part the same as they were way back then.

We headed back to the ferry, which is free for people in wheelchairs. Being directionally challenged as usual I took a wrong turn and was headed back to where we had come from and had to be chased down.

*Thank you Post-Polio Canada, for making all this possible!*

Elizabeth Lounsbury,



Chair, Post-Polio Canada



BRINGING COMMUNITIES TOGETHER ONLINE

We have created an online community for advocates, donors, family, friends, fundraisers, recipients of support, staff and volunteers called **myMOD.ca**

**myMOD.ca** allows you to participate on your own schedule and exposes all of our supporters to the great things March of Dimes does.

You are a key member of our community and without you we could not make a difference enhancing the independence and community participation of people with physical disabilities.

**Join us at myMOD.ca and share the experience of making a difference.**

## Survivors Speak: *continued from page 1...*

Patti didn't let her disability stop her from achieving her dreams. She went to university and studied as a physiotherapist. She moved to Hamilton, Ontario in 1970 to work at the hospital and steadily worked her way through the ranks, eventually switching to managerial roles, until her retirement in April, 2010.

In the last year, Patti began experiencing some of the symptoms of post-polio syndrome, including a weakening of her hand strength and the need to wear an ankle brace – which is also the result of severe osteoarthritis in her knee. She also occasionally needed to use a cane for balance.

As a healthcare professional, Patti is not one to 'bury her head in the sand' when it comes to her own health. She asked a personal trainer what kind of exercises he'd recommend for a polio survivor. When he couldn't answer her questions, Patti began educating herself about post-polio syndrome and in the process, discovered March of Dimes and the Post-Polio Canada program in November, 2010 and has become involved with the Hamilton Polio Support Group. The group is small, but Patti knows that every person who attends, will in turn educate their families, friends and

healthcare professionals, which helps inform more people about life with PPS.

Patti believes in managing PPS like a chronic disease, and has lived most of her life that way. She also thinks that switching from straight physiotherapy to management likely helped her work as long as she did, and potentially stave off any PPS-related fatigue.

Her chronic illness approach to her health has helped Patti lead an incredibly full life. She travels extensively, spends time with her children, grandchildren and friends and exercises regularly.

"I was such a busy 'Type A' person that I didn't know what I would do when I retired," says Patti. "But it has almost helped me to become more spiritual – I just really feel that I am now doing what I am meant to be doing," she continues.

*To learn more about the Hamilton/ Brant Post-Polio Chapter, or sign up for the quarterly newsletter please contact: Nelly Lee at March of Dimes Canada by phoning 905-528-9432 ext. 233 or emailing [southcentralpp@marchofdimes.ca](mailto:southcentralpp@marchofdimes.ca) ■*

## October is Polio Awareness Month!

Help spread the word! October is Polio Awareness Month around the world, and support groups across the country are doing their part - getting involved in their communities to increase awareness of post-polio syndrome (PPS) and the positive impact of peer support groups.

Events are held across Canada to educate the public about PPS and to remind people that for the estimated 125,000 polio survivors in Canada, the virus is still a very real part of their every day lives. An awareness event allows volunteers from Post-Polio Canada® to reach out to fellow polio survivors in the community and connect them to support services.

Some of the more popular events held include mall

displays, a city proclamation; Polio Awareness Month information packages given to local community centres, hospitals, and various healthcare locations; an interview with the local paper about PPS and the benefits of peer support and more.

"I don't believe there is right or wrong way to raise awareness", says Donna Mackay, Associate Director of National Programs for March of Dimes Canada. "The important thing is that people do something because every little bit counts".

For a list of activities across Canada or to learn how your group can participate, please contact Post-Polio Canada by calling toll-free at 1-800-263-3463 or e-mailing [polio@marchofdimes.ca](mailto:polio@marchofdimes.ca)

## Exploring Pain Management

Pain can affect polio survivors in various ways especially as muscles that were normally unaffected by polio begin to show new symptoms. Muscle strain and joint pain in areas such as the shoulders, legs, knees and ankles are most notable and change over the course of a lifetime – what might have been bearable thirty years ago changes dramatically with post polio syndrome. Different types of arthritis and other conditions, such as osteoarthritis, heart disease, diabetes and normal aging, create a complex diagnosis, where polio patients may feel frustrated. Increased pain may come on so gradually that polio survivors ‘shake it off’ until it becomes an unbearable, debilitating symptom affecting their daily activities, functioning and interaction with others.

Pain affects each person differently; it can be physical, emotional, psychological, social or occupational. Suddenly, the simplest of tasks becomes a huge chore or just aren’t possible anymore. Although pain originates as a self-protective strategy for the body, it may feel that the body’s nervous system is turning against itself. What is most important when managing pain is to keep a goal to preserve a quality of life that can be enjoyed where pain doesn’t become a constant unwelcome companion.

When talking with your healthcare professional about your pain symptoms, it’s important to describe your pain verbally so that different solutions may be explored. Is your pain sharp, intense, burning, gnawing, cramping, shooting, dull, deep or superficial, pinching, numbing, nauseating, stabbing, radiating, throbbing, exhausting or aching? A good idea is to keep an on-going diary of your symptoms. Write down descriptive words about the pain and rate it on a scale of 1 to 10. This will give you a perspective over



several days and weeks as to how the pain is affecting your functioning.

Taking note of when your pain occurs is important – ask yourself how long does it last, when does it go away, what time of day does it occur, what may trigger it, and what are your current methods to relieve the pain. Also, think about what your goals are realistically with treatment or trying new therapies – getting back to specific activities like playing with your grandchildren

or volunteering in your community, sleeping better, maintaining your mood and stress level, or participating in exercise are functional goals to work towards or maintain.

Discuss with your doctor about updating adaptive equipment so that it meets your current needs currently and not what worked twenty years ago. Often technology like bracing, wheelchair seating, orthotics, canes and walkers becomes out-dated or, or may not be used properly, so that mobility is actually hindered rather than helped. Consider having a gait assessment completed when there is a noticeable change in your day-to-day functioning. Also, exercise and physiotherapy routines can become out-dated and won’t help maintain muscle function, or conversely, people may become bored with the same routine. Ask your therapist for new ways to stay engaged with exercises so they are completed properly.

Be open to suggestions or alternative therapies that you may not have considered before, such as acupuncture, warm water therapy, rest, massage, and electric stimulation. Talk with your support group members about different pain management options that they have tried or researched and share what you have learned yourself so that pain does not become the main focus of your day-to-day living. ■

## Research Shows the Impact of Falls in Polio Survivors

As the fall season becomes winter, thoughts of cold, icy weather may often keep polio survivors indoors – the fear of falling can have a big impact on how survivors plan their outings and adapt to their surroundings. Falls are a common problem among the general aging population leading to injuries, loss of independence and activity avoidance.

In 2010, The Journal of Rehabilitation Medicine published, 'Circumstances and Consequences of Falls in Polio Survivors' (Bickerstaffe et al.), reviewing a study that surveyed over 300 polio survivors in the Netherlands, asking survivors to complete a questionnaire about their history of falling. Symptoms of post polio syndrome, such as muscle loss and fatigue, are already risk factors associated with falling in the elderly population and therefore, polio survivors should take precautions and plan ahead to avoid circumstances that might increase the chance of falling.

Noted in the study was that the majority of falls occurred when moving around inside the home, where people are perhaps more comfortable with their surroundings and take bigger risks than they would in unfamiliar territory. For example, some people may use a walker when outside but leave it at the door once they enter their house. Survivors must remember, that just because they are in their own environment, doesn't mean the risk disappears.

Another observation found in the study was that most falls occurred in the afternoon hours. The authors speculate that this is attributed to the polio survivors' muscles fatiguing throughout the day. Strategies around pacing throughout the day to balance weariness and low energy can help manage this risk.

Here are some strategies to address risks of falling as a polio survivor recommended by Canada's Safety Council (<http://safety-council.org/>):

- Talk to your doctor about falls prevention. Have regular vision and hearing tests.
- Take prescription and over-the-counter medications correctly. Keep a medication record and review it regularly with your doctor. Tell your doctor if your medication makes you dizzy or lightheaded.
- Install proper lighting throughout your home. Pay special attention to stairs (with a light switch at both ends) and bathrooms. Use night-lights in the hallways, particularly between the bedroom and bathroom.
- Keep your floor and stairs free of clutter. Avoid the use of scatter rugs.
- Be sure to have at least one handrail (preferably two) on all stairways and steps in your home. Ensure handrails are securely attached and in good repair.
- Check that stairs are in good repair and are slip resistant. If any stairs are broken, have them fixed promptly. Add a strip along the edge of each step in a contrasting color to make it easier to see or use reflective anti-skid treads.
- Take the same precautions for outdoor steps. In addition, arrange to have leaves, snow and ice removed on a regular basis. Use salt or sand throughout the winter months.
- Wear proper footwear. Shoes, boots and slippers should provide good support and have good soles. Avoid loose slippers or stocking feet.
- Install grab bars in all bathrooms, by the toilet and in the bathtub or shower. It's a good idea to have two bars in the tub, one on a side wall and one on the back wall. If you need extra support, consider a bath seat or bench so you can have a shower sitting down.
- Use a rubber mat along the full length in your tub, and a non-skid bath mat beside the tub.
- Use walking aids and other safety devices for extra safety. If you use a cane or a walker, check that it is the right height and that the rubber tips are not worn. Install stainless steel prongs (ice picks) on canes for safe walking in the winter. ■

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® are our member groups, which 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: Reny de Jong

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 – 7 A Ave. North

Lethbridge AB T1H 1A4

Contact: Juanita Takahashi

Tel: 403-329-9453

lethbridge@sappss.com

### Saskatchewan Awareness of Post-Polio

2310 Louise Avenue

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\_ecarole@hotmail.com

nonprofits.accesscomm.ca/polio

### Post Polio Network (Manitoba) Inc.

c/o SMD Self-Help Clearing House

Suite 204, 825 Sherbrook Street

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. 7207

polio@marchofdimes.ca

### Association Polio Quebec

3500 Boulevard Decarie, Suite 263.

Montreal, QC H4A 3J5

Contact: Mado Shrivell

Toll Free: 877-765-4672

Tel: 514-489-1143

Fax: 514-489-7678

associationpolioquebec@bellnet.ca

www.polioquebec.org

### Polio New Brunswick

268 Montreal Ave.

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peterhef@nbnet.nb.ca

### Polio Northern New Brunswick

Contact: Claudia LeBlanc

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### Polio PEI

47 Westwood Crescent

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stephen\_pate@hotmail.com

## YOU ARE NOT ALONE - JOIN POST-POLIO CANADA® NOW!

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Name: \_\_\_\_\_

Address: \_\_\_\_\_

City: \_\_\_\_\_ Prov: \_\_\_\_\_ Postal Code: \_\_\_\_\_

E-mail address: \_\_\_\_\_

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

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

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