



Understanding your Post-Polio Patient: Considerations for Healthcare Professionals

To help spread the word about post-polio syndrome, this article has been created to inform health professionals about post-polio syndrome and the polio survivors they may treat. Take this article to your next appointment with your doctor or any medical professional to spread awareness and have a more satisfying healthcare experience.

As the world approaches the year 2010, knowledge and awareness of polio in the medical community has become a challenge for many

survivors. Often, healthcare professionals do not have a thorough understanding of the symptoms of post-polio syndrome (PPS). Practitioners may not think to ask patients if they may have had polio in the past when treating symptoms occurring 30 to 40 years later.

An important aspect that health professionals must consider is the coping mechanisms polio survivors have evolved to adapt to life after surviving polio. Often characteristics such as an

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March of Dimes Canada Represented at International Post-Polio Conference

In April, Sue Jones, Manager of Volunteer and Chapter Services and Elizabeth Lounsbury, Chair of Polio Canada[®] attended both the Post-Polio Wellness Retreat and the 10th Post-Polio Health International Conference in Warm Springs, Georgia.

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Polio Canada[®] Chair Elizabeth Lounsbury at Warm Springs, Georgia.

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**Toll Free Warmline[®]:
1.800.480.5903**

Information and support for polio survivors, their family and caregivers.

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Note from the Chair, Elizabeth Lounsbury



As Chair of Polio Canada® and a polio survivor myself, I believe some of the most significant work of Polio Canada® is providing education and information on post-polio syndrome (PPS) – not only for those of us who are living with the condition – but perhaps even more importantly, for doctors and other medical professionals. If someone asked me what article I think needs to be in this newsletter, it would be one about PPS addressed to healthcare workers – we need them to better understand post-polio syndrome and what our experiences are like living with PPS on a daily basis.

Wow! Not every day do I have a wish granted, but our wonderful team at Polio

Canada® is doing just that. On the first page of this newsletter you will find an article on “Understanding your Post-Polio Patient: Considerations for Healthcare Professionals” that we can all take along on medical appointments. No longer will we have to fight to prove that our fatigue, pain and weakness are really PPS.

I am so excited just as I know you will be. This is a tool we have long-needed.

You may recall that in the last issue we talked about celebrating Polio Awareness Month in October to coincide with Post-Polio Health International and the European Union polio groups. Their theme “We’re Still Here” is such a good one that we plan to extend it to us as well. I look forward to hearing what your groups are planning to do to raise awareness in your

own areas. If you have some great ideas you would like to share please let one of our team members know. Polio Canada® is all about sharing.

So again, I say - we want to hear from you! Please send us any information you think might be helpful to polio survivors, share your personal polio story with us or let us know what your group is doing to help people living with post-polio syndrome. Together, not only in October – but year-round, we can remind Canada and the world, that “We’re Still Here”!

All the best,

Elizabeth Lounsbury
Chair of Polio Canada®

Help Us Walk ‘n’ Roll Across Canada

In our inaugural year, 2009, we held Walk ‘n’ Roll fundraisers in seven sites in Ontario. Help us expand this great event nationally!

Participants raise pledges from friends, family, neighbours, co-workers, etc., in return for a commitment to walk or roll at a local mall.

The Walk ‘n’ Roll is the perfect opportunity for volunteers or fitness groups to get active, improve their fitness, foster a spirit of community involvement and support a great cause. The event is open to people of all ages and abilities. The proceeds raised help stroke and polio survivors, people with an acquired brain injury and other people with disabilities, and in part fund March of Dimes’ critical programs and services.

In March 2009, Walk ‘n’ Roll events were held in York Region, St. Catharines,



A group of happy Walk ‘n’ Rollers in Hamilton, Ontario

Mississauga, Hamilton, Toronto, Ottawa and Barrie. These events raised \$35,000 and we are confident we can do even better in 2010!

We are scheduled to hold our next Walk ‘n’ Roll the weekend of April 9, 2010.

CALL TODAY!

For more information or to set up your own fundraiser, please call 1-800-263-3463 ext. 7213, or email ehancock@marchofdimes.ca

Finding Reliable Health Information Online

With internet search engines like Yahoo™ and Google™, finding information on virtually any subject is simply a mouse-click away. However, determining whether the information is reliable can be overwhelming, especially when searching for health-related topics. Below are some tips to help you navigate the volumes of health information on the internet – so that you or your caregiver can better advocate for your care.

When searching for health information on the internet, try and determine the purpose of the website. Reliable sites will have a mission statement that explains its aim and why it has published the information. For example, HealthyOntario.com's vision is “advancing healthcare, and enhancing physical and mental health in all life's stages, through a high quality system that is easily accessible for all Ontarians.”

A good website should have complete, in-depth and current information. There should be a date detailing when the information was originally posted and last updated.

Find out who is responsible for the information provided on a website – a reliable site should have healthcare professionals with recognizable credentials as contributors. Blogs and other personal sites like support group forums may provide helpful anecdotal evidence, but this advice shouldn't be acted on without first consulting your healthcare provider.

Be leery of websites that ask you to provide your contact information, have large advertisements, or want you to buy a product.

Finally, make sure that the website is user-friendly and that the information you are searching for can be easily understood.

Also important is whether the website is Canadian-based and therefore provides useful information to Canadians, as any suggested treatment, medication and best-practices must comply with Government of Canada rules and guidelines. If the site is not Canadian, recommended therapies and medicines may not be available here.

Keep in mind that consumer health information on the internet cannot replace the valuable knowledge and expertise of a health professional. Always consult with your doctor or medical practitioner about any questions concerning your health.

*Reference:
Locating Reliable Health Information on the Internet,
Information Session hosted by the Toronto Public
Reference Library; <http://chis.wikidot.com/>*

Where Do I Find More Information?

Here are some reliable Canadian health websites, as listed by the Consumer Health Information Services website. Please see this website for a more comprehensive list: <http://chis.wikidot.com>

- **Canadian Medical Association (CMA)** – This website can be used to search by symptoms, diseases, medication available in Canada and their side-effects. www.cma.ca
- **Health Canada/Sante Canada** – The Federal government's official website; helps Canadians find relevant information about health topics, how to improve your health; contains a Drug Product Database and helpful e-magazines you can subscribe to, such as *Just for You* and *It's Your Health*. www.hc-sc.gc.ca
- **Nova Scotia Health Network** – This site was created to provide reliable health information to Nova Scotians with links on the local and national level. www.nshealthnetwork.ca
- **Healthy Ontario** – An excellent website for health information and services for Ontarians; which also links to the service that will help you find a doctor who is accepting patients. www.healthyontario.com
- **Act Now BC** – This website has helpful information on initiatives, especially geared towards different populations regarding physical activity, nutrition, etc. www.actnowbc.ca
- **Service Ontario** – Check out the health, health services and forms sections for general information regarding information particular to receiving healthcare in Ontario. www.serviceontario.ca
- **Toronto Public Health** – Although based in Toronto, this website provides excellent public awareness campaign posters and flyers; as well as current news releases regarding health. www.toronto.ca/health
- **Medbroadcast by Mediresource Inc.** – A Canadian multi-topic website with information on drugs, diseases, conditions and support groups; supports an 'Ask an Expert' section. www.medbroadcast.com
- **Community Care Resources** – Provides information for local health initiatives and support organizations in the Ontario community. Created by the Community Care Access Centre. www.communitycareresources.ca

“Now and Then” Photo Awareness Contest



To acknowledge International Post-Polio Month in October 2009, March of Dimes Canada is inviting members of Polio Canada® and their family/friends to participate in a photo contest that will help raise awareness of polio and post-polio syndrome by sharing artistic abilities and stories.

Submissions can be one or two photos showing how you have journeyed with polio throughout your life, capturing the moments that have helped define you as a survivor, focusing on ‘Now and Then.’

The winner will receive a prize and the

photo will be published in the next edition of this newsletter.

The final deadline for submissions is September 18, 2009. Each submission must include:

- one or two photos (less than 5 MB via email)
- your name and return address
- title and a short description of photo
- completed Publicity Release Form

Please send your submission via email (preferred) to: lklaponski@marchofdimes.ca

or mail to:

Peer Support Department
March of Dimes Canada
10 Overlea Boulevard
Toronto, ON M4H1A4

If you have any questions please contact Laura Klaponski at lklaponski@marchofdimes.ca or by calling 1-800-263-3463 ext. 7212.

Do you require assistance using a camera? Please contact the DesignAbility® program at designability@marchofdimes.ca or 1-800-263-3463 ext. 7250.



AMG Medical Inc.

March of Dimes Canada is very excited about our new partnership with AMG Medical. AMG Medical has been a national partner with *Rock for Dimes* since May 2009 and will be donating a portion of sales from its Airgo Rollators, Airgo Canes and AquaSense Bath Seats to March of Dimes Canada.

To learn about the products and supplies that are a part of this wonderful program, go to www.amgmedical.com



Recycled Devices at Reduced Prices

MODmobility® is accepting donations and providing assistive devices throughout Ontario.

Visit: www.modmobility.ca
e-mail: info@modmobility.ca
or call: 1-866-976-6632
to learn more.



What to Do if You Fall

If you can get up



- 1 Roll onto your side and push up into sitting position.



- 2 Turn onto your hands and knees. Crawl to the nearest stable furniture, e.g. bed, chair, stool, toilet.



- 3 Place your hands on the seat.



- 4 Place one foot flat on the floor.



- 5 Lean forward and push up with your other foot.



- 6 Sit, rest, and then tell someone you have fallen.

If you are injured

Do not try to get up.

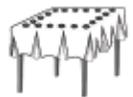
Get help

Drag yourself to a phone. Call 911 and stay on the line.



Keep warm

Use anything that is near: Bedding, a coat, even a tablecloth.



If you are wet

If your bladder “lets go” in the fall, move away from the damp area to keep warm.

Move your limbs

Gently moving your arms and legs will help your circulation, and reduce pressure areas.

Be prepared

- Practice getting up before a fall occurs
- Activate your personal alarm call system if you fall
- Have your phone at table level for easier access
- Find a daily telephone buddy

Choose to be active. Increase your strength, flexibility and balance.



416.338.7600

toronto.ca/health



Understanding Your Post-Polio Patient *Continued from Page 1*

independent sense of self and an emphasis on maintaining a sense of control, are associated with polio survivors. Polio survivors are often seen as resistant to change, especially when it comes to use of adaptive equipment like wheelchairs, walkers or scooters.

Emotions such as anger, frustration and fear are often dominant as polio survivors learn to cope with a post-polio syndrome diagnosis.

As respected professionals, health practitioners are given the opportunity to treat their polio patients with respect and dignity relative to their situation. Polio survivors are often confronted with memories and feelings of their original polio experience as they interact with healthcare providers. Lack of trust in rehabilitation may be a common view, along with feelings of helplessness. On the other hand, survivors may have no memory of their childhood experience with polio and find it hard to deal with being "labeled" with a disability after maintaining a relatively polio-free life.

Understanding the symptoms of post-polio syndrome and their subsequent effect both physically and mentally will help all healthcare providers to provide the best care for their polio survivor patient. Polio Canada®, a program of March of Dimes Canada has fact sheets and information that can help healthcare professionals learn more about PPS and help them better treat polio survivors.

Knowing the symptoms

Symptoms of each patient can vary and this may lead to a misdiagnosis. It is important to keep several important considerations in mind when treating symptoms of post-polio syndrome:

- **Physical and mental fatigue** – Fatigue often leads to decreased arousal, attention and memory. Make sure patients are in a good environment to listen to practitioners' advice and suggestions.
- **Joint and muscle pain and weakness** – May result from overuse, stress and strain of muscle cells that were affected by the original polio virus.
- **Decreased pulmonary function** – May lead to respiratory trouble such as sleep apnea, use of ventilatory support, aggravated breathing problems.
- **Swallowing and coughing difficulties** – As a result of muscle weakness in the pharynx and larynx. This often leads to decreased cough reflex and increased risk of aspirations.
- **Cold intolerance** – Affected extremities have poor circulation, decreasing dexterity, strength and heightening fatigue.
- **Energy conservation** – As a result of continually reduced endurance, patients may need to use wheelchairs, braces, rollators or other assistive devices to pace themselves. It is important to integrate regular rest periods into

daily activities. Polio survivors often experience trouble sleeping and wake feeling unrested.

- **Adverse drug reactions** – Polio survivors may find that certain medications can seriously impair their day-to-day functions. These medications include the following: analgesics, both narcotic and non-narcotic, muscle relaxants, sedatives and hypnotics, use of anesthetics in surgery.

Questions to Ask:

Here are a few important questions to ask a polio survivor needing emergency care:

- Are you currently on any medication?
- Are you adversely affected by any medications (analgesics or sleep drugs?)
- Do you experience unusual fatigue, especially after activity? Do you have to intersperse activity with periods of rest?
- Were your breathing or swallowing muscles affected when you had polio? Do you now have any breathing or swallowing difficulties?
- Do you have problems sleeping? Do you wake frequently in the night?
- Do you experience chronic pain? Is the pain increased with activity or exercise?
- Are you frequently cold?

Warm Springs *Continued from Page 1*

The Roosevelt Warm Springs Institute for Rehabilitation, that was the site of the retreat, was started by President Franklin Delano Roosevelt and was home to people seeking treatment for polio in the early to mid 1900s.

The 2009 Wellness Retreat featured five days of activity sessions, including swimming in "Warm Springs" pools

(originally believed to help ease symptoms of polio), tai chi, yoga, and tours of the area.

Wellness sessions were held on pain control, cardiovascular conditioning, shoulder care and more. There were also sessions for caregivers.

During the evenings, polio survivors shared their stories both of living with polio and its late effects in the form of post-polio syndrome.

After the retreat Elizabeth and Sue attended the 10th Post-Polio Health International Conference which included sessions on understanding poliomyelitis, polio research, bracing and current epidemics.

It was a valuable experience that allowed Polio Canada® to share its expertise on post-polio syndrome, learn from others and reach out to polio survivors from across the globe.



When 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

102-9775 4th St.
Sydney, BC V8L 2Z8
Tel: 250-655-8849
Fax: 250-655-8859
E-mail: ppass@ppassbc.ca
www.ppassbc.ca

Southern Alberta Post Polio Support Society

#7-11th St. NE, Calgary, AB T2E 4Z2
Tel: 403-265-5041
Toll Free: 1-866-265-5049
E-mail: calgary@sappss.com
www.sappss.com

Lethbridge

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

Wildrose Polio Support Society

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

Saskatchewan Awareness of Post Polio Inc.

2310 Louise Avenue
Saskatoon, SK S7J 2C7
Tel: 306-477-7002
www.geocities.com/sapponline

Post Polio Network (Manitoba) Inc.

Contact: Charlene Craig
Post Polio Network (Manitoba) Inc.
c/o SMD Self-Help Clearing House
825 Sherbrook Street
Winnipeg, MB R3A 1M5
Tel: 204-975-3037

Polio Regina Inc.

825 McDonald St.
Regina, SK S4N 2X5
Tel: (306) 477-7002
E-mail: polio@accesscomm.ca
<http://nonprofits.accesscomm.ca/polio>

Polio Ontario

Over 15 groups throughout Ontario
Tel: 1-800-480-5903
or 416-425-3463, ext. 7207
E-mail: polio@marchofdimes.ca

Association Polio Quebec

3500 boul. Décarie, bureau 263
Montréal, QC H4A 3J5
Tel: 514-489-1143
Toll free: 1-877-765-4672
E-mail: associationpolioquebec@bellnet.ca
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

Polio Northern New Brunswick

Contact: Claudia Godin
Tel: 506-548-1919
E-mail: sunrayfifty@yahoo.com

Polio Nova Scotia

Tel: 902-453-6000
admin@abilitiesfoundation.ns.ca
www.abilitiesfoundation.ns.ca

Polio PEI

Contact: Stephen Pate
Tel: 902-566-4518
E-mail: stephen_pate@hotmail.com

You are not alone.
Join Polio Canada® now!

Mr. Mrs. Ms. Miss

Name: _____

Address: _____

City: _____ Prov: _____ Postal Code: _____

E-mail address: _____

Please complete the following information:

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

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

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

I prefer to give monthly \$5 \$10 or Other \$ _____

Please bill me on the 15th or 30th of the month.

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

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1-800-480-5903
www.marchofdimes.ca/polioCanada