PoliO’Canada
National Polio Survivors Network

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Polio Awareness Month a Huge Success

Polio Canada groups from across the country made the second Polio Awareness Month in March a huge success. The phones rang off the hook in the first week of the month as Associated Press and Reuters ran articles nationwide about post-polio syndrome and Polio Canada®. Other news agencies quickly followed suit as Polio Canada® representatives appeared on local, regional and provincial radio and television stations.

Our thanks go to the many dedicated volunteers who helped make this year’s Polio Awareness Month such a success — the group leaders who organized speakers for seminars; the volunteers who manned the booths at local malls; and the friends who donated books on post-polio syndrome to their local libraries.

You too, can spread the word about post-polio syndrome! March may be Polio Awareness Month, but awareness is really a year-round activity. To find out how you can help, contact Polio Canada® at 1-800-480-5903.

Elizabeth Lounsbury
Chair
Polio Canada®

The Late Effects of Polio or Post-Polio Syndrome — Is there a difference?

The late effects of polio and post-polio syndrome are the names given to new health problems affecting individuals who contracted poliomyelitis earlier in their lives. While both are related to polio, they are different in many ways and it is important for survivors and health care professionals to understand how they differ.

Dr. Julian Lo, MD, FRCPC, Physiatrist, West Park Health Care Centre provides this brief explanation:

**The Late Effects of Polio**

The late effects of polio is a general term used to describe new health problems occurring later on in life. These problems occur as a result of many years of living with the residual effects of polio. For example, individuals may experience pain from tendonitis and bursitis due to the imbalances of muscle strength and musculoskeletal deformities. This longstanding stress on the body may also contribute to the development of degenerative osteoarthritis. The late effects of polio is not the same as post-polio syndrome.

**Post-Polio Syndrome**

Post-polio syndrome (PPS) is a neurological disorder characterized by progressive weakness, generalized fatigue and pain occurring many years after the initial polio affliction. Some studies reveal that up to 50% of polio survivors may eventually experience post-polio syndrome.
Randomized controlled trial of strength training in post-polio patients
K. Ming Chan, MD, FRCPC; Nasim Amirjani, MD; Mae Sumrain, BSc; Anita Clarke, BSc; Fay J. Strohschein, BSc
Faculty of Medicine, University of Alberta Muscle & Nerve, March 2003, Volume 27, Issue 3, pp. 332-338

Abstract
Many post-polio patients develop new muscle weakness decades after the initial illness. However, its mechanism and treatment are controversial. The purpose of this study was to test the hypotheses that: (1) after strength training, post-polio patients show strength improvement comparable to that seen in the healthy elderly; (2) such training does not have a deleterious effect on motor unit (MU) survival; and (3) part of the strength improvement is due to an increase in voluntary motor drive. After baseline measures including maximum voluntary contraction force, voluntary activation index, motor unit number estimate, and the tetanic tension of the thumb muscles had been determined, 10 post-polio patients with hand involvement were randomized to either the training or control group. The progressive resistance training program consisted of three sets of eight isometric contractions, three times weekly for 12 weeks. Seven healthy elderly were also randomized and trained in a similar manner. Changes in the baseline parameters were monitored once every 4 weeks throughout the training period. The trained post-polio patients showed a significant improvement in their strength (P < 0.05). The magnitude of gain was greater than that seen in the healthy elderly (mean ± SE, 41 ± 16% vs. 29 ± 8%). The training did not adversely affect MU survival and the improvement was largely attributable to an increase in voluntary motor drive. 

We therefore conclude that moderate intensity strength training is safe and effective in post-polio patients.

Post-polio syndrome and total health status in a prospective hospital study
E. Farbu, T. Rekand and N. E. Gilhus

New loss of function among patients with previous polio is frequently reported and has several causes. All patients referred to the Department of Neurology, Haukeland University Hospital, Bergen, for 13 months during 2000-2001 with diagnosis late effects of polio were examined prospectively to identify their symptoms and loss of function. Eighty-five patients aged 47-91 years with mean of 61 years were included. The most common complaints were pain (44%), muscular weakness (27%), and fatigue (16%). Muscular weakness occurred in lower limbs in 75%, in respiratory muscles in only 5%. Walking in stairs was impaired in 72% and outdoor walking in 65%. Seventeen patients (19%) reported no loss of function.

Post-polio syndrome was diagnosed in 26% of the patients. Polio-related loss of function including cervical and lumbosacral radiculopathies, mononeuropathies and degenerative joint disease were found in an additional 53%. Eleven patients (13%) had distinct nonpolio-related disorders that caused new loss of function. The remaining 8% had a stable condition.

In conclusion, the majority of polio patients who seek hospital, experience a new loss of function because of polio-related disorders. A careful neurological examination is necessary to identify the correct diagnosis and treatment.

Cardiac risk factors in polio survivors
A.C. Gawne, K.R. Wells, K.S. Wilson
Archives Physical Medicine and Rehabilitation, May 2003, Volume 84, pp. 694-696

Objective: To assess the prevalence of dyslipidemia (a condition marked by abnormal concentrations of lipids or lipoproteins in the blood) and other risk factors for coronary heart disease in a sample of polio survivors with and without post-polio myelitis syndrome.

Conclusion: Polio patients have a high prevalence of dyslipidemia. The study sample supports the (United States) National Cholesterol Education Program’s Adult Treatment Panel III statements that hypercholesterolemia (the presence of excess cholesterol in the blood) is underdiagnosed and undertreated. The post-polio population carries a high prevalence of 2 or more coronary heart disease risk factors. Evaluation and rehabilitation of polio patients should include screening for dyslipidemia and education about elimination of controllable risk factors.

Quadriceps muscle strength and voluntary activation after polio
Anita Beelen, PhD; Frans Nollet, MD, PhD; Marianne de Visser, MD, PhD; Bareld A. de Jong, MD, PhD; Gustaaf J. Lankhorst, MD, PhD; Anthony J. Sargeant, PhD
Department of Rehabilitation Medicine, VU University Medical Center, The Netherlands Muscle & Nerve, August 2003, Volume 28, pp. 218-226

Abstract
Quadriceps strength, maximal anatomical cross-sectional area (CSA), maximal voluntary activation (MVA), and maximal relaxation rate (MRR) were studied in 48 subjects with a past history of polio, 26 with...
New Canadian Polio History Book Released:

Walking Fingers: The Story of Polio and Those Who Lived With It
Edited by Sally Aitken, Helen D’Orazio and Stewart Valin

“It is difficult for recent generations to imagine the fear which ‘infantile paralysis’ or poliomyelitis engendered half a century ago. Epidemics developed throughout the world, generally during the summer months, and struck people without warning.” — Dr. Richard Cruess, former McGill Dean of Medicine

Canada’s first major polio epidemic occurred in 1927. Not until the emergence of HIV-AIDS years later would an illness grip the population and preoccupy government and the medical community to such an extent. Between 1927 and 1953 (Canada’s largest epidemic), poliomyelitis tended to increase not only in incidence rate, but also in severity. The development of the Salk and Sabin vaccines was the beginning of the end for a disease the United Nations hopes will be eradicated by next year.

Walking Fingers tells the story of polio, its history and Canada’s pivotal role in the production and mass distribution of vaccine to thousands of children, and the story of determined people and organizations (like the March of Dimes) that raised funds for immunization clinics across Canada in the late 1950s. At the core of the book are 36 poignant stories of polio survivors and their caregivers from all walks of life, including Prime Minister Paul Martin, Jr. Arranged in chronological order (from the date of their infection, ranging from 1923 to 1984), their accounts reveal the evolution of medical treatment in Canada over the last 80 years. Check your local bookstore in April.

If you once had polio and are experiencing new symptoms, it’s important to know you are not alone. There is somewhere you can turn for support, information, and advice from people who can help you understand the late effects of polio, or post-polio syndrome.

Polio Canada’s Coping Strategies
• Don’t get overtired — learn how to pace yourself.
• Remember pain is not gain; conserve to preserve.
• Discuss any exercise program with your doctor or physical therapist before you start. Make sure that he/she is aware of the facts related to PPS and exercise by requesting an Educational Kit from Polio Canada®.

• Don’t get chilled — make it a habit to carry a sweater with you whenever you go out.
• Have periodic muscle strength evaluations by a health care professional who is knowledgeable about post-polio syndrome.
• Eat a nutritious diet, including enough bulk-producing fibre, and watch your weight.
• Maintain a positive attitude toward your health.

Your Post-Polio Action Plan
• Join Polio Canada’s Post-Polio Survivor’s Registry.
• Join the post-polio support group in your area.
• Do some research. Obtain free Educational Kits from Polio Canada®; search your local library and ask your health care professionals.
• Discuss your symptoms with your health care professionals. Contact Polio Canada® and ask us to send them a Health Care Professional’s Educational Kit.
• Ask your health care professional for a referral to a post-polio clinic or medical specialist in your area. Contact Polio Canada® to find the nearest clinic or specialist.
• Attend a local post-polio seminar or conference for the latest information.

www.poliocanada.com
Saskatchewan Awareness of Post-Polio Society Inc.
by Ron Johnson, President

Saskatchewan Awareness of Post-Polio Society Inc. (SAPP) was incorporated in June 1989. In the past, we have sponsored several members to symposia across Canada, from British Columbia to Quebec. Our Saskatoon Post-Polio Society (PPS) Support Group raises a fair amount of money from selling car raffle tickets for the Canadian Paraplegic (Saskatoon) Inc. The money is a necessity, but the exposure we get in our mall locations goes beyond dollars. We reach one to five new polio survivors each time we set up at a mall. Though they may not all take out a SAPP membership, we stay in contact.

Kim Dowds, Manager of Polio Canada®, visited Saskatoon this past November and she and I met with the Saskatoon Meewasin Rotary Club, physiatrists at City Hospital Rehabilitation, Continuing Nursing Education at University Hospital and the physiotherapy and occupational therapy staff at Parkridge Centre.

The Saskatoon PPS Support Group meets monthly. Special annual events include our June barbeque and catered Christmas Supper. A standing joke is that the barbeque will be rained out by a good thunderstorm (I believe we have missed rain twice). In fact, odds are that our Christmas Supper sees a good blizzard as well!

Post-Polio Awareness and Support Society of BC
by Gaile Lacy, Vice President - Mainland

The Polio Canada® meeting and mini-workshop hosted by Kim Dowds, Manager of Polio Canada®, was held in Abbotsford, BC on November 18, 2003. The event was well-attended by members from Mission, Abbotsford, Chilliwack, Maple Ridge, Langley, White Rock, West Vancouver, and North Vancouver.

Many thanks to Miki Boleen of Abbotsford who did a great job of organizing the meeting venue, etc., and to Kim Dowds for taking time to meet with members of Post-Polio Awareness and Support Society of BC (PPASS BC) and to get their feedback.

Our 2004 Polio Awareness Month (March) was a relatively low-key event this year. Our area groups have raised awareness of post-polio syndrome with many mall displays, mini-seminars, and public information and speaking events. Our 2005 plans include a much larger-scale effort that will hopefully tie in with our hosting a special 2005 symposium and the end of Rotary International’s Polio Plus Eradication Program. In the meantime, the Finance and Fundraising Committee of PPASS is working extremely hard to try to find new sources of funding for such events as the proposed 2005 symposium.

Southern Alberta Post-Polio Support Society
by Reny de Jong, President

Southern Alberta Post-Polio Support Society worked on many projects in the past year including:

• an educational booklet for polio survivors and general practitioners that covers diagnosis, treatment, physiotherapy and other information on post-polio syndrome. The booklet is available in English, and information on how to purchase it is on the Polio Canada® Web site at www.poliocanada.com.
• new display boards for mall displays and health care information sessions
• Polio Awareness Month 2003 displays in Calgary
• health care information sessions for over 120 physiotherapists at City Hall, Telus Convention Centre, Market Mall, Senior Resource Fair, Peter Lougheed Hospital, Foothills Hospital, Fanning Centre Rehabilitation Department, and Rockview Hospital
• display and presentation to Federal Pensioner’s National Association
• outreach and contacts with polio survivors

So where do we go from here?
Our plans for this year’s Polio

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www.poliocanada.com
Cross-Country Check-Up  
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Awareness Month have been just as busy. We hosted a day-long public information session on March 27 and we plan to reach out to other communities in southern Alberta including Lethbridge, Medicine Hat, Red Deer, and Hanna.

We are currently working on a booklet for physicians, surgeons and other specialists, as well as one specifically for physiotherapists and occupational therapists.

So, if you think we were busy last year, our 2004 projects are fairly ambitious. However, with the help of our volunteers and members, it is all quite feasible.

Polio Northern New Brunswick  
by Peter Heffernan, Chair

Polio Northern New Brunswick is one of the newest groups of Polio Canada® and we are so excited by the activity to date and our plans for the future.

We now meet monthly in Saint John, held a mall display for Polio Awareness Month, and we’re hoping to have a summer barbeque with other polio survivors from across the province, including our sister group in Bathurst.

Wildrose Polio Support Society, Edmonton  
by Pat Laird, Vice President

This has been a very exciting year for our relatively new support group (established in November 1999). In 2003, we displayed at the Royal Alexandra Hospital during Polio Awareness Month, and received further exposure when Edmonton Mayor Bill Smith declared April 6-12 Polio Awareness Week. In addition to putting up three display boards commemorating the 50th anniversary of the largest polio epidemic in Alberta, we explained PPS and our support group, and displayed photos of the current polio eradication projects. There was also an iron lung for public viewing, courtesy of Rotary Club.

Our members and events have also received positive attention with the local television station and newspaper, including a front-page article in the Edmonton Journal discussing polio, PPS, our support group and our polio physio clinic.

During the 50th anniversary commemoration of the largest polio epidemic in Alberta, we held a banquet and Post-Polio Awareness Conference in Edmonton, September 5-6. Dr. Rubin Feldman, one of Canada’s foremost experts on post-polio syndrome, was the keynote speaker at the Friday evening banquet and recognition ceremony. Our group presented certificates of recognition to organizations and individuals whose involvement in the fight against polio provided hope and support to the survivors and their families.

The Saturday program included three panel discussions. The first dealt with the challenges faced at the time of the epidemic. The second panel discussed medical and technological developments related to polio during the 1960s and 70s, while the third panel dealt with the contemporary polio landscape.

The event was attended by polio survivors, their friends and family and health care personnel who provided front-line care, either directly or indirectly, during the epidemic year of 1953. It was a chance for people to renew old acquaintances and meet new friends. Total attendance for the two days was close to 400.

We are hoping to bring more awareness of PPS to polio survivors, the general public and health professionals in the upcoming year through our partnerships and activities.

Every Mother’s Fear —  
Exhibition on the History of Polio Opens in Edmonton

By Matthew Wangler
Provincial Museum of Alberta

Every Mother’s Fear: Alberta’s Polio Experience explores the varied dimensions of our encounter with one of the 20th century’s most dreaded diseases. The exhibition opened February 7, 2004 at the Provincial Museum of Alberta’s Spotlight Gallery and runs until September 12, 2004.

Few diseases have inspired the sort of terror that polio gave rise to in the first half of the last century. Memories of children with disabilities, school closures, fears of public places, and that most terrifying symbol of polio — the iron lung — have remained vivid for many who lived through polio epidemics. Our cultural understanding of polio is largely defined by that fear, that horror, remembered so well by parents and children who can recall the panic that a stiff neck or a slight flu might arouse during polio season.

The Every Mother’s Fear exhibition in Edmonton seeks to convey a deep understanding of the meaning of Alberta’s polio history. The gallery offers a compelling narrative that extends beyond the particularities of the people and places described, illuminating fundamental dimensions of the human experience of suffering and vulnerability, as well as the remarkable capacity of human beings to respond to crises with intellect, courage, compassion, and even joy.

For more information on the exhibit, please contact Matthew Wangler at 780-453-9100 or visit the museum Web site at www.pma.edmonton.ab.ca.
A Clarification of Nonparalytic Polio

By Ernest W. Johnson, MD

For many years, most physicians have understood that non-paralytic is a loose clinical term implying that neither the patient nor the clinician-examiner reported functional weakness. This determination was often made without the understanding that 50% of the motor units can be lost before a manual muscle grade of 4 occurs. This means that many patients with acute polio were labelled nonparalytic incorrectly but certainly in a well-meaning way.

When the poliovirus is in the gastrointestinal tract of an individual and causes symptoms, the term abortive polio has been used. This is the condition that confers immunity on the individual and also prevents the carrier state. This is why the Sabin (attenuated, live poliovirus) vaccine is preferred in most circumstances. The Salk (inactivated virus) vaccine prevents the invasion of the poliovirus into the central nervous system, but not the poliovirus from living in the gastrointestinal tract.

In those individuals whose immune systems, for whatever reason, permit the invasion of the central nervous system by the poliovirus, a population of anterior horn cells will die. The number of these cells that die will determine whether the clinician will be able to identify paralysis.

In the late 1950s, our electromyographic studies suggested that in all patients who experienced the invasion of the central nervous system by the virus, pain, meningismus, and positive spinal fluid findings revealed abnormal irritability (fibrillation and positive waves) in many muscles that were clinically “normal.”

It should be absolutely understood that patients who were told that they had nonparalytic polio did, in reality, have polio, which affected their anterior horn cells. Now, 30 to 40 years later, these patients are potentially subject to all of the vagaries and insults to the body that affect other persons with post-polio syndrome.

Dr. Johnson is editor of the American Journal of Physical Medicine and Rehabilitation.

Top 10 Signs You May Be Experiencing Post-Polio Syndrome

#10. You require a massage to get to your masseuse.
#9. Your nights are spent moaning and groaning and you sleep alone.
#8. A headache is a welcome relief from the muscle aches.
#7. Your exercise program consists of removing the top of the pickle jar.
#6. You don’t have enough breath to make a good obscene phone call.
#5. You need crutches to get to your wheelchair.
#4. Atrophy isn’t the award you won bowling.
#3. You developed a game show called “Name that Pain.”
#2. You feel like having a nap and you just woke up.

And the #1 sign you may be experiencing post-polio syndrome…

Your Handi-bus driver has to tuck you in at night.

Submitted by Reny and Gerry de Jong, Southern Alberta Post-Polio Support Society (SAPPSS). Reny is the President of SAPPSS and Gerry is her husband and Handi-bus driver.

(Left) Raija Latva-Aro (centre), Chair of the Sudbury and District Post-Polio Chapter of Ontario March of Dimes, shows off her new Dr. Scholl’s shoes to Walmart employees, Christine Gray (l) and Chris Johnston (r). Walmart-Sudbury allows polio survivors to purchase shoes with differing left and right sizes for the cost of a regular pair.
Recent Studies
Continued from page 2
and 22 without post-poliomyelitis syndrome (PPS), and in 13 control subjects. It was also investigated whether, apart from CSA, MVA and MRR were determinants of muscle strength. Polio subjects had significantly less strength, CSA, and MRR in the more-affected quadriceps than control subjects. MVA was reduced in 18 polio subjects and normal in all controls. PPS subjects differed from non-PPS subjects only in that the MVA of the more-affected quadriceps was significantly lower. Both CSA and MVA were found to be associated with muscle strength.

Quadriceps strength in polio subjects was dependent not only on muscle mass, but also on the ability to activate the muscles. Since impaired activation was more pronounced in PPS subjects, the new muscle weakness and functional decline in PPS may be due not only to a gradual loss of muscle fibers, but also to an increasing inability to activate the muscles.

Motor nerve cell ‘factory’ findings may elicit treatments for spinal cord injury, post-polio syndrome
Salk Institute press release, Summer 2003

La Jolla, Calif.—Manufacturing motor nerve cells may someday be possible to help restore function in victims of spinal cord injury or such diseases of motion as Parkinson’s and Lou Gehrig’s disease or post-polio syndrome, a Salk Institute research study has found.

Salk Associate Professor Sam Pfaff and postdoctoral fellow Soo-Kyung Lee reported in a paper in the June 5 issue of Neuron that they constructed a detailed model of how stem cells are prodded, regulated and otherwise encouraged to become not only nerve cells, but specifically motor neurons that the body relies on to move muscles and limbs throughout the body.

The study provides the first blueprint for the cellular factory that produces motor neurons from embryonic stem cells. It could eventually result in new treatments for spinal cord injury, and other diseases that affect motor nerve cells (including post-polio syndrome).

“In the embryonic nervous system, many types of neurons are generated with distinct properties. We used nature as a model to understand how genes interact to develop motor nerves in the spinal cord. This study showed an unusually efficient yield of 60 percent motor nerves,” said Pfaff. “In adults, the growth cues that produce motor neurons from stem cells are gone. The signalling is gone after development is over, denying new, transplanted cells any cues for growth. This model, if it proves effective in humans, may help re-create those cues to help treat these injuries and diseases.”

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UPCOMING EVENTS

Here are just a few upcoming events across the country. For more event listings, check the Polio Canada® Web site at www.poliocanada.com. For details, contact the local support group (contact details are on the back page).

April
5 – Quebec – Montreal
Polio Quebec Inc.
Support group meeting
17 – Saskatchewan – Saskatoon
SAPP
Annual General Meeting with a guest speaker
17 – British Columbia – Vancouver Area
PPASS BC
Display at the Antiques Road Show
18 – Quebec – Montreal
Polio Quebec Inc.
Social event at Scores Restaurant
20 – New Brunswick – Bathurst
Polio Northern New Brunswick
Guest speaker: Dianne Cormier Northrup
Making Choices That Work for You

29 – Saskatchewan – Regina
Polio Regina Inc.
Support group meeting and guest speaker

May
1 – Ontario – Waterloo
Waterloo Post-Polio Chapter –
Ontario March of Dimes Accessibility Expo featuring the new Waterloo Region accessible kneeling bus and product demonstrations and try-outs from Shoppers Home Health Care
Waterloo Adult Recreation Centre from 1:00 p.m. to 4:00 p.m.

3 – Quebec – Montreal
Polio Quebec Inc.
Support group meeting

15 – Ontario – Barrie
Barrie and District Post-Polio Chapter –
Ontario March of Dimes Mini-conference on post-polio syndrome from 9:00 a.m. to 4:30 p.m.

27 – Saskatchewan – Regina
Polio Regina Inc.
Support group meeting and guest speaker

June
(Date TBA) Saskatchewan – Regina
Polio Regina Inc.
Annual picnic at the Neil Balkwill Centre

5 – Quebec – Rouyn Noranda
Polio Quebec
Regional meeting

7 – Quebec – Montreal
Polio Quebec Inc.
Support group meeting

www.poliocanada.com
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
#2-2630 Ross Lane
Victoria, BC V8T 5L5
Tel: 250-477-8244
Fax: 250-477-8287
E-mail: ppass@ppass.bc.ca
www.ppass.bc.ca

Southern Alberta Post Polio Support Society
Reny de Jong
#7 - 11 St. NE
Calgary, AB T2E 4Z2
Tel: 403-265-5041
Fax: 403-265-0162
E-mail: sappss@shaw.ca

Wildrose Polio Support Society
Pat Laird
c/o CPA (Alberta)
305 Hys Centre
11010 - 101 St.
Edmonton, AB T5H 4B9
Tel: 780-992-0969
E-mail: wpss_edm@hotmail.com

Saskatchewan Awareness of Post Polio
Ron Johnson
2310 Louise Avenue
Saskatoon, SK S7J 2C7
Tel: 306-343-0225
E-mail: mjsjohnson@sasktel.net
www.geocities.com/sapponline/

Post Polio Network (Manitoba) Inc.
Carole Einfeld
4264 Wascana Ridge
Regina, SK S4V 2T2
Tel: 306-761-1020
E-mail: bubblecarole@accesscomm.ca

Post-Polio Program
Ontario March of Dimes
10 Overlea Blvd.
Toronto, ON M4H 1A4
Tel: 1-800-263-3463 or 416-425-3463
Fax: 416-425-1920
E-mail: polio@dimes.on.ca
www.dimes.on.ca

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E-mail: polioquebec@hotmail.com
www.polioquebec.org

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Polio Survivors Group
c/o NWT Council of Persons with Disabilities
Doreen Baptiste
5014 47th Street
Yellowknife, NT X1A 1M1
Tel: 867-873-8230
E-mail: dbaptiste@nt.sympatico.ca

Your donation to Polio Canada® will help us continue to provide education and support to polio survivors everywhere.

Here is my donation to Polio Canada® of:  
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