

# POLIO



# POST

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## *President's Report February 2011*

*Christmas* is just a distant memory as we move into the downside of winter- with only February and March left to slog through. *What is my forecast?* I predict that with all this snow that we have accumulated that we are going to need our rubber boots and likely canoes. But, chin up! No mosquitoes yet.

Our annual Holiday Lunch was superb; the weather was excellent, we had a jam-packed house, and the food was exquisite. The best part for me at these gatherings is the camaraderie of our fellow post-polio folks. We had some enjoyable times together this year with the raffle of a marvelous homemade quilt donated by Mrs. Barb Elston, and as usual, our Christmas gift exchange which had fabulous participation by our membership.

We, who had polio, will never forget the devastation of the polio epidemics that swept our country, touched us personally, and left us all with the challenge of post polio syndrome with which we cope today. Our many friendships and the wisdom within our ranks help all of us carry a little lighter load. I am grateful for our fellowship and the many friends that enrich my life.

Despite the fact that, we would like to think that polio is eradicated forever, it really is only a plane ride away. It may not be front-page news, but it should be. There have been two major outbreaks of polio recently, in Tajikistan and in The Congo. Just because we do not see and hear this sad news, doesn't mean others will not suffer and are suffering. But, who better than survivors to tell the story, to ring the bell, so people don't forget?

We must inform others, encourage and support funding for the vaccination of our children against polio. We must support both in word and deed those organizations like the World Health Organization, the Bill and Melinda Gates Foundation, UNICEF, Rotary, and others to eradicate polio through immunization, wherever it may be found.

*This article is reprinted from PPASS News Newsletter*

## **Taking Pains after Surgery**

# **POLIO TIPS 'N' TECHNIQUES**

by Dr. Richard L. Bruno

Polio survivors' most troublesome problem after surgery is pain control. Studies have shown that surgical patients are often under medicated for pain.

Under medication is a serious problem for a post polio patient since two studies have shown that polio survivors are twice as sensitive to pain as those who didn't have polio, increased pain sensitivity apparently being caused by poliovirus killing the body's own morphine-producing cells.

So, while for Anaesthesia the "Rule of 2" is that polio survivors need the usual dose of aesthetic divided by two, the "Rule of 1" for Pain is just the opposite: Polio survivors need two times the dose of pain medication for twice as long.

This rule applies to dental procedures, too, since polio survivors may need two or more times the dose of Novocain. After surgery, polio survivors should have a PCA pump that delivers pain medication on demand when the patient pushes a button, And, doctors need not worry that polio survivors will become addicted to pain medication. Polio survivors are known to be extremely stoic and are not likely to abuse or become dependent upon pain meds, even narcotics.

There is also a "Rule of 2" for recovery after surgery. Polio survivors need at least twice as long to recover as other patients. In keeping with insurance companies' and HMO's wanting to get'em up and move'em out, there is a tendency to get polio survivors up and walking almost immediately after surgery. This is not a good idea. When polio survivors reach the nursing floor, they may still be very sedated. Since polio survivors need a very clear head to be able to control their polio-affected muscles to stand and walk, a fuzzyheaded polio survivor is at serious risk for falling.

Even with a clear head, anaesthetics or other drugs may have temporarily weakened or even paralyzed the cut muscles (like abdominal muscles) that substitute for muscles paralyzed by polio that allow polio survivors to stand and walk. Polio survivors may also have low blood pressure after surgery that could itself cause light-headedness, fainting and falls.

Polio survivors should get up slowly, first sitting up in bed, than sitting with feet

dangling, then getting into a bedside chair with assistance, then standing with assistance and finally walking with assistance and appropriate assistive devices. Gentle physical therapy is helpful to maintain range of motion and for stretching, since polio survivors are prone to developing painful muscle spasms if they are not moving. Physical and occupational therapists need to know that polio survivors have learned to be very aware of what their bodies can and can't do. They are the best judges of when they can safely move, stand and walk.

All hospital staff need be aware that many polio survivors have emotional difficulty merely being in the hospital, having insomnia, anxiety and even have panic attacks. These symptoms are easy to understand when it is remembered that as young children, polio survivors were ripped away from their families and admitted to rehabilitation hospitals for months or even years. Post-polio children underwent multiple surgeries and painful physical therapy, procedures administered often without explanation and certainly without their consent.

Many post-polio patients have had multiple experiences of psychological, physical and even sexual abuse at the hands of hospital staff. Questions or complaints about painful and frightening therapies were not infrequently met by staff anger or punishment. Necessary nursing care could be withheld for no apparent reason. Patients report having been locked in dark closets overnight when they asked questions, spoke out or cried. Many post-polio children were slapped and some were actually beaten with rubber truncheons by physical therapists to "motivate" them to stand-up and walk.

It is not surprising that polio survivors can be terrified of again becoming powerless "patients" who are at the mercy of hospital staff. Nursing staff's appreciation of the childhood trauma polio survivors experienced at the hands of medical professionals, and taking a moment to actually listen and respond to the real needs--both physical and emotional--of the adult post-polio patient, will go a long way toward making the polio survivors feel safe and more comfortable during their hospital stay.

*Dr. Richard L. Bruno is Chairperson of the International Post-Polio Task Force and Director of The Post-Polio Institute and International Centre for Post-Polio Education and Research at Englewood (NJ) Hospital and Medical Center*

NOTE: Our network has recently purchased copies of Laura Halstead's book "Managing Post-Polio A Guide to Living Well with Post-Polio Syndrome" and we have a copy of Dr. Tappers book "Sick and Tired of Being Sick and Tired". Dr. Tapper is a local chiropractor who spoke @ last Octobers meeting. if you are interested in borrowing these books please contact Bob Macaulay @ 474 - 2717. Bob is our book monitor

~ *Zugzwang* [tsu:ktsvan] ~

*How good is your word knowledge? If you think you know the definition to this word then go to our "Members Page" on page 7*

November 9, 2010

## *Congo Republic Declares a Polio Emergency*

By Donald G. McNeil Jr.  
NYTimes.com

An explosive outbreak of polio is taking place in the Congo Republic, with 201 cases of paralysis found in two weeks and 104 deaths, the World Health Organization said Tuesday.

The government in Brazzaville, the nation's capital, has declared an emergency and announced plans to vaccinate the entire population with oral drops three times with help from W.H.O., Unicef and The United States Centers for Disease Control and Prevention.

In Pointe Noire, the port city where most of the cases are concentrated, "We've got two hospitals with hundreds of paralyzed people and many dead," Dr. Bruce Aylward, the W.H.O.'s director of global polio eradication, said in an interview from Geneva. "And a couple of things about this outbreak are different and deeply disturbing."

Polio normally strikes young boys and girls equally, killing no more than 20 percent of those it paralyzes; death ensues when paralysis moves up the spine to the nerves that control the breathing muscles. In Pointe Noire, 85 percent of the cases are in teenagers and adults, most victims are male, and the death rate is much higher.

However, Dr. Aylward said, as his team on its way there learns more, the outbreak could begin to look more typical, albeit still serious. "We've only heard about this in the last seven days," he said. "This is very much under investigation."

Point Noire is unusual in that rebel activity has so cut off its roads that the city is "almost like an island," he said, with few outside children visiting. Routine polio vaccination in central Africa began only in the 1980s and focuses on children under age 5, so few adults are protected. Also, the weakened live virus in the vaccine spreads in the same way the disease virus does, shed in feces. Because mothers and sisters tend to change babies' diapers, they may have picked up that accidental form of protection.

Also, the hospitals are probably seeing only serious cases, making the death rate artificially high. "We're still dealing with the fog of war," Dr. Aylward said. "We don't have exact data."

In 1996, he noted, there was an adult outbreak in long-isolated Albania after a few years in which only children got the modern vaccine.

It will take a few weeks to see whether the intense central African vaccination campaigns of the last few years can fend off this outbreak, Dr. Aylward said. He calls the situation in the Congo Republic an unexpected setback in what had otherwise been a great year in fighting polio.

Nigeria, long Africa's polio hot spot, had a 98 percent drop in cases since 2009, and 14 of the 15 countries with outbreaks of the Nigerian strain snuffed the out.

The Congo Republic outbreak is of an Indian strain that was first found in Angola in 2007 and is creeping north.

Meanwhile, in northern India, another polio epicenter, "it's the middle of the high season, and we've had no cases in five weeks," Dr. Aylward said. The worldwide polio-eradication campaign has \$800 million less than it estimates it needs to finish the job, he said, "and we'll never have an opportunity like this again."

## Quotable

"Now it all comes down to this: *The Final Chapter*, the final push in the fight to rid the world of a killer that has devastated millions of lives. And we all have the historic opportunity—the historic duty to write that final chapter together and eradicate polio forever."

Mr Anthony Lake, Executive Director, UNICEF



POST-POLIO  
NETWORK  
MANITOBA

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## Annual General Meeting

March 29<sup>th</sup>, 2011

1pm – 3pm

The Katherine Friesen Centre

940 Notre Dame Ave

Guest Speaker:

Contessa Benson from CAA Travel Manitoba

Who will speak on Travelling for the Disabled

*Lunch and coffee will be served !*

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**975-3037**

## *How is post-polio syndrome treated?*

reprinted from medicinenet.com

[http://www.medicinenet.com/post-polio\\_syndrome/page3.htm](http://www.medicinenet.com/post-polio_syndrome/page3.htm)

There are currently no effective pharmaceutical or specific treatments for the syndrome itself. However, a number of controlled studies have demonstrated that nonfatiguing exercises can improve muscle strength.

Researchers at the National Institutes of Health (NIH) have tried treating post-polio syndrome patients with alpha-2 recombinant interferon, but the treatment proved ineffective. Another study in which post-polio syndrome patients received high doses of prednisone demonstrated a mild improvement in their condition, but the results were not statistically significant. This, in addition to the drug's side effects, led researchers to recommend that prednisone not be used to treat post-polio syndrome.

In an effort to reduce fatigue, increase strength, and improve quality of life in post-polio syndrome patients, scientists conducted two controlled studies using low doses of the drug pyridostigmine (Mestinon). These studies showed that pyridostigmine is not helpful for post-polio syndrome patients.

In another controlled study scientists concluded that the drug amantadine (Symmetrel) is not helpful in reducing fatigue. And other researchers recently evaluated the effectiveness of modafinil(Provigil) on reducing fatigue and found no benefit.

Preliminary studies indicate that intravenous immunoglobulin may reduce pain, increase quality of life, and improve strength. Research into its use is ongoing.

The future of post-polio syndrome treatment may center on nerve growth factors. Since post-polio syndrome may result from the degeneration of nerve sprouts, growth factors can target these and help to regenerate new ones. Unfortunately, one small study that NINDS scientists participated in showed that insulin-like growth factor (IGF-1), which can enhance the ability of motor neurons to sprout new branches and maintain existing branches, was not helpful.

Although there is no cure, there are recommended management strategies. Seek medical advice from a physician experienced in treating neuromuscular disorders. Do not attribute all signs and symptoms to prior polio. Use judicious exercise, preferably under the supervision of an experienced professional. Use recommended mobility aids, ventilatory equipment, and revised activities of daily living. Avoid activities that cause pain or fatigue that lasts more than 10 minutes. Pace daily activities to avoid rapid muscle tiring and total body exhaustion.

Learning about post-polio syndrome is important for polio survivors and their families. Management of post-polio syndrome can involve lifestyle changes. Support groups that encourage self-help, group participation, and positive action can be helpful. For some, individual or family counseling may be needed to adjust to the late effects of poliomyelitis, because experiencing new symptoms and using assistive devices may bring back distressing memories of the original illness.

## Member's Page

**Do** you have an interesting story to tell? Or do you know any good jokes, inspirational or humorous quotes or poems?

Then your invited to email them to:

postpolionetwork@shaw.ca or mail them to:

Post-Polio Network (Manitoba) Inc.

C/O SMD Self-Help Clearinghouse

825 Sherbrook Winnipeg, MB, R3A 1M5

Member David Morrison suggested this idea:

**“What is your favourite word?**

**What is your favourite way to use it?”**

Send in your favourite word, along with the definition and an example of how to use it.

**Zugzwang** – [tsu:ktsvan] any move, and all moves are equally disadvantageous, typically used in chess. The word could be really used in social services, or government.

(i.e.) *I bet you Mubarak must feel that he has been zugzwanged this week.*

or *When visiting The Motor Vehicles or returning something... as you know you are going to be zugzwanged.*

### Laughter is the Best Medicine

While I sat in the reception area of my doctor's office, a woman rolled an elderly man in a wheelchair into the room. As she went to the receptionist's desk, the man sat there, alone and silent. Just as I was thinking I should make small talk with him, a little boy slipped off his mother's lap and walked over to the wheelchair. Placing his hand on the man's, he said, 'I know how you feel. My mom makes me ride in the stroller too.'

*For Braughan ~ My Daughter*

*She is inventive, original,  
And takes what she wants from life-  
Including many of her mother's clothes.*

*When she comes into a room  
She expects something to happen*

*And, if it doesn't;*

*She takes steps to see that it does.*

*D. Morrison*

*For Taylor ~ My Son*

*Where did he go, that small, fat creature  
Staggering before me?*

*Where did he go, that shy child clutching my hand?  
I feel his bird bones still*

*Still see his face shut against the snow.*

*One day I found he was gone,*

*A stranger in his place,*

*Speaking another language.*

*Strange that I have no recollection of his return.*

*Yet here he is -- prodigal (boy) grown to man*

*And having won a heart, a brain, the courage of a lion.*

*All the lost days brought back in friendship.*

*Now we meet as equals,*

*Having forgiven one another,*

*Having learned to love,*

*Having rediscovered laughter.*

*D. Morrison*

## GREY CUP POOL WINNERS

Glenn Edmonds	Mike Bell	Debbie Essex	Mike Sadowy	Jack Lumbard
Marie Cloutier	James Duma	Christine Coley	Ted Ross	Bruce Bowie
Brenda Wlasichuk	Jack Burton	Rod Tretiak	Thomas Connor	Brian Hanson
Tom Sidebottom	Roberta Hurtig	Kelly Cranswick	Estelle Sabourin	Adam Rankine
Pat Spiring	Donna Machula	Clare Bell	Russell McCreedy	Lissy Kunce

Post-Polio Network (Manitoba) Inc.  
C/O SMD Self-Help Clearinghouse  
825 Sherbrook Street  
Winnipeg, MB, R3A 1M5



## Membership Application Form

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

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

City: \_\_\_\_\_ Province: \_\_\_\_\_ Postal Code: \_\_\_\_\_

Telephone: \_\_\_\_\_ Fax: \_\_\_\_\_ E-mail: \_\_\_\_\_

Please check one or more of the following options:

New Membership - \$10/year

Membership Renewal - \$10/year

I wish to make a charitable donation of \$  Tax deductible receipt will be issued.)

I would like a copy of the newsletter sent to:  
(My doctor, therapist or other individual at the address below)

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

Address: \_\_\_\_\_ City: \_\_\_\_\_ Province: \_\_\_\_\_

Postal Code: \_\_\_\_\_ Telephone: \_\_\_\_\_

Please make cheque payable to the Post-Polio Network (Manitoba) Inc. and mail to the address listed above.

## Membership Renewal

**REMINDER:** It's time to renew your membership for the year 2011 due on January 1st. \$10.00 covers the cost of our newsletter published 4 times a year. A tax receipt will be issued for any other financial donations, as membership fees are not tax deductible.

Thank you. Estelle, secretary

### Post-Polio Network's Privacy Policy

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You may visit our website at [www.postpolionetwork.ca](http://www.postpolionetwork.ca) or email us at [postpolionetwork@shaw.ca](mailto:postpolionetwork@shaw.ca)

If at any time you wish to opt out of any services, simply contact us by phone at (204) 975-3037, or write us at 825 Sherbrook Street, Winnipeg, MB R3A 1M5 and we will gladly accommodate your request.