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# Have a Great Summer



## Message from the President

Our Annual Christmas turkey dinner was enjoyed by all who attended. It was held at Nicky's Café and the staff did a terrific job of catering to us!

Time flies by as we all get a wee bit older. It is already the time to enjoy our Spring Picnic at the home of Mavis and Adam. We thank them in advance for opening up their home to us again.

We do hope the weather will co-operate and be a nice, warm and sunny evening but bring your parkas just in case!



Three years ago, I wrote in the Polio PostBox, 'pretty soon, I will retire'. Well that statement still rings true, 'pretty soon I will retire'. It gets closer every year. I have worked in the same line of business for 52 years and it is time to say, 'I'm done!'

The good news is that our polio group is still going strong. We have a great nucleus of strong members, as it is so important that we continue to support and help each other. We have an excellent executive who work diligently to have scheduled meetings, and open forums from our members are so valuable. Everything seems to be well organized with plenty of great information for us to fall back on, when we have a special concern, pertaining to post-polio.

Both Carole and I hope you all have a healthy, safe and full of fun summer. Looking forward to seeing you all again in September. God Bless you.

*Wilf Tiefenbach*

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## Is Polio Coming Back?

*There has been a lot written in the press lately about polio. In February there were reports of a rare polio-like disease in California. There have been 20 suspected cases of the new infection, mostly in children, in the past 18 months. A detailed analysis of five cases showed enterovirus-68 - which is related to poliovirus - could be to blame. In those cases all the children had been vaccinated against polio.*

*continued on page 2*

### *Is Polio Coming Back continued*

*Symptoms have ranged from restricted movement in one limb to severe weakness in both legs and arms. It makes you wonder if these children will suffer the effects of Post-Polio Syndrome in 40 years. The following is an article by Dr. Bruno:*

### **When “Polio Isn’t ‘Polio’.”**

Remember “polio” merely means “gray” in Greek and refers to neurons NOT covered with insulation (myelin). So “poliomyelitis” simply means inflammation of “gray neurons” in the spinal cord, not the CAUSE of the inflammation.

In India, as cases of “poliomyelitis” due to the 3 polioviruses decreases, the number of cases of “poliomyelitis” caused by other viruses -- e.g., Coxsackie viruses that damage the brain, spinal cord and HEART and Enterovirus 71 that some call poliovirus Type IV because its effects are so similar to the 3 polioviruses -- have skyrocketed to 60,000 cases a year! So, polio vaccination has traded 250,000 cases of paralysis due to the 3 polioviruses in India for 60,000 cases of paralysis due to Coxsackie and other enteroviruses. So, the anti-polio campaign is getting rid of a virus for which we have a vaccine but allowing to run rampant viruses that paralyze and kill at 4 times the rate of the polioviruses for which there will never be vaccines.

So there are many polioviruses other than our friends polioviruses Types I, II and III that cause spinal cord and brain neuron damage plus additional symptoms different than Types I, II and III. These California and UK cases are apparently due to Enterovirus 68, (which causes a respiratory illness plus spinal cord damage.

By the way, British researcher the late Betty Dowsett has evidence that Chronic Fatigue Syndrome (or ME in Canada and the UK) is cause by a Coxsackie virus damaging the brain activating system, as does the poliovirus.

**If you fall, I'll be there.**

*- Floor*

*Polio is on the rise. The following appeared in the New York Times:*

### **Polio Spreading at Alarming Rates, World Health Organization Declares**

May 5, 2014

*By Rick Gladstone*

The World Health Organization on Monday declared the spread of polio a public health emergency of international concern.

Alarmed by the spread of polio from conflict zones in three continents, the agency issued the health alert to try to stop the further spread of the disease, a paralyzing virus once thought to be nearly eradicated.

An emergency committee convened by the organization announced in Geneva that three countries — Pakistan, Syria and Cameroon — had allowed the spread of the virus and should take extraordinary measures to stop it.

The committee announced via a telephone news conference from its Geneva headquarters that all children in these countries should be inoculated or reinoculated and all travelers from these countries should be reinoculated and should carry proof in the form of an internationally recognized document.

*Maria Cheng of the Associated Press writes:*

Experts are particularly concerned that polio is reemerging in countries previously free of the disease, such as Syria, Somalia and Iraq, where civil war or unrest now complicates efforts to contain the virus. It is happening during the traditionally low season for the spread of polio, leaving experts worried that cases could spike as the weather becomes warmer and wetter in the coming months across the Northern Hemisphere.

The vast majority of new cases are in Pakistan, a country which an independent monitoring board set up by the WHO has called “a powder keg that could ignite widespread polio transmission.”

Dozens of polio workers have been killed over the last two years in Pakistan, where militants accuse them of spying for the U.S. government. Those suspicions stem at least partly from the disclosure that the CIA used a Pakistani doctor to uncover Osama bin

Laden's hideout by trying to get blood samples from his family under the guise of a hepatitis vaccination program. U.S. commandos killed the al-Qaeda leader in May 2011 in the Pakistani town of Abbottabad.

At the end of last month, there were 68 confirmed polio cases worldwide, compared with just 24 at the same time last year. In 2013, polio reappeared in Syria, sparking fears the civil war there could ignite a wider outbreak as refugees flee to other countries. The virus has also been identified in the sewage system in Israel, the West Bank and Gaza, although no cases have been spotted.

*It must be frustrating for organizations like Rotary International and the Gates Foundation to have worked so hard and spent so much money trying to eradicate polio and being so close to achieving their goal, to have this kind of set-back. The one thing that we can do is to encourage everyone you know to get their children and grandchildren vaccinated. Polio is only one plane ride away from coming to Canada.*

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*Reprinted with permission from Dr. Bruno*

## **Slow Guts and Polio Survivors**

*Dr. Richard L. Bruno, Chairperson, International Post-Polio Task Force and Director, The Post-Polio Institute, International Centre for Polio Education*  
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<<I have trouble swallowing but no one believes me. Food doesn't get stuck in my throat, but seems to lodge somewhere behind my breastbone. I had a normal swallowing study and the doctor doesn't believe I have a problem. But, food sticks and it hurts when it does! Do other polio survivors complain about this?>>

They surely do. It's hard enough to "swallow" having PPS without doctors refusing to believe you're having trouble swallowing.

It's true that most Post-Polio Institute patients report having only occasional, mild problems swallowing. The problem is usually high in the throat: not being able to get down pills, largish pieces of meat and, maybe even more often, difficulty clearing their own

secretions. A barium swallow study (where you eat and drink food containing barium and "video" is taken with an X-ray camera) usually shows mild muscle weakness in the throat or sometimes, as in your case, no problem at all. This "negative" finding is just like a muscle test of an arm or leg not showing weakness in the doctor's office, even though you feel weaker or even stumble at the end of the day as you get more tired.

Polio survivors also have swallowing problems below the throat. What you describe -- food getting stuck behind your breastbone in the esophagus (the tube connecting the throat to the stomach) is not uncommon in polio survivors. The muscles of the throat and esophagus should contract in a coordinated sequence, like a snake, to move the food downward and into the stomach. Food gets stuck when the esophagus doesn't contract and its muscles go into spasm, not unlike when back muscles go into spasm when your leg muscle are too weak to hold you up. Food usually gets stuck right behind the top of the breastbone. And, yes, stuck food is painful... and scary! Even if food does make it down to the bottom of the esophagus, in some polio survivors the "valve" at the bottom of the esophagus doesn't open and prevents food from entering the stomach, a condition called *acalasia*.

Why do polio survivors have trouble with muscles from their throats to their stomachs? Fifty years ago, Dr. David Bodian discovered that every polio survivor had some damage to neurons in the brain stem, the so-called "bulb" of the brain. When brain stem damage was severe and "breathing neurons" stopped working, "bulbar polio" was diagnosed. But the most common bulbar polio symptom was trouble swallowing not trouble breathing, because the poliovirus also damaged the bulbar neurons that control the vagus nerve, the nerve that activates and coordinates muscles from your throat down to your stomach.

Unfortunately, 99% of gut doctors have never seen food get stuck in the esophagus and don't know what to do about it. We've found that a low dose of the muscle relaxants Klonopin and Bentyl, taken 30 minutes before eating, can relax the esophagus and allow food to slide down to its intended destination.

But wait! There's more! Vagus damage likely explains our 1985 Post-Polio Survey finding that diarrhea, colitis, ulcers and constipation are as much as six times more common in polio survivors than in the general population. Some polio survivors report that their stomachs don't empty, a condition called gastroparesis. Others have their intestines abruptly stop moving -- as a side effect of medication, after surgery, a gall bladder attack, or for no reason at all -- a condition called paralytic ileus. Often, the muscles of the stomach and intestines get moving again on their own. But, sometimes the drug Reglan is needed to jump-start the stomach and intestines. Reglan can have bad side effects, since it enters the brain. DOMPERIDONE, a drug that does not enter the brain (or the US, so you have to buy it from Canada) is the better choice if you can take it by mouth). Also, polio survivors need to try to prevent gut slowing by being careful when taking drugs that are anti-cholinergic (drugs that have dry mouth as a side effect) since they block the activity of the vagus nerve.

Finally, polio survivors who have a chronic sore throat, husky voice, or burning in the chest should be evaluated for reflux by an ENT doc, who'll look at the upper throat and vocal cords, and a GI doc, who may do a gastroscopy to look down your esophagus and into your stomach. If you have a gastroscopy, make sure that the doctor goes light on the anesthesia and uses the anesthetic Propofol, since it's short-acting and allows polio survivors (usually) to wake quickly.

<I>Dr. Richard Louis Bruno director of The Post-Polio Institute and International Centre for Polio Education: E-mail [postpolioinfo@aol.com](mailto:postpolioinfo@aol.com)<I>

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**Setyourbrowserto: <http://www.PostPolioInfo.com> for MIA FARROW'S POST-POLIO LETTER.**

***Click the menu on the left side of the page for information about the cause and treatment of PPS, including surgical and dental precautions and The Post-Polio Library.***

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*Reprinted with permission from Dr. Bruno*

## Constipation Nation

***Dr. Richard L. Bruno, Chairperson, International Post-Polio Task Force and Director The Post-Polio Institute and International Centre for Polio Education***

I've gotten a bunch of e-mails on constipation. Polio survivors have slow guts, thanks to poliovirus-damage to the vagus nerve that should fire to move food from your mouth all the way through to the other end (see articles in The Post-Polio Library at <http://www.postpolioinfo.com/>). Here are some things about constipation you may not know:

1) Constipation isn't one thing. Sometimes poo gets stuck in the ascending colon on the right side of your belly, sometimes in the transverse colon across the top of your belly, sometimes in the descending colon on your left side or in the rectum. So, you have to focus treatment where constipation occurs.

2) Not all laxatives work in the same way or in the same place:

- Roughage and Senna irritate the whole colon to make it move;
- Miralax and Colace add water to your poo to "lubricate" the colon;
- Dulcolax stimulates the ASCENDING colon if you get plugged there;
- Psyllium absorbs water and expands to stop diarrhea but also combines with sludge to make

one single poo (and not lots of little “rocks”) that itself stimulates the colon naturally to make things move. (You should plan to sit on the throne after eating to take advantage of the natural stimulation caused by food in the colon);

- Suppositories are for rocks in the lower colon and rectum.

3) If nothing is moving, your stomach isn't emptying or the colon won't respond to the above treatments, there is a great drug -- domperidone (sadly NOT Dom Perignon) -- that directly turns on the muscles that empty the stomach and move the colon. Domperidone has no side effects and doesn't enter the brain (as does Reglan, which can cause Parkinson's-like shaking and should not be used by polio survivors). Of course, the FDA hasn't approved domperidone even though it's been sold over the counter for 20+ years in Europe for nausea during pregnancy! (Apparently, not enough payola to the FDA.) You CAN get domperidone from Canada with an Rx.

So, there's a short course on pushing poo. You may need a combination of treatments or different treatments at different times for different types of constipation.

Keeping a poo diary (quantity, quality and time of day) that includes symptoms and what laxatives you've taken is vital so that you can identify your natural rhythm, where things get stuck and what you need to take to make things work.

Happy eating (and the other thing).

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## At the Meetings

**November 2013** – Our November meeting, which was our Christmas party, was held November 27, 2013 at 5:00 p.m. at Nicky's Café at Eighth Avenue and Winnipeg Street. We all enjoyed a turkey dinner with all the trimmings and were able to visit with fellow members after the meal.

**February 2014** - Living With a Disability conference March 31, 2014. Ivan Jorgensen spoke about the conference that will be put on by The March of Dimes Canada. Ivan moved that we have a booth at the conference. Ivan distributed an updated Polio

Regina brochure. We discussed materials for the booth and urged members to bring relevant materials to the next meeting. David Cotcher led the open forum. This was a general discussion with everyone having a chance to tell us about their experiences in the last year.

**March 2014** – Our March meeting was our annual general meeting with the election of officers. The following are the Executive Officers of Polio Regina Inc. for 2014-2015:

**President** – Wilf Tiefenbach

**Vice-President** – Carole Tiefenbach

**Secretary** – Ivan Jorgensen

**Treasurer** – David Cotcher

**Phone Co-ordinator** – Carole Tiefenbach / Blenda Ramsay

**Archivist/Librarian/Web Master** – Dr. Mavis Matheson

**Post Box Editor** – Ivan Jorgensen

On behalf of the nominating committee, Mavis Matheson presented flowers to the members of the executive in appreciation of their work for Polio Regina.

**Open forum:** Zenny Burton led the open forum. The subject was “Dentistry and Post-Polio Syndrome”. Zenny talked about the different types of polio and the risks that dentistry can cause people with Post-Polio Syndrome. She talked about the frustration of trying to get dentists to take it seriously and the difficulty of getting a knowledgeable second opinion. Other members shared their experiences with dentists. An article about dental surgery by Dr. Bruno is included in this issue.

**April 2014** - The Spring picnic will be held on May 29th at 5:00 p.m. at 15 Trudeau Bay. Carole and Wilf Tiefenbach will look after getting the food.

**Open Forum:** The open forum was a discussion of the “Living with a Disability” conference by the members who attended the conference. A summary of the presentations is in this issue.

# PREVENTING COMPLICATIONS IN POLIO SURVIVORS UNDERGOING DENTAL PROCEDURES

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Set your browser to:

<http://members.aol.com/ppsend/pps.html>  
for the PPS Library and all of our papers describing our research and treatment of PPS.

Unfortunately, only a handful of specialists treat Post-Polio Sequelae (PPS) - the unexpected and often disabling fatigue, muscle weakness, joint pain, cold intolerance, and swallowing, sleep and breathing problems - occurring in America's 1.63 million polio survivors 40 years after their acute polio.<sup>1,2</sup> However, all medical professionals need to be familiar with the neurological damage done by the original poliovirus infection that today causes unnecessary discomfort, excessive physical pain and occasionally serious complications with surgery. This is a brief overview to inform patients and professionals about the cause and prevention of complications in polio survivors undergoing dental surgery.

## PRE-OPERATIVE PREPARATION

The pre-operative period is the most important, since it is when polio survivors must establish communication with their dentist or oral surgeon. Patients need to ask the dentist to read this article and the references cited. Then, patients must meet with the dentist (and anesthesiologist, if one will be involved) to discuss in detail patients' complete polio and general medical histories and the problems that may arise before, during and after the procedure.

**The Psychology of Polio Survivors.** Polio survivors often have difficulty with any medical procedure, even dental surgery. They may have 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 underwent multiple surgeries and painful physical therapy, procedures administered often without explanation and certainly without their consent.<sup>2,3,4</sup> Questions or complaints about painful and frightening procedures were not infrequently met by staff anger or even physical abuse.

It is not surprising that polio survivors can be terrified of again becoming powerless patients at the mercy of medical professionals. The dental staff's appreciation of the childhood trauma polio survivors experienced, and taking a moment to actually listen and respond to the real needs of the adult post-polio patient, will go far toward making the patient feel safer and more comfortable.

**Breathing and Swallowing.** We recommend that all polio survivors have pulmonary function studies before surgery, especially if a gaseous anesthetic will be used.<sup>5</sup> This is vital for those who had bulbar polio, which affected the respiratory centers in the brain stem, whether or not patients used a respirator or an iron lung following the acute polio. Even patients who have (or had) neck, arm or chest muscle weakness or have swallowing problems should have their lung function tested, since even these individuals may have difficulty breathing or clearing secretions (swallowing saliva) during or after the procedure. Polio survivors with a lung capacity below 70% may need respiratory therapy or even a respirator after surgery if a gaseous anesthetic was used.<sup>1</sup> Of course, polio survivors who use a respirator during the day or at night must discuss their respirator use in detail with their dentist, anesthesiologist, and their own pulmonologist before any surgery.<sup>5</sup> It should also be noted that breathing and swallowing can be compromised in those who had bulbar polio or chest wall paralysis, not only by anesthetics, but also merely by reclining in the dental chair. Polio survivors often have difficulty breathing or swallowing saliva when reclining. A comfortable reclined position must be identified before the procedure begins. And the

procedure may need to be interrupted frequently to allow the patient to breath fully and to swallow. Also, a number of polio survivors have experienced severe neck or back pain following lengthy procedures, since their muscles spasm easily when placed in unusual or awkward positions, including hyperextension (extreme bending backward) of the neck.

**Physical Assistance.** Transferring to and from the dental chair are important considerations for polio survivors who have long-standing paralysis, newly weakened muscles or joint instability and pain due to PPS. Some patients may not be able to stand or pull themselves into the dental chair. Thus, polio survivors must ask for help in transferring, especially after the procedure when they are still partially anesthetized.

Polio survivors, who typically never ask anyone for help under any circumstances, need to find a phrase with which they are comfortable that will communicate their needs. Long explanations about having had polio or PPS or the specifics of which muscles are weak or paralyzed are not necessary. For example, a simple “My legs (arms) are paralyzed and I can’t get into/out of that chair. I will need help” should suffice. This phrase may have to be repeated before the polio survivor will be assisted.

If the professional replies, “Oh, I bet you can do it by yourself if you try!” or “Don’t expect me to lift you,” an appropriate response is “I cannot get into the chair. Please ask someone else to help me or let me speak to the doctor.” A pleasant but steadfast refusal to do difficult or dangerous transfers is the polio survivor’s best defense against injury before or after the procedure.

**General Anesthetics.** Polio survivors are exquisitely sensitive to anesthetic. It has been known for 50 years that the poliovirus damaged the area of the brain stem - called the reticular activating system (RAS) - responsible for keeping the brain awake.<sup>6,7</sup> Because the RAS was damaged in those who had paralytic and non-paralytic polio, a little anesthetic goes a long way and lasts for a long time.

For example, the pre-operative medication used to “calm” patients - often a combination of Valium™ and Demerol™ - may by itself put polio survivors to sleep for 8 hours. Such excessive and prolonged sedation can also occur when I.V. Valium™ is used alone. Add

to a pre-operative “calming cocktail” an intravenous anesthetic (like sodium pentothol) or a gaseous anesthetic, and polio survivors have been known to sleep for several days. In addition, polio survivors with respiratory problems may have trouble clearing gaseous anesthetics. A number of our patients have awakened from anesthesia on a respirator in I.C.U. to the frightened faces of their family, surgeon and anesthesiologist several days after surgery.

Here is the first of rule of thumb - we call them “Rules of 2” - for polio survivors’ having surgery:

## **GENERAL ANESTHETIC RULE OF 2:**

Polio survivors need the typical dose of general anesthetic divided by 2.

This first “Rule of 2” is certainly not intended to dictate the dose of anesthetic, but merely to remind oral surgeons that polio survivors need much less anesthetic than do other patients. This does not mean that a given polio survivor might require less than 1/2 the typical anesthetic dose, or that another won’t need more anesthetic. As always, the dose of anesthetic must be individually adjusted (for body weight, lipid space, etc.) and be adequate to keep patients under during surgery but not cause them to sleep for a week.

**Nerve Blocks.** Unfortunately, polio survivors also have problems with local anesthetics. While polio survivors are more sensitive to general anesthesia, they seem to require more local anesthetic. Two research studies have shown that polio survivors are twice as sensitive to pain as those who did not have polio, apparently as a result of poliovirus-damage to endogenous opiate-secreting cells in the brain (paraventricular hypothalamus and periaquiductal gray) and spinal cord (Lamina II of the dorsal cord).<sup>6,7,8</sup>

## **LOCAL ANESTHETIC RULE OF 2:**

Polio survivors need 2 times the typical dose of local anesthetic.

However, the injection of a local anesthetic can result in both pain-conducting and motor nerves being anesthetized. Polio survivors are very sensitive to anything that further impairs their poliovirus-damaged motor neurons, and a local anesthetic

may cause facial, tongue and pharyngeal (throat) muscles to be paralyzed for many hours, impairing swallowing and breathing, especially in those who use accessory (shoulder and upper chest) muscles to assist their diaphragm in breathing.

Also, polio survivors sometimes have adverse reactions - e.g., tachycardia, panic attacks - to the epinephrine that is typically included with the local anesthetic to cause vasoconstriction (narrowing of blood vessels) to prevent the spread of the anesthetic. If additional doses of local anesthetic are required, a reparation without epinephrine may be advisable.

Regardless of whether a local or general anesthetic is used, the following applies:

## **POST-ANESTHETIC RULE OF 2 :**

Polio survivors need 2 times as long to recover from the effects of any anesthetic.

Even applying the “Anesthetic Rules of 2” polio survivors may be very sedated, if not asleep, or have their breathing and swallowing impaired for many hours after the surgery. This is one of the reasons why in-office surgery for complicated dental procedures is not advisable for polio survivors. Sleeping, excessively sedated or facially paralyzed polio survivors cannot be expected to return home and take care of themselves after surgery, since sedation-impaired coordination makes falling likely and complications may go unnoticed. In spite of HMO pressure or usual practice, **NO POLIO SURVIVOR SHOULD HAVE IN-OFFICE OR SAME-DAY SURGERY** except for the most simple procedures that require only a small dose of local anesthetic that does not compromise breathing or swallowing.

**Blood and Guts.** There are yet additional concerns. Polio survivors with muscle atrophy, especially in the thigh muscles, will have a smaller blood volume than would be expected for their height or weight. Therefore, excessive bleeding during surgery may be more of a problem. Prolonged gum bleeding is also more likely since many polio survivors are taking the maximum dose of non-steroidal anti-inflammatory drugs. The dentist should be informed before the

procedure of all medications the patient is taking, including over-the-counter preparations.

Also, polio survivors can be sensitive to atropine-like drugs used to dry secretions during surgery.<sup>9</sup> Atropine-like drugs also slow the gut, and polio survivors may be excessively constipated after surgery or, rarely, actually have their intestines stop moving (paralytic ileus) for a period of time. These problems can be treated symptomatically as they would in someone who did not have polio.

## **POST-OPERATIVE CARE**

**Pain.** The single most troublesome problem after surgery is pain control. A number of studies have shown that many surgical patients are under medicated for pain. Under medication is a serious problem for post-polio patients since they are twice as sensitive to pain as those who did not have polio.<sup>8</sup>

### **RULE OF 2 for PAIN:**

Polio survivors need 2 times the dose of pain medication for 2 times as long.

Since polio survivors are known to be extremely stoic, they are not likely to abuse or become dependent upon narcotics.

**Vomiting.** Another post-op problem related to brain stem damage is vomiting. As in anyone who receives a general anesthetic, polio survivors can develop nausea and vomit. However, polio survivors are more apt to faint (have vasovagal syncope and even brief asystoles) when they attempt to vomit.<sup>9</sup> It is very important that postoperative emetic (anti-vomiting) control be discussed and administered before the procedure and that additional medication is provided as needed post-operatively.

**Choking.** As has been described, polio survivors may not be able to clear secretions, may choke (or feel like they are choking) and even aspirate if they are lying on their backs, still half asleep, as the anesthetic is clearing. Polio survivors’ secretions need to be monitored after the procedure and they should be positioned on their side so that secretions can drain.<sup>10</sup>



## RECOVERY

When polio survivors do awaken from a general anesthetic they may still be twice as sedated as are other patients. Since polio survivors need a very clear head to be able to control their weakened, polio-affected muscles to stand and walk, a fuzzy-headed polio survivor is at serious risk for falling. Polio survivors may also have low blood pressure after surgery that could itself cause lightheadedness, fainting and falls.

### **RULE OF 2 for RECOVERY:**

Polio survivors need 2 times longer to recover than do other patients.

Under any circumstances, polio survivors should get up slowly after the procedure, first sitting up, then getting into a chair with assistance, then standing with assistance and finally walking with assistance and appropriate assistive devices. Polio survivors have learned to be very aware of what their bodies can and cannot do. They are the best judges of when they can move, stand and walk safely.

Post-Op PPS? The 1985 National Survey of Polio Survivors has shown that emotional stress is the second most frequent cause of PPS (physical overexertion being the first).<sup>4</sup> Certainly, there are few emotional or physical stressor more potent than surgery. So, polio survivors should expect some increase in fatigue and muscle weakness resulting from the combination of the physical and emotional effects of the surgery, anesthesia and other medications. However, patients should be reassured that only a small handful of post-polio patients permanently lose function after surgery. Strength or endurance lost after surgery are typically recovered. Polio survivors need to remember:

### **RULE OF 2 for FEELING BETTER:**

Polio survivors need 2 times longer to feel “back to normal” again.

## CONCLUSION

All of the “Rules of 2” are suggestions for polio survivors, the dentist and oral surgeon; they are not intended as substitutes for specific information about

the individual patient, communication between doctor and patient, and clinical judgment. All polio survivors must be evaluated and managed according to their individual needs. Please take the time to read the following references so that you will be fully knowledgeable about and be able to help meet polio survivors special needs before, during and after dental procedures.

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- Bruno RL. Preventing complications in polio survivors undergoing dental procedures. PPS Monograph Series. Volume 6(1):1-8. Hackensack: Harvest Press, 1996.

## **POLIO SURVIVORS' DENTAL PROCEDURE CHECKLIST**

Give PPS articles to dentist and discuss:

- Pre-op lung tests and breathing problems.
- NO same day surgery!
- Medications taken and possible excessive bleeding.
- Positioning in the chair during the procedure.
- Difficulty clearing secretions during and after the procedure.
- Lower dose of pre-op calming medication.
- Lower dose of general anesthetic.
- Longer-term sedation with general anesthetic.
- Post-op anti-vomiting medication.
- Higher dose of local anesthetic.
- Paralysis of face, throat and tongue muscles with local anesthetics.
- Not standing or walking until you are fully awake and able.
- Increased dose and duration of pain medication

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### **My inconclusive travel plans for 2014**

I have been in many places, but I've never been in Cahoots. Apparently, you can't go alone. You have to be in Cahoots with someone.

I've also never been in Cognito. I hear no one recognizes you there.

I have, however, been in Sane. They don't have an airport; you have to be driven there. I have made several trips there, thanks to my friends, family and work.

I would like to go to Conclusions, but you have to jump, and I'm not too much on physical activity anymore.

I have also been in Doubt. That is a sad place to go, and I try not to visit there too often.

I've been in Flexible, but only when it was very important to stand firm.

Sometimes I'm in Capable, and I go there more often as I'm getting older.

One of my favorite places to be is in Suspense! It really gets the adrenalin flowing and pumps up the old heart! At my age I need all the stimuli I can get!

And, sometimes I think I am in Vincible, but life shows me I am not.

People keep telling me I'm in Denial but I'm positive I've never been there before!

I may have been in Continent, but I don't remember what country I was in. It's an age thing. They tell me it is very wet and damp there.

## **Living With a Disability Conference, March 31, 2014, Quality Inn, Regina**

This was a conference that was organized by the March of Dimes Canada. It was co-sponsored by Muscular Dystrophy Canada, Heart and Stroke Foundation and Saskatchewan Voice of People with Disabilities Inc. There were no presentations that had anything to do with Polio. Six members of Polio Regina attended. Polio Regina had a booth at the conference where we displayed Polio Regina brochures and information about post-polio syndrome as well as issues of our newsletters, the Polio PostBox. Materials at other booths were: the Heart and Stroke had several useful handouts one especially helpful was a wheel which listed approximately 100 foods, their calorie, fibre and fat content as well as how many minutes of activities such as swimming and cycling to burn a specific portion of the food listed. March of Dimes and Saskatchewan Voice of People With Disabilities had material which was basic.

**Welcome Address** - The welcoming address was by Eryn Kelly the Regional Manager for the March of Dimes for the prairies. This was Eryn's last day at the March of Dimes; Kirsten Sztain will be taking her place.

**Keynote Address, Morning** – The keynote address was by Jacqueline Tisher the president of Hope's Home in Regina. Hope's Home is a daycare for disabled children. Jacqueline started the daycare after she had fostered a child named Hope who was severely disabled and passed away at 10 months old. Jacqueline found that there was no place for parents to take children with disabilities for daycare or respite so she founded Hope's Home. Jacqueline also had a daughter named Acacia who had Spina Bifida. She passed away at 18 years old. With the attitude that "Anything is Possible" and a lot of hard work and fund raising Jacqueline and her associates were able create a place where disabled children could come and be kids and be away from hospitals and institutions. Hope's Home has expanded to six locations in Regina with 160 staff, eight beds and

one respite room. They also have 90 spaces in Prince Albert with four beds. They are in the process of purchasing land to build a new home for 90 spaces in Regina. They are also considering opening a home for adults.

**Workshop** – Finding Balance by Will Dinu of the Phoenix Residential Society. This was a presentation about brain injury. Will Dinu was a network specialist for the government of BC. He was driving a moving van through the Rockies in BC when a front wheel fell off the van and it rolled. Will sustained a concussion and after a while he started to have memory loss, lack of balance, confusion and difficulty speaking. His brain was gradually swelling so he had a shunt put in to relieve the pressure but he still had mental difficulties. His wife finally left him so his parents had to take care of him. All he did was sit in the bathroom and smoke for 12 hours a day. His weight was up to 372 pounds. Finally he went to the Phoenix Residential Society where he received help from health professionals, counselling as well as training in a residential group setting. He started cleaning buildings for them and became their receptionist at their main office. He was motivated to keep learning and trying. He has lost weight and is back to his trim former self. He was able to do the whole presentation without notes or aids. The Phoenix Residential Society has four buildings in Regina where they provide assistance and training for people who have had brain injuries.

**Workshop** - Accommodation and Assistive Technology by Nikki Langdon of the Neil Squire Society did a presentation on adaptive keyboard and mice for computer use by people with disabilities. The session focussed on devices to assist computer usage where there is limited upper limb mobility. I cannot recall anything related to lower limb mobility or lack thereof. The important take away message was to involve the client in decision making related to the chosen device.

**Workshop** – Nutrition Basics by Michelle Archer, RD, owner and Registered Dietitian of Eatwell Nutrition Consulting. Michelle explained how to read and use the Canada Food Guide. She gave

general information on portions of Protein, Fat, Carbohydrates, Fruit and Veggies. Something useful which I found was which colors of veggies have the most vitamins i.e. yellow, green, red, orange and purple. There were 2 handouts, one Canada's Food Guide regular and one geared for First Nations, Inuit and Metis. We did an exercise where we cut out pictures of food from grocery store flyers and pasted them onto a paper plate to come up with a well-balanced meal. She recommended to cook once and eat twice to make good use of leftovers. She also said that children aren't taught how to cook anymore.

**Workshop** - The Road Not Chosen by Barb Butler and Larry Carlson who spoke about their personal experience, recovery and support for brain injury.

**Lunch Presentation** – Kristen Sztain of the March of Dimes spoke about a wage subsidy program by the March of Dimes called ABC or Accessible Biz Connections. It offers a wage subsidy to employers who hire persons with self-defined disabilities for permanent employment, paying 100% of their hourly wage for six months or longer.

**Keynote Address, Afternoon** – The keynote address was by Lee Cayer a board member of the Heart and Stroke Association. She is a barrel racer who lives and works on the Eagle Spirit Ranch at Willow Bunch, Saskatchewan. Two years ago she was a vibrant middle-aged woman when she suffered a stroke. The ambulance attendance had just received training on TPA protocol so they knew to take her straight to Moose Jaw rather than Assiniboia. TPA or tissue plasminogen activator is a drug that is given to break down blood clots. It must be administered within four hours of the stroke. It only works on a stroke caused by blood clots. If it is given to a person who has received a hemorrhagic stroke it makes it worse therefore the patient has to be taken to a hospital that has a CT scanner to determine which kind of stroke it is. The stroke paralysed the right side of her body but thanks to TPA she was able to walk out of the ICU two days later. It took time to overcome the physical and mental damage caused by the stroke but she is almost back to normal. She still has problems thinking under pressure.

**Workshop** – Creative Arts by Rhonda Rosenberg was a session about imagining and appreciating what it was like to deal with other people’s disabilities.

**Workshop** – Living with Stroke Program by Shannon Sigfusson. Shannon spoke about how technology can be used to support services for those in rural and remote areas or even those who are unable to commit to coming out for regular education/support programs. Living with Stroke™ is offered as a series of regular sessions. Each session features a video, informal group discussions and activities. All sessions are designed to help make living with stroke easier for the patient and their caregiver. These are available at all health regions in Saskatchewan as well as on line. She also talked about the warning signs of stroke and to use FAST to determine if someone has had a stroke. F – Face: Ask the person to smile. Does one side of the face droop? A – Arms: Ask the person to raise both arms. Does one arm drift downward? S – Speech: Ask the person to repeat a simple phrase. Is their speech slurred or strange? T – Time: If you observe any of these symptoms call 911 immediately.

**Workshop** – Emergency Preparedness by Brent Page the National Manager, Regional Development of the March of Dimes. He spoke about being prepared for any emergency. The Saskatchewan Emergency Management Organization (SaskEMO) leads the co-ordination, collaboration and co-operation of all organizations involved in the prevention, preparedness and response to disasters and emergencies but it seems that persons with disabilities are not on their radar. Some of the emergency measures that Brent talked about are:

Establish a personal support network of individuals to assist you during an emergency and inform them of where you keep your emergency survival kit, health information and health care directive.

Have a plan for evacuation and know where to go for shelter.

Label all of your special needs equipment and attach laminated instruction cards on how to use, retrieve and/or move each assistive device during an emergency.

Prepare a 72 hour emergency survival kit which includes:

Water – at least 2 litres per person

Food that won’t spoil (canned or dried)

Manual can opener

Wind-up or battery powered flashlight and radio and extra batteries

First aid kit

Prescription medications, Medic Alert and ID

Extra keys to house and car

Cash in small bills as \$10 and change for pay phones

Copy of emergency plan and contact information

Disability equipment and supplies

Candles, matches or lighter, toilet paper, toiletries, and garbage bags

Sleeping bag, blanket and change of clothing

Other personal item you require to survive 72 hours

Get Prepared Emergency Preparedness Planning for People with Disabilities –

[www.getprepared.gc.ca/cnt/rsrscs/pblctns/pplwthdsblts/pplwthdsblts-eng.pdf](http://www.getprepared.gc.ca/cnt/rsrscs/pblctns/pplwthdsblts/pplwthdsblts-eng.pdf)

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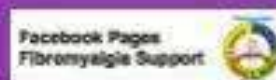
## Chair-Leaders

Doc Bornholdt represented Polio Regina at the Canadian Paraplegic Association (Saskatchewan) Inc. 1<sup>st</sup> Annual chair Leader Luncheon on May 7<sup>th</sup>. The goal was to raise awareness and funds in support of CPA Saskatchewan programs and services for persons with mobility disabilities in our community.

CPA Sask. arranged for local community leaders to act as Chair-Leaders by spending a portion of the morning of May 7<sup>th</sup> in a wheelchair conducting day-to-day activities. By doing so, these respected community leaders experienced the challenges individuals who use a wheelchair overcome daily in their everyday activities. As well, Chair-Leaders assist CPA Sask. in raising awareness towards helping Saskatchewan to become a leader in creating a barrier-free province.

The luncheon was sponsored by Sask Power. There were about 50 people in attendance; many of them in wheelchairs.

## 6 Things about Chronic Pain You Didn't Know You Knew



*Pain is exhausting:* You may not have consciously realized it, but the pain that has relentlessly nagged you through out the day has drained you as bad as any flu.

*Pain causes poor sleep:* You would think that after a long day of fighting with constant pain sleep would be a great reprieve. Unfortunately, this is just a dream (pun intended).

*Pain makes you cranky:* Chronic pain sufferers aren't (all) just cranky buggers by nature. Pain drains you physically and mentally.

*Pain kills your concentration:* Most chronic pain patients fight like crazy to live a normal life. They try to ignore the pain and go about their days, but it's just not that easy.

*Pain damages your self esteem:* You can't do what you want to do with your time even when you try and it seems like everyone is mad or unhappy with you no matter your efforts.

*Pain causes isolation:* When you're in constant pain, the last thing you want to do is attend the company party, the neighbour's backyard barbecue, or even small gatherings with your closest friends and family.

## You Are Invited

Polio Regina is inviting people who have had poliomyelitis and are now experiencing new symptoms such as fatigue, muscle weakness and cold intolerance, to join our self-help support group to learn how they can cope with post polio syndrome. Spouses and partners of polio survivors are also welcome. Polio Regina Inc. was formed to help people from southern Saskatchewan.

### Our Objectives:

- To develop, promote and increase awareness of Post Polio Syndrome.
- To disseminate information concerning research and treatment pertaining to Post Polio Syndrome.
- To provide support to survivors of polio, other than financial aid.

### Where to meet

Our Polio Regina group meets in room H203 at the Wascana Rehabilitation Centre 2180-23rd. Ave., Regina, SK. Enter the main doors of the Wascana Rehabilitation Centre and turn left and take the elevator that is across from the information desk. Push button "2" (not 2R) on the elevator. When you leave the elevator turn left and go past the information desk, through a recreation area, past the pool table to room H203 which is the first meeting

room. Our group should be in there. There are no meetings in January, June, July, August or December.

The following are the dates of our 2014 meetings: Thursday, September 25 and Thursday, October 30. All meetings are at 3:30 p.m. We usually have our Spring Picnic in May at a private residence and our Christmas Party in November at a different location.



### Web Site:

Check out our website for more information on Polio Regina and links to other useful related information at:

<http://nonprofits.accesscomm.ca/polio/>

or you can just Google **Polio Regina**.

Our email address is: [polio@accesscomm.ca](mailto:polio@accesscomm.ca)

### Disclaimer

Information published in the Polio PostBox may not represent the opinion of Polio Regina. It is not to be regarded as Polio Regina's endorsement of treatment, products or individuals. If you have or suspect you may have a health problem, please consult your health care professional.

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## MEMBERSHIP APPLICATION POLIO REGINA Inc.

Name \_\_\_\_\_  
Active ( ) if you had polio    Associate ( )    New ( )    Renewal ( )

Address \_\_\_\_\_  
\_\_\_\_\_  
\_\_\_\_\_

Postal Code \_\_\_\_\_ Phone: \_\_\_\_\_

Annual membership fee: (Jan.- Dec.)

\$10 Single; \$15 family                      \$ \_\_\_\_\_

My donation to Polio Regina Inc.:\*                      \$ \_\_\_\_\_

Total \$ \_\_\_\_\_

(If you require sponsorship for your fee, inform our membership chairman)

Please make cheque payable to: **Polio Regina Inc.** and mail this application form and cheque to:  
Polio Regina Inc., 825 McDonald St. Regina, Sk. S4N 2X5

\*(Official receipt of donation for income tax purposes will be mailed.)

# Polio Wellness Retreat

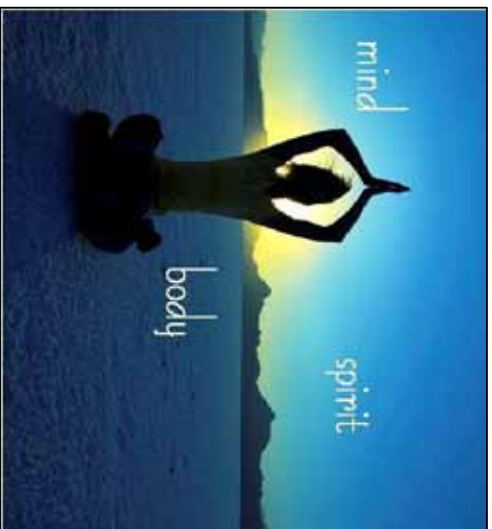
You are cordially invited to attend  
our Polio Wellness Retreat!

**Dates: September 8<sup>th</sup> – 12<sup>th</sup>, 2014**

**Location:** In the foothills of the Rocky Mountains...  
Easter Seals Camp Horizon  
Bragg Creek, Alberta

**Price:** \$375 (all included – save transportation to retreat  
center)

For more information please contact:  
Xilonem Lopez  
[lopez@marchofdimes.ca](mailto:lopez@marchofdimes.ca)  
1800 263 3463 extension 7209



An Invitation!



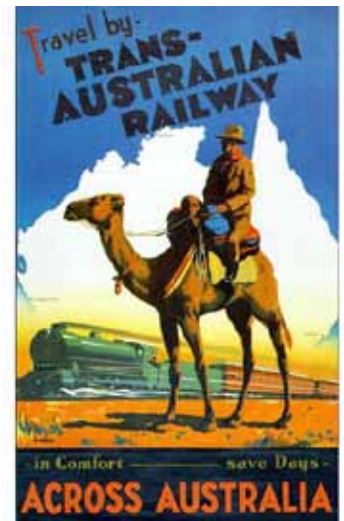
# Christmas Party 2013

Our Christmas Party was held November 27, 2013 at 5:00 p.m. at Nicky's Café at Eighth Avenue and Winnipeg Street. We all enjoyed a turkey dinner with all the trimmings and were able to visit with fellow members after the meal.



*The following is an offer from Murray Grant:*

One year ago, the downtown Regina Public Library asked if I could provide shows for the Monday afternoon "Armchair Travel" series in winter, as I had done in the past. We're speaking then of 35mm Kodachrome film, cameras and projectors. Sadly, all gone. However, I saved images to digital files and was able to provide two shows this past winter.



At no cost (I can bring equipment) I can offer a show for a Polio Regina meeting. In fact, if a member of Polio Regina is also active in an organization that invites me, I'd consider the offer.

Murray [genmurr@sasktel.net](mailto:genmurr@sasktel.net)