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Christmas 2010

Polio Regina Incorporated

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IN THIS ISSUE

2010 Executive	1
At the Meetings.....	2
Avoiding PPS: "A Pound of Prevention Is Worth a Ton of Therapy".....	3
Polio and the Science of Inducing Sleep.....	4
Taking Pains after Surgery	5
Saskatchewan Loses a Pioneer in Polio Vaccine Research.....	6
You Are Invited.....	7
Where to Meet	7
Membership Application.....	7
Don Lekivetz.....	8

2010 Executive



Back Row Ivan Jorgensen - Secretary and Polio PostBox Editor, Carole Tiefenbach - Vice President and Phone Co-ordinator, Wilf Tiefenbach - President. Front Row David Cotcher - Treasurer, Mavis Matheson - Archivist and Webmaster.

Season's Greetings

*May the Peace and Happiness of the season be yours today and every day.
Many thanks for your friendship and support. Merry Christmas and Happy New Year.
Polio Regina*

At The Meetings

September 2010 – We discussed the results of “Survey – Polio Regina Meetings”

The results of the survey were published on page 3 of the October Polio PostBox. Ivan read some observations about the survey. There was some discussion and the following were some of the suggestions that were agreed on:

1. The time and location of the meetings was satisfactory. (7:00 p.m. on the last Thursday of the month at room H203 of the Wascana Rehabilitation Centre.)
2. We decided that we did not need to have coffee, tea, or juice or snacks at the meetings. If people wanted refreshments they could bring their own to the meeting.
3. We will try to keep people more informed through the internet or email. A member list was passed around for people to put their email address on.
4. We did not feel it was necessary to have a social or program director.
5. We agreed that at each meeting a member would volunteer to choose a subject that they are interested in finding out more information about. They would research the subject and we would discuss the subject at the open forum at the next meeting. It would be up to that member to decide whether they wanted to bring in an expert or speaker from that subject area.
6. Most people still think that Polio Regina serves a useful purpose.

Zenny Burton volunteered to present the subject “Aids that are available for the handicapped and what financial assistance is available” at our next meeting, October 28, 2010.

Christmas Party – We tentatively agreed that our annual Christmas party would be held at Broadway Terrace on November 25th 2010. Blenda Ramsay and Carole Tiefenbach will look into hiring a caterer. We will be having a buffet style turkey dinner.

Open forum - We went around the table and each

member told us how their summer was.

Program - Carole Tiefenbach gave a presentation on a “Sitter Service” that is available through the Regina Qu’Appelle Health Region which is a form of volunteer home care that is available to care givers who need a break. For more information contact Carole at 761-1020.

October 2010 - This month Blenda had a birthday celebration and asked people to make a donation to Polio Regina or the Alzheimer’s Society instead of giving a card. They were amazed at the end of the day to find they were fortunate to receive \$100.00. Therefore, they divided the money in half and donated a cheque from money received for \$50.00 to Polio Regina and the other \$50.00 will be donated to the Alzheimer’s Society. Thank you very much Blenda and Fred.

Mavis Matheson volunteered to present a subject that she would like to have discussed at our next meeting. The subject will be motivation. Blenda Ramsay said that she would try to bring in a speaker from Mental Health to speak on depression and how to overcome it, for one of our spring meetings.

Pat Allonby resigned as phone co-ordinator. Carole Tiefenbach volunteered to serve as phone co-ordinator for the rest of the term.

Open forum - Zenny Burton led an open forum on the subject “Aids that are available for the handicapped and what financial assistance is available”. She brought a number of catalogues from various suppliers as well as several aids and devices that would make life easier, including simple devices like a pair of barbeque tongs for reaching things from high places. She also spoke about services that were available from

SAIL (Saskatchewan Aids to Independent Living.) and RQHR (Regina Qu’Appelle Health Region) and the Disability Tax Credit that is available from Revenue Canada. Her presentation prompted vigorous discussion.



Avoiding PPS: “A Pound of Prevention Is Worth a Ton of Therapy”

Dr. Richard L. Bruno

Dear Aggie:

Forty years ago I caught a virus that killed more than half of the nerves in my spinal cord and brain stem. The nerves that survived were damaged by the virus but have been doing double the work to make up for the nerves that were killed. Even though my leg has been paralyzed for forty years, I have always been very hard-driving and am constantly busy: I work two jobs, have ten kids, take care of my 90-year-old mother and mother-in-law who live with me, volunteer at a hospital and a homeless shelter, and raise money to “Save the Whales” in my spare time. Other people who caught this virus are also very busy all the time and are having severe problems with fatigue, new muscle weakness, and pain. However, I feel fine right now—except for daily headaches. Should I change my lifestyle to try to prevent the new problems others are having?

“Symptomless in Seattle”

There has never been a longitudinal study that looks at the emergence of Post-Polio Sequelae (PPS) -- new fatigue, muscle weakness, joint and muscle pain, cold intolerance and sleep, breathing and swallowing difficulty – in polio survivors who have no symptoms. However, each time someone surveys polio survivors, the percentage of individuals reporting PPS goes up. The first population-based study in 1983 found that 22.4% of paralytic polio survivors had PPS. The 1987 National Health Interview Survey estimated that of America’s 1.63 million polio survivors, 58% who had paralytic polio and 28% who had non-paralytic polio had PPS. In England, where they don’t even “believe” in PPS, 78% of polio survivors are reporting new symptoms. Something must be going on that causes more and more polio survivors to report PPS as the years go by. But what?

A 1985 survey found that PPS developed in those who were at least 10 years old when they had had polio and in those who had had a more severe infection, i.e. those who had been hospitalized at polio onset and had had more limbs paralyzed. A 1988 study found that it wasn’t just the severity of the polio but how much you

recovered in the succeeding years that predicted new symptoms. That is the more damage the polio virus did and the more muscle strength you recovered, the more stress was placed on the remaining, polio-damaged motor nerves. The more muscle strength you had to lose, the more likely you were to have PPS.

Then, the 1985 and 1990 National Post-Polio Surveys found that both physical overexertion and emotional stress trigger PPS. Further, polio survivors who were “Type A” (hard-driving, pressured, time-conscious, perfectionistic and overachieving) were more likely to develop PPS. It appears that both physical and emotional stress on a polio-damaged and overworked central nervous system lead to the development of PPS. This conclusion is supported by the 1991 follow-up study showing that, in individuals who already have PPS, fatigue, weakness, and pain just get worse if patients don’t follow their therapists’ recommendations to decrease physical and emotional stress.

So what do polio survivors like “Symptomless in Seattle” do if they don’t currently have symptoms? Well, it doesn’t take “Dear Aggie” or even a post-polio specialist to figure out that people with a smaller number of polio-damaged and severely overworked neurons are at risk for developing symptoms, especially if they constantly stress themselves, physically and emotionally. A 1997 study found that motor nerves actually die at a rate of 7% each year in polio survivors who have muscle weakness. Doesn’t it make sense to not get to the point where the motor nerves start giving up the ghost?

Will all polio survivors eventually develop PPS? Many PPS experts think so. Will all polio survivors develop all post-polio sequelae, from fatigue through swallowing problems? Certainly not. But just as people who’ve had a heart attack are advised to reduce stress, shouldn’t polio survivors without PPS try to protect their damaged and overworked nerves?

We advise all polio survivors to follow “The Golden Rule:”

IF SOMETHING YOU DO CAUSES FATIGUE, WEAKNESS, OR PAIN, DON’T DO IT!

Why shouldn’t polio survivors try to protect their quality of life by decreasing physical and emotional stress through the moderation and pacing of activities, the use of appropriate assistive devices (especially those that were discarded so many years ago), and by reducing hard-driving, Type A behavior? Will these self-care activities prevent the onset of PPS? No one knows.

Both our patients' reports and two follow-up studies clearly show that the progression of PPS symptoms is at least halted, if not markedly reduced, when patients start to take care of themselves. So it's hard to imagine that self-care won't have some preventative effect with regard to PPS. And if prevention is possible, it would certainly be a lot less difficult and expensive than the physical, occupational and psychological therapy that are necessary to treat PPS.

What if self-care merely holds PPS off for a while, or reduces the severity of symptoms when they do occur? Or what if self-care has no long-term effect on PPS? Why should polio survivors spend their lives beating up their bodies and their spirits by taking care of everyone around them, to the point where they don't even spend a moment of the day thinking about – let alone caring for – themselves?

Polio survivors say, "Self-care is selfish! I feel too guilty to take care of myself." Self-care, moderation, and reduced stress have been recommended as the foundation for a peaceful and even happy life for nearly 2,500 years, since the time of the Buddha. Taking care of yourself isn't selfish, say the Buddhists, it is "The Middle Way" between sloth and excess. Buddhists say that, since compassion for everyone is the basic principle that leads to peace and happiness, people cannot be peaceful or happy if they spend their days exhibiting compassion for the whole world with the exception of just one person: themselves.

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Dear "Symptomless:"

I don't know anything about viruses. But I do think it makes sense for you to start taking better care of yourself. Why is it so hard for us to take care of ourselves? Why should you be doing for everyone else and ignoring and abusing yourself? Don't you at least deserve not to have your head hurt all the time? Why don't you start by doing one thing for yourself for each thing you do for someone else? Maybe you won't prevent new physical problems. But the worst that could happen is that other people will still be helped and you'll feel better. Why should you "Save the Whales" and not save yourself?

Aggie

Dr. Richard L. Bruno is chairperson of the International Post-Polio Task Force and director of The Post-Polio Institute and The International Centre for Post-Polio Education and Research at Englewood (New Jersey) Hospital and Medical Center.

Polio and the Science of Inducing Sleep

TIPS AND TECHNIQUES FOR POLIO SURVIVORS

By Dr. Richard L. Bruno

I've talked here recently about drugs that make polio survivors sleepy. But, I haven't discussed medications that are *intended* to put polio survivors to sleep.

In our 2000 Post-Polio Survey, 237 polio survivors told us about complications after receiving anesthesia. Polio survivors' biggest problem reported was being excessively sedated after being "put under." Just over half told us that they were snowed after receiving a general anesthetic and 43% said that they were overly sedated when they had an endoscopy or colonoscopy, sometimes with frightening results: "It took two days to awaken from the general anesthetic after a hysterectomy," one respondent reported. "It took probably six weeks to feel fully awake."

After a colonoscopy, another respondent said, "I was in the recovery room at 10:00 a.m. but didn't wake up until 6:00 p.m. I was very frightened and very sleepy. But the nurses made me leave, even though I was not fully awake, and were angry because it would prolong their workday if they had to put me in the hospital."

The 2000 Survey also found that 20% of polio survivors had difficulty breathing after receiving general anesthesia, in part because breathing neurons were damaged in everyone who had polio and can be "turned off" by anesthetics. Curare-like drugs during major surgery (which paralyze muscles to be cut and makes it easier for the ventilator to fill the lungs while patients are on the table) also affect breathing. Obviously, any drug that interferes with already damaged motor neurons—including spinal anesthesia—will prevent polio survivors from moving or even breathing for hours longer than would non-polio patients.

Breathing difficulties are both frightening and can be life threatening, as another poll respondent described: "My operation was at 9:00 a.m. and I was to be in recovery and awake by 10:00 a.m. At 2:00 p.m., I was in intensive care, not breathing and on a ventilator. I eventually woke at 4:00 p.m. The ventilator was removed the next afternoon, but I really had to fight for every breath. I had a very difficult time breathing and staying awake for three days."

Some anesthetics seem better for polio survivors. Propofol should be the only drug given to induce anesthesia and for endoscopies, not the old cocktail of Valium, Vistaril and Demerol. The anesthetic gas Desflurane also seems better tolerated by polio survivors who need general surgery. What's more, a BIS (Bispectral index) monitor that measures brain waves and depth of anesthesia, should always be used so that polio survivors undergoing surgery can be given as little anesthetic as possible.

The bottom line is the first of our rules for preventing complications, the Rule of 2: Doctors need to divide by 2 the amount of anesthesia or sedative medication and polio survivors need 2 times longer for the effect of anesthesia to wear off.

This rule is not intended to dictate the dose of anesthetic polio survivors receive, but to remind anesthesiologists that polio survivors typically need less anesthetic. As always, the dose of anesthetic must be individually adjusted for body weight and other factors, be adequate to keep patients under during surgery, but should not cause polio survivors to stop breathing and sleep for a week.

Another finding of our survey was that 20% of polio survivors vomited, sometimes violently and for several days, after general anesthesia. Today, anti-vomiting drugs are widely used and typically given before and after surgery. Ask for them!

Because of polio survivors' classic intolerance to cold, it's no surprise that nearly one third of subjects told us that they were freezing in the recovery room. You should ask for a heated water blanket or a Bair Hugger, an electric, warm-air filled device that surrounds you, during surgery and in recovery.

Because of these issues, there is another Rule: Polio survivors should never have same-day surgery or procedures.

Even applying all the Rules, polio survivors may be very sedated, if not asleep, for hours after surgery. This is why same-day surgery—even complicated dental procedures—is not advisable. Sedated polio survivors cannot be expected to return home and take care of themselves after surgery, since surgical complications may go unnoticed and sedation-impaired coordination makes falling likely. Doctors should perform simple procedures that would usually be done in their offices—including endoscopies—in the hospital and be prepared to admit polio survivors overnight for their

own safety.

Next time I'll talk about the single most troublesome problem after surgery: pain control.

Dr. Richard Bruno is Director of The Post-Polio Institute at Englewood (NJ) Hospital and Medical Center.

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 postpolio 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 Anesthesia the "Rule of 2" is that polio survivors need the usual dose of anesthetic divided by two, the "Rule of 2" 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 the 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, anesthetics or other drugs may have temporarily weakened or even paralyzed the muscles needed to stand and walk, especially if a spinal anesthetic was used. What's worse, the surgery may have

cut muscles (like abdominal muscles) that substitute for muscles paralyzed by polio and that allow polio survivors to stand and walk. Polio survivors may also have low blood pressure after surgery that could itself cause lightheadedness, fainting and falls.

Polio survivors should get up slowly, first sitting up in bed, then 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 postpolio 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 safer and more comfortable during their hospital stay.

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Saskatchewan Loses a Pioneer in Polio Vaccine Research

Dr. Hugh Robertson of Regina passed away peacefully at age 91 on Monday, October 25th, 2010 at William Grace Hospice following a short battle with cancer. Hugh was born in Lawson, Saskatchewan.

Hugh finished two undergraduate degrees and a M.A. at the University of Saskatchewan just as the Second World War was beginning. He was assigned to the research unit at International Nickel where he discovered a process for developing a nickel alloy unaffected by heat. This was used in the after-burners of jets. He was bestowed a Manhattan Award from the US government along with a lifetime membership in the Ontario Association of Professional Engineers.

After the war, Hugh returned to Regina to take over Dr. William Riddell’s position of Director of the Provincial Laboratories, located at that time in the Grey Nuns Hospital. He was granted a leave to obtain his PhD degree from the University of Minnesota. During his time in Minnesota he became an associate professor of medicine. He worked at the Mayo Clinic under the guidance of Dr. Paul Boyer. During his time in the U.S., Dr. Robertson was involved in polio research where he and Dr. Sabin were colleagues. Dr. Robertson along with Connaught Medical Research Laboratories conceived the first trivalent Sabin oral polio vaccine that became a world standard. His family was later amongst the first 500 people in North America to receive and demonstrate the effectiveness and safety of the oral polio vaccine. In 1953, given the assurance of a new Laboratory, and reporting directly to the Deputy Minister of Health, he returned to establish the first full-service virus laboratory in Canada. His foresight moved the Provincial Health Laboratories to the forefront in the field of public health at the national level. Dr. Robertson remained the director for 33 years until his retirement in 1986.

After his retirement his loves included playing bridge, sailing, travelling and spending time with his family. Dr. Robertson has served as chairman of the Laboratory section of the Canadian Public Health Association, the Canadian Association of Clinical Microbiology and Infectious Diseases and worked with World Health Organization. Dr. Robertson was also an adjunct professor at U of R for 10 years until his retirement, former chairman of the Regina Housing Authority, member of the Urban Environment Advisory Committee and Regina Plains Museum. In 2000, for distinguished work, the U of R presented an honorary Doctorate of Laws degree to Hugh.

Polio Regina Loses a Long-time Member and Friend. We Remember Donald George Lekivetz 1930 – 2010

One day late in the fall of 1952, Don Lekivetz began his chores in the farm yard just southwest of Riceton, Saskatchewan. He had been raised there by his parents, Anna and George Lekivetz. When his father died in 1946, Don quit school at 16 to operate the farm, together with his mother and sisters Mary and Margaret.

Don had married a Grey Nuns Hospital nurse who had graduated just a year earlier, Grace Kirchhofer, in February of 1952. Now he found himself stumbling and falling on the ground. After several days in hospital, they learned the diagnosis – polio.

His left leg began to weaken increasingly, but Don persevered in his farm work. They had four children: Sharon late in 1952 (who survived just 9 weeks), son Rick in 1954, Cheryl in 1955 and Kathie in 1959.

They decided in 1960 to move to Regina. As Rick explained in his eulogy at the funeral mass Oct. 9th in St. Cecilia Church –

“Dad graduated from Moose Jaw Technical School in 1961 as a Journeyman Plumber, started his own business (Lekivetz Plumbing and Heating) in 1968, build his own home in 1978-79 and eventually retired in 1989.

He was a proud member of Alcoholics Anonymous and had been since he joined in 1977. He met a lot of new friends there, many who still remain friends and are here today. I remember us attending his 25th year celebration of sobriety and we were all very proud of him; and he was proud of himself too.

He faithfully attended weekly AA meetings in Lumsden until 2005 when his mobility became more and more limited, as the severity of his post polio syndrome increased. From then on, he was only able to walk with the assistance of a cane or a walker.”

Grace recalls taking part in Polio Regina meetings, beginning in the early Nineties. Both attended until Don grew weaker.

Rick recalled that Don’s joy in life “included helping his children with a multitude of carpentry and plumbing tasks as they began purchasing their first homes and raising their own families. With several houses in the family there was always some odd job

that required his skills and expertise, and he loved being the one they called upon for help.



58 years -- Grace and Don celebrated their wedding anniversary in February of 2010.

Another of Dad’s enjoyments in life was attending weekly church services. He enjoyed Sunday breakfasts with fellow parishioners after mass. He was friendly and people always enjoyed his company.

Late in 2009, Dad moved to the Santa Maria Senior Citizens Home. He was well liked by all the staff there, and again, always looked forward to attending mass several times during the week. After mass he especially enjoyed coffee and the companionship of Father Ken Koep, other volunteers and residents of Santa Maria.

Dad passed away at Santa Maria on Saturday, Oct. 2nd at the age of 80.”



January of 1960 -- the year the young family moved to Regina: Don and Grace, Cheryl (4) Kathie (9 months) and Rick (6).