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Polio Regina Incorporated

Editor: Ivan
Jorgensen

Phone: 757-8051 ivan.jorgensen@sasktel.net

3344 Baneberry Drive, Regina, Sask. S4V 2V2

Happy Thanksgiving

My Polio Story

The following is Noella Sylvester's Polio Story. Noella has been long time member and faithful supporter of Polio Regina.

Noella Sylvester



I was born Noella Hayden December 24th, 1939 in the small town of Welby, Saskatchewan. I was one of 12 children; I had five other sisters and six brothers. We grew up in a log cabin like home on a farm. We had livestock such as

cows, horses, chickens and pigs. We grew our own vegetables in a large garden. We attended school continued on page 2

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Editorial

Ivan Jorgensen



I hope everyone had a good summer. It has been rather a strange summer with the spring being so wet with massive flooding and then July and August being hot and dry. Is it my imagination or are there fewer comfortable days in the

low twenty degree range without a wind that you can enjoy your back yard or balcony? We can't change the weather so we might as well adapt and make the best of it.

In this issue of the *Polio PostBox* I have tried to put together some articles about medical issues, dealing with doctors, and drugs and their reactions. I will start with my experiences.

I had polio when I was 18 months old and it left me with atrophied muscles in my left leg and foot. I am unable to stand on my toes on the left foot so I walk on my heel. My left leg became shorter than my right as I grew. I had two operations to reshape my left foot and had some muscles transferred around when I was 11 years old. Then I had staples put into my good right knee to stop the leg from growing so my left leg could catch up. The staples kept coming out so I had to have them replaced three times. I finally had them removed when I was 16 years old. Through all of this I became bow-legged on my right leg.

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My Polio Story - continued

about a mile from where we lived. We walked to school and back every day, sometimes even home for lunch, but sometimes we stayed at school as lunch was brought to us or we had lunch with our teacher, Mrs. Mitton, at her home another mile away from school.

We were a modest family; my father worked for Canadian National Railway (CNR) for 35 years. He went to work every morning and returned home every evening, then worked on the farm. My mother was a stay at home mother as our family had 14 members – 12 children and two adults. My grandfather on my Mom's side originated from Main, Quebec, a small French community. He met my grandmother here in Saskatchewan. My grandfather on my Dad's side came from Ireland on a year's journey to get here on oxen and covered wagon. He then met my grandmother, married and settled down in St. Joseph, Saskatchewan.

My great aunt Margaret Belhumeur on my father's side actually married Louis Riel here in Saskatchewan but moved to St. Boniface, Manitoba. The house that they occupied still remains standing to this day. It has become part of a heritage site.

I was one of my five siblings that got Polio. This happened to me when I was 12 years old in 1952. Three of my siblings only received minor symptoms of Polio not requiring hospital care. My younger brother, Henry, and I got worse complications of Polio. Henry required hospitalization for six months. He also got Rheumatic Fever with the Polio; half of his body became crippled with this disease and he got an enlarged heart from it but lived until he was 35 years old.

I was hospitalized for two months; I became unable to walk with this disease. I was bed-ridden; the Polio went down my left leg and into my spine and neck. I was told that I would be in a wheelchair for the rest of my life and that I would never have children. But miracles happen; I had two children – a daughter and a son.

My daily rituals in the hospital were that of being alone, unable to see anyone, not even my brother.

The rooms were kept dark; the medical staff wore protective clothing. I was wrapped in hot towels around 10 times a day. If I was in a lot of pain, they would give me a needle to take the pain away. After about a month in the hospital, after being told that I would not walk again, I made up my mind that they were wrong and that I would indeed walk again. One day when no one was around, I got myself out of my bed, hung on tight to the bed and got myself to walk slowly around my bed. This became a daily ritual for me day after day for the next month. No one knew that I was doing this. I got to go home after the second month of being in the hospital. My Dad had to carry me from my room to the truck. Once I got home, during the day I had to lie in my bed but at night I would do my same routine of getting up and walking around the bed while everyone was sleeping. After three weeks of being home and doing my nightly routine, I surprised my parents and my family by telling them that I could walk; not the best, I had a limp in my left leg but I could walk. I was determined that I was going to live a normal life; this disease was not going to get the best of me. I was a child and wanted to be like other children, out playing, going to school and growing up to have a family of my own.

I did meet my husband in 1956 and we married in 1958. We had two children. We would have had more but because of my disease, this is all that we were blessed with.

To this day I still suffer from complications of Polio. My leg still bothers me; I still have a limp but I keep on going and today I am still going at age 71. Oh yes, I am a grandmother of five and great-grandmother of four.

Editorial - continued

I have led a normal life and been able to do everything that any other person would do except I have a limp but over the last few years I have been experiencing pain in my right knee. I self diagnosed it as osteoarthritis. This spring I decided to ask my family doctor about it. He sent me for an

x-ray; then he had me make an appointment to have three doctors assess my situation. When I came for my appointment there were only two doctors - my family doctor and a chiropractor (I didn't think that doctors and chiropractors worked together). The other doctor was sick. My doctor read the results of the x-ray which I didn't really understand other than it confirmed that I had osteoarthritis. They asked me to walk up and down the hallway while they watched me. They asked me what I thought should be done and I said that I thought that I would be able to get a knee brace that would take the pressure off my inside knee. They both agreed that a brace would be of no benefit. They recommended that: I go to the chiropractor for some manipulation of the knee to loosen it up, that I go to the Dr. Paul Schwann Centre for an exercise program to strengthen my knee, and that I see my Podiatrist to make sure that my shoes had the proper modifications.

I went to the chiropractor three or four times and my knee did get loosened up a bit but it didn't really make much difference for the pain. I gave him a copy of the last Polio PostBox which he actually read. The one article recommended that polio survivors should see a neurologist to see if they have Post Polio Syndrome so he referred me to a neurologist.

The neurologist did a quick assessment and said that I do not have Post Polio Syndrome and to come back and see him in a year. He also said that there are some doctors who don't believe that there is such a thing as Post Polio Syndrome.

My chiropractor also referred me to the Dr. Paul Schwann Centre for an exercise program so I booked three sessions. The first two sessions were showing me exercises that I could do at home without equipment and the last session was exercises that used the machines in the gym. They both included warming up on a bicycle. The first exercises included things like: knee push-ups, different leg exercises, balancing, as well as arm exercises. Most of the exercises made use of a grey theraband.

I thought that I was in pretty good shape but after doing these exercises I was tired and kind of sore the next day. I went home with full intentions of doing the exercises at home. I dusted off my bicycle and rode it until my butt got sore. (Not for very long.) I have never done exercises or been to a gym in my life. I always thought that I was active enough with the work that I did to stay in shape so I found it very difficult to do an exercise program. I was doing quite a bit of work in my yard that involved shovelling stones and dirt and I was too tired to do exercises. Anyway that was my excuse. So my exercise program was a failure but I still intend to try it again this winter.

About a year ago my family doctor was concerned about my blood pressure and cholesterol so he put me onto Micardis and 81mg ASA for blood pressure and Crestor for cholesterol. Now my blood pressure and cholesterol are both good but I keep wondering if some of the reason for my muscle aches and feeling tired may have something to do with the medication or if it is part of the aging process. I recently turned 65.

About a year ago I purchased a new pair of shoes and had them modified by a Pedorthist as per a prescription from my Podiatrist. I wasn't walking properly on them so I had hardly worn them so I went back to my Podiatrist and he gave me a new prescription for modification and orthotics to go inside the shoes. The modifications and the orthotics were suppose to make me walk more on my left toes and to tilt inward so there would be less pressure on my inside right knee. The shoes seemed to take some of the pressure off my right knee but after walking in them for awhile I developed pain in my right hip and thigh. It was so bad that I had difficulty sleeping at night. I have never had any pain in my hip before so I am very frustrated with these shoes considering that they have cost me close to \$1,000.00. I have an old pair of shoes that were made for me that seem to work fine and give me no pain but they are starting to wear out. I am going to see my Pedorthist again to see what changes can be made. He is very helpful and tries everything he can to make it right but I guess that I am just a difficult case.

After all this I think I can tolerate pain in my knee. It is not so bad as long as I am active and don't overdo it. I take Tylenol Arthritis pain tablets when the pain is bad and that seems to help.

10 things doctors say patients should know

Article By: Elizabeth Rogers, 50PLUS.com - Aug 11, 2011

Article courtesy of 50PLUS.com http://www.50plus.com/category/home/, where you'll find thousands of articles on health, money, travel, lifestyle, work, relationships and more!

It can be a matter of life and death: the doctor-patient relationship is one of the most important ones in our lives, yet both physicians and patients feel the other half could



do more to hold up their end of the bargain. In North America, it isn't unusual for patients to complain of long waiting room times, hurried appointments, a lack of bedside manner and ineffective treatments.

But how do doctors feel about the situation? To get the other side of this healthcare story, *Consumer Reports* surveyed more than 660 primary-care physicians in the U.S. about the challenges they face everyday — and how they think patients could be getting more from this important relationship. Even though the survey focussed on the United States, many of the lessons learned are universal.

Here are 10 things physicians wish their patients knew, according to the CR report and current research.

Come prepared

Would you walk into a meeting with a busy executive without an agenda or notepad? Like their Canadian counterparts, U.S. doctors feel the pressure of increasing workloads and busy schedules. It's easy to feel hurried, or for patients to forget questions they had.

That's why experts recommend being better prepared. How, exactly? Make a list of your top

health concerns and write down any questions you have before your appointment. You may also have to prioritize because it may not be possible to cover it all during a single time slot. (If needed, ask your doctor for a follow up.)

Keep better track of your health

Even with electronic health records, doctors and patient advocacy groups warn that patients should be taking more responsibility for their health. Almost 90 per cent of doctors surveyed reported it would be valuable to take notes during appointments, keep track of your symptoms, make a list of any medications and supplements you're taking and keep a log or journal of past appointments and procedures. Unfortunately, only one third of patients actually use these strategies.

What about backup? Nearly 80 per cent of doctors think it's a good idea to bring along a friend or family member to an appointment, but less than 30 per cent of patients do. (See Become an empowered patient [1] for more ways to take charge.)

Know your medical history

Though the CR survey only touched on this issue, other studies have warned that knowing your family's medical history is crucial for understanding your risk of many chronic illnesses like cancer and heart disease. In fact, a family health tree can be even more effective than genetic testing.

Why is this important? Not only can it help you and your doctor gauge your risk, you'll also be able to target strategies to prevent the illness or catch it in its earliest and most treatable stages. For example, if you have a family history of a certain cancer, your doctor might suggest screening at an early age. (Read A family tree for better health [2] for tips on compiling your family medical history.)

Understand your coverage

Unfortunately, many people face unpleasant financial surprises when it comes to healthcare costs, so experts warn to keep tabs on your coverage. Stateside, most doctors surveyed felt that rules and restrictions impacted their ability to provide care.

And no, that's not just an issue for Americans.

Even in Canada it's helpful to know what is or isn't covered by your province's healthcare plan or your company's benefits plan. For instance, your group insurance may cover certain medications but not others, and it may reimburse the cost of seeing a physiotherapist. Knowing the details means your doctor can better suggest treatments that won't cause undue financial stress.

Follow instructions

The biggest gripe doctors have about patients? They don't always follow instructions or take their medications. Almost all of the doctors in the CR survey reported that non-compliance affected their ability to provide the best care. One third were especially concerned about this issue.

However, the issue isn't just simple misbehaviour. Sometimes treatment plans can be confusing or cause unpleasant side effects — issues that can be resolved by better communication between patient and doctor. Experts warn to discuss any concerns you have with your doctor and make sure you understand instructions before you leave the office. If you experience side effects, don't make changes yourself — talk to your doctor first.

Be honest

While not covered in the CR survey, honesty is closely connected with compliance. When patients aren't upfront about not following orders, doctors are basing their decisions on faulty information and they can't address the patient's concerns — like switching to a medication that causes fewer side effects.

Other lies that can be risky include alcohol or drug use, use of complementary or alternative therapies (which can interact with prescribed medications), memory problems, depression and problems in the bedroom or bathroom. (See 10 secrets not to keep from your doctor [3] for more details.)

Respect goes both ways

Are patients playing nice? Over 60 per cent of doctors in the survey felt that patients would get better care if they showed more courtesy and respect. Unfortunately, 70 per cent of doctors reported that since they started their practices they've seen a

decline in respect and appreciation from patients.

However, being nice doesn't mean that you have to simply smile and nod. The majority of doctors also felt it was "somewhat helpful" or "very helpful" for patients to ask questions and even question their recommendations. Many educational campaigns — like the Manitoba Institute for Patient Safety's It's Safe to Ask [4] program — encourage communication that gets answers without causing offense.

Rapport is important

The most important thing you can do to get better health care? Have a long-term relationship with a single provider. Three quarters of doctors noted that continuity is important, especially when serious and chronic health issues are at stake. Jump from doctor to doctor and you won't receive the same level of care.

That's why many American doctors wish people would do a little research before choosing a physician. Learning more about a doctor's approach, personality and treatment style was key to finding a good fit.

Unfortunately, some Canadians are lucky to even find a family doctor let alone hand pick the best one — and many physicians won't accept new patients looking to "break up" with their current provider. Still, a little research could be useful if you're seeking alternatives, like integrated medicine or complementary and alternative medicine practitioners.

Be cautious online

Many surveys about Internet use report the same trend: the majority of people go online to research their symptoms and conditions. However, not everyone is convinced that websites are quite so useful. In fact, only 8 per cent of doctors thought the Internet was "very helpful" — and almost half thought it had little or no value at all.

That's not to say you shouldn't be better informed, but rather you should be choosier about your sources. Medical and media experts alike recommend skipping the search engine and sticking to reliable sources instead. (We've got tips and sources in Beyond Dr. Google [5].)

Some conditions are tough to treat

Chronic conditions, especially where chronic pain is involved, can be difficult to diagnose and treat effectively — often leaving patients feeling frustrated and dissatisfied. In a previous survey of patients conducted by CR, those who suffered from a chronic condition like an autoimmune disorder or chronic pain were more likely to complain of ineffective treatments. Only one third were "highly satisfied" with the doctor overall.

However, doctors are hard on themselves too: in the physician survey, only 37 per cent of respondents felt they were "very" effective at treating chronic conditions, while 60 per cent more thought they were "somewhat" effective. Unfortunately, medical science doesn't always have the answers, but a little patience and good communication can go a long way. The most satisfied patients had doctors they felt were willing to listen, learn more about the condition and involve them in decisions.

Doctors talk to sales reps

While there are many things doctors want their patients to know, this is one they might want to keep secret. According to the survey, U.S. doctors spend a few hours a week dealing with pharmaceutical salespeople. The majority of doctors reported they were contacted by sales reps about 10 times a month, and one third reported their calls were double that amount.

Why is that an issue? According to the patient survey, one quarter of respondents thought their doctors were a little too eager to prescribe medications, and many felt their doctors weren't willing to consider alternatives. What do the experts at CR say? If you're concerned, talk it over with your doctor at your next appointment.

Overall, it's important to note that most patients and most doctors are satisfied — at least in the U.S. However, there's always room for improvement, and the message from experts continues to be that patients need to be more active and involved in their care — and that means managing their doctor-patient relationship too.

ON THE WEB
Read the report from Consumer Reports here [6].
READ MORE
10 symptoms you shouldn't ignore [7]
10 tests that could save your life [8]
Dangerous medical mistakes [9]
Foods to ease the pain [10]

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Medical conditions we don't understand [11]

say-patients-should-know/106209/

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PPS Forum

By Richard Louis Bruno May 2007 The following three articles are reprinted with permission from Dr. Bruno.



Richard L. Bruno

Dr. Richard 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. His new book, How to STOP Being Vampire Bait: Your Personal Stress Annihilation Program, will be

published in 2004. E-mail him at ppsforum@newmobility.com.

Note: This column is for information purposes only and is not intended as a substitute for professional medical advice.

Q: I have osteoporosis and acid reflux. I just read that the anti-reflux drug I'm taking may cause my bones to get thinner. I already am taking Fosamax, which I also just read can cause my jawbone to die! Should I stop both these pills?

Polio survivors are finding themselves between drugs and a soft place, that soft place being their bones. Last year, osteonecrosis -- bone death -- was reported in the jaws of 63 polio survivors taking bisphosphonates, drugs that are given to increase bone density. Fifty-seven received intravenous bisphosphonates as treatment for cancer. But, six took Fosamax, the well-known oral anti-osteoporosis medication. Dentists across the country have reported about 50 cases of jaw osteonecrosis. Given that about 3 million women take Fosamax, 50 is a small number of cases. Even if you assume that only about

1 percent of problems caused by a given medication are reported, jaw osteonecrosis would occur in only two-tenths of 1 percent of women taking Fosamax. Still, if it's your jaw that's dying, who cares about percentages? So, the FDA now wants labels on all bisphosphonates to warn about the possibility of osteonecrosis.

If drugs to treat osteoporosis aren't causing enough worry, in late 2006 a study of nearly 150,000 people over 50 years old found that taking proton pump inhibitors (anti-acid reflux drugs like Nexium) for more than a year increased their risk of a hip fracture by 44 percent. The higher the dose and the longer the drugs were taken, the risk of a hip fracture, especially among men, rose nearly 200 percent. The increased risk of fracture may be caused by proton pump inhibitors interfering with your body's ability to deposit calcium inside your bones to increase their strength. This unfortunate side effect of proton pump inhibitors is a two-headed dragon for polio survivors. The first head is that polio survivors with paralysis, both female and male, have osteoporosis more frequently because they either haven't been "pushing" on their bones by standing on their legs (the result of using a weight-bearing brace, crutches or a wheelchair) or because their weak or paralyzed muscles haven't been "pulling" on bones. It's the pushing and pulling that makes calcium bind inside bones so they won't become brittle.

The second dragon's head is that our 1985 Post-Polio Survey found that gut problems, including ulcers and acid reflux, are between six and 15 times more common in polio survivors than in the general population. To make things worse, sleep apnea, which we have found in 25 percent of our Post-Polio Institute clients, may increase reflux.

Oh, and another "head" has just reared its ugly self. A 2007 study of 5,000 adults 50 years old and older found that daily use of the newer antidepressant medications (selective serotonin reuptake inhibitors -- SSRIs -- like Prozac) decreased bone density by as much as 4 percent and doubled the chance of breaking a bone. What's more, the higher the dose of an SSRI, the risk of falling increased by 50 percent.

So, what's to be done about your belly, brain and

bones? All female polio survivors, and males who have muscle weakness or paralysis, should have a DEXA bone density scan to determine if they have osteoporosis or osteopenia, a lesser decrease in bone density that still increases your risk of fracture. If you have decreased bone density, ask your doctor if you could try to increase calcium, vitamin D and protein before starting a bisphosphonate. If you need medication, ask about using calcitonin, a hormone that also increases calcium inside your bones, or the non-bisphosphonate drug Evista, while you also increase calcium, vitamin D and protein.

If you are taking a proton pump inhibitor or an SSRI, ask your doctor if increasing calcium would be helpful in combating these drugs' unwanted effects on bone density and falling. And, postmenopausal women should talk to their gynecologist about whether hormone replacement is an appropriate treatment.

Unfortunately, fatiguing exercise or walking to "push and pull" on bones is not a treatment for osteoporosis or osteopenia in polio survivors, since exercise can cause muscle weakness and exactly what you're trying to prevent: a fall and a fracture.

Quick Witty Dictionary

ADULT: A person who has stopped growing at both ends and is now growing in the middle.

BEAUTY PARLOR: A place where women curl up and dye.

CANNIBAL: Someone who is fed up with people.

CHICKENS: The only animals you eat before they are born and after they are dead.

COMMITTEE: A body that keeps minutes and wastes hours.

DUST: Mud with the juice squeezed out.

EGOTIST: Someone who is usually me-deep in conversation.

T'N'T for POLIO SURVIVORS

By Dr. Richard L. Bruno

No polio survivor - no one with breathing problems – should take Vesicare

Jane Smith went to her gynecologist with a common complaint: The Ditropan she was taking no longer was controlling her overactive bladder. So, her doctor prescribed a new medication, Vesicare, which Jane started on November 18. Four days later Jane was too exhausted to leave the house. The next day, all she did was sleep. By Wednesday, Jane was unable to stay awake. When she was awakened she stared into space, unable to understand or respond appropriately to questions. Even more frightening, Jane's ability to breathe was compromised. While asleep, her oxygen dropped to 78% (normal 90%). When she was awakened, her oxygen was in the low 90s (normal 95%) and carbon dioxide rose to 55% (normal 45%). Jane was placed on a ventilator with a facemask. Vesicare was stopped on November 24th. The next day, Thanksgiving, Jane was still unable to stay awake on her own but, when prompted, did try to eat. discovered that her stomach and intestines had shut down, a side-effect of medications like Vesicare that are anti-cholinergic, that stop you from peeing, that cause a dry mouth and, especially in polio survivors, can turn off your gut. Jane was placed on a liquid diet and given domperidone, a drug available through Canada, which activates the stomach and intestines without entering the brain, as does Reglan, the medication typically used to treat gastroparesis.

Unfortunately, Vesicare has an extremely long half-life. It would take Jane's body anywhere from 10 to 14 days for the Vesicare to clear out. During those days, although Jane mostly slept, she became progressively more aware and mentally sharp when awakened, but she could only eat very small amounts.

On the 15th day after Vesicare care was stopped, Jane awoke like Sleeping Beauty. She was able to stay awake on her own and was her usual intelligent and funny self, albeit easily tired. Although her intestines were functioning thanks to domperidone, Jane could still only eat small portions. She was given erythromycin, an antibiotic that also stimulates stomach emptying. After three days, Jane was eating normally. Today, one month after waking from her Vesicare-induced stupor, Jane is back on the Ditropan,

which is again controlling her bladder. Unfortunately, Jane still requires the ventilator at night and at times throughout the day when her diaphragm is unable to push enough carbon dioxide out of her lungs. Jane will need the ventilator for the rest of her life.

What are the morals of this frightening story? First, no polio survivor – no one with breathing problems – should take Vesicare. When I called the drug's maker, Astellas, about Jane's condition, the physician director of "adverse reactions" was aware that Vesicare not only turns off the bladder, but also turns off the stomach and intestines and enters the brain. Vesicare is known to block activity in brain areas damaged by the original polio infection, the brain activating system. In fact, the doctor told me that Astellas had just been required by the FDA to add "somnolence" to Vesicare's list of side effects. Somnolence? How about coma? To date, Astellas has not notified physicians that "somnolence" is one of Vesicare's side effects.

I also discovered that Vesicare is also known to block brain diaphragm stimulating neurons. So, Vesicare did to Jane what the poliovirus had not done 60 years earlier: put Jane on a ventilator and, in effect, gave her the symptoms of "bulbar" polio.

I told Astellas' doctor that I was concerned Vesicare would very likely have the same effect in other polio survivors, especially those who originally had bulbar polio or any polio survivors who had breathing problems, such as central sleep apnea. What's more, I told him I was worried that individuals who had both difficulty breathing and bladder problems and might be prescribed Vesicare – those with muscular dystrophy, multiple sclerosis and traumatic brain injury – might have a reaction like Jane's. The doctor told me that people at Astellas were "discussing the issue."

The second moral is that polio survivors can have difficulty blowing off carbon dioxide and should not be given oxygen without having their carbon dioxide monitored, since oxygen levels can be normal while carbon dioxide can become dangerously high.

The final moral is that a polio survivor should never take a drug that is anti-cholinergic or that enters the brain without your doctor researching the side effects. The coma you prevent will be your own.

Dr. Richard Bruno is Chairperson of the International Post-Polio Task Force & PPS Institute. He may be reached for consultation at postpolioinfo@aol.com

Courtesy of the South Plains Post-Polio Support Network on behalf of their members who have experienced this serious "side effect!"

Treating Tremors POLIO TIPS AND TECHNIQUES

by Dr. Richard L. Bruno

Last column, we talked about types of tremor, essential tremor being one, which is often treated with beta-blockers. Beta-blockers have been a first-line drug to treat high blood pressure. The problem for polio survivors is that the side effect of beta-blockers—and of most antihypertension drugs—is fatigue, something polio survivors don't need more of. So, here are some suggestions to take to your doctor about drugs to lower your blood pressure that, hopefully, will not also put you to sleep:

- The first drug prescribed to treat hypertension used to be a diuretic, a "water pill." Diuretics, like Diazide and Furosemide, lower blood pressure by decreasing the amount of fluid in your arteries. But diuretics work by making you pee...and pee and pee. Polio survivors with fatigue and weaker arms and legs shouldn't be running (or rolling) to the bathroom and getting on and off the throne a dozen times throughout the day and night.
- Those beta blockers I mentioned lower blood pressure by stopping adrenaline from stimulating the heart muscle. The problem is that these drugs block adrenaline from stimulating brain activation, too. Of all the antihypertensives, beta blockers are probably the worst offenders when it comes to producing fatigue. The drug companies' own studies show that fatigue was a side effect in a high percent of patients: Kerlone (3%); Corgard and Tenormin (4%); Trandate, Zebeta, Visken (5%-8%); Sectral, Lopressor, Inderal (11%-17%); and Coreg (24%).
- Another older antihypertensive that causes fatigue is the alpha blocker. This drug stops adrenaline from stimulating blood vessels and thereby allows arteries to open, lowering pressure by increasing the size of the "pipes" blood can flow through. But, as with beta blockers, anything that blocks the stimulating effects of adrenaline can cause brain "deactivation" and fatigue. Fatigue was reported in more than 7% of subjects taking alpha blockers Cardura, Hytrin and Minipress;
- Newer antihypertensives have been developed that don't block adrenaline and are less likely to cause fatigue. The calcium-channel blockers (CCB) open

- blood vessels and reduce the force of contraction of the heart. CCB Procardia and Norvasc caused fatigue in from 4% to 6% of subjects. But, fatigue was not reported with CCB Cardene and Verapamil;
- Differences in fatigue reports were also seen among members of another class of newer antihypertensive, the angiotensin receptor blockers (ARB). These drugs block angiotensin, a hormone that causes blood vessels to narrow. ARB Diovan and Avalide caused fatigue in 4% to 5% of subjects. Fatigue was not reported with ARB Atacand, Micardia, and Cozar;
- A varying ability to produce fatigue was also seen among the angiotensin converting enzyme (ACE) inhibitors, which block the production of angiotensin. ACE inhibitors Accupril, Lotensin, Vasotec and Zestril were found to cause fatigue in about 2% to 5% of subjects. However, fatigue was not reported with ACE inhibitors Aceon, Altace and Monopril.

Should polio survivors never take certain antihypertensives and always use others? First, some of these "antihypertensive" medications have applications other than lowering blood pressure, like beta blockers, which treat abnormal heart rhythms. Calcium-channel blockers also treat angina and can prevent migraines. And alpha blockers treat enlarged prostates and can help to warm cold hands and feet. Second, since some people have hypertension that is difficult to manage with only one medication, a combination of drugs may be needed that might necessarily include a beta or alpha blocker.

When taking any medication, it is important that polio survivors keep a log of side-effects and discuss these with their doctors. The dose or time of day when you take a drug—taking a fatigue-producing medication before bed or taking a long-acting, slowrelease form of a drug-may minimize fatigue. As we've discussed before, don't let doctors tell you that a drug couldn't cause fatigue because "other patients" haven't complained. Polio survivors are not like other patients. If your doctor doesn't listen to you, get another. If you're not comfortable with the medications your doctor is using to treat your hypertension, or if your blood pressure isn't coming down in spite taking a combination of drugs, don't hesitate to consult a cardiologist who's also a hypertension specialist.

Remember: The stroke you prevent by keeping your blood pressure down will be your own!

Dr. Richard L. Bruno is Director of The Post-Polio Institute and International Centre for Post-Polio Education and Research at Englewood (NJ) Hospital and Medical Center. March 16th, 2010

MEN ARE JUST HAPPIER PEOPLE

EATING OUT

- When the bill arrives, Mike, Dave and John will each throw in \$20, even though it's only for \$32.50. None of them will have anything smaller and none will actually admit they want change back.
- When the girls get their bill, out come the pocket calculators.

MONEY

- A man will pay \$2 for a \$1 item he needs.
- A woman will pay \$1 for a \$2 item that she doesn't need but it's on sale.

BATHROOMS

- A man has six items in his bathroom: toothbrush and toothpaste, shaving cream, razor, a bar of soap, and a towel.
- The average number of items in the typical woman's bathroom is 337. A man would not be able to identify more than 20 of these items.

ARGUMENTS

- A woman has the last word in any argument.
- Anything a man says after that is the beginning of a new argument.

FUTURE

- A woman worries about the future until she gets a husband
- A man never worries about the future until he gets a wife.

SUCCESS

- A successful man is one who makes more money than his wife can spend.
- A successful woman is one who can find such a man.

MARRIAGE

- A woman marries a man expecting he will change, but he doesn't.
- A man marries a woman expecting that she won't change, but she does.

DRESSING UP

- A woman will dress up to go shopping, water the plants, empty the trash, answer the phone, read a book, and get the mail
- A man will dress up for weddings and funerals.

NATURAL

- Men wake up as good-looking as they went to bed.
- Women somehow deteriorate during the night.

Pit-burial for Curing Polio

The following story from the Deccan Herald in India was posted on their website in 2009.



When millions across Asia watched the partial solar eclipse, Bilalabad, Naya Mohalla and Kharibowdi areas of Gulbarga took

recourse to 'eclipse therapy' as a means to cure children afflicted with polio and paralysis.

So deeply ingrained is the superstition, primarily among some Muslims, that the parents subject their children to inhuman torture, partially burying them while the eclipse is on. The parents say they are optimistic their children would be cured of polio, paralysis, and acute facial paralysis.

The therapy involves partially burying the children, including the affected limbs, in piles of manure.

The manure dumps were cleaned of other refuse and the pits dug. About 100 children with varying degrees of polio and paralysis gathered in Bilalabad, Naya Mohalla and Kharibowdi. Each was partially buried into a pit, a few minutes before the eclipse began. Those who suffered polio of the legs were buried till their abdomen, while children whose arms were poliostricken were buried till their necks.

They wailed and cried, but nothing would move the parents who merely pacified them by offering biscuits and candies. A few of the hapless children, unable to struggle any more, fainted and the more resilient fell asleep. Once the children are removed from the pits, a massage oil is applied over their bodies.

The believers in 'eclipse therapy' are many. Nasir Ahmed from Hutti Gold Mines said his child's left limb was bent and after burying him during the eclipse it got cured. Mohammed Hussain, a State government employee, said his eight-year-old child's condition improved after the "third treatment".

Orthopaedic surgeon Dr S S Gubbi said there was absolutely no scientific basis for the practice or connection between the two. He cautioned that children subjected to burial for a long duration may develop gangrene due to compression of vessels and muscles as vacuum is created in the pits in which they are buried.

A Rough Road

Patrick J. Bird pbird@ufl.edu

The following was sent to me by Patrick Bird.

Dear Mr. Jorgensen,

I have just published a memoir titled A Rough Road that perhaps readers of Polio Postbox might find interesting. The following is a publicity summary of the book.

Cordially,

Pat Bird

After contracting polio at age four in 1940, Paddy spends nineteen months in a "reconstruction home" far from his family. This is his story of that time, presented mainly from the child's point of view.

Enduring aching sadness and loneliness along with the pain and disappointments of rehabilitation, Paddy learns to prevail physically and emotionally through his interactions with a colorful cast of hospital staff—from a friendly giant orderly and a light hearted nurse to a no-nonsense physical therapist and an evangelical swimming instructor as well as an imposing and frightening physician and his unsympathetic nurse.

Perhaps most important to his "reconstruction," however, is the arrival of roommate Joey. An older, adventure loving youngster with spina bifida, Joey introduces Paddy to the joys and tomfoolery of boyhood and inspires him with his physical and mental toughness. Then there are the infrequent—but significant—visits of Paddy's mom, who is sure the Blessed Virgin will cure him, and his pop, who fears in his heart that he will have a *cripple* for a son.

Also woven gently into the fabric of this deeply personal story are relevant aspects of the polio experience during the early 1940's including the painful immobilization in casts, the dreaded iron lung, the often unwise corrective surgery, and the stigma (feeble and likely retarded as well) associated with survivors—even President Roosevelt, for instance,

stricken with polio in 1921, went to great lengths to hide his atrophied legs from the public.

A Rough Road is a testament to the capability of children to overcome the most difficult of times. It is a walk down memory lane for some, a lesson in history for others, and a moving experience for all.

ISBN-13: 9781452892955 \$10.45 Trade Paperback For sale at Amazon.com, Kindle eBooks, book stores & through other channels.

Congratulations to Jeanne Hoffman who celebrated her 90th birthday in September.



Quick Witty Dictionary

HANDKERCHIEF: Cold Storage.

INFLATION: Cutting money in half without damaging the paper.

MOSQUITO: An insect that makes you like flies better.

RAISIN: Grape with a sunburn.

SECRET: Something you tell to one person at a time.

SKELETON: A bunch of bones with the person scraped off.

TOOTHACHE: The pain that drives you to extraction.

TOMORROW: One of the greatest labour saving devices of today.

YAWN: An honest opinion openly expressed.

WRINKLES: Something other people have, similar to my character lines.

Ivy Glover

Ivy Glover was Blenda Ramsay's cousin and dear friend. The following is her obituary.



GLOVER It is with deep sadness that we announce the sudden passing of Ivy Lois Glover (nee Reinson) on Tuesday, August 16, 2011 at the age of 79 years. Ivy always got great pleasure from golfing and it was at the golf course with her friend when she suffered a bleeding aneurysm. Ivy was born in Birmingham, SK but spent all of her adult life in Regina. After her children were older she embarked on a career for herself, the highlight of which was working in the executive office of the Premier of Saskatchewan for 8 years. Ivy was happiest when helping others and took it upon herself to be the caregiver for many of her friends and family. She is predeceased by her loving husband, Tony Glover in 1995 and her mother, Marjorie in 1990. Ivy will be sadly missed by her daughter, Leslie (Phil) Graham their children, Jordan and Jenny Red Deer, AB; sons, Grant (Lisa) Shaunavon, SK and Craig, Regina, SK; sisters, Audrey Akerman, Mavis (Mike) Davidson, Donna (Larry) Koper; brothers, Bud (Jan) Reinson, Lorne (Irma), Bob (Lee) and Don as well as many nieces, nephews and a host of good friends. Many thanks to the wonderful nurses and doctors at the SICU Unit at the General Hospital. Memorial Service will be held at 11:00 a.m. on Saturday, August 20, 2011 at Broadway United Church, 105 Broadway Ave., Regina, SK with Rev. Jim Balfour officiating. In lieu of flowers donations may be made to Polio Regina Inc., 825 MacDonald St., Regina, SK, S4N 2X5. Paragon Funeral Services entrusted with arrangements. 359-7776

I Remember Ivy

by Blenda Ramsay

Where do I start? There are so many wonderful memories I have of my "fuzzy cuzzy" Ivy that it's hard to know where to start.

I kind of remember days so many years ago when she was about 11 years old and I would have been about 9. Our dad had died and my mom needed help so Ivy came to the rescue and lived with us for about a year. Even at that early age she was kind of our "hired girl" and helped with looking after us kids and household chores she that could handle.

She told me that my mom gave her a new blue pleated skirt and a white sweater which may have been the first new outfit that she'd ever had. Her clothes would have been hand me downs from Audrey or the Steeper box so she was very proud of having a new outfit to wear to school. She mentioned several times how happy she was to get that outfit.

Ivy went to school with us during that time. After school we would change our clothes (we had school clothes and chore cloths) and get to work. Once the work was done, we would have supper and then we were allowed to have some play time. Our favorite thing was to "walk and run" on gas barrels back and forth between the house and the barn

One summer our Moms took all of us to what was then "Devils Lake" (now it's called Good Spirit) where we rented a cabin. (I have pictures). There must have been 14 or 15 of us. We only had one car so I guess the older ones rode in a trailer (or stone boat) tied behind the car. No seat belts in those days! But boy, did we have fun! We all remember that summer! I imagine Audrey and Ivy looked after all the kids.

When I was about 15 Ivy invited me to come to Regina and spend a few days with her. She was living with Aunt Louise and working for SaskTel at the time and I remember taking the street car down town to Simpson's where we did some shopping. A photographer on the street took our picture walking down 11th Ave. They use to do that in those days. I remember the dress I had on. Ivy has her white high

heels on and I think she's got white gloves on. We were all dressed up.

A couple years later I ended up in the General Hospital for six months while re-cooperating from Polio and Ivy would come and visit me on her days off. Sometimes she would put me in a wheelchair (I have a picture) and push me down to the Met Theatre and we'd go and see a movie. It didn't matter that it was March and the streets where full of ice and snow and slush, she would almost break her back pushing me. My own family were on the farm at Melville and it was too far to come and see me. Mom was home with kids to look after and cows to milk. Remember that was 1954.

Ivy met Tony and they got married October 20, 1956 and lived in Regina. Mavis and I were her bridesmaids. (I have a picture). Fred and I got married the following summer, June 29, 1957 and we moved to Red Deer. Ivy was at the guest register at our Reception. (I have a picture). Pat Griffith was flower girl.

Sheree was born the following April in Red Deer and Ivy sent a lovely gift for Sheree's first Christmas of pink baby lotion and I don't remember what else, but I was thrilled. (No picture).

I guess we moved back to Saskatchewan in 1960. Pam was born in Regina on July 2, 1961. The summer was a terribly hot summer. We lived in a hot apartment on Grey Street. My ankles where all swollen up. Ivy invited me to her place and I sat in the shade many days with my feet in cold water during that hot month. Ivy took care of Sheree (age 3) when I went to hospital. Sheree got sick that first night and threw up all over the place. Ivy told me that story several times! Ivy was likely there again when Robert arrived Aug. 11, 1968.

Ivy and Tony lived in Gladmar Park. It's ironic because now we live next door to what use to be called Gladmar Park. Those were to good old days. Later Ivy and Tony moved to a lovely home in Whitmore Park. When Sheree got married, Ivy hosted a lovely bridal shower for her and Tony was MC at their wedding.

We stuck together through thick and thin. There were

Christmas parties, New Year's parties, children's birthday parties etc. (I have pictures). While raising kids we took sewing classes, typing classes, cake decorating classes, volunteered when we could and took care of our kids, husbands and moms.

She was so good at everything, but I think I beat her in typing speed. I got my 60 words a minute certificate, (still have it) but I don't think she ever got hers. I can say that now because she's not here to defend herself. Good old Remington typewriter!

When it was election time you would find Blenda and Ivy working at the Polls. I didn't think I was smart enough, but she encouraged me and we did it. We even got paid! One year when we were working the polls and there were two old "fuddy-duddies" working next to us. They seemed to have problems every time someone came in to vote. Ivy and I just sneered at them thinking how dumb they were. End of story? They were the first ones to balance and left, and we had a heck of time balancing our ballots and we were the LAST ones out!

Eventually our kids were old enough and we were able to get jobs. That was huge! I would call Ivy at the Legislative Building and she was on switch board. She put me on "hold" several times while we tried to talk. I got work in Reservations at the Hotel Sask. I could have free lunches every day, so I invited Ivy to join me a couple times and we really thought we were "big shots" having a power lunch in that lovely dining room.

Time marched on. Over the years I had ended up falling and breaking my ankle or something or having surgery. When I had back surgery she came and washed my hair. She'd come with food! I don't know how I'll get through Christmas this year without her yummy shortbread cookies or tarts.

We spent many birthdays together. (As usual I have pictures). I'd invite her to come over for her birthday and she'd bring the Angel Food Cake (plus candles) and food. How good was that!

When we moved, she came and brought packing boxes and wrapped up all our good dishes and packed them. She also came and unpacked and washed them when we got here. Her aim in life was to HELP!

And Help she did. She helped many, many people.

Since Fred went into the nursing home, she went and helped feed him lunch. Who is going to do that now??? She made sure I would get some days off from going to the Home. I haven't told him yet that she won't be coming anymore. I don't know if I will.

Who will pick up my family from the airport when they arrive??? Who will go to Wall Mart for me to pick up stuff? She bought some big storage bags from Wall Mart this spring and was going to come and help me put away my winter sweaters. However, Fred got sick in April and we didn't get it done. Now it's almost time to wear winter sweaters again.

She was my "rock". We e-mailed almost daily. We usually ended the e-mails by saying "now don't fall down." The reason being was because we each took some spills over the years. Now she's fallen down and won't get up. If anyone deserves Heaven, she surely does! I hope to see you again some day.

Good Bye to my awesome fuzzy-cuzzy!

With all my love, BJ

At the Meetings

Our **March** meeting was our annual general meeting which included the election of officers. The incumbents agreed to let their names stand for reelection and were all elected by acclamation. The executive is as follows:

President - Wilf Tiefenbach

Vice-President – Carole Tiefenbach

Secretary – Ivan Jorgensen

Treasurer – David Cotcher

Phone Coordinator – Carole Tiefenbach

Archivist/Librarian/Web Master – Dr. Mavis Matheson

Post Box Editor – Ivan Jorgensen

We agreed to hold our spring picnic at the home of Dr. Mavis Matheson.

Open forum: Our guest speaker was Donna Bowyer, Branch Director for the Canadian Mental Health Association in Moose Jaw. Donna gave a very

informative presentation on Depression and Mental Illness which was followed by discussion. The slides from her presentation are available on the Polio Regina website.

At our **April** meeting Murray Grant informed us that the Arthritis Aquacise program at the Wascana Rehabilitation Centre Therapeutic Pool is no longer run by the Arthritis Society but is now administered by the City of Regina. This is an Aquatic exercise program designed for people with arthritis but it would also be helpful for polio people. Swim in a comfortable, accessible pool that is heated to 33°C. The program runs from early May to late June on various days of the week.

Open Forum: David Cotcher led the open forum; his subject was: Pension Plans, Wills, Power of Attorney, and Health Care Directives. He discussed various pension plans including company, government and personal plans, wills and estates, choosing an executor, probate, power of attorney, health care directives and how getting professional advice in these areas can be very helpful and save time and money in the long run. An outline of David's presentation is on the Polio Regina web site.

At our **May** meeting Blenda Ramsay informed us that Fred Ramsay had been in the hospital for more than a month. He was treated for a bleeding ulcer and other complications. After his physical health improved he was moved to the Sunset care facility. Our thoughts and prayers are with Fred and Blenda at this difficult time.

Spring Picnic: Our annual spring picnic was enjoyed by everyone with lots of great food and conversation. Due to the rain and wind we had to move inside after the meeting but there was plenty of room and everyone was comfortable. Thank you to Mavis and Adam for hosting us in your lovely home and thank you to Carole and Wilf for getting the food and setting everything up.

Next Meeting: The next Polio Regina meeting will take place at on September 29th at 7:00 p.m. in the Auditorium of the Wascana Rehabilitation Centre. Ivan Jorgensen volunteered to lead the open forum. The subject will be: Our Experiences with the Medical System and Have You Been Officially Diagnosed with Post-Polio Syndrome? (See "Editorial" in this issue).

Coffee Filters

Better than paper towels and a lot less expensive...

Coffee filters Who knew! And you can buy 1,000 at the Dollar Store for almost nothing even the large ones.

- 1. Cover bowls or dishes when cooking in the microwave. Coffee filters make excellent covers.
- 2. Clean windows, mirrors, and chrome... Coffee filters are lint-free so they'll leave windows sparkling.
- 3. Protect China by separating your good dishes with a coffee filter between each dish.
- 4. Filter broken cork from wine. If you break the cork when opening a wine bottle, filter the wine through a coffee filter.
- 5. Protect a cast-iron skillet. Place a coffee filter in the skillet to absorb moisture and prevent rust.
- 6. Apply shoe polish. Ball up a lint-free coffee filter.
- 7. Recycle frying oil. After frying, strain oil through a sieve lined with a coffee filter.
- 8. Weigh chopped foods. Place chopped ingredients in a coffee filter on a kitchen scale.
- 9. Hold tacos. Coffee filters make convenient wrappers for messy foods.
- 10. Stop the soil from leaking out of a plant pot. Line a plant pot with a coffee filter to prevent the soil from going through the drainage holes.
- 11. Prevent a Popsicle from dripping. Poke one or two holes as needed in a coffee filter.
- 12. Do you think we used expensive strips to wax eyebrows? Use strips of coffee filters.
- 13. Put a few in a plate and put your fried bacon, French fries, chicken fingers, etc on them. It soaks out all the grease.

- 14. Keep in the bathroom. They make great "razor nick fixers."
- 15. As a sewing backing. Use a filter as an easy-to-tear backing for embroidering or appliqueing soft fabrics
- 16. Put baking soda into a coffee filter and insert into shoes or a closet to absorb or prevent odours.
- 17. Use them to strain soup stock and to tie fresh herbs in to put in soups and stews.
- 18. Use a coffee filter to prevent spilling when you add fluids to your car.
- 19. Use them as a spoon rest while cooking and clean up small counter spills.
- 20. Can be used to hold dry ingredients when baking or when cutting a piece of fruit or veggies. Saves on having extra bowls to wash.
- 21. Use them to wrap Christmas ornaments for storage.
- 22. Use them to remove fingernail polish when out of cotton balls.
- 23. Use them to sprout seeds. Simply dampen the coffee filter, place seeds inside, fold it and place it into a plastic baggie until they sprout.
- 24. Use coffee filters as blotting paper for pressed flowers. Place the flowers between two coffee filters and put the coffee filters in phone book.
- 25. Use as a disposable "snack bowl" for popcorn, chips, etc.

OH YEAH THEY ARE GREAT TO USE IN YOUR COFFEE MAKERS TOO.



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 at 7:00 p.m. on the last Thursday of the month at 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 June, July, August or December. We usually have our Spring Picnic in May at a private residence and our Christmas Party in November or December 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

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.

MEMBERSHIP APPLICATION POLIO REGINA Inc.

Name				
Active () if you had polio	Associate ()	New ()	Renewal ()	
Address				
Postal Code	F	Phone:		
Annual membership fee: (Jan Dec.)				
\$10 Single; \$15 family	\$	_		
My donation to Polio Regina Inc.:*	\$	_		
Tot	al \$	_		
(If you require sponsorship for your fee, i	inform our memb	ership chairn	nan)	

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.)