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March 2011

Polio Regina Incorporated

Happy Easter



Polio Regina Loses Founding Member

In Memory of Joan McIver

Joan McIver passed away on December 2, 2010 at the age of 85 years. Left to cherish her memory are her cousins Joan in Wales, Nola McKay and Esther Dybvig; and her many dear friends who will remember Joan for her extraordinary strength, courage and determination in the adverse circumstances of life. Joan is predeceased by her



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My Polio Story

The following is Nora Schlosser's Polio Story. Nora is a long time supporter of Polio Regina and served as secretary for four years. Nora was presented with a Polio Regina Life Membership in 2009.

Nora Schlosser

My name is Nora Schlosser and this is my polio story.

I was born in Strasbourg, Saskatchewan in 1931 and moved to Regina to complete my high school education. In 1952 I got married and a year later was expecting my first child. It was August 1953 and I was not feeling very well. The doctor said I was in labor, however, he couldn't figure out why I had such a high fever. I was taken to the General Hospital by ambulance and that is where my nightmare began. After 12 hours of pure hell they were ready to deliver my baby but I was not allowed to deliver in the maternity ward. They made a delivery room out of a small room which the doctor was complaining about the poor lighting and at this point I was praying to die. I delivered a baby girl.



In the morning, three doctors came into my room and informed me that I was a lucky lady to be here today because I have polio. I was thinking – what is polio?

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In Memory of Joan McIver - continued

parents and dear brother Allan. Joan was a resident at Sunset Extencicare since 2008.

Joan contracted polio during an epidemic in Winnipeg when she was two years, 10 months old. "Treatment meant complete bed rest and tying my legs to the crib to prevent movement. This caused contractures of my unused muscles and I had many operations to cut the muscles to release the contractures, Joan recalls. By the age of four, I learned to walk using crutches and heavy steel braces to support my useless legs" she said.

After graduating from Business College at Caronport, Saskatchewan, her mother and Joan moved to Regina where she began a 38-year secretarial career, first in the provincial finance office for five years; then five years at the Wheat Pool. The remainder of her working time was with the provincial health department.

"During our first week in Regina, I saw an advertisement in the paper announcing an organizational meeting for a local branch of the provincial Handicapped Civilians' Association (HCA)," Joan recalls. "This was in 1948 just after the war when many clubs had formed to help returned disabled servicemen. There were no clubs for the civilian population such as polio survivors" she recalls.

"It was really amazing that at every meeting of handicapped people, I was always drawn to those who had polio," Joan said. "There seemed to be a special bond among us. We met in each other's rooms, ate our meals and attended all the social events together," Joan added.

"This was when the beginning of my dream to start an organization of only polio survivors began. I mentioned it to others but no one seemed to catch my enthusiasm so my dream lay dormant for many years. This was in the early '50's before the terrible polio epidemics began", Joan said.

Finally in the late 1980's Joan's hard work and diligence, along with other polio survivors, resulted in assembling a post polio organization on the provincial level called Saskatchewan Awareness of Post Polio Inc. (SAPP).

A Regina branch of SAPP was formed spearheaded by Joan McIvor and very quickly other Regina area people joined the movement. Among them were Ruth Adelia, Javonne Miller, Deryl Quinn, Drs. Elisabeth and Lewis Brandt, Virginia and Maurice Denzin, Olga Robinson, Blenda Ramsay, Dorothy Slater, Georgina Heselton, Peggy and Don Gliddon, Irv Richards, Darlene Krause, Dorothy Sweet and Chris Davies. The group elected Joan McIver as president of the Regina branch and, in slow steps, the Regina group increased membership. The Regina branch became an independent organization in 1995 and changed our name to Polio Regina Inc.

As an original organizer and the prime instigator and motivator of our Polio organization, Joan McIver was the recipient of our Polio Regina life membership award in 2005.

Polio Regina Inc. members are proud of Joan's work and will miss her.

My Polio Story - continued

My baby girl was healthy and was not affected by the polio.

Polio had paralyzed my stomach muscles, created a curve in my spine and made my right leg very weak but I was never in a wheel chair. I was also informed that my sister and brother were both in the same hospital with polio.

After two weeks I was allowed to go home as long as I had help with the baby. When my therapy began I was taken by bus to the General Hospital where my sessions were out of the basement, I also had swimming therapy at the YMCA.

My life became fairly normal, I have six children; the last two were twins. In the last couple of years with post polio my muscles have deteriorated and fatigue is a large problem. Doing stairs is a no no and I am limited to only walking a block before taking a rest. With the support of my family and friends I would have to say that I'm doing OK.

Message from the President and Vice President



Wilf and Carole

Since the last newsletter, a lot has transpired. Firstly, we had a great Christmas party held at Broadway Terrace. What a great meal we had and also a great attendance! Carols were sang, led by beautiful music on the piano, accompanied by trumpet, played by two very talented upcoming music teachers.

Thank you to Blenda Ramsay for arranging to have the room at Broadway Terrace, the dishes, cutlery and coffee, the setup of chairs, and the decorating of the hall. It was so much fun getting ready for the party! Thank you to our friend Sylvia Danyluk, who helped us so much too. It was a wonderful start to a wonderful Christmas season.

We had a marvellous Christmas this year. We had our annual trip to Winnipeg. We saw all of our children and grandchildren this time and that makes Christmas wonderful. Everyone knows we had plenty of snow to go along with that!

If it wasn't for our upcoming trip to Florida, January would have been much harder to take. However, counting sleeps along with the grandchildren made it bearable, until we left on Jan. 31st. That was a bitterly cold day when we left here, Chicago was a bit warmer and Orlando was Heaven on earth! What a smell! Hibiscus flowers everywhere!!! Green grass, no snow!! Family joined us on Feb. 3rd and we were so busy up until the day they left on the 15th. The grandchildren were determined to wear us out and that they did!

After a lot of coaxing, Carole's great adventure started when we all went on Space Mountain! What a mistake that was. Her first mistake was closing her eyes for the entire ride while hanging on for dear life! She could not move after and needed help to get out of the seat. She was helped out to a nearby bench while the EMT's came with a stretcher! (Of course the ride was shut down temporarily). Her blood pressure was taken, (it was higher than normal, naturally), she didn't want to lie down on the stretcher, so they got a wheelchair and she was pushed to the First Aid Station in Magic Kingdom. There she laid on a bed with a pillow for about an hour, feeling very nauseous and weak. So sick she could hardly feel embarrassed.

After she felt a bit better, she sat in the wheelchair again and we actually had a very good view of the fireworks from there. She was a very sick lady that evening.

A few days later, Carole's shoulder froze up and it was dreadfully painful. We made the big mistake of not going to a doctor to get an MRI, as she has been waiting to get one for over two years. After about one week, it started to have a bit of movement. Now she is going for treatments from her chiropractor.

We arrived home around 8:15 pm. on the 24th of February, dreadfully cold, wondering why we came home to this! We had left Florida where it was 82 degrees! All good things come to an end, they say, now life has turned back to normal, whatever normal is, back to work, as retirement is not here yet! We certainly understand why people from the Prairies want to become snowbirds now. We are looking forward to Spring as everyone else is, I am sure. Let's get out the rubber boots! Hope you all were able to keep warm these past few months.

Cheers, Wilf and Carole

Spring Picnic

Don't forget our spring picnic on May 26th at 5:00 p.m. at 15 Trudeau Bay. More information will be supplied on the web site, at our next meetings and by the phone committee.

The following article is reprinted with permission from the Polio Quebec Association, Folio Polio #45 Winter 2010-2011 newsletter.

RESEARCH STUDY TO IMPROVE RESPIRATORY HEALTH

By Dre Marta Kaminska MD, FRCP(C), McGill University Health Centre, Respiratory Division, Montreal.

Certain individuals who have suffered from polio may have a weakened respiratory function. This problem affects those who have been left with a chest wall deformity or weakness of respiratory muscles (like the diaphragm). These individuals may feel no breathing difficulty for a prolonged period. However, with increasing age, respiratory function deteriorates and difficulties may occur. Moreover, those with the post-polio syndrome may have an accelerated loss of their muscle strength, potentially including the muscles of breathing.

A team of researchers (*Dre Daria Trojan, Dre Angela Genge, Dr Basil Petrof, Dre Marta Kaminska, Mrs Franceen Browman, Respiratory Therapist, and Christine Kupka, research coordonnator*) from the Montreal Neurological Institute and the Royal Victoria Hospital (McGill University Health Centre), affiliated with the post-polio clinic of the Montreal Neurological Hospital, is presently conducting a research study aimed at improving respiratory health of persons living with the post-polio syndrome who are starting to have a drop in their respiratory function. Two other illnesses are included in this study, Steinert's myotonic dystrophy and amyotrophic lateral sclerosis. This study examines an exercise for the respiratory system – the “manual hyperinflation technique”. It involves insufflating a volume of air into the lungs using a balloon (similar to those used in emergency situations for resuscitation), as if the person was taking a big breath. The amount of air that is insufflated (pushed in) somewhat exceeds that which the person could inhale on their own, given their muscle weakness. This allows to “recruit” a maximal lung capacity. This could be considered as physiotherapy for the respiratory system. The goal of

these exercises is to maintain or improve the elasticity of the lungs and the chest wall. They tend to become stiff when not fully used, as is the case when there is respiratory muscle weakness.

These exercises are entirely safe. Their main inconvenience is related to the time required to perform them. For optimal results, it is suggested to do three to four sessions daily. People with more pronounced respiratory muscle weakness from various neurological conditions already commonly perform these exercises. In addition to increasing elasticity of the respiratory system and therefore facilitating breathing, they improve the strength of cough, which allows to clear secretions more effectively and potentially to decrease the risk of pneumonia in these patients. To present, these exercises have not been formally studied to find out if they help prevent deterioration of respiration. The study currently under way is innovative as its goal is to demonstrate a beneficial effect for individuals with only mildly reduced pulmonary function. Ultimately, these exercises might be able to slow down the progressive deterioration of respiratory function. When there is a more marked deficit in breathing, respiratory assistance during sleep is required using a ventilator which is a machine that pushes air through a nasal or oro-nasal mask, somewhat similar to CPAP machines used for sleep apnea. The ventilator allows an adequate exchange of oxygen and CO₂ by assisting the patient's weakened muscles with each breath. The “manual hyperinflation technique” could delay the moment when the use of a ventilator is necessary at night, by maintaining better lung health.

Those who have participated in the study have generally appreciated the experience. It is too early to draw conclusions on the effectiveness of the exercise on physiologic measures, but preliminary results are encouraging. At least some participants have noted improvement in their breathing and endurance, and it appears that benefits are most notable in those with the post-polio syndrome compared with the other two disorders studied. No complications have been observed. Researchers are confident that these exercises can really have a positive impact on those with weakening respiratory muscles, particularly those with post-polio syndrome. They continue looking for candidate subjects for this study.

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Rancho Los Amigos Post-Polio Support
Group Newsletter – February 2011

Treating Polio – Now and in the Future

Including research from around the world

With Susan L. Perlman, M.D.

Clinical Professor of Neurology
David Geffen School of Medicine
University of California, Los Angeles
Presented at the Orange County, CA. PPSG
meeting, May 23, 2010

Reported by Mary Clarke Atwood

Editorial assistance by R. Daggett and
S. L. Perlman, MD

Dr. Perlman has learned about PPS from her patients – more than 500 of them in the last two decades. We always look forward to this annual presentation when Dr. Perlman generously shares her time and energy with local polio survivors.

This year's review begins with patient care guidelines and includes the exciting work being done with stem cells. Although there is not yet a group working with stem cells in patients with post-polio in the United States, there has been a great deal of stem cell work in patients with other neurological disorders. What is learned from them may also apply to post-polio. Other research topics include mental and physical fatigue, pain, and predicting which polio survivors will develop polio problems and who will be spared.

Standard Patient Guidelines

Everyone needs a good primary care doctor, a knowledgeable physical therapist, and attention to good general health practices (weight management, exercise, appropriate assistive devices, relaxation training, sleep hygiene, emotional health). If a survivor has symptoms that impinge on these areas, they can be directly attacked to improve quality of life.

These standard polio survivor guidelines of the last ten years are still valid:

- Make sure your symptoms are polio related. They may be due to another medical or neurological illness or to orthopedic problems, which must be identified and treated. New symptoms in a polio survivor are only related to polio about 1/3 of the time.
- Treatment of other illnesses in a polio survivor must be monitored relative to the sensitivities of PPS (e.g. surgery, chemotherapy, use of cholesterol lowering medication).
- Polio survivors with symptoms of PPS must take care to modify lifestyle and use rehabilitation medicine or services to develop a program of appropriate non-fatiguing exercise and reconditioning, assistive devices, pacing of activities, and finding their own limit. They need to work with somebody who is knowledgeable about rehabilitation to address these issues.

Caution: Do not push yourself past the limiting point of pain and fatigue.

No one is talking about “Conserve to Preserve” anymore. If you are a polio survivor and are beginning to experience fatigability and weakness, nobody should recommend that you stop doing everything, to never exercise again and get a wheelchair.

Why Increase the Awareness of Post-Polio?

Doctors treating polio survivors need to be aware that these patients are going to be different from patients who never had polio. Polio survivors report poorer functional status and poorer health-related quality of life than non-polios.

The life-altering effects of post-polio have not been adequately addressed by health care providers. They are not aware that they actually have tools they can use right now to help polio survivors with some of these unique problems.

Many publications indicate that polio survivors are best served in multidisciplinary clinics staffed by knowledgeable professionals. We need to make this known to others.

Will Healthcare Reform Make these Guidelines Achievable?

A personal experience:

Dr. Perlman recently saw a typical polio survivor with PPS. This patient had been seen in clinic during 2007-2008 and returned two years later.

Those earlier visits included recommendations for:

- physical therapy to develop a non-fatiguing home exercise program
- a sleep study for symptoms of obstructive sleep apnea possibly contributing to daytime fatigue.

However, a perfect storm of potential rationing and misinformation followed:

- The patient's HMO approved physical therapy but only for treatment of what appeared to be carpal tunnel syndrome. There were only the minimum number of treatments and that was it.
- No home exercise program was developed.
- No counseling about activity modification and pacing was achieved.
- A sleep study was done confirming obstructive sleep apnea. But the physician in charge counseled that the mask to assist breathing would be very uncomfortable and it could take the patient a year to become satisfied. With a build up like that, the patient chose not to try it.

The patient returned to Dr. Perlman two years later with the same complaints: symptoms of sleep apnea, daytime fatigue, plus weakness and fatigability in muscle areas - all because of potential rationing and misinformation.

There is no excuse for this, but it happens all the time. Polio survivors need to be aware and proactive with health care providers. Bring them information, but don't overwhelm them while being firm. Show them what has been published defining the standard of care for a person with post-polio syndrome.

Will Dr. Perlman's recommendations be provided this time? The patient has a new HMO, so time will tell.

Limited treatment and misinformation are very frustrating because this patient could have had two years of improvement instead of continuing and

probably worsening personal health status.

Polio Vaccine

Dr. Perlman believes that polio vaccinations need to be continued because the virus is out there. Just recently in Los Angeles there has been an outbreak of mumps because some people get lazy, or are afraid, and don't get the vaccines for their children. So mumps comes back; polio will come back.

Globally, the number of new polio cases registered in the first four months of 2010 is down to 56, which is a 75% drop from the same period last year.

- In Nigeria only two children have been paralyzed by wild polio virus compared with 123 during the same period in 2009.
- For the first time in India, there has not been a single case caused by the most virulent polio viral type for four months straight.

Editor's Note: Centers for Disease Control (CDC) - Outbreak Notice

Polio Outbreak in Tajikistan, Cases in Russia Risk of Spread to other Central Asian Countries

This outbreak represents the first importation of polio in the World Health Organization (WHO) European Region since it was certified polio-free in 2002. As of October 14, 2010, the Tajikistan Ministry of Health has reported 706 cases of acute flaccid paralysis. Of these cases, 458 have been laboratory-confirmed as polio. Russia has reported 14 polio cases to date, five of which are linked to travelers. <http://wwwnc.cdc.gov/travel/>

Research around the World

United States, Canada, Spain, Sweden, Israel, France, and The Netherlands

Stem Cell Therapy

Lou Gehrig's disease (ALS) research is looking at problems of upper motor neurons, typically spared in post-polio and lower motor neurons, which are typically affected in post-polio. These neurons are both being targeted with stem cell therapies in ALS patients. The nine ongoing therapeutic stem cell trials look very promising, both in Europe and one study in the United States.

The U.S. group is spearheading an ALS trial with stem cells derived from bone marrow. These results should open the doors to similar treatment trials in post-polio because the cells are the same, the target is the same, and ideally the outcome would be the same.

Researchers in the U.S. and some scientific colleagues in Europe are working on ways to make stem cells behave like nerve cells, and to make them go to the part of the nervous system in which they are interested (spinal cord, basal ganglia, memory centers) and do what they are supposed to do.

It is important to point out that some of the fringe groups in China and Costa Rica may not have done as much advance preparation of the bone marrow or umbilical cord stem cells. Perhaps the preparation may not have been the right kind, they may not have been modified in the right way, or they may not have been stimulated with the right growth factors. In fact, China has abandoned treating ALS atients with stem cells because that didn't work.

Although our U.S. stem cell studies for Parkinson's disease and ALS began three or four years after the Chinese, we are now working with stem cells whose behavior can be predicted and are assured they will not cause cancer.

Dr. Perlman expects to have much more information on stem cells when she speaks to this group again on Sunday, May 22, 2011.

Quality of Life

A study from two post-polio clinics in Israel found that approximately 70% of the participants expressed the belief that exposure to up-to-date information about post-polio, as well as participation in social activities, might improve their quality of life. Dr. Perlman pointed out that a support group provides those things.

Reviews and reports from other large polio clinics have also shown that education and getting people to take control of their symptoms and condition definitely improves their quality of life.

This study from Israel concluded that information about the physical and mental components of polio survivors, as well as the desire to partake in specific

activities for polio survivors, may serve as a basis for the operations and prioritization of service providers. Dr. Perlman recommends including the importance of this information on grant applications.

Fatigue

Eighty-percent of polio survivors with new symptoms have fatigue, or pain, or both. Dr. Trojan's group in Canada studied General, Physical, and Mental Fatigue to determine what modifying factors could be changed and which could not.

These non-modifiable factors, which seemed to have an effect on general fatigue, could not be changed:

- respiratory function
- fibromyalgia
- muscle strength
- age
- time since acute polio

In this Canadian study there weren't any non-modifiable factors which seemed to correlate with mental fatigue. However, the ongoing Mental Fatigue study at the U.S National Institutes of Health (NIH) may discover some non-modifiable hardwiring changes relating to the original polio that contribute to brain fatigue. So theoretically, if you have brain fatigue, it is modifiable.

Potentially modifiable factors account for a portion of fatigue in PPS. Dr. Perlman said the presence of these needs to be dealt with to help reduce fatigue. If you deal with stress and depression, then general fatigue scores will improve, theoretically.

Reducing Physical Fatigue

Physical fatigue is the most common symptom and the most disabling in patients with post-polio syndrome. A Spanish study analyzed the effectiveness of various treatments used to improve fatigue syndrome in post-polio patients. They retrieved 396 articles, of which 23 were analyzed in detail. These treatment techniques reduced fatigue in 705 patients.

- lamotrigine (Lamictal)
- bromocriptine (Parlodel)
- aerobics and flexibility exercises
- hydrokinesitherapy
- technical aids

Dr. Perlman suggests that when you pace your physical activity you should be able to manage physical fatigue. If you treat the pain, physical fatigue will improve.

Mental Fatigue in Polio Survivors

The study of “Mental Fatigue in Polio Survivors” at NIH examines whether mental impairment is present in PPS patients. If it does exist, how does it interfere with self-functioning of patients?

One of the biggest mysteries in post-polio is problems with slow thinking and memory which seem to go right along with motor difficulties. Is this truly a brain mediated fatigue that affects thinking, learning, etc.? Or does it relate more to psychological or emotional factors?

The term “brain fatigue” is frequently used by patients to express problems in the areas of attention, concentration, memory, and clear thinking. Unfortunately, little is known about cognitive fatigue of PPS patients.

It has been accepted that polio survivors tend not be burdened by psychological baggage that is going to add to their neurologic and physical symptoms. If you happen to have depression it is obviously going to impair you, but it is not directly related to polio.

Polio treatment really needs to be focused on physical and neurologic hardwiring. Many studies have been done trying to sort out what is going on above the anterior horn cell, but there is still no consensus.

Pain

A study in Sweden concluded that pain is common in PPS patients; most patients experienced pain caused by an injury to body tissues. Women have pain more often than men. Older patients experience pain less often than younger patients. Age at time of primary polio infection is important for the development of pain. When neuropathic pain is present, it is important to proceed with a neurological examination to find an adequate diagnosis.

Orthotics for the Knee

Orthoses play an important role in the therapeutic care of polio survivors. The aim is usually to secure the knee, preventing excessive recurvatum while

respecting the patient’s own gait.

A study in France by Francis Genet’s group concluded:

- Orthoses must be light and pressure-free if they are to be tolerated and therefore effective.
- Some deformities may be helpful for the patients’ gait and, therefore,
- corrections may worsen their gait, especially if a realignment of segments is attempted. It is therefore essential to carefully pre-assess any change brought to the orthoses as well as proper indications for corrective surgery.
- In addition, it is essential for the patient to be monitored by a specialized team.

Impact of Age and Comorbidity on the Progression of Disability

A study from The Netherlands concluded that despite a reduction in muscle strength over a five-year period, the PPS patients’ disability level increased little.

- Increased weakness in a quad or in a shoulder muscle really didn’t have a significant impact on levels of disability, as measured by disability scales.
- Increased age and the other number of medical factors or surgical problems do have a negative effect on disability.

Predicting which Polio Survivors will Develop PPS

Looking at the long-term ongoing studies, there is probably about a 60 % risk of developing PPS and probably a 40% risk of just living with the original deficits.

In 1995 Post-Polio Health International (PHI), an excellent website and group <http://www.post-polio.org/index.html>, established The Research Fund which is dedicated to seeking scientific information leading to eventual amelioration of the consequences of poliomyelitis and/or neuromuscular respiratory diseases.

- In 2007 the fourth PHI award was looking for biomarkers in blood and spinal fluid of polio survivors to see if they could identify a marker that would determine if a person will probably

develop post-polio symptoms, or probably not develop them.

How can each group be identified? It has been confirmed that individuals with PPS have higher levels of antibodies and regulatory T cells (which are part of the immune system) circulating in the blood, compared with healthy age-matched controls who never had polio. The immune factors that have been discussed in previous years (tumor necrosis factor Alpha, the interferons, and a few others) are definitely at a higher level in people experiencing active post-polio symptoms.

In this study a cross section was assessed. Stable polio individuals who do not have any new symptomology had variable intermediate levels...a little higher than average, but a little lower than the true post-polio population - not normal but not abnormal.

These easier blood tests are a nice first step that can be built upon. A larger prospective study of stable polio individuals over five years would probably indicate who might develop post-polio symptoms (fatigue, weakness, new atrophy) and who would not. What will happen to their blood tests over that period of time?

- The final report data from the 2009 PHI award indicate that there is a low level of polio virus (PV) protein activity persisting for decades in most polio survivors. The debris is there; it is not infectious, but it is there.

The goal will be to develop a treatment for polio survivors, or survivors of other neurologic infectious illnesses, that may linger and cause problems. Perhaps an effective antibiotic will prevent PPS in the future or prevent progression.

Conclusion

As PPS research in many areas continues worldwide, we look forward to learning more from Dr. Perlman in May 2011 when she presents research updates and answers personal questions.

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The History of APRONS

I don't think our kids know what an apron is. The principal use of Grandma's apron was to protect the dress underneath, because she only had a few, it was easier to wash aprons than dresses and they used less material, but it was also used for other purposes:



It served as a potholder for removing hot pans from the oven.

It was wonderful for drying children's tears, and on occasion was even used for cleaning out dirty ears.

From the chicken coop, the apron was used for carrying eggs, fussy chicks, and sometimes half-hatched eggs to be finished in the warming oven.

When company came, those aprons were ideal hiding places for shy kids.

When the weather was cold grandma wrapped it around her arms.

Those big old aprons wiped many a perspiring brow, bent over the hot wood stove.

Chips and kindling wood were brought into the kitchen in that apron.

From the garden, it carried all sorts of vegetables.

After the peas had been shelled, it carried out the hulls.

When unexpected company drove up the road, it was surprising how much furniture that old apron could dust in a matter of seconds.

It will be a long time before someone invents something that will replace that 'old-time apron' that served so many purposes.

Grandma used to set her hot baked apple pies on the window sill to cool.

Her granddaughters set theirs on the window sill to thaw.

They would go crazy now trying to figure out how many germs were on that apron.

I never caught anything from an apron but love!

Stems Cells and Neuroprotectives

POLIO TIPS AND TECHNIQUES

By Dr. Richard L. Bruno

Stem cells are remarkable, embryonic “baby cells” that will grow up to be any kind of cell that the body makes. With all the excitement about stem cells curing spinal cord injury, many polio survivors are wondering if stem cells could cure post-polio syndrome (PPS), or even reverse the damage caused by polio itself.

The hope with SCI is that stem cells, injected into the spinal cord, would “bridge the gap” in cut spinal cord axons, which are like long telephone wires that connect brain motor neurons to spinal cord motor neurons and allow the brain to “tell” muscles to move again. This notion requires intact motor neurons below the cut in the cord. And here lies the problem with stem cells “curing” polio or PPS. Even in “mild” cases, the poliovirus killed off at least 50% of neurons throughout the spinal cord. Stem cells injected into a polio survivor’s spinal cord would not have to just bridge a gap, but become new, functioning motor neurons.

What’s more, those new neurons would have to send out their own axons to find and activate the specific muscles that were paralyzed when the original axons disappeared 50+ years ago after poliovirus-infected neurons died, by burrowing inches, or in the case of the leg three feet, through the tissues inside the arms and legs.

Finally, the brain’s motor neurons would have to send out new axons as well, since the brain’s neurons and axons also died. These axons would have to burrow through the entire brain, the brain stem and down through spinal cord to get to the newly-implanted motor neurons— indeed a tremendous tunneling task!

So the idea of rebuilding a polio-damaged spinal cord would require a “hat trick” of creating new brain and spinal motor neurons, new axons tunneling from the brain to the spinal cord and from the spinal cord to the muscles. Reconnecting a lesioned spinal cord would “only” require the physiological “goal” of bridging the gap between cut axons.

Yes, a possible use for stem cells would be to inject them into the brain, as is done in Parkinson’s disease (PD) patients, where they could produce the main brain-activating neurochemical, dopamine, which is decreased in polio survivors and causes post-polio fatigue. But, such injections are not widely accepted even in PD patients yet.

So, if stem cells aren’t the answer, is there anything polio survivors can do to help their remaining poliovirus-damaged neurons? Recently, there has been research on “neuroprotective” drugs, medications that protect neurons’ innards from overuse/abuse that causes post-polio symptoms. Several studies have focused on degenerative diseases, such as Parkinson’s and Huntington’s disease, which involve damaged dopamine neurons. Minocycline, a common antibiotic used to kill a variety of bacteria, and creatine, which helps to provide energy to muscle cells, have been given to PD patients, who showed a less rapid a decline in function compared to those taking a placebo. However, a study comparing creatine and placebo in 60 PD patients found that, while their mood improved and their need for medication decreased, their symptoms did not lessen.

Vitamin E has been found in eight studies to have some neuroprotective effect in PD, while vitamin C and beta carotene were not helpful. Some research even links coffee’s ability to limit blood vessels from opening to protecting neurons against PD, with one cup a day cutting the risk of developing PD by as much as fifty percent. Another dietary supplement, coenzyme Q-10, is being tested to see if it protects PD patients’ neurons.

Huntington’s disease patients have also benefited from potential neuroprotectives. Huntington’s patients given minocycline had slower progression or no decrease in physical ability, thinking and memory. Creatine had similar beneficial results in HD.

Should polio survivors take minocycline, creatine and Vitamin E, or order a Starbucks’ grande, three-shot cappuccino to prevent post-polio brain fatigue? Not yet. There aren’t enough studies to prove that any of these is truly neuroprotective in Parkinson’s or Huntington’s disease, let alone helpful for polio

survivors, in which these substances haven't been studied at all.

Double-blind, placebo-controlled studies of potential neuroprotectives are warranted in polio survivors. For now, the only neuroprotective that we know works in polio survivors is "The Golden Rule:" If anything causes fatigue, weakness or pain, don't do it! (Or do less of it.)

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Polio Outbreaks in Central Africa and South Asia

POLIO TIPS AND TECHNIQUES

by Dr. Richard L. Bruno

Last November, an unusual polio outbreak occurred in The Congo Republic. A "wild" (naturally-occurring) Type I poliovirus, imported from Angola, has paralyzed at least 409 and killed 170. What is unusual is that those affected are not children under five but adults 15 to 29 and that 41% have died, versus the norm of 15% in an epidemic. Historically, more deaths do occur when older individuals get polio, but not nearly half. This epidemic, in a country that had been polio free for 10 years, adds to the continued outbreaks in countries where polio remains endemic: Afghanistan, India, Nigeria and Pakistan.

There is an aspect of the Congo epidemic that is not unusual: There has been no mention of it in the American press. However, there was wide-spread attention given to a polio outbreak in May 2010. A wild Type I poliovirus imported from India triggered an epidemic in Tajikistan that spread to three other previously polio-free countries and all the way to Moscow, affecting 476. This outbreak was more typical; 86% of those initially infected were children and 6% died.

This European pandemic caused the American Academy of Pediatricians in July 2010 to warn that "Low immunization rates in parts of U.S. could pave

way for polio outbreak [showing] how precarious our control of the disease can be when immunization rates fall below the target level of 90%. The polio immunization rate in Tajikistan is 87%." The article goes on to warn that "polio immunization rates are lower than 90% in many areas of the United States" because of parents having "no recent experience" with polio, "concerns about vaccine safety and religious objections to immunization. With increasing globalization, the United States could be just an asymptomatic traveler away from an outbreak." Remember, 70% of individuals infected with the poliovirus have no symptoms but can carry and spread the disease.

In 2007, the International Post-Polio Task Force began the National Immunization for Polio Prevention in Infants and Toddlers—or "NIPP- IT"—Campaign, when CDC reported drops in polio vaccination and that one million US infants and toddlers were unvaccinated against polio. The NIPP- IT motto: "America's next polio epidemic could be just a plane ride away."

This theme was adopted by an August 2010 *Houston Chronicle* editorial: "Polio's return to Tajikistan has raised some unsettling questions. International medical activists had planned to snuff out the disease by 2000. What's going wrong? The ongoing problem seems to be a mix of factors. Some are political, such as Muslim leaders in Nigeria who originally branded the vaccine a western sterilization plot. Meanwhile, isolated tribes or subcultures can harbor the disease."

Not mentioned were the effects of war and corruption, lack of sanitation, basic public health and medical infrastructure and that the Sabin oral vaccine mutates and actually causes polio.

The editorial concludes, "Houston residents have reason to watch this battle and wish its warriors well. Even if polio is almost gone, the last cases will always be only a plane ride away from our own city." Indeed, Houstonians need worry. CDC found that Houston has the lowest polio vaccination rate of any reported US city—87%—a drop of 5% from last year.

"Polio outbreaks highlight our global vulnerability to infectious disease," said Dr. Robert Scott, chair of Rotary's polio eradication effort. "It reinforces the

fact that polio ‘control’ is not an option, and only successful eradication will stop the disease.”

Unfortunately, eradication is not happening in spite of \$800 million spent on vaccination. In 2010, polio was at all time high in Pakistan, primarily in the war-torn tribal areas bordering Afghanistan.

Perhaps it is time to admit that polio eradication is not possible given the political and social conditions in the Third World. Perhaps the millions being raised for polio eradication would be better spent, as the *Chronicle* proposed, “improving health care or hygiene more broadly,” and, as Dr. Scott prescribed, a “fast, large-scale, high-quality immunization response” to any polio outbreaks, plus treatment for polio survivors and those with Post- Polio Sequelae.

The International Post-Polio Task Force has proclaimed 2011 “The Year of Getting Serious About Polio,” serious about vaccinating America’s children, about treating the world’s 20 million polio survivors who have post-polio sequelae and about containing—not eliminating—polio.

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Aging

Aging: Eventually you will reach a point when you stop lying about your age and start bragging about it.

The older we get, the fewer things seem worth waiting in line for.

Some people try to turn back their odometers. Not me, I want people to know why I look this way. I’ve traveled a long way and some of the roads weren’t paved.

When you are dissatisfied and would like to go back to your youth, think of Algebra.

You know you are getting old when everything either dries up or leaks.

One of the many things no one tells you about aging is that it is such a nice change from being young. Ah, being young is beautiful, but being old is comfortable.

Aphorism: A Short, Pointed Sentence Expressing a Wise or Clever Observation or a General Truth; Adage

1. The nicest thing about the future is that it always starts tomorrow.
2. Money will buy a fine dog, but only kindness will make him wag his tail.
3. If you don’t have a sense of humour, you probably don’t have any sense at all.
4. Seat belts are not as confining as wheelchairs.
5. How come it takes so little time for a child who is afraid of the dark to become a teenager who wants to stay out all night?
6. Business conventions are important because they demonstrate how many people a company can operate without.
7. Why is it that at class reunions you feel younger than everyone else looks?
8. No one has more driving ambition than the boy who wants to buy a car.
9. There are no new sins; the old ones just get more publicity.
10. There are worse things than getting a call for the wrong number at 4 am - it could be the right number.
11. No one ever says “It’s only a game,” when their team is winning.
12. I’ve reached the age where the happy hour is a nap.
13. Be careful reading the fine print. There’s no way you’re going to like it.
14. The trouble with bucket seats is that not everybody has the same size bucket.
15. Do you realise that in about 40 years, we’ll have thousands of old men and old ladies running around with tattoos? (And rap music will be the Golden Oldies!) No! Say it isn’t so!
16. Money can’t buy happiness -- but somehow it’s more comfortable to cry in a Porsche than in a Yaris.
17. After 60, if you don’t wake up aching in every joint, you are probably dead!
18. And probably the best and most pertinent - Always be yourself. Because the people that matter don’t mind, and the ones that mind, don’t matter.

The following article is reprinted with permission from St. Michael's Hospital, Toronto, Ontario.

Study links long-term use of osteoporosis drugs to unusual fractures

Women who take commonly prescribed drugs for osteoporosis known as bisphosphonates for five years or more may be at higher risk of certain kinds of fractures of their thigh bone, a new study has found.

by Leslie Shepherd

However, the drugs do prevent hip fractures. And, since the overall risk of thigh bone fractures caused by the drugs is low, women at high risk for hip and other osteoporosis-related fractures should not stop taking bisphosphonates, according to researchers at St. Michael's Hospital and the Institute for Clinical Evaluative Sciences.

The study was published today in the *Journal of the American Medical Association (JAMA)*.

Typical hip fractures caused by osteoporosis occur in the upper part of the femur close to the hip joint and are an important cause of disability, need for long-term care and even death in the elderly. The risk of these kinds of fractures is reduced by bisphosphonate treatment, which was confirmed by this study.

But the study found that less common fractures lower down from the hip and closer to the middle of the femur – sometimes called “atypical” or “unusual” fractures — occurred more than 2.5 times as often in women who had taken bisphosphonates for more than five years than short-term users of the drug.

“Prolonged use of bisphosphonates is associated with rare and unusual fractures of the femur,” said the lead author, Laura Park-Wyllie, a pharmaceutical safety and outcomes researcher at St. Michael's. “But the proven benefit of these drugs for the much more common fractures of osteoporosis usually outweighs the harm, especially in the initial years of treatment for osteoporosis. Women with osteoporosis, at high risk for osteoporotic fractures, should not stop taking bisphosphonate therapy

because of the small risk of these thigh fractures.”

Park-Wyllie said the study was prompted by an increasing number of reports of thigh bone fractures among older women who have taken the drugs sold as Fosamax, Actonel or Didrocal for five years or more and by conflicting findings from small, observational studies.

The St. Michael's-ICES study is the largest assessment of the issue to date. The researchers identified 205,466 women over age 68 who had been prescribed bisphosphonates between 2002 and 2008.

Of those, 716 women (0.35 per cent) had a fracture of the femur. These women were compared to other women of similar ages who had also been prescribed the drugs but who did not have femur fractures.

“Our study estimated that the risk of fractures to the femur was 0.13 per cent for women entering their sixth year on the drug – or just over one in 1,000,” Park-Wyllie said. “Use of bisphosphonates for less than five years was not associated with a significant risk of thigh fractures.”

About 50 per cent of women over 50 will suffer an osteoporosis-related fracture. The most common involve the wrist and the spine, but hip fractures can have some of the most severe consequences, with one in five of those women expected to die within 12 months.

If you have access to the internet check out the article at the address below. It was featured in the March 4th Globe and Mail. It talks about the effort to vaccinate all children in the impoverish areas of India and trying to include all of the migrant population.

India on the front lines in the battle to eradicate polio

By STEPHANIE NOLEN from the Globe and Mail

Polio is all but gone from India, source of most of the recent critical outbreaks. Yet this success has gone unnoticed by a world bored by the ‘this-close’ narrative of the disease, leaving the battle all but bankrupt.

<http://www.theglobeandmail.com/news/world/asia-pacific/india-on-the-front-lines-in-the-battle-to-eradicate-polio/article1929578/>

At the Meeting

The February meeting of Polio Regina was at the Wascana Rehabilitation Centre on a very cold night but we still had 15 members attend in spite of the cold. President Wilf Tiefenbach, Vice President and Phone Co-ordinator Carole Tiefenbach were unable to attend so Dr. Mavis Matheson chaired the meeting.

Treasurer David Cotcher presented the annual financial statement for 2010 with comparative figures for 2009. David explained the statements and there was some discussion. David Cotcher made a motion to present a resolution that Polio Regina waive the requirement to have a member of a recognized accounting profession audit or review the financial statements the same as we did last year. It was carried unanimously.

Phoning Committee - Grace Lekivetz would like to be relieved of her phoning position. Nora Schlosser volunteered to take her place.

Ivy Ludwig is back home after having a stroke in November and spending some time at Wascana Hospital.

Volunteers were requested for a nominating committee for election of executive at our annual general meeting March 31, 2011. Elaine Cotcher, Mavis Matheson and Blenda Ramsay volunteered.

Spring Picnic: Mavis Matheson volunteered to host the spring picnic at her home again this year. We decided to have it on May 26th at 5:00 p.m. We talked about having cold cuts and buns and a cake similar to what we did last year. We will confirm the details at the next meetings.

We welcomed new members Evelyn and Al Bank. We went around the table and everyone briefly talked about their polio experience and how it has affected them.

Open forum: Dr. Mavis Matheson did a presentation on motivation. She talked about making some changes in our lives, our readiness and commitment to change and methods of achieving our goals. Her presentation prompted meaningful discussion.

Next Meeting: The next Polio Regina meeting which will be our annual general meeting will take place Thursday March 31, 2011 at 7:00 p.m. in room H203 at the Wascana Rehabilitation Centre.

We will be having a guest speaker, Donna Bowyer at the March 31st meeting speaking about Depression and Mental Illness.

Donna Bowyer (pronounced Boyer) has been the Branch Director for the Canadian Mental Health Association in Moose Jaw since 1991. Donna has worked in the delivery of direct service to people with mental illness in a variety of programs including, social recreation, vocational, and prevocational. She also advocates for people with mental illness, and lobbies for better services.

Since January 2003, Donna has spent most of her time as an educator around the issues of mental health and mental illness. This includes presentation, public speaking, newspaper articles, and working as a consultant.

As the Director for Friends for Life and as an ASIST (Applied Suicide Interventions Skills Training) trainer she travels throughout Saskatchewan training front line workers, parents, and professionals.

Donna lives in Moose Jaw and is married with 4 adult children.

This is WOW!! Go figure..

This year we will experience 4 unusual dates

1/1/11

1/11/11

11/1/11

11/11/11

Now go figure this out... take the last 2 digits of the year you were born plus the age you will be this year and it WILL EQUAL....111!!!

Christmas Party 2010

Our annual Christmas party was held at Broadway Terrace on November 25, 2010. There were 34 people in attendance. After a short meeting, we dined on a delicious buffet style turkey dinner. After the dinner we sang Christmas carols led by beautiful music on the piano, accompanied by trumpet, played by two very talented upcoming music teachers. Thank you to Blenda Ramsay for arranging to have the room at Broadway Terrace, the dishes, cutlery and coffee, the setup of chairs, and the decorating of the hall. Thank you to Carole Tiefenbach for all the work making the arrangements, getting the entertainment, decorating, cleaning up and for just being cheerful Carole.

