

Christmas 2013

Polio Regina Incorporated

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# Season's Greetings



This issue of the Polio Regina PostBox is dedicated to Verna Copeland who passed away August 23, 2013. We all remember Verna for her many years of tireless work as our treasurer and for her organizing our Christmas and Spring Picnic parties. We send our sincere condolences to Ross. Verna will be missed. The following is from Verna's obituary.

VERNA AUDREY COPELAND (nee Shaw) March 17, 1931 - August 23, 2013. It is with great sadness we announce the passing of Verna on Friday, August 23, 2013. She was predeceased by her parents, Weldon and Edna Shaw and brother Norman. Verna is lovingly remembered by her husband of 62 years Ross; brother-in-law Don Copeland; sister-in-law Mary (Les) Larter; as well as numerous nieces, nephews, cousins and dear friends. Funeral Service was held at Speers Funeral Chapel, 2136 College Avenue, Regina, SK on Thursday, August 29, 2013 at 1:00 p.m. with Pastor Lois Munholland officiating.

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The following is a reprint of Verna's Polio Story as it was printed in the March 2009 Polio PostBox.

# Verna Copeland



My life began 78 years ago on a mixed farm at Davin, Saskatchewan 25 miles southeast of Regina. I did all types of work mostly with horsepower those days. We had a pony and cart or cutter or horseback to attend the one room school (10 grades, 1 teacher). After passing my grade 10, I looked forward to

registering at Balfour Technical School in Regina to take my grades 11 & 12, then go into nurses' training. August 17, 1947 changed all that. The summer was going well and harvest had started. I was driving the tractor that pulled the binder to cut the crops. My dad rode on the binder to use the levers and drop the sheaves to be picked up later to be threshed in a machine.

It was Monday morning and I started throwing up but felt okay so kept on driving all day. The nausea stopped around 6 p.m. I didn't have much appetite so went to bed as usual. Tuesday morning I felt kind of tired and sickly so mom took me to our family doctor. He did what exams he could to see if there were any signs of Polio. I told him it felt as though something was missing in my throat. It appeared to be Strep Throat and he gave me medication.

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# My Knee Replacement

By Ivan Jorgensen



The staples that were in my knee.

I had Polio when I was 18 months old. This left my left leg weak and I had no strength in my toes

– I walked on my heel. By the time I was 11 years old my left leg was two inches shorter than my right leg. My orthopedic surgeon pounded two staples that were about an inch wide with one inch leg into each of four places in my knee. These staples were placed on the growth rings of my leg and were to stop the growth of my right leg to allow the left leg to catch up. The problem was that the staples kept working their way out so they were no longer doing their job so I had to have them replaced three times. The last time they came out only on the inside of my knee so I became knock-kneed so I had to have the staples removed from the outside of my knee and new ones put into the inside of my knee. The problem was that I left them in for too long so I ended up being slightly bow-legged. Over the years this became aggravated and my shin bone also became bowed. This led to increased pressure on the inside of my knee and the development of arthritis and eventually my knee was bone on bone.



*X-ray before surgery* 

I was referred to an orthopedic surgeon in July of 2012 and finally received total knee replacement surgery on October 18<sup>th</sup> 2013.

On August 19th Judy, my wife and coach, and I attended an information session on knee replacement at the Surgical Assessment Centre which is located in the old Superstore building on Albert Street. This session was over two hours long. All the medical aspects were explained to us by a nurse and the physiotherapy and exercise aspect were explained by a physiotherapist. We were also given a handbook, to take home with us that explained everything they had talked about plus the exercises to do before the operation.

On October 7<sup>th</sup> Judy and I went to the pre-admission clinic at the Surgical Assessment Centre. A nurse asked us all the usual questions about my medical history, surgeries, and medications. Then a doctor came in and asked basically the same questions. Then an anesthetist came in to talk about the kind of anesthetic that I would prefer, general or a spinal. He recommended a spinal. I mentioned that I had had Polio but my neurologist said that I do not have Post-Polio Syndrome. I said that I have articles about Polio and anesthesia which say that Polio may have caused central neuronal changes, especially in the Reticular Activating System even if I don't have Post-Polio Syndrome. Then he said that maybe I should have a general anesthetic. I asked him whether the amount of anesthetic should be reduced (the rule of 2) because in Polio patients, it takes twice as long to wake up. He said so what if it takes longer you aren't having day surgery. I guess I didn't look very satisfied with his answer. He then said if you are that concerned about the anesthetic maybe you shouldn't have surgery at all. I said that I didn't care anymore and would do whatever he recommended. He left the room for a few minutes and came back later with some research that he had done and said that they would make an appointment with my neurologist to get his consult on which would be the best anesthetic for me. At that point I was very sorry that I had mentioned anything about Polio.

The above description of what the doctor said may not be an exact account but it is what came across to me and it is what I remember. I am not very good at expressing myself and I certainly do not know the proper medical terms. I probably made matters worse by asking the wrong questions. I had some articles on anesthetic and Polio that I showed the doctor which he just glanced at. He was probably tired of people coming in with information off the internet and questioning his expertise. I left the session very frustrated and depressed.

My appointment with my neurologist was the day before my surgery. He asked me if anything had changed since I last saw him and I said not really. He said that he would send the consult to the Surgical Assessment Centre. I went back to the Surgical Assessment Centre and met with a different anesthetist who said that the consult said that I did not have Post-Polio Syndrome and to proceed as normal. He had some research about Polio and asked me if I wanted a copy. I said no because I already had the same documents. He recommended that I have a spinal. I said OK.

On October 18<sup>th</sup> the morning of the surgery the anesthetist who was different person than the other two that I had talked to explained what he was going to do. He didn't have any special instructions about my having had Polio. When I got into the operating room he gave me a spinal, then he gave me a needle in the upper thigh which he said would stop most of the pain in the leg for 24 hours. After I lost all feeling in my lower half they put a curtain up so I couldn't see past my chest.



Knee replacement components

I was awake and aware throughout the operation. I had been given something so I was relaxed and I had no anxiety and time went by quickly. I could hear the

drilling, sawing, and I could smell the glue. My stomach jiggled when they were pounding the parts in place.

I was awake and aware in the recovery room and I think I spent more time in there than was required because they were waiting for a room to become available on the ward.

When I was in my hospital room the pain was not as bad as I had expected. I was waiting for the shot that they gave me in my thigh to wear off but the pain didn't get much more than 6 on a 1 to 10 scale. I had a morphine pump but I only used it three times in the first two days. I couldn't really tell whether it relieved any of the pain. I did vomit once in each of the first two days but I felt a lot better after. I don't know if I was allergic to the morphine.

I am certainly glad that I had the spinal. I felt clear-headed throughout the operation and after. There was no grogginess or nausea after the operation. It was certainly better than the general anesthesia that I had when I was a teenager where I was sick for two days after but I guess a lot of things have improved over the last 50 years.

The day after the surgery they got me out of bed and I took a few steps using a walker. I also got to sit in a wheelchair. I guess using a wheelchair is like riding a bicycle, you never forget how. I was able to maneuver in and out of tight spaces and tear around the ward like I did when I was a kid.

On the second day after surgery and every day after I went to physiotherapy for exercises. I did quite well but the exercises were painful but it wasn't too bad as long as I had the pain medication a half hour before going to rehab. The most painful part of the hospital stay was when they put a machine on my leg that continually bent and straightened my knee. It was especially painful when the pain medication was starting to wear off. The last day they got me to walk up and down stairs with a crutch. This was no problem since I had lots of experience with crutches when I was a kid.

I was discharged on October 22<sup>nd</sup>. I was given exercises to do three times a day which were quite tiring. Gradually the exercises became easier but were still painful when I tried to bend my knee to 90 degrees. On November 15<sup>th</sup>, four weeks after surgery, I went to the physiotherapy department at the General Hospital for an assessment. The physiotherapist was pleased with my progression and he said that I no longer had to use a walker but use a cane just for balance. He gave me some new exercises to do to help straighten and bend my knee. I was still unable to bend my knee more than 80 degrees. I am able to

put my full weight on my operated leg without any pain. My knee is still swollen.

My recovery continues and I am satisfied with the results. Hopefully with this "wheel alignment" I will be able to walk better and with less pain. It just bugs me that I can't shovel snow for three months.

The following are a couple of web-sites with information on Anesthesia and Polio: *Anesthesia Update: Separating Fact from Fear by Selma Harrison Calmes MD* 

# http://www.post-polio.org/net/10thConfAnesthesia Calmes.pdf

Preventing Complications in Polio Survivors Undergoing Surgery or Receiving Anesthesia by Dr. Richard Bruno which explains the Rule of 2 http://www.postpolioinfo.com/library/surg.pdf This is also available on the Polio Regina website under PostBox archives, February 1999 issue.

For our readers who do not have access to the internet and wish to have a copy of these articles or a number of other articles on anesthesia, phone me at 306 757-8051 or write to me at the address on the PostBox masthead and I will mail paper copies to you.

# Verna Copeland - continued

Wednesday morning I felt the same only weak from not eating. By the end of the day, I was having trouble swallowing and the muscles seemed weak in my neck.

Thursday morning I couldn't swallow the pills that were prescribed and when mom phoned the doctor he told us to go to the observation wing at the General Hospital, Regina. By this time I couldn't cough, hold my head up straight and was seeing double. A spinal tap told us it was Polio. It took 3 nurses to walk me up the stairs to the isolation wards.

The first night I started choking and the hospital phoned my parents to hurry in as I was delirious and they had trouble keeping me in bed. Mom insisted they get private duty nurses round the clock. It was hard to find nurses to care for Polio patients as they were afraid of this "terrible" disease. At that time an 8 hour shift was \$8.00 so mom offered them double pay if they would only come. This meant \$48.00 for 24 hrs. There was an iron lung waiting outside my

door, but I didn't need it.

After 4 or 5 days my mind straightened out and it was safe to be without constant care, so the nurses were let go. I was fed with IV and chewed ice cubes when I was thirsty. I had to be careful and not let any water down my throat as I would choke, so I would have to spit out the water.

On day 12 one of the nurses tried to feed me some juice. What an experience, most of it came out my nose, but after an hour we put away 1 ounce. Every day was a little better and after 2 ½ weeks I was able to swallow some soft food.

After 3 weeks I was taken to a 4 bed ward in the main part of the hospital. I spent another 2 weeks there taking physiotherapy everyday on my neck muscles.

October 2<sup>nd</sup> was a happy day for me, after 5 weeks in hospital, I was finally going home. I continued going to the General for physiotherapy every Tuesday and Thursday. In summer I went by bus and when winter came the roads would block and I had to go by train. We would have to go by team and sleigh 3 ½ miles to Davin and meet the train at 7:30 a.m. and return at 8:30 p.m. Sometimes the train would be late and not get to Regina till noon or maybe get us back at night at midnight. Then too it could be 0 or -30.

March 15, 1948 found me back in the hospital. The roads were snow blocked so had to go by air ambulance. I had a bad chest cold and not being able to cough my lungs filled up and needed lots of sulfa drugs and penicillin every 3 hours. When it was taking too long to get better, the doctors had a meeting and decided I needed a bronchoscopic procedure. This is when they put a steel pipe down to the lungs and another glass tube inside to force some of the mucous out that is clogging the lungs. I never ever want to go through that again. After having Polio I was told to get to the doctor for antibiotics before it got so bad. After 2 years of physiotherapy I felt it was no longer helping if it ever did.

I had a mostly normal life, married and we had a mixed farm. I enjoyed all the jobs of farming and showing our registered cattle in Canada and U.S.A. After 46 years I had to slow down as Post Polio

Syndrome caused my larynx to close up. November 1993, I had to have a trache put in and now I don't fear choking any more, but my voice is weaker and I get out of breath talking. However, I had a good life and when I look around me, I see so many that are worse off than I am.

The following are tributes to Verna Copeland from some of our members:

# I Remember Verna:

By Blenda Ramsay

I wish I had kept a daily diary as Verna did so I could check to see when Fred and I first met Verna and Ross. It was several years ago and it must have had something to do with Polio. Verna was a Polio survivor so she may have been looking for information on Polio.

Soon Verna and Ross became members of our Polio Support Group. They were willing to help our organization and got involved right away.

Verna was elected to the Executive and became the Treasurer, a position she held for several years. She did an admirable job of keeping the membership list up to date and the budget balanced.

When help was needed, Ross and Verna were right there! I remember them coming to our house one day and picking up our barbeque to take over to the Senior Centre on Elphinstone St. for our spring wind-up. We had the Club House for the day. (At that time we brought our own hamburgers and needed a barbeque). It was just one of the many events Verna and Ross volunteered to arrange and organize. They were the first to arrive and put the coffee on and set up tables. Verna knew how the alarm system worked so took charge of opening and closing the club house. Verna and Ross were valuable and dependable members. Through their efforts we relied on them for arranging and organizing functions such as the Annual Christmas party. Each November Verna would write letters to different organizations asking for donations to give as door prizes at our Christmas party. Each year they would drive all over town picking up those donations and each year there were plenty of prizes to go around.

Verna managed to reserve the Church Hall at their church for some of our Christmas parties. The church had an elevator so it was accessible for everyone. The ladies of the church cooked and served us lovely turkey dinners with all the trimmings! (It should be noted that Verna wasn't fond of turkey, yet she always ordered turkey for our banquets). The day of the party Ross and Verna spent all afternoon decorating and setting up the tables for the dinner. She also booked entertainment for the evening, set out all the door prizes and greeted us at the door. There would be 80 or more attending the dinner.

At our April 1999 meeting Verna and Ross were given a Life Time Membership to Polio Regina and their names are engraved on the plaque.

When we first met them, they were living on their farm east of Regina. Fred and I were invited to their home for several visits and dinners. They worked hard with their animals and kept their yard neat as a pin! Their basement displayed many, many red and blue ribbons won for showing their Shorthorn cattle. They hold the record for the highest selling Shorthorn heifer at Agribition.

When they were ready to retire from farming, we attended their auction sale. I think I bought a big



Ross and Verna's 50th Anniversary, October 2000

pickle jar! When they moved into their new home at Pilot Butte, I think Fred and I were amongst the first to see their new home.

After we moved into Broadway Terrace (where I live now) we invited Ross and Verna to come for Brunch one Friday. Verna's health was starting to decline

and they had been thinking about their future. We gave them a tour of our building and they must have liked what they saw!

A couple years later a suite became available here and Ross and Verna decided to move in. The rest is history. Before too long Verna and Ross got to know residents here and became involved with the card sharks. Verna taught several people how to

play "Rook" and to this day "Rook" is played most evenings.

Some of the ladies tried their hand at playing "Pool" and Verna played that too! She became a whiz at "Shuffle Board" and as a mater of fact, she may have helped arrange the first "Shuffle Board" tournament which is now played here every month. Verna and Ross showed off the trophies they had won playing Shuffle Board and Pool.

Verna was playing cards with the residents a few nights before she fell and went to hospital. She isn't able to come back to play cards any more.

Polio Regina has to continue without them but we are so thankful and appreciate all the wonderful work they did for us for so many years! We miss them!

Blenda Ramsay

(I think Fred would totally agree with what I have said if he was able to be here).

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I will always think of Verna when I recall our Christmas dinners. She did so much in planning the events. She must have made many calls, in person, to solicit prizes that were awarded at the dinners. We should always be grateful to Verna for the marvelous work she accomplished for Polio Regina.

Murray Grant

# **Greetings from Jeanne Hoffman**

Jeanne Hoffman has kept in touch with us. She sent me an article from the March 15, 1984 *Maidstone Mirror* honouring pioneers from Paradise Hill. The family lived in Vernon, B.C. where polio broke out in 1908. A doctor friend advised them to move east so they moved to escape the threat of polio and ended up in the Paradise Hill area.

Jeanne phoned recently and wanted to wish everyone at Polio Regina a Merry Christmas and Happy New Year. She asked about our Christmas Party this year and said that she misses everyone. (We miss her too.) She said that she is doing well in Calgary. She is still living in her son's house. He lives there on weekdays but she is alone on weekends. She has grocery stores and her church within walking distance so she is well set. She sounds as spry as ever.

# **Tribute from the President**

I met Verna Copeland around 1992, the year I joined a post-polio support group in Saskatchewan. At that time, I believe she was the treasurer and she held that position until her health deteriorated.

I remember Verna as being a great gardener, a wonderful cook, (I loved her wheat salad!), and an ambitious cattlewoman, (often meeting her and Ross at our local Agribition show), held here in Regina every year. She was very proud of the awards they won at the cattle shows.

Verna and Ross kept their home and yard in Pilot Butte in meticulous order.

Together, they worked tirelessly every year asking for donations from different organizations, for door prizes, to be given at our Annual Christmas parties for our Post-Polio Support group. We will always remember her, along with Ross, as being so dedicated to whatever they were asked to do.

May she rest in Peace with a now perfect 'polio-free' body. May we remember her and give thanks for her life, as we enjoy our Christmas party this month.

We have lost many of our dedicated post-polio members. Our numbers are definitely getting smaller every year and that is sad but, also a part of life.

Wilf and I would like to thank our members of Polio Regina for accommodating the time changes that had to be made, so we could accept our responsibilities as group leaders of our Addiction Recovery Program with our church. We will be finished, officially, on January 21st, and then we are off to Florida, for a few weeks.

We sincerely hope you all have a wonderful Blessed Christmas and a Happy New Year filled with health, peace and love. We shall see you at the March meeting!

Wishing you all the best, Carole Tiefenbach, president Wilf Tiefenbach, vice-president

The executive of Polio Regina would like to wish all our members and their families a Merry Christmas and a Healthy and Happy New Year.

# **Irvin Richards**

Irv Richards was a long-time member of Polio Regina. We offer our sincere condolences to his family. He will be missed. The following is his obituary.



Irv Richards at the 2010 Polio Regina Spring Picnic

Irv Richards died Saturday, June 29, 2013 at his home in Regina. He was born June 14, 1926, in Regina, to Richard and Martha Galenzoski. In his earliest years, his parents farmed near Halbrite. Driven out by the Depression, they moved to Wadena in 1934, and in 1938 they returned to the Galenzoski homestead at McLean. Irv finished grade 8 at Rosenburg School and worked on the farm for a few years, before moving to Regina and studying at Balfour Tech to become an electrician. In the late 1940s and early 1950s, he worked as an apprentice and later a journeyman for several electrical contractors in Regina - including Cameron Electric, Northern Electric, and Hube Electric – as well as for the RCMP (his favourite job ever). In 1955 he went to work as an electrical inspector for the Department of Labour, a job he held until his retirement in 1976. During his early retirement, Irv enjoyed golfing and travelling, including a trip to New York City to visit relatives, and an Alaska cruise. He was also involved in Regina Little Theatre (working both on lighting and sets, and on their archives), University of Saskatchewan

Seniors Education, Core Community Association, and the Polio Survivors Group. After physical disabilities made it impossible for him to continue most of those activities, he still enjoyed reading, mostly non-fiction; listening to classical music and opera on his home-built stereo, and watching ballet on DVD, cooking, and spending time with his family. Irv was predeceased by his parents and his sister Edna Paholko. He is survived by his five children: Ronni Richards (Ewan Campbell), Judy (Joe) Hawes, John Richards (Linda Roberts), Ruth (Ray) Hill, and Stephen (Connie) Richards; seven grandchildren: Marsh (Jen) Hawes, Helen Hawes, Zach Richards (Angel Frank), Chelsea Richards, Wayne (Marie) Hill, Ivy (Brenden) Claypool, and Erica Hill; five great-grandchildren: Colton and Mica Hawes, Anika and Emilie Hill, and Liam Claypool; and his youngest sister Marian (Jim) Brown. He was also survived briefly by his older sister, Irma McClintock, who died on July 1. The family would like to express their appreciation to Diane Neale of Neale Elder Support Services, and the Palliative Home Care Program. An informal gathering in his memory was held on Sunday, July 7, from 2:00 to 4:00 p.m. at his daughter Ruth's home in White City. Published in The Regina Leader-Post on July 3, 2013.

# **Meeting Dates for 2014**

The dates are as follows:

Thursday February 27, 2014 at 3:30 p.m.

Thursday March 27, 2014 at 3:30 p.m.

Thursday April 24, 2014 at 3:30 p.m.

Thursday September 25, 2014 at 3:30 p.m.

Thursday October 30, 2014 at 3:30 p.m.

All regular meetings are held at in room H203 at the Wascana Rehabilitation Centre.

Our Spring Picnic and Christmas Party dates and times will be determined at future meetings.

# At the Meetings

May 2013 – Our May meeting was our spring picnic which was held at the home of Dr. Mavis Matheson.

Dates and times for 2014 meetings. We had a vote and it was decided by a narrow margin to continue to have the meetings at 3:30 in the afternoon on Thursdays or Wednesdays.

Our annual spring picnic was enjoyed by everyone with lots of great food and conversation. The weather was pleasant and we were able to spend the evening on the deck. 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. Carole Tiefenbach presented David and Elaine Cotcher a Lifetime Membership to Polio Regina.

**September 2013** - Arrangements for Christmas Party. Party will be held at Nicky's Café, Eighth Avenue and Winnipeg Street on Wednesday November 27<sup>th</sup> at 5:00 p.m. We will have a brief meeting to be followed by a turkey dinner. The cost will be \$15.00 each.

Dates and times for Polio Regina meetings in 2014: February 27<sup>th</sup>, 2014, March 27<sup>th</sup>. 2014, April 24<sup>th</sup>, 2014, September 25<sup>th</sup>, 2014 and October 30<sup>th</sup>, 2014. These are the last Thursday of each month. All meetings will be held at 3:30 pm at in room H203 of the Wascana Rehabilitation Centre. The dates for the spring picnic and Christmas party will be decided at later meetings.

**Open Forum:** Our guest speaker was Cindy Leggott the Client Service Coordinator (Southern Region) of the Canadian Paraplegic Association of Canada (Sask.) Inc. She spoke about the services and goals of the Canadian Paraplegic Association of Canada (Sask.) Inc. and how Polio Regina members would be eligible for membership and what benefits we would receive. For more information see page 9 of this newsletter.

**October 2013** - A Tribute to Verna Copeland was discussed. Blenda Ramsay suggested dedicating the next Issue of Post Box in Memory of Verna Copeland subject to approval from Post Box Editor Ivan Jorgensen.

**Open Forum:** Guest speakers at our October meeting were Bev Morrell and Krista Christensen from Speers Funeral Home here in Regina. Bev recognizes the benefits that pre-planning offers families at a time of emotional and financial stress. She believes that with proper education and knowledge, the choices made in advance can greatly reduce the emotional stress and financial burden. She is trained and licensed and has worked with families for 12 years.

Krista assists families after the Funeral. She became interested in the area of grief and loss 26 years ago, after her brother died tragically. At that time, there were very few supports available for grieving families so she became very active in this area and facilitated a grief support group for twenty years. Krista enjoys doing presentations like this because she believes that education about funeral service and bereavement is very important.

We watched a short video explaining different options available for Funerals. We received a folder that held several informational brochures. One such page is entitled "Funeral Planning: 101 + Things To Do". A question and answer followed their presentation and I'm sure we all came away with something important to think about. We thanked them for their informative presentation.

**Meeting with March of Dimes**. On October 9<sup>th</sup> I met with Eryn Kelly the Regional Manager for Alberta, Saskatchewan and Manitoba for the March of Dimes Canada. We discussed what polio Regina does and what the March of Dimes is doing in our area. They will be hosting a "Living with a Disability" conference in Regina on March 31, 2014. The information is on page 15 of this newsletter. They will also be holding a "Polio Wellness Retreat" at Bragg Creek from September 8<sup>th</sup> to 12<sup>th</sup>, 2014.



# Members of Canadian Paraplegic Association (Saskatchewan) include Polio survivors

Canadian Paraplegic Association (Saskatchewan) Inc. assists individuals with spinal cord injuries and other physical disabilities to achieve independence, selfreliance and full community participation.

Our core services are:

- \* Peer Support Program
- \* Rehabilitation Program
- \* Education Program
- \* Employment Program
- \* Information Services
- \* Community Advocacy
- \* Case Management/Service Coordination

The annual membership fee (\$40.00) is waived for the first year. Membership benefits for \*qualifying members include – Vehicle Registration Rebate Program, SaskTel Mobility Cellular Phone Benefit (minimum 16 years of age), and Saskatchewan Blue Cross/CPA Scholarship.

All current members receive the provincial newsletter, *Parascope*.

# Who can join?

Qualifying members are those diagnosed with Spinal Cord Injury, Multiple Sclerosis, Cerebral Palsy, Spina Bifida, Polio and Post-Polio, Muscular Dystrophy, or Transverse Myelitis.

For more information, please contact:

CPA Regina Office 3928 Gordon Road Regina, SK S4S 6Y3 Phone: (306) 584-0101

Email: regina@canparaplegic.org

Website: <u>www.spinalcordinjurysask.ca</u> Facebook: <u>www.facebook.com/CPASaskatchewan</u>

Sheila Flasko
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CPA National is now Spinal Cord Injury Canada

The Canadian Paraplegic Association National Office has changed its name to

Spinal Cord Injury Canada.

Spinal Cord Injury Canada's address is

512 - 130 Albert Street,

Ottawa, Ontario KIP 5G4.

Visit SCI Canada online at

www.spinalcordinjurycanada.ca.

The following is an article that has been submitted by Don Volpel. It was written by his grand-daughter, Haileigh DeGrow.

# Growing Up With A Parent Who Has A Disability

By Haileigh DeGrow April 29, 2010

In life, we all need to grow up and mature sometime. This can be a challenge for some children. Growing up with a parent with a disability makes that challenge even more daunting and can compel a child to grow up and mature faster than his or her peers.

Children of a disabled parent may suffer emotionally, physically or both. At a young age, a child may become scared of their parent's disability because they do not understand why their parent is not like their friends' parents. As a child gets older, however, some learn to cope with this obstacle and develop a means to not let it get in the way. But this isn't always the case. In fact, many families don't employ strategies that can help a child develop coping mechanisms to alleviate their stress in dealing with this kind of situation [1].

Emotional uncertainty is often felt by children faced with this situation. A child can never be sure if their parent is going to have a good or bad day which can lead to domestic instability and conflicts. Some may feel stress when worrying about inheriting their parent's disability and the debilitation that can be associated with it. This can trigger a major fear in these children. To quote a child of an MS sufferer from a Canada-wide survey, "Watching them deteriorate is painful" [2].

Having a parent with a disability can also limit a child's quality of life. For example, he or she may not get a chance to go on as many vacations, take as many walks in the park or participate in as many recreational activities. This is due to mobility issues or the parent being too hot or tired to go anywhere. Having a disabled parent can also restrict a child's social activities with friends [3]. For example, going to the mother/daughter sleepover for Brownies, going bowling for a birthday party or playing physically taxing sports.

The child of a disabled parent can also assume more responsibility around the house as compared to their peers. He or she helps out with the laundry, meal preparation, grocery shopping, babysitting younger siblings and personal hygiene for their parent. The disabled parent may say they don't expect anything more than the average parent but as it turns out, this is not what happens. In a survey given out to families dealing with Multiple Sclerosis in particular, kids have said that they are affected by their parent's disease or disability more than their parents perceive them to be [4].

People have done many wonderful things to help affected families. There are national societies and local chapters that one can become a member of, support groups and online chat rooms dedicated to talking about certain difficulties. The Canadian Cancer Society, the MS Society of Canada, the Canadian Arthritis Society and the Canadian National Institute for the Blind are just a few examples of national organizations that hold fundraisers year round to raise awareness for their cause. Examples include the MS Bike Tour, the Terry Fox Run, the CIBC Run for the Cure and the Arthritis Society's Jingle Bell Run. Individuals can raise money or pledge others and the money that is raised goes towards medical research and development. A new breakthrough in medical science came out a few of months ago for Multiple Sclerosis victims. It is called Chronic Cerebrospinal Venous Insufficiency, or CCSVI for short. It is a hypothetical test developed by an Italian doctor. He alleges that there is vein drainage constrictions in the neck that leave behind iron deposits on the brain. These deposits may interfere with nerve function [5]. I am the child of a disabled parent. My mom has had Multiple Sclerosis for nearly eighteen years, and I didn't find growing up with her affliction all that difficult. She was diagnosed before I was born so as I grew older and her disease progressed, I just adapted. I do have extra chores around the house though, because my mom doesn't have the dexterity in her left leg or hand to do much by herself. She often makes the comment, "I just need you to be my legs"[6]. I was doing some of the family's laundry by the time I was twelve and I learned to do many things on my own long before my friends; such as how to cook, do the ironing and yard work. I learned how to wash the dishes properly and how to ask people at the store where certain items were.

I learned how to use a debit machine because my mom had difficulty walking to the back of the 7-11. When she got her scooter, I helped my dad load it into the van when we wanted to go places like the Exhibition or Christmas shopping. But life isn't all that bad having a mom with a disability. Because she can't run around like other moms, she and I have the time to talk about anything and everything. She genuinely listens to me and gives me sound advice. We take her scooter and go shopping together every once in a while and go for walks (or in her case, 'scoots') in the park by our house. Sometimes we act more like silly sisters than mother and daughter. It's awesome to have a friend right there when you need her.

I make contributions to charities that support families struck by diseases and disabilities as often as I can. Every year I am involved in the CIBC Run for the Cure either as a participant in the actual run or as a volunteer. When I was younger, I raised money for the Terry Fox Run in elementary school. This upcoming year I am planning to participate in the Walk for MS.

Every two weeks I give a small portion of my pay check to the Real Canadian Superstore Children's Charity. I am also pro-stem cells and pro-CCSVI because I believe these treatments will help people get better. Unfortunately, stem cell therapy is considered controversial and CCSVI is still in its testing stages in North America. In my heart I know these two treatments will make people better; they are going to make my mom better. There would be no greater gift than that.

I want to become a doctor who helps people like my mom gain control over their life, like a neurologist. I want to support other children who may be going through the same thing I have been going through my entire life. Also, since possible CCSVI testing is being considered in Saskatoon, it won't be readily available to everyone in Canada. I want to ensure that it is made available to all Canadians. These are a few things that I can do and they will all take some time to complete. Time which, unfortunately, is something not everyone has on their side.

Growing up with a disabled parent is never easy; it never has been and it never will be. But it can be a truly humbling and inspiring experience. It teaches children how to be more independent and

compassionate when they need to be and how to be an adult in some situations. It may be difficult at times but you take so much away that strengthens your character and moulds your personality. I only wish that everyone could understand that.

[1]http://www.mssociety.ca/en/pdf/OverviewSurveyResults

[2] http://www.mssociety.ca/scripts/texis.exe

[3] and[4] http://www.mssociety.ca/en/pdf/

*OverviewSurveyResults* 

[5] http://en.wikipedia.org/wiki/Chronic\_cerebrospinal\_venous insuffiency

[6] Quote from Janet Degrow

# **New Polio Cases**

Polio has returned to Syria for the first time in 14 years, infecting at least 10 young children. The highly contagious virus thrives in war-torn communities where poor sanitation and conflict hasten its spread. In Syria, civil war has driven immunisation rates down to less than 70 percent, from more than 90 percent in 2010, creating exactly the sort of environment where polio tends to strike.

Egypt has begun a new round of vaccinations against polio, one of several national efforts in the Middle East after the crippling disease recently resurfaced in war-torn Syria.

No new cases of wild poliovirus have been reported in southern Afghanistan in the last year, marking a crucial milestone in the country's battle against the debilitating disease.

Afghanistan is one of the three remaining countries (along with Pakistan and Nigeria) where polio is still endemic. Of the 334 worldwide cases reported this year by the Global Polio Eradication Initiative, only nine have been in Afghanistan's Eastern Region along the Pakistani border. That figure is one-third the total from 2012.

Nigeriaisoneofonlythreeremainingendemiccountries worldwide (along with Pakistan and Afghanistan). Traditionally, polio has been entrenched across the north of Nigeria. In fact, it is from here that the disease has repeated spread into other west African countries.

The following letter and information was provided to us by Dorathea Little.

# GOVERNMENT OF THE PROVINCE OF SASKATCHEWAN



DEPARTMENT OF PUBLIC HEALTH

REGINA,

November 9, 1938.

Mr. Max Reicken, Girvin, Sask.

Dear Sir: Re: Dorothy Reicken, Age 9.
Infantile Paralysis.

Enclosed herewith please find circular dealing with the special clinic carried on in the Grey Nuns Hospital under the direction of this Department.

If it is your wish that your daughter attend this clinic, kindly let me know and also let me know that you will agree to come for the girl at the end of three weeks and take her home to carry on treatment as instructed in the clinic. I would also like to have the railway station which you will use when coming to Regina.

Kindly discuss the matter with your physician.

Yours very truly,

C.F.W. Hames, M.D., Medical Officer.

H/A

1. Patient should be kept in splint at all times except when being treated.
Patient should have a treatment for a half hour, twice a day.

- When splint is removed, care should be taken not to allow the part to hang; no stretch or strain should be allowed on the muscles which are being kept shortened by the splint.
- 3. When splint is removed, the leg should be kept straight and should be supported (1) on each side to keep if from rolling in or out (2) at the bottom of the foot to prevent the foot from dropping down.
- 4. Examine the limbs and back carefully to see if the skin is irritated by pressure. Rub any such-irritation lightly with elechel to help the circulation and put in a small amount of soft padding (cotton batting) wherever there is irritation, but never allow the padding to be lumpy or to fill the cast to such an extent that it keeps the limb in an incorrect position.
- 5. As the limbs become semewhat stiff while at rost in the splints, they should be exercised daily. Each joint should be put through its full range of movement and if the muscle is too weak to perform the complete movement, it should be assisted.
- 6. Do not exercise the part too long, as paralysed muscles are weak and tire easily.
- v. when doing a usego, too much pressure will injure the musele but jest touching the surface has no effect.
- 8. Always stroke upwards, never stroke both ways or downwards.
- 9. Patients with Infantilo Paralysis have pror circulation and therefore, become cold very easily. They must be kept warm, but eare must be taken when using het water bettles, and. Do not have them too het, nor in direct contact with the patient, as these patients burn easily. Don't have the water too het and wrap the bettle in a cover.
- 10. Be sure that the weight of the bedelethes do not press on the feet. A small box or pillow should be placed below the feet to lift the clothes above the feet.
- 11. Nover allow the patient to sit, stard or welk.

Dorothy Ricken Exercises: stroking - always stroke upward.
 circular movement.
 do stroking before and after circular movement. Stretching: Strotching: -Teg-2. bring leg out to side. 3. bend knee. streighten elbow. 6. berd wrist beek and forwards. puch foots Exercise: Exercises: raise leg up.
push leg down.
bring leg out to side.
bring leg into centre.
roll leg in.
roll leg out. Shoulder: es chest 3. bring orm Knee: Bilbows Straighten nee. straichten olow. Z. turn hand ever Ankle; Bring foot up & in.
Bring foot out to side.
Bring foot up.
Push root down. Wrist: bend wrist. 2. streighten wrist. Pingers: General Exercises: 1. Deep breathing. 2. Abdominal contract one fill had.
3. bloow parting.
4. Back extension. straighten fingers. 5 mother hold hips firm . Patent reaches aum body though Metro eirole with thomb, bringing thumb well out from tend and then 501038 hand to bouch distinctingen. 6. fuel lips together

# You Are Invited

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

# **Our Objectives:**

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

### Where to meet

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

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



the dates of our 2014 meetings: Thursday, February 27; Thursday, March 27; Thursday, April 24; Thursday, September 25 and Thursday, October 30. All meetings are at 3:30 p.m. We usually have our Spring Picnic in May at a private residence and our Christmas Party in November at a different location.

### Web Site:

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

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

or you can just Google Polio Regina.

Our email address is: polio@accesscomm.ca

### **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	Assoc	iate ( )	New ( )	Renewal ( )	
Address						
D 10				NI.		
Postal Co	ode	Phone:				
Annual n	nembership fee: (Jan Dec.)	Members	hip Fees (	are due Janua	ary 2, 2014	
\$10 Sir	ngle; \$15 family	\$		_		
My donation to Polio Regina In		\$		_		
		Total \$		_		
(If you re	equire sponsorship for your fo	ee, inform	our meml	ership chairn	nan)	

Please make cheque payable to: **Polio Regina Inc.** and mail this application form and cheque to:

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

Polio Regina Inc., 825 McDonald St. Regina, Sk. S4N 2X5









# LIVING WITH A DISABILITY



Date: March 31, 2014

Location: Quality Inn, 1717 Victoria Ave,

Regina, SK



Time: **8:30am - 3:30pm** 

Join us for a **day of sharing and learning**. Sessions on:

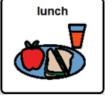


- Nutrition
- Relaxation
- Depression
- Access to Services
- Health and Wellness
- Display Booths
- And much more!



**FEE: Participant \$10** Professional \$25

A light healthy **lunch** will be available.



To **register** contact:

Xilonem Lopez, March of Dimes Canada

Phone: **1-800-263-3463** x **7209** Email: xlopez@marchofdimes.ca



registration

# **Spring Picnic**

Our annual spring picnic was enjoyed by everyone with lots of great food and conversation. The weather was pleasant and we were able to spend the evening on the deck. 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. Carole Tiefenbach presented David and Elaine Cotcher a Lifetime Membership to Polio Regina.













