



Christmas 2015

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Season's Greetings

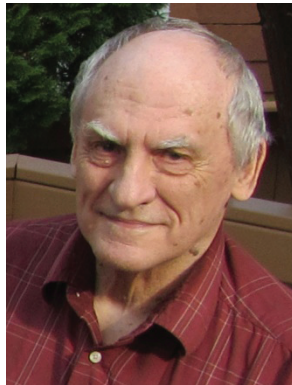


My Polio Story

Clarence Biberdorf has been a faithful member of Polio Regina since it began. He is an active participant at our meetings and a supporter of our group. The following is Clarence Biberdorf's Polio Story.

Clarence Biberdorf

I was born October 2nd, 1939 in Oxbow, Saskatchewan. I was born two months premature and weighed just over two pounds. I have two sisters and one brother. We lived on a farm 18 miles from Oxbow near the United States border.



I was admitted to Oxbow hospital on June 15th, 1953 with polio. My legs and arms were paralysed and I had a bad headache and a high temperature. My brother and a neighbour were also admitted for polio at the same time. My brother had some paralysis in one arm. I was in isolation but my little sister, who was four or five years old, and was also in the hospital, would sneak into my room and crawl into bed with me because she missed her big brother. There were no locked doors in those days. They brought in a washing machine-like tub which heated steaming hot damp cloths that they put all over my body, especially on my legs and arms. That made my headache even worse.

I was in the Oxbow hospital for 21 days, and then I was transferred by air ambulance to Regina General Hospital. I was put into the DVA wing with 18 other people for a week because they didn't have room anywhere else, then I was transferred to the Red Cross wing. At the General Hospital I was in a Boy Scout Troup which held meetings once a month and on Fridays they would take us to the basement for a picture show. They did some therapy at the General and they had a small pool but from Monday through Friday they would take us by bus to Wascana Hospital for therapy and exercises. It was in the same building as a boy's reform school. We also had a couple of hours a day of school work but that didn't really amount to much.

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I finally came home June 30th, 1954. I had splints on both my legs. I got rid of the splint on one leg after two months but I still used crutches. After six months I got rid of the other splint and was able to walk without crutches but I still had problems with my one leg buckling. This was a permanent affliction and I always had to be careful to lock my knee when I took a step.

After I got home, I finished my high school in Oxbow. We lived too far away from Oxbow to drive in every day so I stayed in a dormitory where we were expected to help out with household duties and make our beds with military precision. After I graduated, I came to Regina and stayed with my Grandma and Grandpa while I took an "All Day Drafting Course" at Balfour Tech for one year. While I was there I did the layout and placement of the pictures for the yearbook.

After I graduated from Balfour, I got a job drafting for Shell Oil for about nine months. My next job was at Roger's Lumber drawing house plans and taking orders at the order desk. I was laid off after about a year when the company ran into financial difficulties. Then I worked for Stock Keith's as an electrical draftsman for four years until the company split, then I worked for Stock for two years. My last employer was SaskPower where I worked for 33 years. I worked 10 years supervising draftsmen for power plants and 20 years as a draftsman for switching stations.

I started to notice the signs of Post-Polio Syndrome in 1999 when I retired from SaskPower. I would get tired and just hit the wall and not be able to do anything. It has gotten much worse over the last 10 years.

In the summer of 2014 my knee buckled and I fell and broke my little toes. I was hospitalised for two and a half months. They took me for therapy at Wascana for an hour twice a day but I could only do it for about 10 to 15 minutes at a time before I hit the wall so the rest of the time was wasted. I convinced them to give me therapy three times a day for 10 to 15 minutes a time and that really worked. They put a big boot on my foot but it was so heavy that I couldn't move it. Finally Dr. Fink prescribed a hard plastic insole so my toes wouldn't move and that worked well.

I used to use crutches but now both rotator cups are gone in my shoulders and I can't lift my arms over my head and I don't have much strength left in my arms. I have a scooter but the seat is too low and it is difficult to get on and off it. Dr. Fink prescribed an electric wheelchair for me that has a 23" high seat which is easier to get into and out off. In my home I have a hospital bed, raised toilet seat and raised bench in the shower. I still drive the car.

My wife Carol, who is also active in Polio Regina, is a great help to me. We have been married for 52 years. We have two daughters. Both have Multiple Sclerosis. Both have had the Liberation treatment in San Diego. It worked for one but not the other; she can't walk anymore. We also have two grandsons.

My hobby is coin collecting. I will probably eventually give my collection to my grandsons.

My advice to fellow polio survivors is to do as much as you can but not too much and know your limitations. There are some people who don't understand that.

Message from the Vice-President and President



Once again, our beautiful summer has up and left us! She left behind a beautiful fall which we are all very grateful for! Many of us have flowers still blooming in pots, which is quite abnormal for the middle of November! I was so happy to be able to pick the last of my swiss chard in November.

We, Wilf and I, again, had a pretty busy summer, as usual. We certainly 'feel the years' a bit more every year as we end another busy day in the yard. That is when we go looking at condos in the evenings to see what is actually out there!! It is the toughest decision we will ever have to make, I'm sure. It is getting much closer every day.

Of course, we made a few trips to Manitoba to help with Crystal's yard work. In May, we extended the driveway 16 feet wider and put new culverts in, I burnt, literally tons of brush that Crystal had sawed down with the help of her brother, all day, while Wilf built a larger built up garden, built up the front sidewalk plus numerous other jobs! There seems to be no end sometimes.

On July 16th, we left Regina pretty early in the morning with intentions of sodding the next day, Friday, in our daughter's yard. We arrived there around 1 p.m. and the sod had been delivered already. It was suppose to be delivered the next day. The weather was suppose to be really hot the next day, so we all decided we might as well start right away. Crystal asked 3 of my grandson's friends to come help us carry the sod and she would pay them each \$50 for the day! Starting at 2:30 p.m. we finished at 4:30, so those 3 musketeers made out pretty well getting \$25 per hour! Riley even got his face out of gaming for those two hours which was a miracle to behold!

We did not carry one piece of sod as the young ones did that, but we were so exhausted just cutting and fitting the pieces in, on our hands and knees. It looked so beautiful when we were done, it was worth the work!

As I was admiring the work we had done, I stepped on a soft piece of sod and twisted my ankle which reminded me of that glorious work day for 4 months after!

Another weekend when we were there, Wilf made another garden bed for Crystal, also built up a flower bed with bricks, and put in a brick fireplace in the back yard so there were always things to do in the naked yard!! Now it looks more like home and it is indeed a very lovely home!

In total, only 3 or 4 trips this year, which was far better than every second weekend all summer last year. Our daughter is always so grateful when she comes home from work for both of us. We are surprised at the energy we have getting as much done as we do.

We are always very tired when driving home on the Sunday after church, and in July we hit the ditch, just

before Brandon, MB. Wilf fell asleep at the wheel and we went flying into the ditch, the van stayed straight up and plowed thru tall grass and yucky mud, luckily missing any big rocks underneath that grass, until we pulled up on the other side of the highway facing oncoming traffic, driving on the bicycle lane until we reached a crossover where we could pull in and catch our breath!!

A very nice lady had been following us and watched us go into the ditch and continued to follow until we had stopped, clearly thinking we were going to roll, stopped across the highway and ran over to ask if we were okay! She couldn't believe how well we flew through that ditch!! Wilf's good driving skills when he wakes up, I guess! It certainly woke me up very quickly! However, we were blessed from above and know that to be true, and we were so very grateful for our safe journey home! Tired to be sure!

In October, we headed for Park City, Utah, again, where we really have a lazy holiday, just walking and exercising in the pool, visiting Temple Square to do more family history and visiting with friends.

Our next journey will be Florida near the end of January until mid-March.

We are grateful to Nicky's Cafe for catering to our needs for our meetings and providing home cooked meals for us to order as we wish.

Our last meeting of this year is November 26th which will be our Christmas party!

Wilf and I wish you and all of your families; love with many blessings for health, happiness and prosperity for the coming New Year of 2016!!!



At The Meetings

May 2015: Our annual spring picnic was enjoyed by everyone with lots of great food and conversation. Although it was inside at Nicky's Café we still had a picnic-like atmosphere with hamburgers, hotdogs and all the fixings. Blenda Ramsay gave a tribute to Mavis Matheson and Adam who will be moving to BC in June. Ivan read and circulated a Facebook post by Jim Allonby announcing the passing of his wife Gail Allonby on May 23rd.

September 2015: David Cotcher mentioned that he had seen obituaries for former members William Calibaba and Albert Ludwig in the Leader-Post.

Open Forum: Anne Bartel introduced our guest speaker Jan Shearer, who is a retired nurse who worked for many years at Wascana Rehab Centre. She is an international laughter yoga instructor. She explained the history of laughter yoga and gave us a demonstration and got us all laughing.

October 2015: Diane Lemon passed around a list of Flu clinics that are to be held in Regina. She also passed around a brochure about a device called "Frog Leg" which aids people who have limited leg mobility in moving while lying in bed. Frog Leg allows users to bend and straighten their legs, as well as roll from side to side. The web-site is: <http://www.frogmobility.com/>

Diane also told us about a web-site describing "Unnecessary Surgical Procedures Performed on Polio Patients". The web-site is: http://www.naturalnews.com/042170_polio_pandemic_tonsillectomies_surgical_procedure.html

Open Forum: Diane Lemon introduced our guest speaker Maria Tuchscherer, a Speech Language Pathologist, who was the Director of Speech at Wascana for many years. Maria gave a very interesting presentation on swallowing. She described the components of our mouth and throat and how they work. She gave advice on how to avoid choking and showed us some aids that make drinking and swallowing easier. Some of her tips are: To control choking, eat in an upright position at all times. It is a dangerous practice to elevate your chin to get the medication to the back of your throat. Raising

your chin causes the vallecular space to disappear and swallowed material may drop directly into the airway. Avoid this practice. Children's sippy cups or Styrofoam cups with a piece cut out for your nose can be used as aids to keep your head straight. The article "New Swallowing Problems" is printed in this issue.

Future Meetings: The next Polio Regina meeting will be at our Christmas Party, 5:00 p.m., November 26th at Nicky's Café. The spring meetings for 2016 will be held March 31st and April 28th, 2016. We will decide on the dates and times for the Spring Picnic and fall meetings at future meetings.

5 Questions You Should Ask Your Pharmacist

1. What is the name of my medicine and how should I take it? Ask your pharmacist to explain the instructions on your prescription label.
2. What information do you need to know about the other medicines that I am taking? Keep a medicine list with the name, dose, and schedule of all the medications, vitamins, and herbal products you take. Share it with your pharmacist or doctor.
3. When should I take this medication? The time of day you take your medicine can affect how well it works. Ask your pharmacist about what time to take your medicine.
4. What are the common side effects of this medicine? Ask your pharmacist or check SafeMedication.com for potential side effects and what to do if they occur.
5. What should I do if I miss a dose or take a dose incorrectly? Your medication will not work as well or may cause side effects if it is not taken properly. Ask your pharmacist.

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New Swallowing Problems in Aging Polio Survivors

Carl A. Coelho, PhD, Gaylord Hospital, Wallingford, Connecticut

In the normal swallowing process, three phases are typically described. The oral phase involves food being placed in the mouth, chewed if necessary, and positioned or formed into a ball (bolus) which is then moved backwards to the anterior faucial arch, an area near where the tonsils are, or used to be, and where the swallow response is triggered. During the pharyngeal phase, three things happen simultaneously. The tongue pumps the bolus back into the pharynx, the epiglottis, (a chunk of cartilage near the base of the tongue), slams down on top of the airway, the larynx (voice box) elevates slightly, and the vocal chords close. These activities prevent aspiration (food or liquid from entering the airways). If the synchrony of any of these is disturbed in any way, significant problems can occur. At the same time, the third and final phase of swallowing is occurring, a coordinated muscular activity which transports the bolus through the throat where a small sphincter (muscle) at the top of the esophagus called the cricopharyngeus relaxes (dilates) so that the bolus can enter the esophagus and eventually the stomach.

In 1988, three individuals triggered my interest in swallowing problems of post-polio individuals. They had a mean age of about 53 and were between 30 and 60 years post-onset. All complained of coughing and the sensation of food sticking in their throats. Examination found that some had reduced strength in oral musculature, some had problems with

pharyngeal transit, and others had a delayed swallow response. Although there was no aspiration, all three were judged to be at risk. In 1991, a project I was involved with sent out a questionnaire to post-polio individuals. Twenty-nine of the 109 respondents reported periodic or consistent problems with their swallowing. Of 21 studied, 20 had some type of swallowing dysfunction, some with multiple problems. Nine had problems with bolus control or weakness of the musculature, four had a delayed swallow response, and 17 had problems with pharyngeal transit. While none aspirated, two were judged to be at significant risk.

Problems with swallowing reported in the literature .

In 1991, a study published in The New England Journal of Medicine was conducted by Barbara C. Sonies, PhD, and Marinos C. Dalakas, MD. They followed 32 individuals. Only 14 of the 32 reported swallowing problems, but when examined 31 had objective signs of difficulty with swallowing. Problems were found during the pharyngeal phase, with pooling in the valleculae, the V-shaped space formed by the base of the tongue and the epiglottis. Two individuals with pooling aspirated.

Another paper published in 1991 by Alice Silbergleit, MA, et al, studied 20, post-polio individuals with a mean age of 49, 17 to 66 years post-onset of acute polio. Of these, 75% percent were noted to have reduced pharyngeal transit and pooling. Some also reported problems with esophageal motility and weakness of the oral musculature. Two individuals aspirated.

Interaction between breathing and swallowing.

Breathing and swallowing are reciprocal functions. When swallowing occurs, breathing halts. Seventeen of the 20 individuals in our study who had swallowing problems also had significant problems with decreased breathing capacity. There were some individuals with minimal swallowing problems, while others with very significant problems. Both groups also had moderate or severely reduced breathing capacities. It can be concluded that, although breathing problems can complicate or hinder swallowing, one cannot be predicted from the other. Significant breathing

problems will not necessarily predict swallowing problems.

Currently, we are studying seven of the 15 of the original group of 21. We did a breathing assessment, a swallowing evaluation, and a vocal assessment because we are now looking at problems with voice. We measured strength and function of the oral musculature, ran a modified barium swallow, conducted pulmonary function testing, and voice testing.

Of six individuals who demonstrated swallowing problems during the initial assessment, three demonstrated an increase in the severity of their swallowing problems, and three remained essentially unchanged. Generally speaking, those individuals who were most severely involved from the initial assessment were the individuals who demonstrated the most significant progression. Again, there was no aspiration, but the two who had been at risk previously, were judged to have increased risk. All five of the individuals who had significant breathing problems earlier had their breathing capacity diminished over the four-year period.

Diagnosis.

The modified barium swallow procedure is absolutely critical, not only for diagnosis, but also for focusing on the management of swallowing problems. It defines the physiology of the swallow. In addition to the standard modified barium swallow (MBS) procedure, we added what we call stress testing. Just because an individual goes through the standard MBS procedure and does not have difficulty does not mean that over the course of a normal meal they will not experience difficulties. In the stress testing, we increase the quantity of liquids, purées or solids for swallowing, and attempt to tax the swallowing system. We have also tested people after a full meal when there might be some fatigue, or we bring them in after a normal workday when there might be a fatigue factor as well.

Management.

Compensatory positioning or relatively minor adjustments in posture during swallowing can significantly affect the swallow. Basic changes, such as dropping the chin or turning the head can help,

the rationale being that many times the weakness in the pharynx is unilateral (on one side) and that by turning the head, the weakened side of the pharynx is shut off, forcing the bolus to go down the more intact, stronger side. Other management suggestions include dietary modifications and avoiding meals when fatigued. Longitudinal monitoring of swallowing problems, including pulmonary function testing is recommended.

Additional Insights

DR. Coehlo referred to studies conducted by Barbara C. Sonies, PhD, Chief of Speech Language Pathology, and Marinos C. Dalakas, MD, Neurologist, at National Institute of Neurological Disorders and Stroke (NINDS) at the National Institutes of Health. Dr. Sonies contributed Chapter 8, “Long-Term Effects of Post-Polio on Oral-Motor and Swallowing Function in Post-Polio Syndrome,” edited by Lauro S. Halstead, MD, and Gunnar Grimby, PhD.

The additional insights below are extracted from Dr. Sonies’ chapter.

It appears that some individuals have speaking or swallowing problems of which they are unaware and which slowly emerge in the same manner as has been seen with limb muscles. This progression of symptoms in limb muscles may cause new disabilities. However, swallowing problems and associated complications, such as aspiration pneumonia, can be life-threatening.

Many, but not all, individuals with swallowing problems report having had acute bulbar polio. It appears that the more severe the original condition, the greater the likelihood of new problems. In their study of 32 individuals, 31 had some difficulty with swallowing, even though only 14 reported being aware of symptoms. It should be noted that the severity of the swallowing problems were significantly greater than those who did not. Normal aging does not cause changes in speech and swallowing, so any new signs of problems most likely are due to neuromuscular changes.

Common complaints reported by post-polio individuals included: intermittent choking on food, pills sticking in the throat, difficulty swallowing pills, food sticking in the throat, coughing during

meals, and difficulty swallowing.

Individuals with suspected swallowing problems should seek an evaluation from a speech pathologist with expertise in dysphagia (swallowing). This evaluation will include a thorough history of eating, a clinical examination of swallowing, and a videofluorographic examination of the oral and pharyngeal swallow. Persons with complaints of indigestion may need evaluation of the esophagus - which can be done during the modified barium swallow study.

None of the individuals in the follow-up study at NINDS aspirated. Credit for improvement is given to the cooperation between therapists who developed the treatment plans and polio survivors who carried out suggested strategies.

Marylou Brewer, RN, Director, Training and Information Dissemination, NIDRR Research and Training Center, Rehabilitation in Neuromuscular Diseases, Department of Physical Medicine and Rehabilitation, University of California, Davis, California 95616-8655 describes their current swallowing research project directed by E.R. Johnson, MD.

The goals are:

- To evaluate swallowing disorders in neuromuscular disease;
- To develop and validate quantitative measurements of pharyngeal transit time using new techniques;
- To determine the effect of bolus consistency, temperature, and head position on swallowing and kinematic pharyngeal transit times;
- To develop and validate specific remedial rehabilitation techniques for individuals with neuromuscular disease. Data are still being selected and analyzed. Results are not yet available.

In Polio Network News (Vol. 6, No. 4), in the article, "A Review of Swallowing Difficulties in Post-Polio Individuals," Roberta Simon, RN, offered these common-sense suggestions:

- Chew slowly. Cook all foods until they are soft.

Do not talk while eating. It can increase the risk of aspiration.

- Avoid large bites and big gulps of liquid. Liquids are sometimes managed better if the chin is tucked down to delay the swallow.
- To control choking on saliva, avoid foods that thicken secretions, such as milk and milk products. Discuss calcium supplements with your physician if you do limit milk products. To control choking, eat in an upright position at all times.
- Do not eat when fatigued. Consider eating several small meals each day. Combining different textured food makes eating and swallowing easier for some. Place a sauce or gravy on dry, difficult-to-swallow food such as meat.
- If liquids are a problem, thicken them with commercial starches or preparations to facilitate swallowing. Liquid soups are not recommended for individuals with tongue weakness. Cream soups are better tolerated as are juices with a thicker consistency such as nectars and tomato juice.
- If taking medication is a problem, applesauce or jelly may help, and so may drinking water through a straw to get the medication to the back of the throat. It is a dangerous practice to elevate your chin to get the medication to the back of your throat. Raising your chin causes the vallecular space to disappear and swallowed material may drop directly into the airway. Avoid this practice.
- Esophageal problems can be managed by eating in an upright position. Drinking a glass of water after eating helps in clearing the contents of the esophagus into the stomach. If a stricture is found during an esophageal evaluation, dilation may be needed.
- If weakness is present on only one side of the throat, turning the head to the opposite side while swallowing is, at times, helpful.
- Weight loss may be a problem and a high protein or high calorie liquid substitute is advised. Seek your physician's assistance so your nutritional intake may be monitored.

- Surgical intervention is the extreme end of treatment for these difficulties. Care must be taken in any corrective surgical procedure because of the weak, underlying muscles.
- Vocal cord weakness can be a problem for some and speech therapy is helpful in providing compensatory techniques. A small microphone to amplify the voice can be prescribed. Fatigue seems to play a role in vocal cord weakness.

June Price, editor of Living SMArt, a newsletter for individuals living with spinal muscular atrophy, and Nicole Roberts, suggest the following from their personal experiences on ways individuals with swallowing problems can better cope with eating out.

- Be honest with hosts ahead of time about your problem/needs. Tell people what you can and cannot eat. Sometimes it may be better to be up front and say no to their desire to feed you.
- A solution at restaurants is simply to eat ahead of time, or after. Drink a protein shake before going to a friend's house and then nibble.
- At restaurants, instead of a large meal, order an appetizer to be served with the dinner course. Salad bars are usually filled with soft peas, beans, cottage cheese, tomatoes, soups, sauces, puddings, as well as the hard-to-eat lettuce and crunchy, raw vegetables. Potato bars offer cream sauces and finely minced meat and vegetables.
- Do not be afraid to ask for substitutions or a reduced volume of food (so you do not have to stare at a huge plate of uneaten food). Make up your own meal. If all you want is a baked potato and applesauce, ask for it.



The follow articles are a collection of articles that Dr. Richard Bruno has submitted to the Facebook page "The Post-Polio Coffee House" which is a forum for Polio Survivors. They are reprinted with Dr. Bruno's permission.

Posted by Dr. Bruno September 8, 2015

Polio Survivors Who Had Childhood Surgeries

(These researchers found increased anxiety in monkeys after anesthesia. But polio survivors really had things to be anxious about!)

Emotional Behavior Altered After Multiple Exposures to Anesthesia During Infancy

Released: 31-Aug-2015 12:00 PM EDT

Source Newsroom: Mount Sinai Medical Center

Newswise — (NEW YORK – September 3) Repeated exposure to anesthesia early in life causes alterations in emotional behavior that may persist long-term, according to a study from the Icahn School of Medicine at Mount Sinai in collaboration with the Yerkes National Primate Research Center, and published in the Online First edition of *Anesthesiology*, the official medical journal of the American Society of Anesthesiologists®.

Each year, approximately one million children under the age of four undergo surgery with general anesthesia, according to the U.S. Food and Drug Administration (FDA). Retrospective birth-cohort studies of children have found an association between learning problems and multiple exposures to anesthesia early in life, and research in animal models, mainly rodents, has shown that early anesthesia exposure causes cell death in the brain and cognitive impairments later in life.

Nevertheless, uncertainty remains about the extent to which anesthesia specifically may be a risk factor in humans, when compared to other factors and comorbidities associated with anesthesia and surgery. Additionally, the applicability of rodent studies to humans has been questioned on a number of grounds, including a lack of correspondence of developmental stages between the species.

The Mount Sinai/Yerkes study is the first to address the question of whether repeated postnatal anesthesia exposure, in and of itself, caused long-term behavioral changes in a highly translationally relevant rhesus monkey model. The stage of neurodevelopment of rhesus monkeys at birth is more similar to that of human infants compared to neonatal rodents; with respect to brain growth, a six-week-old rhesus monkey corresponds to a human in the second half of his or her first year of life. Because these kinds of controlled studies cannot be carried out in humans, it is essential to use a comparable animal model to discover if anesthesia may be affecting the brain. Unlike previous research, the study was conducted in the absence of a surgical procedure, co-morbidities that may necessitate surgical intervention or the psychological stress associated with illness.

“The major strength of this study is its ability to separate anesthesia exposure from surgical procedures, which is a potential complication in the studies conducted in children,” says Mark Baxter, PhD, professor in the Departments of Neuroscience and Anesthesiology at the Icahn School of Medicine at Mount Sinai. “Our results confirm that multiple anesthesia exposures alone result in emotional behavior changes in a highly translational (i.e., comparable to humans) animal model. This raises concerns about whether similar phenomena are occurring during clinical anesthesia exposure in children.”

Specifically, the study team exposed 10 nonhuman primates (rhesus monkeys) to a common pediatric anesthetic called sevoflurane for a comparable length of time required for a significant surgical procedure in humans (four hours). They were exposed to the anesthetic at postnatal day seven and then again two and four weeks later, because human data indicate that repeated anesthesia results in a greater risk of learning disabilities relative to a single anesthetic exposure.

Researchers evaluated the socioemotional behavior of exposed subjects compared with that of healthy controls at six months of age using a mild social stressor (an unfamiliar human). They found the anesthesia-exposed infants expressed significantly more ANXIOUS overall compared with controls.

“The task we used is designed to be similar to the task used for assessing dispositional anxiety and behavioral inhibition in children, thus increasing the study’s applicability to humans,” says first author Jessica Raper, PhD, research associate in the Division of Developmental and Cognitive Neuroscience at Yerkes National Primate Research Center at Emory University, where the testing was conducted. The study results also demonstrate that alterations in emotional behavior persist at least five months after anesthesia exposure, suggesting long-term effects.

Co-investigator Maria Alvarado, PhD, also of the Yerkes Research Center adds, “Events that impact the developing brain have the potential to affect a wide range of later-developing behaviors.” These findings are part of a larger longitudinal study, and researchers at the Icahn School of Medicine at Mount Sinai and the Yerkes National Primate Research Center will continue to follow these study subjects behaviorally to fully characterize the length of time that these emotional changes persist and whether they resolve over time.

Considering that most pediatric surgeries are non-elective, future studies can use this primate model to develop a new anesthetic agent or prophylactic treatment to counteract the impact of anesthesia on behavior in children. The findings also suggest that additional work is required to identify the mechanisms by which anesthetics may cause long-term changes in central nervous system function that impact behavior.



I've recently been hearing unwelcome old songs from polio survivors: "I'll use assistive devices when I need to," "I don't want to look disabled" and "I can't ask for assistance, even when it's offered." It's time for a Roosevelt injection...

We Have Nothing to Fear?

By Dr. Richard L. Bruno

Post-Polio Sequelae Monograph Series, 2014;14 (1): 1-3.

"We have nothing to fear but fear itself," declared history's most famous polio survivor. Well, that may be true if 1) you're a multimillionaire 2) have an executive job that pays the same salary whether you're working or retired 3) have the world's best medical care 4) are surrounded by eager servants and a coterie of men with guns sworn to protect you. But, for those who are disabled and aren't president of the United States, there's a lot to fear. Having treated people with disabilities for more than 30 years, let me tell you about disability's "Fundamental Fears" and ways to stare them down and send them away.

Death & Danger. I was amazed when I read a study that people without disabilities most often "thought of death" when they saw pictures of someone who had a disability. One enlightened insurance company sold their disability policies using the slogan, "Be Prepared for Disability, 'The Living Death'."

Since those who have disabilities are people first and disabled second, they too can see their own disability as a harbinger of death. But, disability isn't synonymous with death. Yes, some disabilities end in death. Others can potentially reduce your life span. But, the overwhelming majority of physical disabilities are not life threatening.

Holistic teacher Don Miguel Ruiz suggests, "Death is not the biggest fear we have; our biggest fear is taking the risk to be alive and express what we really are." However, for people with obvious disabilities, expressing what they really are can generate another fear. One study found that people with diabetes, which can lead to blindness and leg amputations, are more afraid of disability than they are of death. One reason is that looking disabled announces vulnerability. Bill, a para who lives in New Jersey, refuses to venture into New York City: "I feel like

an easy mark, a guy in a wheelchair who can't run or fight. I'm a mugging waiting to happen!" But, Carla, who has cerebral palsy and was mugged, she believes as a direct result of her limp and cane, isn't letting fear keep her a prisoner. "I won't leave the house without pepper spray and my taser," Carla says. "C'mon muggers. Make my day!"

Abuse & Abandonment. Unfortunately, a more common disability-related fear than being attacked by a stranger is being physically or emotionally abused by someone you know. Our 1995 International Survey found that polio survivors reported 34% more physical abuse and 94% more emotional abuse than did those without disabilities. All that "extra" abuse was due to polio survivors having had "the dread disease" and looking disabled. And, abuse was meted out not only by strangers -- nurses, doctors and physical therapists -- but also by parents, siblings and neighbors. Polio survivor Molly returned home from the rehabilitation hospital to be accosted in the street by neighbor who said her wheelchair was "... upsetting people. You cripples shouldn't be allowed in public!"

It's stunning that the same polio survivor who promised, "We have nothing to fear but fear itself!" also said, "I'll walk without crutches. I'll walk into a room without scaring everybody half to death. I'll stand easily enough in front of people so that they'll forget I'm a cripple." Echoed polio survivors Jim: "Anxiety, inferiority, uselessness. Fear in the pit of my stomach is always there, for as long as I can remember. Why? I had polio. That's why."

These fears are nowhere more evident than in the research showing that changes most obvious to family members -- using assistive devices, buying special equipment, and home modifications -- were adopted by the fewest polio survivors in spite of these changes being the most effective in decreasing PPS symptoms. That's why about 10% percent of those treated at The Post-Polio Institute refuse any assistive device that makes them appear disabled. One patient told me she'd rather be dead than use a cane, saying "Why don't you just paint a bulls-eye on my chest and say 'Shoot the Cripple'?"

Despite Billy Crystal's old line, "It is better to look good than to feel good," it isn't! Be you a polio

survivor, a para, someone with muscular dystrophy, MS, spina bifida or CP, it's better to feel good than to try to hide your disability and stumble, fall or crawl along without the assistive devices you need. To paraphrase a line from another abused and abandoned polio survivor, "I limp, I'm a gimp, get used to it!"

Helplessness & Homelessness. "The only time I ever cried after being diagnosed with MS was because I was terrified that I would no longer be able to earn a living and become a financial burden to my family," said Ray.

People with new disabilities often expect the worst – that they will become helpless and unable to work – rendering themselves and their families penniless and homeless. Even those who are disabled and have worked for decades can reach a point where they run out of muscle strength, are pummeled by pain, done in by fatigue. They are terrified to retire early, fearing that they will become their family's financial albatross. It's no wonder that a report on deaths under Oregon's assisted suicide law found that almost half of those motivated to end their lives were prompted by fear of becoming "a burden on others."

First, depending on your physical circumstances and education, even those with severe disabilities are working. That's what state vocational rehabilitation agencies and the ADA are all about, helping people with disabilities use their remaining abilities to earn a living.

Second, if you can't work any longer, your company may have a private long-term disability policy that typically pays 60% of your salary.

Third, if you don't have long-term disability, Social Security Disability Income is available; although SSDI only pays about \$1,500.00 a month it provides Medicare two years after you are approved. Please don't believe the Internet reports that "everyone is denied SSDI on their first try." A complete protocol to apply for SSDI that accompanies my Social Security Ruling for Post-Polio Sequelae in the POST-POLIO LIBRARY at PostPolioInfo.com. But, even before the Social Security Ruling, since 1987 when Senators Bill Bradley and Tom Harkin helped me get the SSDI regulations for polio survivors released, we have had not one polio survivor denied for SSDI.

Dependence Creates Independence. That Oregon report found the most common motivation for suicide (about 66%) was fear of "loss of autonomy" and "loss of control of bodily functions." Poet Bonaro Overstreet said, "Perhaps the most important thing we can undertake toward the reduction of fear is to make it easier for people to accept themselves, to like themselves." To both accept and like themselves, those with disabilities -- both newbies and the old hands -- need to understand that loss of autonomy or control of bodily functions should not be reasons for taking the pipe. These changes, as well as other symptoms of disability -- and of aging itself -- are just variations on "The Burden Beguine," that dance between dependence and independence that polio survivors have learned to dance so well. As Dr. Nancy Frick frequently said, "There is ALWAYS an alternative – physical or emotional – to deal with any problem."

As people with disabilities lose function or age, they often get angry when others, especially family members, offer assistance. This anger is hiding a fear of dependence and being a physical burden. But, we've found that family members do not feel burdened, but actually want to help. The true burden is seeing a loved one in pain and unable to function, not being asked to vacuum the living room rug. Since our studies show, for example, that family support increases polio survivors' acceptance of new symptoms and decreases depression, it's vital that family and friends are allowed to help with physical tasks and that family members with disabilities feel valued regardless of reduced abilities. It is a wonderful contradiction that the more disabled you "look" -- the more assistive devices you use, the more you ask for help, and the less you abuse your body -- the better you feel and functional and the more independent you become. As hard as it is to believe, dependence creates independence.

"We have nothing to fear but fear itself?" Perhaps a more helpful quote comes not from Franklin Roosevelt but from Eleanor: "You gain strength, courage and confidence by every experience in which you really stop to look fear in the face. You must do the thing which you think you cannot do."

Posted by Dr. Richard Bruno November 3, 2015

48 Hour Lag

Most polio survivors have experienced the “48 HOUR LAG,” where you scrub the floor Monday, feel great Tuesday and are so sore, fatigued and weak on Wednesday that you can’t get out of bed yet can’t figure out why.

Here’s an interesting article about muscle soreness in non-polio survivors...

NY TIMES

November 3, 2015

By Gretchen Reynolds

“After rigorous exercise, the muscle pain is more acute a day or two later rather than immediately. Why is that?”

Welcome to the equivocal effects of Delayed Onset Muscle Soreness, the scientific term for aches that accumulate and intensify a day or two after a strenuous workout. Usually, D.O.M.S. involves not just pain but also “loss of strength and range of motion in the affected area,” said Scott Sailor, a professor of kinesiology at Fresno State University in Fresno, Calif., and the president of the National Athletic Trainers’ Association.

D.O.M.S. commonly occurs after exercise that involves lengthening muscles while they contract, Dr. Sailor said, such as running downhill. But it can develop after any exertion that is more intense or prolonged than is normal for you.

Such strenuous workouts can cause multiple slight tears to the muscle tissue, after which a variety of cells and substances migrate to these muscles to help them start healing.

Interestingly, these substances are not necessarily the same as those that arrive after a more severe muscle injury. Molecules that promote inflammation and swelling, for instance, tend to predominate in tissues affected by a serious injury, but can be absent in tissue affected by D.O.M.S., recent studies show.

Similarly, “there was a time when we attributed the muscle soreness to lactic acid,” Dr. Sailor said. “We

have now learned that lactic acid leaves the muscle so quickly” that it cannot be involved in causing D.O.M.S.

In essence, researchers remain puzzled about what cellular reactions cause D.O.M.S.

Likewise, there is controversy about how best to treat it.

“Various treatments have been attempted over the years,” said Dr. Sailor, including massage, icing and anti-inflammatory painkillers. “At best, they have decreased the perception of pain,” he said, but only temporarily. No treatment yet has been shown to actually reduce the length of time that muscles remain sore and weak.

So if you do develop D.O.M.S., accept that, for the next five to seven days, you are going to be sore. Refrain from strenuous exercise during this time.

<http://well.blogs.nytimes.com/2015/11/02/ask-well-why-do-muscles-ache-a-day-or-two-after-exercise/?ref=todayspaper>

Posted by Dr. Richard Bruno September 23, 2015

FALL is here...and so are purple, cold polio feet:

Here’s a reminder on how to keep warm and stay warm all day:

“Of Frozen Fingers and Polio Feet” A warming winter tale for everyone who hates the cold.

Polio survivors are extremely sensitive to changes in temperature. At merely cool temperatures, polio survivors report that their feet have always been cold to the touch, their skin a purplish color. However, as polio survivors have aged, 50% report intolerance to cold and that their limbs have become more sensitive to pain as the temperature decreases. Cold was reported to cause muscle weakness in 62% of polio survivors, muscle pain in 60%, and fatigue in 39%. (Bruno & Frick, 1987).

When polio survivors were cooled in our laboratory from 86° F to 68° F, motor nerves functioned as if

they were at 5° F and polio survivors lost 75% of their hand muscle strength. (Bruno, et al., 1985a) And, although polio survivors were twice as sensitive to pain as those without polio at room temperature, no increase in pain sensitivity was found at lower temperatures. (Bruno, et al., 1985b)

The reason polio survivors have such trouble with cold is that the parts of the central nervous system that should control body temperature were damaged by the poliovirus. In the brain the hypothalamus (the automatic computer that controls the inner bodily environment) was damaged by the poliovirus, including the body's thermostat and the brain area that tells your blood vessels to constrict. (Bodian, 1949) In the spinal cord, the nerves that carry the message from the brain that tells the capillaries in the skin to contract when it's cold were also by the poliovirus. (Bodian, 1949) Thus, polio survivors are unable to stop warm blood from flowing to the surface of the skin as the outside temperature drops. This allows loss of heat from the blood near the surface of the skin and causes the limbs to cool. When the limbs cool, arteries carrying blood to the skin and veins that should carry blood out of the skin narrow passively as they get cold, trapping blue venous blood in the capillaries and causing the feet to look blue and to become even colder. The cold skin chills the motor nerves, causing them to conduct more slowly and to be less efficient in making muscles contract. The cold also chills tendons and ligaments (like putting a rubber band in the freezer) making movement of weak muscles more difficult. As polio survivors know, it takes hours under an electric blanket or a long, hot bath to warm cold legs and regain strength.

However, when polio survivors take a hot bath, blood vessels do exactly the opposite of what they do in the cold. Polio feet and legs become bright red as arteries and veins relax and blood rushes to the skin. Then, when polio survivors stand to get out of the tub, they can feel dizzy or even faint as blood pools in their legs and causes their blood pressure to drop (see Bruno, 1996). The pooling of blood in the feet also explains why polio survivors' feet swell, swelling that increases as they get older. And polio survivors' easily losing body heat explains why they have an increase in symptoms, especially cold-

induced muscle pain, as the seasons change.

Polio survivors need to dress as if it were 20° F colder than the outside temperature. The trick is to stay warm from the get-go. You need to dress in layers and wear heat-retaining socks or undergarments made of a woven, thin, breathable plastic fiber called polypropylene (marketed as Gortex or Thinsulate) that should be put on immediately after showering when the skin is warm in the morning. Then put on warm socks, even electric socks with battery-powered heaters. Also, try to keep your feet elevated during the day.

For your hands, Valu-tek (www.cleanroomconsumables.com) makes lightweight gloves that are designed for dexterity indoors. We tested three gloves in polio survivors whose hands are cold inside the home. The nylon "Glove Liner" (VTGNLR-1/1) and the "Conductive Glove" (VTGCONKT), made of polyester knit, have full-length fingers. Of the two, the polyester knit is warmer, but somewhat thicker. There is also a nylon glove liner" (VTGNLR-1/2) that has half-fingers that allow more dexterity, but isn't as warm. Polio survivors found that the gloves keep hands warm and allowed them to use their fingers, to read, to eat and even to knit, but they liked the nylon "Glove Liner" with full fingers best. The gloves come by the dozen, so you can launder them and have some to wear. The gloves liners are about \$13.00 a dozen. The conductive gloves are about \$42.00 a dozen. Since these are disability-related products, they should be tax deductible.

If you still can't stay warm, you can talk to your doctor about taking the anti-hypertension drug Minipress that open your arteries and get more hot blood to your feet. However, these drugs can open arteries too much and cause you to lose heat from your uncovered skin and drop your blood pressure when you stand. These are drugs of last resort to be used very carefully!

Also, polio survivors need to remind doctors that EMGs or nerve conduction tests must be performed in a room that is at least 75° F to prevent false abnormal readings and that a heated blanket is necessary in the recovery room after polio survivors have surgery (Bruno, 1996).

Sleep, Perchance To....Sleep?

A recent study has shown that disturbed sleep (e.g., due to breathing or twitching) provides less rest than the same amount of reduced, but continuous, sleep. This study has found that a consistent sleep schedule may be even more important...

Weekday Sleep Changes May Raise Risk of Diabetes, Heart Disease

Study first to find link between “social jet lag” and metabolism

Washington, DC—Monday mornings could be harmful to your health. Even routine sleep changes such as waking up early for work during the week may raise the risk of developing metabolic problems such as diabetes and heart disease, according to a new study published in the Endocrine Society’s Journal of Clinical Endocrinology & Metabolism.

Researchers have long recognized that shift work can contribute to metabolic risk because of the continual disruption to the circadian system. Shift workers are more likely to develop metabolic syndrome, coronary heart disease and Type 2 diabetes than employees with regular daytime shifts.

Sleep disruption is among the factors that have contributed to rising rates of diabetes and obesity. More than 29 million Americans have diabetes, and 35.1 percent of American adults are obese, according to the Endocrine Society’s Endocrine Facts and Figures report.

“Social jetlag refers to the mismatch between an individual’s biological circadian rhythm and their socially imposed sleep schedules. Other researchers have found that social jetlag relates to obesity and some indicators of cardiovascular function,” said author Patricia Wong. “However, this is the first study to extend upon that work and show that even among healthy, working adults who experience a less extreme range of mismatches in their sleep schedule, social jetlag can contribute to metabolic problems. These metabolic changes can contribute to the

development of obesity, diabetes and cardiovascular disease.”

Researchers examined sleep patterns and cardiometabolic risk in a group of 447 men and women who took part in the Adult Health and Behavior Project Phase 2 study. The participants were between the ages of 30 and 54, and they worked at least 25 hours a week outside the home. Participants wore a wristband that measured their movement and sleep 24 hours a day for a week. The researchers used questionnaires to assess the participants’ diet and exercise habits.

Among the participants, nearly 85 percent had a later halfway point in their sleep cycle – a measurement known as midsleep – on free days compared to work days. The other 15 percent had an earlier midsleep on free days than on work days.

Participants who had a greater misalignment between their sleep schedules on free and work days tended to have poorer cholesterol profiles, higher fasting insulin levels, larger waist circumference, higher body-mass index and were more resistant to insulin than those who had less social jetlag. The association persisted even when the researchers adjusted the measurements to account for variation in other sleep measures and health behaviors such as physical activity and calorie intake.

“If future studies replicate what we found here, then we may need to consider as a society how modern work and social obligations are affecting our sleep and health,” Wong said. “There could be benefits to clinical interventions focused on circadian disturbances, workplace education to help employees and their families make informed decisions about structuring their schedules, and policies to encourage employers to consider these issues.”

<http://www.newswise.com/articles/view/643216/?sc=mwhn>



Posted by Dr. Richard Bruno August 21, 2015

Since several recent posts discuss surgery and anesthesia I thought this timely:

Polio Survivors and Anesthesia Complications: Need for Clinician Education

Presentation to the American Association of Nurse Anesthetists.

Seattle: August, 2010.

Laura L. Ardizzone and Richard L. Bruno

Columbia University College of P&S

International Centre for Polio Education

OBJECTIVE: To examine anesthesia providers' and students' knowledge about anesthesia use in polio survivors and PPS.

BACKGROUND: There are more than 1,000,000 United States survivors of the polio epidemics of 60 years ago reporting mid-life neurologic, musculoskeletal and systemic symptoms called Post-Polio Sequelae as a result of failing, poliovirus-damaged neurons in the brain stem and spinal cord. Excessive and prolonged sedation during anesthesia is one of the sequelae of polio.

METHODS: A survey was e-mailed to a convenience sample of 130 anesthesia providers and students to document their knowledge about PPS and anesthesia.

RESULTS: The survey response rate was 86% (n=113); 92% practiced in the Northeastern United States (n=104); 68% were female (n=77); 73% were nurse anesthetists (n=68); 65% had five or more years of experience (n=56).

We found that 85% of respondents were "NOT familiar" or only "VAGUELY familiar" with PPS or anesthesia's implications in polio survivors; only 14% had previously cared for a polio survivor (n=16).

CONCLUSION: Much more education of anesthesia providers is needed if polio survivors are to receive safe and effective anesthesia during surgical and diagnostic procedures.

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Posted by Dr. Richard Bruno July 15, 2015

WOOPS! YOU MEAN WE DONT NEED A VACCINE FOR D68?

Mystery Polio-Like Illness Linked to New Virus

For a while, researchers studying a mysterious polio-like illness in Colorado last year felt like they were coming close to pinpointing the cause of the disease. Now they're not so sure.

According to a report in livescience, new research has uncovered that while there may be a connection between enterovirus D68 (EV-D68) and cases of acute flaccid paralysis in about 100 children in various parts of the United States during 2014, new studies have found the presence of another virus in at least one patient. That virus, called enterovirus C105, like D68 belongs to the same species as the polio virus. The patient, a 6-year-old girl, tested negative for EV-D68. Hers was the first report of enterovirus C105 in the US.

The discovery further clouds speculation that the EV-D68 virus was at the root of the neurological impairments. There are more than 100 other enteroviruses now circulating that cause 10 to 15 million infections every year. An infection usually causes no symptoms or only mild to moderate cold or flu symptoms. In rare cases, the virus attacks the heart (causing myocarditis) the brain (causing encephalitis) or the spinal cord (causing meningitis and possibly nerve damage)

"Since cases of paralysis have been associated with isolation of EV-D68 from spinal fluid in only 20% of the patients, the role of EV-D68 in the outbreak remains to be determined," authors write in a report to the US Centers for Disease Control and Prevention. "As the results from this case indicate, it is possible that other viral pathogens with neurovirulence may be contributing to the outbreak."

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

The next two Polio Regina meetings will be held at Nicky's Café, on the corner of Eighth Avenue and Winnipeg Street, on Thursday March 31, 2016, and Thursday April 28, 2016 at 3:30 p.m. Nicky's has extra parking at the back and it is wheelchair

accessible. Our Spring Picnic will be held at a time and location yet to be determined.

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.

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.

MEMBERSHIP APPLICATION POLIO REGINA Inc.

Name _____
Active () if you had polio Associate () New () Renewal ()

Address _____

Postal Code _____ Phone: _____

Annual membership fee: (Jan.- Dec.) *Membership Fees are due January 5, 2016*

\$10 Single; \$15 family \$ _____

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

Total \$ _____

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

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

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