SAPPLING'S

NEWSLETTER #45 2310 LOUISE AVE - SASKATOON - SASK. - S7J 2C7

IN THIS ISSUE:

MESSAGE FROM THE PRESIDENT

We are now “POLIO SASK.”

If your address label reads less then 2004 your Membership is not paid to date.

To the Medicinal Professionals receiving “SAPPLING’S”. If you find our Newsletter beneficial we would appreciate a small donation to help us out. Remember, a donation to us is tax deductable.

POLIO SASK. It’s official, passed by the membership at the AGM in April. We also brought in a Privacy Code and placed it in writing to the membership, though the code has been policy since our beginning, now it is placed before you in writing. Our new Board of Directors are Jim Allonby, Regina, Vic-President / Brian Boucher, Saskatoon / Donna Dobrowolsky, Craik, Recording Secretary / Ron Johnson, Saskatoon, President / Dale Schiissler, Saskatoon, Treasurer / Betty Sherdahl, Saskatoon / Don Thompson, Saskatoon.

The Saskatoon PPS Support Group is have a problem with our Special Needs Transportation now called Access Transit for meetings “no returns” though buses run till 10:45 pm. Our 9:30 pm return is the main problem in the service here is not serving the genera public but is serving (contract) subscription clients from 9:00 pm. We had no return problems both in May & June meeting / wind-up, we had 20 members out in June and all enjoyed a great time, after with no returns bus, the group paid Cab fare home for those using SNT, the media was notified but no press showed, the election was on. In May we had the local CTV News crew out and had good coverage Tuesday night, Wednesday morning & noon news broadcast. On July 1, all services were supplied by City personnel with a push 1/or phone, before we had separate contracted services Bus / Dispatching. Time will tell if there is any real improvement.

On Wednesday, May 26, 7:30 pm, McNally Robinson Booksellers gave S.A.P.P a great display for Walking Fingers with time for discussion on the book in their Prairie Ink Restaurant. I wish to thank Deneen Gudjonson for her cooperation. We gained 2 polio survivors. The Book is available at McNally Robinson in Saskatoon or check with your local Book Store. They are.also available to POLIO SASK. At a group price.

Since our last Newsletter we have had 2 members leave our midst. We of POLIO SASK. extend our sinker sympathy to their family's & friends.

The funeral for Maurice Denzin will be held at Faith Baptist Church, 437 Broadway Ave. E. (and Central Ave.) on Thursday April 8 @ 2 pm. Maurice was a member of our Board of Directors 1990

The family of Verne Clemence announces that his death occurred Wednesday, May 12, 2004. He was 67. Verne was a gentle, nurturing man who loved his family and friends. He was born into the farming community around Kindersley to Hazel and Stan Clemence. He also lived in the communities of Cereal, AB, and Yorkton, but since 1972 proudly called Saskatoon home.

Your CPA Racing Team wish to thank you for your past support, and once again ask you to be a supporter this September. By collecting Pledge Donations from others, or by making a donation yourself, prizes are being offered by the CPA based on your amounts collected. Our POLIO SASK team the "SAPPY SAPPS" will participate in the 2004 Wheel Challenge at the Saskatoon Fieldhouse at 10:00 am Saturday September 25, 2004. This year CPA and POLIO SASK. will split 50-50 the net contributions collected by POLIO SASK. Team. An official receipt will be issued on all donations regardless of amount.

Advisory from the Royal Canadian Mounted Police. Please take note and forward to any/all interested parties.

Keep alert for people with cell phones in hand standing near you in the checkout line at retail stores, restaurants, grocery stores, etc., With the new camera cell phones, they can take a picture of your credit card, which gives them your name, number, and expiration date. Identification theft is one of the fastest growing crimes today, and this is just another example of the means that are being used. So, be aware of your surroundings. Please forward to all your friends and family,

Wishing to dispense to someone that needs 1 Everest Jennings - 16" Hand Wheelchair older model, removable foot rests, seat & back in good condition. 1 Fortress 2000 Scooter older Model needs Batteries has not been used for some time was operating fine when last used, tires are flat. Contact Margaret, (306) 652-0082

FOR SALE. 16" AVANTI 5000 Power wheelchair $1,500.00 Less Batteries. Contact Allen 652-0617 Sorry not able to get much information on chair.

Cheerio,

Ron Johnson

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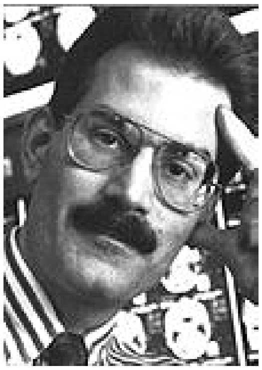
Ask The Doctor

T'N'T for Polio Survivors

Question:.

I don't know what happened. I was sound asleep and the next thing I know my wife is yelling and blood was running out of her nose. She was screaming, "You hit me!" But I was asleep, I swear. She said my arm flew out sideways and smacked her in the face. I know I snore. And she's been telling me for years that I stop breathing and that my muscles twitch in my sleep. But why would I hit her? Please tell me it's a polio thing.



Answer:

Yes, it is a polio thing. We have done three studies of sleep problems in polio survivors. In the

Check out our website at:
http://www.geocities.com/sapponline
Sponsored by Extendicare Saskatchewan

1985 National Post-Polio Survey, 63% of polio survivors reported that their muscles twitch and jump during sleep and half of those said that their sleep was disturbed by twitching.

In 1995 a group of our post-polio patients underwent sleep studies. Forty percent of the patients had periodic leg movements in sleep (PLMS), the common form of twitching where only leg muscles move. Almost 30% had what we dubbed Generalized Random Myoclonus (GRM), where not just the legs but muscles all over the body, including toes, arms, hands—even face and chest muscles—contract randomly throughout the body during the night. Almost 30% had PLMS plus Restless Legs Syndrome (RLS). RLS is not twitching but a feeling that you must make your legs move, a sensation that increases during the evening and often prevents sleep. And we found one patient who also had nighttime shadow boxing, called a “Sleep Start.” Her arms forceful flew outward from her body as she began to fall asleep. Had her husband been in the bed and his nose in range at the time she was falling asleep, there could have been bloodshed.

Sleep starts are obvious since they can wake polio survivors and their bed partners. And restless leg syndrome is also no secret, since it prevents polio survivors from falling asleep. Other muscle movements that can happen night or day are also obvious: fasiculations (muscles fibers that can been seen moving just under the skin), cramps (sustained and very painful muscle contractions, usually in the calf muscles, that pull your feet downward) and muscle spasms (also a kind of sustained contraction that makes a muscle hard and painful, usually occurring in back or neck versus leg or arm muscle). But PLMS and GRM are sneaky. Sixty percent of the patients who had sleep studies didn’t know that their muscles were twitching and jumping. This is the sneaky part, since patients also didn’t know that twitching was responsible for them getting too little deep sleep or dream sleep and that their brains woke up repeatedly during the night, even though they thought they were sleeping soundly.

In 2001, we reviewed all the sleep studies ever performed on Post-Polio Institute patients. One-third were found to have abnormal muscle movements that disturbed their sleep. Nearly half had breathing abnormalities: Ten percent had central sleep apnea, where the diaphragm stops moving; fifteen percent had obstructive sleep apnea, where muscles in the back of the throat become relaxed during sleep, closing off the throat and physically preventing air from entering the lungs; and a whopping 60% had hypopneas, where air enters the lungs, but oxygen in your blood decreases anyway because the diaphragm is not able to move enough air in and out. Hypopneas are the sneakiest of all sleep disorders because even if someone were looking, they couldn’t tell that you weren’t moving enough air in an out of your lungs and that your blood oxygen was dropping and that your brain was being awakened hundreds of times a night. Overall, the combination of twitching and breathing problems resulted in our patients losing 60% of their deep sleep and 20% of dream sleep. Is it any wonder that these folk felt fatigued during the day?

We have found that a very low dose of Xanax (alprazolam) taken 30 minutes before sleep stops twitching and jumping, even in patients with flailing arms. But breathing problems have to be treated before taking Xanax, since any muscle relaxant can impair breathing. The most effective treatment for apneas and hypopneas is positive airway pressure (PAP), where a bread-box sized machine blows air into the nose, mouth, or both during the night to prevent floppy throat muscles from closing off the air passage, and to keep the lungs fully inflated.

Any polio survivor who has muscle twitching while falling asleep or during the night, who snores, wakes in the middle of the night with anxiety, racing heart, choking, or shortness of breath, has headaches, isn't rested in the morning and has severe daytime fatigue should have a sleep study. Don't wait until you've hit your spouse to have your sleep evaluated.

Dr. Richard Bruno
Chairperson of the International Post-Polio Task Force and Director of The Post-Polio Institute and International Centre for
Post-Polio Education and Research at Englewood (NJ) Hospital and Medical Center.

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Diabetes and Post-Polio Syndrome: Conditions Which Are Chronic but Manageable

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(It is estimated that 5.2 million Americans have diabetes and don't know it. Diabetes is more treatable when caught early. If you have any of these symptoms — frequent urination, excessive thirst, extreme hunger, unusual weight loss, increased fatigue, irritability or blurry vision — see your health care professional.)

I was diagnosed with post-polio syndrome in 1989, and I assumed that my extreme exhaustion was due to overusing my muscles. It should have dawned on me that it isn't wise to dismiss all symptoms as due to having post-polio syndrome. Last spring, during a routine visit to my physician, a simple blood test revealed an elevated blood glucose level over twice the normal amount. I, unfortunately, became one of the 18.2 million Americans who have diabetes.

Looking back, I now see I had several of the common symptoms of diabetes, including a family history. I was over my ideal weight, and since I come from a long line of short, heavyset women, I tended to think my weight was inherited. What I had inherited was a body type, not my weight. (Being overweight makes it more difficult for the body's insulin to change food into energy.)

My immediate response to finding out I had type 2 diabetes was to eliminate all sugars from my diet. My blood glucose numbers declined to under 200 mg/dl very quickly and to 110 mg/dl in a couple of months. The next step was to devise a low-calorie meal plan that I could live with and adjust as needed. Even though I was familiar with the American Diabetes Association's exchange lists for meal planning, my meeting with a Certified Diabetes Educator (or Registered Dietitian) was a great benefit as she helped adapt meal plans for my individual needs.

My family started reading labels to find the amount of sugars in products, and we were disturbed to find that "high fructose corn syrup" was in more and more of the foods. We changed to low-fat dairy products and started to choose healthier fats, like extra virgin olive oil. Maintaining glycemic control is also very important for those of us with diabetes. I use the glycemic index (GI).* My goal as a diabetic is to use this "tool" to keep my blood glucose levels as normal as possible.

Complex carbohydrates (whole grains, fruits and vegetables), proteins (lean meats, fish, poultry and soybeans) and fiber are very important in our diet. I found that, like most people, I needed more fiber. (The average person only eats about half of the 20 to 35 grams of fiber they should eat each day.) I began to substitute whole grains, brown rice, wild rice, various beans, legumes and nuts for less nutritious alternatives. It was a pleasant surprise to find I could add small amounts of sweets back into my dietary plan and still keep my blood glucose numbers at the desired levels. Some fresh fruit on whole grain cereal, low-sugar jam on whole grain bread, and a little bittersweet (dark) chocolate on occasion, were welcome additions to my new nutritional plan.

I had been eating low-calorie meals for years, but I was unable to lose any weight. My physician told me that it was due to the high blood glucose levels. As my glucose levels fell, I slowly lost weight. I now eat six small meals a day (3 meals and 3 planned snacks). I use smaller luncheon plates since they make the portions appear larger. At a restaurant, I will share an entrée, or bring half of it home with me.

So far, I haven't switched to artificial sweeteners. My decision is a personal preference to nourish my body with natural foods. I'd rather use a small amount of pure maple syrup in my muffins than use something artificial. I don't drink soft drinks or juice anymore and prefer filtered water or unsweetened teas (sometimes flavored with lemon).

I am taking an oral diabetes medication, not insulin shots, and am using my glucose meter daily to monitor my progress. My health care professionals are pleased with my progress and, I'm very thankful that my choices seem to be working for me.

How has my new lifestyle affected my post-polio symptoms? I am pleased that I have much less fatigue. While I still take a nap when I am tired, I am no longer taking a two-hour nap every afternoon. I have not driven for the past couple of years since I was unsure of my reactions. Fortunately, I have not needed to drive, and I am less fatigued now when riding in a car, when previously it was very stressful. I now feel in control of my emotions and in better health than I have in years.

*The Glycemic Index (GI) is a listing of carbohydrate foods ranking them according to how quickly they are changed to glucose and thus increase the glucose level in the blood. (More about this in future issues.)

Jann Hartman,
Baltimore, Maryland

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Post-Polio Breathing and Sleep Problems Revisited

(Reprinted from Post-Polio Health (formerly called Polio Network News) with permission of Post-Polio Health International (www.post-polio.org). Any further reproduction must have permission from copyright holder.)

"Post-Polio Breathing and Sleep Problems" was published in the fall of 1995 (Polio Network News, Vol. 11, No. 4). As a result of the continual flow of phone calls and emails from polio survivors and family members about this life and death topic, Judith Fischer, editor of Ventilator-Assisted Living (our other quarterly newsletter), and I decided to revisit and revise the original article. Our goal is to educate and to clarify misinformation about breathing problems of polio survivors. - Joan L. Headley, Editor, Post-Polio Health (ventinfo@post-polio.org)

New breathing and sleep problems in aging polio survivors can be insidious and often go unrecognized by either polio survivors, their family members or their health care providers. Polio survivors may have weakened breathing muscles as a result of the initial damage by the poliovirus; the lungs themselves were not affected. Those who were in an iron lung during the acute phase should be aware of the potential for developing problems later in life and educate themselves in order to recognize important signs and symptoms which may indicate underventilation which may lead to respiratory failure. Even those who did not need ventilatory assistance during the acute phase may also be at risk for underventilation and should be aware of problems with breathing and sleep.

Underventilation (hypoventilation is

the medical term) means that not enough air reaches the lungs to fully inflate them. The result may be too little oxygen and too much carbon dioxide (CO2) in the blood. Underventilation can be caused by one or more of the following: weakness of the inspiratory muscles (mainly the diaphragm and rib muscles) for breathing in, weakness of the expiratory muscles (the abdomen) for breathing out and producing an effective cough to clear secretions, scoliosis (curvature of the spine), and sleep apnea.

Other factors contributing to a polio survivor's breathing problems are a history of smoking, obesity, undernutrition, and other lung diseases such as asthma, bronchitis and emphysema.

Vital capacity (VC) is the volume of air that can be expelled after taking a big breath and is a measure of how well the lungs inflate. VC normally decreases with age, but this decrease in VC is more serious in an aging polio survivor with weakened breathing muscles. Many polio survivors had impairment of their inspiratory muscles, and the normal changes due to aging may cause them to lose VC at a greater rate. Polio survivors may not experience symptoms of underventilation until their VC falls to 50% or less of predicted (normal).

Signs and symptoms of underventilation during sleep include:

-inability to breathe when lying flat — the need to sleep sitting up (orthopnea)
-inability to fall asleep and/or to stay asleep (insomnia)
-anxiety about going to sleep
-restless fragmented sleep with frequent awakenings
-shallow breathing or pauses in breathing
-awakening from sleep with choking sensation
-nightmares, night sweats, bedwetting or need to urinate frequently
-excessive daytime sleepiness
-morning headaches
-worsening mental status and impaired memory, concentration and cognition

Other symptoms may include:

-shortness of breath on exertion
-fatigue or exhaustion from normal activities
-claustrophobia and/or feeling that the air in the room is somehow bad
-general anxiety
-difficulty in speaking for more than a short time
-low voice/volume speech with fewer words per breath
-use of accessory muscles, such as neck muscles, to breathe
-weak cough with increased respiratory infections and pneumonias.

Polio survivors experiencing one or more of the above signs and symptoms should seek a respiratory evaluation (simple and noninvasive pulmonary function tests) by a pulmonologist, preferably one experienced in neuromuscular disorders. Physicians are listed in the Resource Directory for Ventilator-Assisted Living (www.post-polio.org/ivun/d.html).

Pulmonary function tests should include the following measurements. The values that indicate a warning sign for respiratory problems are in parentheses.

-VC — upright (<50%)
-VC — supine (a drop of >25% from upright to lying down)
-MIP — maximum inspiratory pressure (<60 cm H2O)
-MEP — maximum expiratory pressure (<60 cm H2O)
-peak expiratory cough flow (<300 L/min)
-end-tidal CO2 (>45 mm Hg)
-overnight oximetry may be prescribed to detect episodes of oxygen desaturation (<88% during sleep).

Management of breathing and sleep problems can be achieved largely through the use of nocturnal noninvasive ventilation, commonly in the form of small, lightweight bilevel positive pressure units. The units have a long tube/circuit that attaches to a mask (nasal, facial or oral), nasal pillows or mouthpiece worn during sleep. Polio survivors may find themselves gradually extending periods of ventilator use, perhaps during a daytime nap. Some polio survivors may need to use a volume ventilator to guarantee delivery of a larger volume of air than a bilevel unit can provide. Noninvasive ventilation may eventually fail, and invasive tracheostomy positive pressure may be necessary.

Treating underventilation with oxygen therapy instead of assisted ventilation can lead to respiratory failure and death because supplemental oxygen can blunt the function of the brain's respiratory control center. However, polio survivors who use assisted ventilation and have additional medical problems such as COPD, pneumonia or heart problems, or who are undertaking long airplane flights, may benefit from oxygen therapy under careful supervision.

Polio survivors may also have sleep apnea contributing to underventilation. Sleep apnea, an interruption of breathing during sleep, can be obstructive, central or mixed. Obstructive sleep apnea (OSA) is the most common form and is prevalent in the general population. The standard test for OSA is a sleep study; the standard treatment is the use of a continuous positive airway pressure (CPAP) unit with a nasal mask or nasal pillows during sleep. However, polio survivors with both weakened breathing muscles and sleep apnea should use bilevel positive pressure or volume ventilation, not CPAP.

Question: Why would my physician add oxygen to bilevel positive pressure ventilation, such as BiPAP®, if there is no underlying lung problem?

Answer: It would be extremely worthwhile to request that PHI members who use a ventilator due to post-polio breathing problems ask that their physicians explain their oxygen advice so we can all benefit, or at the very least develop a list of justifications that can be reviewed. The question is simple and can be stated, "The use of oxygen for people with neuromuscular disease without any lung disease or pneumonia is a subject of considerable interest, and some controversy. Please explain why oxygen is advised as part of my post-polio treatment plan." Send your physician's comments to PHI (editor@post-polio.org).

A physician might advise adding oxygen to BiPAP® when there is no underlying lung problem, if the person is traveling by air, where the air has a lesser concentration of oxygen. Another possibility is that the bilevel device is not satisfactorily set up and not adjusted from time to time. If that is the case, the oximetry or ABG oxygen saturation might be below 95% and the physician might prescribe oxygen. The advised response to this, of course, would be to increase the IPAP (inspiratory positive airway pressure) to improve ventilation, and then to re-check the oxygen level until it stayed at 95% or better while using ventilation.

Reliable small portable oximeters, such as the Nonin Onyx® 9500, can now be purchased on the Internet without a doctor's prescription. Having one at

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home to monitor assisted ventilation would allow minor adjustments of the IPAP as needed — if the treating physician agrees. Prices vary considerably on the Internet so search carefully. Most often an oximeter is not covered by health insurance. *(Edward Anthony Oppenheimer, MD, FCCP, Member of PHI's Medical Advisory Committee Pulmonary Medicine (Retired, consultation only), Los Angeles, California (eaopp@ucla.edu))*

Question: I am a polio survivor who uses a ventilator during the night. My physician wants me to undergo a colonoscopy, but I am worried about anesthesia for this procedure. Should I proceed?

Answer: A colonoscopy is an important test that can be performed safely on polio survivors who use assisted ventilation. In your case, I suggest a pulmonary evaluation before the procedure to document your respiratory reserve and a candid discussion with whomever is performing the colonoscopy. Sedation is needed because this procedure is uncomfortable. Usually a gastroenterologist does the colonoscopy with a nurse giving the sedation and supposedly monitoring the patient.

The colonoscopy should be done in a hospital (not an outpatient surgery center) with an anesthesiologist in attendance and administering the sedation. The procedure can be in the hospital's GI lab or in an operating room. The GI lab has adequate monitors; someone (the anesthesiologist) needs to watch you closely and to be careful with sedation. Afterward, you can be observed for respiratory problems in the regular recovery room and, if necessary, go to a "monitored" bed for an overnight stay — one night should be enough. You can bring and use your own home ventilator, just be sure this is discussed with the hospital staff ahead of time. I have received this question several times and after dispensing the above advice, I have not heard of any problems. *(Selma Harrison Calmes, MD, Member of PHI's Medical Advisory Committee Chair, Department of Anesthesiology, Olive View/UCLA Medical Center (shcmd@ucla.edu)*

Judith R. Fischer, MSLS,
Editor, Ventilator-Assisted Living,
and
Joan L. Headley, MS,
Editor, Post-Polio Health

RETURN UNDELIVERABLE CANADIAN ADDRESSES TO:

Saskatchewan Awareness of Post Polio
2310 Louise Ave.
Saskatoon, SK
S7J 2C7

email: rnsjohnson@sasktel.net

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