



Canadian Addison Society **La Société Canadienne d'Addison**

8 Francis Street, Brantford,
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1-519-751-4472

ISSUE NO.19

JANUARY 2000

Greetings from the office of the Canadian Addison Society:

I am writing to inform you all that effective immediately, the Canadian Addison Society has a new telephone number – listed under the Canadian Addison Society. The new telephone number is 519-751-4472 and we also have a newly purchased fax machine with its number 519-751-4473. For those that wish, please send along your fax numbers so that we can compile an address book of all those that we may need to contact and/or keep on file. We are all pleased with these changes and hope that we will be able to reach even more members and potential members than before. Thank you for all your support.

We also have more copies available of the Dutch report #1 and #2. They are \$25.00 EACH, which includes postage. Please contact Joan Southam at jsoutham@home.com or the Addison's Society at any of the above mentioned numbers to arrange for a copy of both/either of these most informative publications.

I would also like to thank you all for the lovely cards sent for the Addison's Society. Your thoughtfulness was appreciated.

Joan Southam

Happy New Year

President's Message:

Dear Fellow Addisonians,

I hope everyone had a pleasant, healthy Christmas and New Year. I want to thank all of you who came to the Brantford Meeting, or sent suggestions. I especially want to thank those who came to the business meeting and helped us by making decisions for our future.

I congratulate Angela Timms, our new vice-president, and thank Don Archi for being our replacement board member. Also Sybil Harrison who agreed to be our new Quebec rep. Congratulations to Lynda Daniels who has taken over as president for the Brantford group. I also want to thank Helene Perry for taking on the newsletter and thank you Francisca for the last year of the same.

May everyone enjoy the new Millennium.

Sincerely Greta

Canadian Addison Society Annual Meeting Brantford, Ontario November 20, 1999

Meeting opened at 11:00am

Present: Lois Bleth, Lynda Daniels, Greta Fraser, Sybil Harrison, Ruth Ann Kruger, Dianne, Helene Perry, Joan Southam, Isabelle Rathbun, and many others.

New Proposals: None

Agenda: Joan motioned, Sybil seconded it.

Recording Secretary: Angela Timms

Financial Report: Submitted by John Gordon. Approval to print; Joan motioned, Lois seconded

Items Discussed:

- Joan is resigning the Brantford Chairmanship. Lynda Daniels has graciously accepted new term.
- Sophie Lapointe resigned as Board Member. Don Archi has accepted position for coming year. Unanimous approval.
- Charitable status still being pursued. This is being handled mainly by Don Archi voluntarily, as time permits. When achieved, this will open many doors and privileges, permit sponsorships, and create a legal entity. Motion approved by Ruth Ann, seconded by Lynda.
- Name change to Canadian Adrenal Society has been delayed; it was felt we don't have enough expertise to handle it yet and should be included when we have charitable

- status. At that time the issue will be put to a general membership vote. This is not meant to exclude others; but we need experts to assess other conditions. (a) Isabel: leave as is. (b) Short Term motion put by Isabel, seconded by Ruth Ann. (c) Time limit closer to charitable status; vote then.
- Need for telephone and fax # for National Group. Motion by Lynda; seconded by Sybil. Unanimous vote; for 2000.
- Fax machine purchase to be made by Joan; Don Timms will supply at cost through Future Shop.
- Membership Dues. Joan proposed for new memberships and renewals, a fee of \$25.00. \$20.00 to go to the National Office and \$5.00 designated to go to an approved local group of one's choice. Seconded by Lois.
- Correspondence:
 - a) Neil Atwood of Australia has designed a professional quality emergency response card to include our logo and laminated at approximate cost of \$10.00, (exchange rate may alter this a bit.) He is offering this service to members at his cost. It is a one-time only card with basic instructions/meds etc. so no data base will be kept. For those interested, a "batch mailing" will be made May 1, 2000, so get your orders in to Joan. More info will follow in the next newsletter. Motioned by Lynda; seconded by Ruth Ann.
 - b) A letter by James Sadlish from the Victoria Group was read with his views and some thoughts on several of the proposed agenda items. Noted.
 - c) Cheque for \$102.20 from estate of Mary Chadwick has been received with thanks to the Canadian Addison Society.
 - d) Dorothy Frewing, a recently deceased member, was remembered to us by her daughter with a \$50.00 cheque. In a letter read to us, she expressed her mother's gratitude at having discovered our society and the realization that there were others like herself.
- Proposal by Greeta for a memorial plaque to be purchased with the names of deceased members, as a reminder of the deadliness of this disease. This will be displayed at annual meetings. Joan will source out details. Seconded by Ruth Ann.
- Newsletter will be handled for the time being by Helene Perry, a new member from Hamilton. We thank Francisca for her excellent work and wish her well. Motioned by Joan, seconded by Angela.
- Don Archi has resigned the Vice-presidency; post will be taken up by Angela Timms. Motioned by Joan and seconded.

Following is a copy of the financial statement for the Canadian Addison Society:

Canadian Addison Society

Statement of Income & Expenses For the Year Ending December 31, 1998 And the 10 Months Ending October 31, 1999

Cash in Bank	January 1, 1998 \$4,519.91	January 1, 1999 \$7,415.64
<u>Income</u>		
Dues Received	3,640.00	1,842.88
Donations	817.37	352.00
Book Sales	425.00	25.00
<u>Expenses</u>		
Books	411.87	292.16
International Dues	74.45	74.55
Postage, Stationary and Supplies	1,401.44	944.65
Travel – Guest Speaker	23.75	-
Memorial Donation	-	50.00
Bank Charges	<u>66.16</u>	<u>50.00</u>
Cash in Bank	December 31, 1998 <u>\$7,415.64</u>	October 31, 1999 <u>\$8,224.16</u>

From: Francisca Swist - Alberta Addison's Support Group:

Ginny LaValley from Morinville, Alberta was planning a trip to the US during December and investigated the health insurance possibilities. Most of the insurers would not cover her because of her pre-existing condition, (Addison's). Two of the insurers offered coverage only if her medication/dosage had not changed in the last six months. Blue Cross has a policy that covers those under 55 as long as the pre-existing condition was not cardio related, (angioplasty etc.). ***It may be wise to double check this information before leaving the country.***

On December 10/99, Francisca Swist of the Alberta Addison's Support Group spent 2½ hours at the University of Alberta with Dr. E. Toth, Endocrinologist and spoke to a total of 70 first year medical students about Addison's Disease. She explained her symptoms prior to diagnosis and then spoke about her current treatment. She also told

them about the need for doubling the medication when feeling ill as well as the occasional need for hospitalization for intravenous treatment when it is impossible to

take the medication orally. We hope by the time these students finish with med school, some of them will remember in case they see somebody with Addison's.

From: Jim Sadlish - Vancouver Island Support Group:

Marjorie Moulton, who is a Doctor of Traditional Chinese Medicine and a member of the Vancouver Island Support Group, has discovered a detailed article entitled, "Integrating the Traditional Chinese Understanding of the Kidneys into Western Herbals". This report focuses on the functions of the kidney-urinary system plus the endocrine systems and specially the adrenal glands. The article describes the prominent symptoms of imbalance and outlines beneficial herbal treatments for the improvement of affected systems. You may view this extensive report at the following web site: <http://www.acupuncture.com/Herbology/Kidney.htm>

Highlights From Local Meetings

Vancouver Island Support Group:

November 20/99

Room 1814, Victoria General Hospital
(12 people attended including 9 addisonians)

Two pharmacist, Vivian Leung and Anne Sawoniak, of St. Anthony's Clinic Pharmacy, presented a wealth of information, and answered a barrage of questions at the November 20th meeting. The group, which regularly shares endocrine tips and experiences, kept them busy for the two hour meeting and beyond. Just some of the topics included:

- Research on different timing and strength of doses of any one type of cortisone during a 24 hour period.
- Leveling total cortisone response by taking a long-acting type at one time of day and a short-acting type at another.
- Comparable potencies of different cortisone, (37.5mg cortisone acetate, 30mg hydrocortisone, 7.5mg prednisone, 1mg dexamethasone) and their potential side-effects.
- DHEA as an adrenocortical hormonal precursor to testosterone and estrogen and its current status as over-the-counter in the United States versus prohibited in Canada.
- Natural estrogen versus the synthetic equine estrogen generally prescribed.
- Pre-filled dexamethasone syringes; the pharmacists addressing the meeting have also tried talking with the manufacturer of these unavailable-in-Canada emergency products.

- The percentage of glucocorticoid and mineralocorticoid in any one type of cortisone replacement.
- Hypothyroidism in Addison's Disease, (Schmidt's Syndrome). It was noted that the body normally changes its thyroid hormones from one form to another, (T4 to T3, as required), and research is underway to change the amounts of these in current replacement pills to give better-timed response. It was also pointed out that thyroid pills should not be taken with cortisone, but later.
- Osteoporosis caused by glucocorticoids and the trend towards prevention. Points noted: There is a decrease in bone formation, requiring osteoblast cells, with an increase in bone breakdown. "Elemental" calcium is what benefits the body and this is what one should look for on labels of either calcium citrate or calcium carbonate. Calcium carbonate requires sufficient stomach acid to be useful, is not recommended for anyone prone to kidney stones, and some sources may have high levels of lead and other minerals. Calcium carbonate should be taken with food, but calcium citrate need not be. It was agreed that Tums® is one of the most refined, (least metal), of the cheaper, over-the-counter products for calcium carbonate. Vitamin D helps support intestinal absorption of calcium and prevents loss of it in the kidney; so helps build bone. Calcium decreases the amount of zinc in the body; so zinc supplementation may be advisable for hair, nails and skin. Fluoride stimulates production of bone, but in a weak form. Low daily doses of the product Fosamax are being studied as a potential preventative measure for osteoporosis. Post-menopausal women with Addison's need estrogen supplements to help prevent bone loss.

The next meeting of the group is scheduled at 1 p.m., Saturday, February 12, 2000, in Room 1814, Victoria Hospital. For more information, please call Jim Sadlish at 250-656-6270 or e-mail at wx699@victoria.tc.ca or Florence Weekes at 250-598-0321 or fmweekes@islandnet.com

Alberta Addison's Support Group: - October 23/99

Save-On Foods at Mayfield Common

(10 attended with one new person who saw the notice in the newspaper)

We decided to take a more informal approach to the meeting. The use of an emergency syringe was brought up by Colleen Lane who does carry a kit with her and has used it a couple of times – thereby saving a rush trip to the emergency. We had a nutritionist as a guest speaker. She handed out the Canada Food Guide and we went over some of the items in the guide and then took those of us who wished to go, on a tour – to learn how to read labels, (i.e. how much fat, etc.).

Ontario – Brantford and District Support Group: - November 20/99

Brantford Police Department – 37 In Attendance

The meeting was brought to order after a lunch break following the Canadian Addison Society Annual Meeting of that morning. It was opened with a brief introduction of ourselves and greetings to new members. Introduction of our guest speaker: Azim Gangji and Zabeen Hajiani, who are both pharmacists from West Street Day & Night Pharmacy in Brantford. Azim is also a physician, graduated from McMaster University.

The topic of discussion, which included a well done slide show, and was precluded by the basic physiology of Addison's Disease by Azim included:

- **Everyday maintenance of Addison's Disease**
- **The importance of the Medic-Alert bracelets or pendants**
- **Injectable dexamethasone, (subcutaneous or intra muscular) for emergencies**
- **Goals of current treatment:**
 - Lowest possible dose to relieve symptoms
 - Decrease of hyperpigmentation
 - Lower early morning fatigue
- **Newer Regimens:**
 - Trend towards longer-lasting steroids that "flatten out" some of the symptoms, i.e. Prednisone lasts 24 hrs; hydrocortisone 4-5 hrs.
 - Because cortisol levels start rising around 3:00am, the theory that larger doses should be given at night to peak around daybreak to more closely mimic body's own mechanisms.
 - Drawback to this is for some people it would keep them up at night. Solution to this is to have meds just prior to sleeping.
 - Advantage is that the meds would be slowing down towards night.
 - Best time for cortisol replacement is between 3-4am, (not a practical reality). Alternative is at bedtime.
 - With longer lasting meds, less dosing is required. Careful timing is essential. "Top ups" can be done with hydrocortisone.
- **Aims of Treatment:**
 - Prevent sodium loss – Fludrocortisone (Florinef)
 - Adequacy of treatment – Blood Pressure
 - Dose adjustments – i.e. summer, sweating
- **Adjustments:**
 - Increase during illness, surgery, pregnancy, minor procedures
 - Extent of illness and individual variation

- Usually dose is doubled; increase, whether this is sufficient or not and enough dosage
- **Adverse Effects of EXCESS Steroids:**
 - Obesity, high blood pressure
 - Skin, acne, bruising, facial hair (esp. in women)
 - Muscle, weakness
 - Bone, osteoporosis
 - Eyes, cataracts
 - Brain, depression, psychologically emotional
 - Gonads, impotence
 - Ovaries
 - Metabolism, Diabetes Mellitus, Kidney Stones
- **Interactions:**
 - Anti-inflammatory drugs
 - Estrogens increase effect
 - Oral hypoglycemia
 - Ketoconazole
- **Prognosis:**
 - Life expectancy is near normal under good management
 - Afterwards – other diseases like diabetes, heart, thyroid
 - Potassium levels must be kept good or this leads to cardiovascular problems
 - Steroids affect and decrease the effect of aspirin. Coated aspirin is better because of possible bleeding of the gut.

Questions were fielded and Azim very kindly answered our concerns. Thanks were expressed and a gift was given in appreciation by Joan.

The following article was written by Florence Weekes and is copyrighted to her and may not be reproduced in any form, including electronic, in whole or in part, without her written permission.

When Minutes Count, What Can We Count On?

The doctor was updating my prescription for a pre-filled emergency syringe of cortisone. "Always, carry it with you," he warned. "And if you go canoeing, tape it to your belly!" I started to laugh at the thought; then stopped abruptly as he added a terse, "I'm serious!"

It was 1969. I was sitting in the office of an endocrine specialist at the Mayo Clinic in Rochester, Minnesota, where they had diagnosed my primary Addison's disease the previous year. In primary Addison's, the outer part of the adrenal glands, the cortex, dies and stops producing the cortical hormones essential for life. In addition to a few

other essentials like oxygen and water, the body needs cortisones to cope with every kind of stress, physical, mental and emotional, and to meet every call for energy, be it major surgery, family tragedy, or “simpler” things like fasting, keeping warm or cool - or just staying alive in a coma.

At the Clinic, they educated me about my then-rarely-diagnosed condition and prescribed not only daily pills but also a pre-filled, ready-with-one-poke, syringe of emergency medicine (dexamethasone, a potent form of cortisone). The physician who mentioned canoeing was referring to the outdoor life I led then, monitoring bald-eagle nests, generally alone. Another warned that a major stress (such as a tree falling and breaking my leg) that would be “serious for a normal person could be fatal for me within 15-20 minutes without an immediate large dose of cortisone.

Diligently, I carried pre-filled dexamethasone syringes in my backpack, on my belt, in my purse, in my car. They were small, sturdy, easy to carry. Once during a stand-off with an angry fox I did wonder if I could grab the one-poke syringe in time, but we managed an uneasy truce and I didn't need it. Another time, when I injured my leg skiing, I was able to take pills from my pocket and scoop up snow to help swallow them. The pre-filled syringes were like life jackets or fire extinguishers, something one hopes never to use but dare not be without. Now I can't get them anymore because I moved back to Canada and my original prescription has long since run out. I understand that even in the U.S. they are often hard to find.

So far, neither I nor any of my Canadian Addisonian associates have been able to convince a Canadian pharmaceutical company to make or import these pre-filled syringes. Even though Addison's is better known and more often diagnosed these days, we are still too-few to present a profitable market. So they remain unavailable - and in most cases even unheard of. Oh, there is a so-called pre-filled syringe of hydrocortisone available, but it is a mockery compared to the quick response of the ready-aye-ready dexamethasone expedient. It is bigger and more fragile; so is inconvenient to carry and a worry to break. Worse, the hydrocortisone comes in a crystal that must be mixed with solution before it can be injected. The syringe has an hour-glass shape, with the crystal in one section and fluid in the other. This might do if another person were right there, knowledgeable about Addison's, practiced in mixing such drugs, willing and able to inject them without instruction or delay. Or if the patient herself could do it all. That is not the way of Addisonian crisis. As one physician explained, if a body runs out of cortisone, it is “like turning off a light.” If energy delivery stops, you're dead. When a stressed Addisonian slides toward crisis, his or her mental capacity drops as precipitously as does physical capacity. Believe me, I've been there. I'm not normally “mentally challenged,” (they even let me into Mensa); with even a small amount of energy left, I might stand a reasonable chance of being able to make the necessary decision, jab myself with a needle and press a plunger. Or, with less trauma and more time, I might perform the mix-it-up routine. But even a few minutes delay in an

emergency while I tried to remember how to mix the two parts of the syringe and attempted to do it, or struggled to explain the procedure to someone else, could be too much. The syringes I bought most recently in the United States were made by Organon in New Jersey. (Years ago, I had some from another company but it discontinued them.) Mine are sturdy enough that in all the years I carried them one never broke or leaked. The fluid remains clear after their printed expiry dates. Each holds 1.0 milliliters Dexamethasone Sodium Phosphate (USP) (strength, 4 milligrams per milliliter), marketed as HEXADROL®. The barrel is marked so you can use 0.5ml and save the other 0.5ml for later if you wish. With the plunger up and including the rubber-sheathed needle, these are its approximate measurements. Length is just under 12 centimeters (4¾ inches). The barrel is one centimeter (just under half -inch) in diameter. The widest part, at 1.75cm (a bit under 3/4th inch) is the flange at the top of the barrel (to stop the plunger when you push it down to eject the solution). The syringe fits easily into a toothbrush holder, with room for an alcohol wipe and instructions if you roll them around it. (Though if I really needed the stuff I wouldn't worry overmuch about an alcohol wipe!) Canadian pharmacies do sell vials (not syringes) of injectable cortisone; they are routinely on hand in hospital emergency rooms. I tried these, using needles and syringes normally sold for insulin. The syringes were too big, the needles too small but they were all I could get. The smallest vial available held five milliliters, which I proposed to decant into five emergency doses. A simple task? Hah. First you are supposed to turn the vial upside down; then poke in the needle from below (through a thin rubber top-capping); then push in the plunger to eject the air from the syringe; then draw back the plunger to pull out the required one milliliter; then remove the needle from the vial and cap it. So far, so good. When you try to repeat the procedure for the next syringe, trouble starts. You turn the vial upside down and poke in the second needle, making a new hole in the rubber (the first punch-hole is there but invisible). You push in the plunger to clear the air from the syringe - and the pressure starts forcing out fluid through the first hole you made in the rubber capping. It dribbles down your fingers. You take a fresh syringe and try pushing out the air before you insert the needle into the vial. You try to withdraw solution but without that additional air in there you're just creating a vacuum. You keep experimenting but soon the fluid/air balance is all off, the rubber capping is full of holes, you're wet to your elbows and you have, at most, 2 filled syringes that are maybe sterile and maybe not and that look like too much trouble to carry anyway.

One Canadian pharmacy that enquired, without apparent success, into importing the pre-filled syringes reckoned they would have to retail at \$27 Canadian each, or \$81 for three. My last order of the three from the United States cost, in U.S. funds, \$9.86. At current foreign exchange rates, that would be around \$14.50 Canadian. Go figure. Some doctors say pre-filled syringes are unnecessary if you live within driving distance of a hospital, but this assumes everybody knows all about Addison's and will deal with it quickly and appropriately. That is, unfortunately, an overly-optimistic assumption, and another story.

***LET'S HEAR IT FOR
LIFE:***



In order to maintain a well-balanced perspective, the person who has a dog to worship him should also have a cat to ignore him.

---Peterborough Examiner

No man knows his true character until he has run out of gas, purchased something on the installment plan, and raised an adolescent.

*Edna McCann
The Heritage Book 1985*

Easy/Healthy Corn Meal Muffins:

Preheat oven to 400 degrees

Blend or sift together:
ingredients.

7/8 cup sifted all-purpose flour

1/4 cup sugar

4 teaspoons baking powder

fat)

3/4 teaspoon salt



Blend in 1 cup of corn meal

Make a well in center of dry

Combine and add:

1 beaten egg

1 cup of milk (skim if watching

1/4 cup vegetable oil

Stir only until combined. (The batter should be lumpy.) Fill greased muffin cups two-thirds full. Bake in preheated 400 degree oven for 20 to 25 minutes.

Yield: 10 medium-sized muffins.

Delicious served warm with butter or margarine for a mid-morning pick-up. Great source of fiber.