



# **The Canadian Addison Society** **La Société canadienne d'Addison**

193 Elgin Avenue West

Goderich, Ontario N7A 2E7

Toll free number: 1-888-550-5582

Email: [liaisonsecretary@addisonsociety.ca](mailto:liaisonsecretary@addisonsociety.ca)

<http://www.addisonsociety.ca>

---

**ISSUE NO. 53**

**JANUARY 2009**

---

## **In this issue:**

---

- President's Message
- 2008 Annual General Meeting: Q and A with Dr. Richard Phillips
- Announcements
- Personal Experiences
- Highlights from Local Meetings
- Medical Q & A
- 2008 Financial Statements
- Membership Renewal Form

**PLEASE NOTE:** The content of this newsletter is intended for basic information only and not as personal medical advice. Readers are advised to consult their own doctors before making changes to their Addison management program.

---

## ***Reminder:***

---

***It is now time to renew your membership for 2009 (see attached form). Your membership is very important to allow the Society to continue to function, hold local meetings and produce this newsletter. Please – take a moment immediately and send in your dues of \$25.00.***

***Thank you from all of us.***

\*\*\*\*

---

## **President's Message:**

---

I would like to thank Athena Elton for holding the position of President for the past two years, John and Irene for all their diligence as Treasurer and Secretary/Webmaster, Patricia Hehner for the doing such an excellent job as Editor and those who took positions of office for 2009. Without all your time and effort the Canadian Addison Society could not function.

This year, as in the past, the need for a standardized emergency room protocol for each province needs pursuing. The success of Ginny Snaychuck in AB shows us that it can be done.

Members are looking into fundraising for research on Addison's Disease - a topic that frequently arises at local meetings. No fundraising is being done in Canada at the moment but hopefully we will be able to initiate interest in a project.

Thanks also go to two BC teenagers who took the initiative and started a Face Book page for young people with Addison's. The forum has youth from around the world participating. It lets them interact and discuss their condition, which takes away the feeling of isolation that even we as adults can appreciate.

And to everyone a healthy 2009!

Judythe Stanley

---

## **Annual General Meeting: Q and A with Dr. Richard Phillips**

---

The guest speaker at our 2008 AGM guest speaker was Dr. Richard Phillips, a Victoria clinical endocrinologist, who did his training at the University of Alberta. Dr. Phillips structured his talk around a series of questions.

*How long does it take for cortisone acetate to be converted by the liver into cortisol? I just had a molar removed by a dentist and had no idea how far ahead I needed to increase the cortisone acetate to be effective for the surgery.*

Cortisone acetate was one of the first glucocorticoids used in the 1950's. Both cortisone acetate and prednisone are pro-drugs, which need to be converted in the liver into the active drugs hydrocortisone (cortisol) and prednisolone respectively using a conversion enzyme. Although there is no answer in the literature that I could find on how long this conversion takes, it is likely very quick. The delay occurs in the ingestion of the drugs through the digestive tract. As well, there are individual variations with respect to the activity of the enzyme.

In secondary Addisons (where growth hormone may be deficient), the enzyme necessary for conversion may be hyperactive, which would make the conversion quicker. If someone were on growth hormone replacement, this would slow the conversion, potentially bringing on

....

Addisonian symptoms. A few people may lack the enzyme for conversion, but this would be extraordinarily rare.

Before dental surgery, take a double dose whether it is cortisone acetate or prednisone or cortef.

*How do you monitor glucocorticoid sufficiency?*

There is no lab test for this. It is best determined through clinical observation. How do you feel? If levels are insufficient, the Addisonian will have some (or all) of the usual symptoms (fatigue, appetite, nausea, weight loss, aches and pains, emotional impacts). If levels are too high, there is usually weight gain, the person will have full cheeks, and may bruise easily (especially on the forearms).

*Why is it so difficult to get the dose right?*

We can never truly mimic the body's normal physiology. When you take your hydrocortisone, the levels rise quickly in the blood and the hydrocortisone binds to the CBG (Corticosteroid Binding Globulin) in the blood. The CBG is quickly saturated, and excess is then present as 'free cortisol' and rapidly excreted in the urine. To more closely mimic natural physiology, it is helpful to take smaller doses more often, such that the CBG binds to the hydrocortisone and then rebinds to the next small dose, giving more cortisol exposure within the body.

Prednisone and dexamethasone are both longer acting synthetic steroids. They bind more weakly to CBG and therefore the exposure in the body is different than for hydrocortisone. Each person may feel best on a different drug – there is no right drug and no lab tests; it takes trial and error to determine what is best for each individual. Different glucocorticoids for different people, and different doses for different people.

*What is the relation of primary immunodeficiency to Addisons?*

There is no direct link between primary immunodeficiency and Addisons. The cause of Addisons in the majority of primary Addisonians is autoimmune.

Polyglandular autoimmune syndrome type I is associated with candidiasis, hypoparathyroidism, and Addisons. It involves the mutation a single gene: AIRE (autoimmune regulator).

Polyglandular autoimmune syndrome type II (Schmidt's syndrome): The individual has autoimmune Addisons and thyroid disease and/or diabetes type 1, and may also involve premature ovarian failure and/or vitiligo and/or pernicious anemia. Often, they carry the HLA genotype (a specific part of a chromosome), which is what recognizes self as self or as a foreign invader (HLA needs to match for a successful organ transplant). However, it is possible to have Schmidt's without this genotype, or to have this genotype and not develop Schmidt's.

....

Since it takes millennia for genes to change, yet there has been a great increase recently in autoimmune problems, such as thyroid and diabetes, there may well be environmental factors implicated.

*Can you explain the role of DHEA in our system and how the lack of DHEA can affect those with Addison's disease?*

The science of hormone replacement and regulation is still very basic.

We know the role of DHEA in the fetus and at puberty, its role in adults is not clear. In a fetus, the adrenal glands are larger than the kidneys. The fetus pumps out large amounts of DHEA in utero, which cross the placenta and is converted to estrogen in the mother, which is necessary to support the pregnancy. Indeed, the majority of the rise in estrogen in pregnant women comes from the fetus. DHEA levels in humans are then very low until puberty, when levels increase and cause the growth of pubic hair. In young adults, DHEA levels are high; indeed, it is created in greater amounts than cortisol or aldosterone. Levels in adults diminish over time, as do the levels of many hormones. Males have sufficient androgens as they make testosterone, and thus seem to need less DHEA. Females need DHEA to provide the necessary androgens. A sign of insufficient adrenal function in women is often a thinning of pubic hair.

DHEA seems to play a role in quality of life, libido, and mood. However, the results of studies are still unclear, and we do not routinely recommend the use of DHEA. We may recommend DHEA if both gluco- and minerocorticoids are optimized, yet quality of life, libido or mood is still an issue, starting at 25 mg a day up to a maximum of 50 mg a day. Currently, the DHEA on the market is not pharmaceutical grade, and, as it is not regulated, there is no quality control.

DHEA in men increases estradiol levels; in women, it increases testosterone levels. DHEA may be implicated in breast cancer in women. As well, if someone takes DHEA and tries to mimic the levels of a 20-year old woman, what is the impact on a 60-year old woman? This would not mimic the levels of nature.

*I am older, have Addisons, and am very fatigued with various other medical issues. How do I know if these are due to Addisons? Extra cortisone doesn't seem to help.*

If quality of life is lower for an Addisonian, how do we know if these other symptoms are caused by Addisons or by other issues? Even when well regulated, an Addisonians' quality of life will be lower than before Addisons, as there are limitations to our replacement therapy. Taking excessive replacement cortisone brings on its own problems. Other sources of the fatigue should also be looked at. Since Addisons is frequently associated with thyroid issues, celiac disease and B12 deficiency, it is worth having these checked out.

*Can you take too much B12?*

Not really. B12 is very safe. B12 levels may be high yet you're not on supplements. A B12

....

blood test actually tests transcobalamin, which transports B12. So, if transcobalamin levels are high, it may show as if B12 levels are high. These are reflections of the transport protein not necessarily the B12 levels. These are not diseases per se, simply individual differences in the carrier protein levels. These are not detrimental.

*Are there special difficulties coping with Addisons and diabetes type 1?*

Yes. Addisonians must take a glucocorticoid to control the Addisons. This will make control of the diabetes much more difficult. When you take your medication in the morning, this raises glucocorticoid levels above normal physiological levels. This will affect your insulin sensitivity. Your insulin will not be as effective when your cortisone levels are a little high as compared to when they are a little low. When your cortisol levels are a bit high, you require more insulin. When your cortisone levels are dropping, you are more prone to hypoglycemia. Addisons makes type 1 diabetes hard to control. You must be on modern insulin regimen (rapid acting insulin analogues, more with earlier meals, cautious about background insulin levels). It is easier to become hypoglycemic when glucocorticoid levels drop overnight.

*What is the impact of Addisons on adrenaline?*

If the cortex of the adrenals is not producing cortisol, then the medulla produces less adrenaline. The adrenal medulla needs cortisol locally produced to convert noradrenaline to adrenaline. While most of the adrenaline in the system is derived from nerve synapses (nerve endings) from noradrenaline, Addisonians are low on the form of adrenaline produced in the medulla. And this contributes to Addisonians' inability to respond to stress.

*What is the impact of Addisons on life expectancy?*

With proper patient education, there need not be an impact. However, there are implications since Addisonians cannot mount a stress response to things such as pneumonia, infection, etc. If this is controlled, it shouldn't affect life expectancy. If stress is not handled properly, it can lead to cardiovascular collapse and shock, caused by low blood pressure, caused by insufficient cortisol.

If run-down, fatigued, or ill from a cold or flu, double or triple your cortisone dose for 2-3 days. If you can't keep fluids down, you will need IV medication and fluids from a hospital. Every Addisonian should also have an emergency kit with IM (intramuscular) cortisone.

There is no need to increase Florinef for management of sick days unless suffering from diarrhea. You may need to increase Florinef if sweating profusely (ex. extremely hot weather). Addisonians often take different doses of Florinef depending on whether it is summer or winter.

If undergoing radiation or chemotherapy, you will need to increase your glucocorticoid to deal with both the physical and emotional stress, especially if suffering from nausea.

*Will glucocorticoid cause immunocompromise?*

....

Glucocorticoids will not cause immunocompromise if on a physiological dose. It's only if you are on too much that there will be increased risk of infection. One of the responses to overwhelming infection is increased cortisol production, to prevent the immune system from harming you. Cortisol dampens the immune response so that the body can fight infection but not kill the host. So too much glucocorticoid affects cell mediated immunity. When Addisonians get certain infections (ex. MRSA), it can be hard to find ways to contain the infection in balance with the glucocorticoid, i.e. such that the glucocorticoid does not prevent the antibiotic from working.

### *What about day-curves?*

These are common in the UK, but not in Canada. A study from Birmingham compared day-curves to clinical assessment and found the day-curve offered no advantages.

### *What about Chronocort?*

Chronocort is a new drug under development which hopes to provide slow or sustained release glucocorticoid to better mimic the body's natural release of cortisol. The company is hoping for approvals in 2010.

### *Do Addisonians have a predisposition to celiac disease and pernicious anemia?*

People may be born with a predisposition for Addisons and may also have a predisposition for other autoimmune diseases, such as celiac disease, pernicious anemia, thyroid disease, pituitary issues, etc. If you have untreated celiac disease, absorption of medications for the Addisons may be suboptimal.

### *Addisons and sleep disorders?*

Addisonians are more likely to have sleep disorders. Addisonians sleep a lot. If you have trouble sleeping, try taking your last dose earlier in the day. Others may take their dose during the night. Those on Dexamethasone may take it late at night as its absorption and metabolism is different than cortef. Play around and find what works best for you.

### *Standard lab work for an Addisonian?*

- Sodium
- Potassium
- Plasma renin
- TSH (thyroid)
- Fasting glucose
- B12
- TTG antibody to check for celiac, every 5 years

....

### *What causes autoimmune?*

We don't know. Autoimmune simply means that the body attacks itself. The immune cells of the body all go through the thymus, which is where the cells learn to recognize 'self', what is host, what is not, and to attack foreign cells, not self. Autoimmune means lack of tolerance to self; something happened in the programming of immune cells in teaching them to leave self alone.

---

## **Announcements:**

---

- Annual **membership dues of \$25.00** for 2009 are due in **January 2009**. Please use the form attached to this newsletter to renew your membership.
- A member in Eastern Ontario who has an eight-year-old son recently diagnosed with Addison's would like to be in touch with parents of an Addisonian child – for mutual support and advice. If you can help, please contact [varcoe\\_rediker@hotmail.com](mailto:varcoe_rediker@hotmail.com).
- We regret to inform you that Florence Weekes, a founding member of the Vancouver Island support group, passed away in November 2008. Our condolences go out to her family and friends.
- Charlotte Ciccanti, past member of the B.C. Lower Mainland group, passed away January 2009. Charlotte attended meetings regularly from 1997 to 2003. Our sympathy goes out to her family.

---

## **Personal Experiences:**

---

I had been suffering from weakness, fatigue, vomiting, loss of appetite, dark tan, weight loss, pain in legs and shoulders, craving for anything salty and not being able to stand which made shopping impossible. This went on for four months. My doctor thought I might have stomach cancer and made the necessary appointments. I must say at this stage the doctor had carried out loads of tests but could not find anything wrong.

One morning, I tried to get out of bed and it was very difficult. I managed to get to my computer and sat there most of the day trying to find out what was wrong with me. In the end, out of desperation, I typed in all of my symptoms and up came Addison's disease. I saw my doctor immediately and the first thing she did was look at the inside of my hands which had brown lines. I was admitted to hospital for 9 days after seeing an endocrinologist, and am taking hydrocortisone and flurinef and things have improved greatly.

Submitted by M Marley, U.K.

\*\*\*\*\*

After diagnosis in 1992, I was on 37.5 mg of cortisone acetate and .05 mg of Florinef daily. Over the years, I had a lot of difficulty with fainting, and tried varying amounts of the Florinef.

....

Alternating 0.1 mg (Mon, Wed, Fri and Sun) with 0.05 mg (Tues Thurs and Sat) worked the best.

Last winter, my new endocrinologist switched me to hydrocortisone, 30 mg per day. That was too much. My face bloated, I gained weight, felt sluggish and had "grey fog". Because there is some of the fludrocortisone in the Cortef, the dose of Florinef was also high. After trying different amounts, I am now taking 20 mg of Cortef (15 on rising and 5 in late afternoon) and am back to 0.05 mg of Florinef daily. I generally feel much better and my mind is clear.

We are monitoring the Cortef (since it can be measured in the blood, it is much easier to test than cortisone acetate) as some days I get very tired.

Submitted by M. Thauberger

\*\*\*\*\*

I was diagnosed with Addison Disease in November 2008. In May 2008, I was admitted to the hospital for 3 weeks with severe vomiting and diarrhea, thought to be food poisoning. I received 18 I.V. bags in a matter of 2 days or so. I didn't know the date or year; apparently I even started talking with a foreign accent. I was diagnosed with a thyroid gland problem. In the autumn, I was admitted for a second time. I was unable to walk on my own, see straight, was dizzy, with stomach ache...etc. I felt like a train had hit me. After two weeks of tests – scopes, blood tests, I.V. the whole nine yards – it was diagnosed as either Addisons or Celiac Disease. Finally, it was determined to be Addisons Disease. I'm taking medication to balance my body's needs. All I know is the last week and a half, I feel like a new person – like I have been given a second chance at my life, with my wife and daughter. I'm new at this, and I am learning.

Submitted by C Telfer

---

## **Highlights from Local Meetings:**

---

### **Vancouver Island Support Group**

The Vancouver Island support group will meet 3 times during 2009 at the Victoria General Hospital:

- **February 14**, in the Lecture Hall, from 1:00 until 3:00 PM
- May 30, in Room 1814 by the Cafeteria, from 1:00 until 3:00 PM
- October 3, in Room 1814 by the Cafeteria, from 1:00 until 3:00 PM

For further information or to contact the Vancouver Island Support Group, please contact Jim Sadlish at [wx6999@gmail.com](mailto:wx6999@gmail.com) or (250) 656-6270. For information on Central Island activities, please contact Barbara Hunn at [bhunn@shaw.ca](mailto:bhunn@shaw.ca) or (250) 714-0036, or Sharon Erickson at [ericksons@shaw.ca](mailto:ericksons@shaw.ca).

....

## **BC Lower Mainland Support Group**

Thanks to Marilyn for making arrangements with Dr. Agnieszka Zelichowska MD FRCPC, our guest speaker at the Sept. 29 meeting. For full context and/or the presentation with overheads of the meeting, please email Judy Stanley from the Society website – BC Lower Mainland Group.

### *Illness or Surgery:*

In someone without Addison's, cortisol secretion increases with the stress of illness and for surgery. So the usual clinical practice is to give higher doses of glucocorticoid to patients with adrenal insufficiency in these situations. Unfortunately, there is little information about how much additional glucocorticoid is needed.

“Doubling Up” during Illness: What does it mean exactly?

Ex: If on Hydrocortisone 15 mg in am/5 mg in pm - then increase to 30 mg in am/10 mg in pm. You do not double up on Florinef.

Q. How long to double up for?

A. Generally 3 days and then back to usual dose if not improving in 3 days à seek medical help.

Q. What is considered an illness?

A. Cold, flu, gastrointestinal illness.

Q. What about emotional stress?

A. No clear guidelines, but I think it is reasonable if severe stress (death of loved one)

Q. Unusual physical activity?

A. Usually no, but keep up with fluids

Surgery: Mineralocorticoid does not need to be increased during surgery if IV hydrocortisone is used at high doses. I usually omit the Florinef those days because hydrocortisone has some mineralocorticoid activity.

Minor procedures: an extra dose hydrocortisone 25 mg is suggested for the day of procedure; return to the usual replacement dose on the second day.

Moderate surgery: IV/oral doses hydrocortisone 50 to 75 mg are suggested on the day of surgery, and the first post-operative day.

Major surgery: IV 150 mg hydrocortisone for 2-3 days, then return to usual dose or days 2 and 3 use 50% of surgery day.

### Chemotherapy and Radiation Therapy

Q.: What adjustments, if any, are needed for our medications when we undergo these treatments for cancer?

A: It depends...some chemotherapies have steroid as part of the regimen – so may actually decrease glucocorticoid. Chemotherapy/Radiation weaken immune system therefore more prone to infections, therefore, I would hesitate to increase glucocorticoids

....

### *Menstrual Cycle and Cortisol*

Q: Does a body normally produce more cortisone when a female has her period?

A: Yes - Normally there is a small rise in cortisol just before ovulation. Could not find any literature if this should be mimicked in women with Addison's disease.

### *Menopause and Cortisol:*

Q: Recently my Husband read/heard something about the menopause & increased adrenal activity during this period. He thinks it was in a Mayo Clinic report. Is there any fact to that issue?

A: Yes, around the transition to menopause some studies showed increased cortisol for about 5 months in some women.

Q: If so, it may explain my extreme external body heat?

A: Women with increased cortisol had more severe hot flashes than those women without changes; there was no difference in age, weight, levels of estrogen, exercise, mood, sleep or stress levels.

### *Cortisol and Digestion:*

Q: I find that following a meal I usually feel extremely tired and like to lie down for a short period. It was suggested to me that perhaps it is because much energy (i.e. cortisol) is required to digest the food, thus weakening the rest of me. My family physician has checked out Celiac Disease, and it is negative.

A: High or low blood sugars post-eating, Low blood pressure post-eating, Malabsorption.

### *Adrenoleukodystrophy (ALD):*

Genetic disorders that cause damage to the myelin sheath, an insulating membrane that surrounds nerve cells in the brain, high levels of saturated, very long chain fatty acids (VLCFA) in the brain and adrenal cortex because they do not produce the enzyme that breaks down these fatty acids. The most common form is the X-linked form of the abnormal gene which is located on the X-chromosome. Women have two X-chromosomes and are the carriers of the disease. Since men only have one X-chromosome and lack the protective effect of the extra X-chromosome

Clinical Symptoms of ALD: Onset between ages 4 and 10

Most common symptoms: abnormal withdrawal or aggression; Learning disabilities; visual loss; seizures; difficulty swallowing, deafness, coordination, fatigue, nausea/vomiting, increased skin pigmentation

Q: Testing for ALD: Is there routine testing done on boys at birth for this disorder?

A: Blood VLCFAs tests should be done in all boys with adrenal insufficiency but no adrenal auto-antibodies.

....

Treatment of ALD: Corticosteroid is essential in those with adrenal insufficiency; Diet: Lorenzo's oil – little benefit; Lovastatin (cholesterol lowering medication) - some benefit but a bit controversial, bone marrow transplant or gene therapy - experimental

Q: Does having Addison's disease increase risk for (grand) children, siblings?

A: It depends on the cause: if cause of Addison's disease is bleeding into the adrenals, tuberculosis, medications, cancer spreading to adrenals, then no. If cause of Addison's disease is due to antibody destruction (most common cause in North America), then yes.

Submitted by Judy Stanley

The next meeting will be **February 21**, 2009, 1:00 pm in the Sherbrooke Lounge, Sherbrook Centre, 260 Sherbrooke St. New Westminster BC. Our guest will be Nana Osei, a Public Health Inspector, speaking to us on food safety, specifically issues for those with challenged immune systems, food-borne illnesses, travel, food recalls and advisories, endocrine inhibitors, etc.

Our ongoing 'Advocacy for Addison's' will have members participating in interviews with 1st year medical students who will present their findings as part of their curriculum. Interviews will take place late February/March.

For further information on this support group or any upcoming meetings, contact Judy Stanley, (604) 936-6694 or [bugbee@shaw.ca](mailto:bugbee@shaw.ca).

### **Alberta Support Group**

For information on this support group, contact Ginny Snaychuk at [ginray@shaw.ca](mailto:ginray@shaw.ca) or (780) 454-3866 in Edmonton.

### **Saskatchewan Support Group**

For information on this support group, contact Elizabeth Hill at (306) 236-5483 [kesahill@sasktel.net](mailto:kesahill@sasktel.net) or [elizabeth.h@pnrha.ca](mailto:elizabeth.h@pnrha.ca).

### **Southern Ontario Support Group**

We had terrific attendance at our meeting in Mississauga in November 2008, with a total of 30 people. The addition of a Mississauga location for some of our meetings has given those members who can't get to Brantford a chance to attend at least one meeting a year. Our thanks to everyone who helped organize this meeting. Thanks to our Volunteer Drivers who made it possible for two members in Toronto to attend.

A member in the Acton area is looking for a drive to the May 2009 meeting.

\*\*\*\*

Welcome to Melanie Keezer, who learned of the meeting from a posting we placed on the Facebook site just a week before the meeting. The Facebook site was started by Aleita Northey in British Columbia.

A round of self-introductions followed, and I would like to thank all members for their willingness to reveal medical details. Hearing how others are dealing with issues can often help us with our own issues.

John Gordon, Treasurer, presented a report on the AGM, a Financial Report, and the new membership card. All members are reminded to submit their \$25 membership for 2009.

Our Guest Speaker, Dr. Stan Van Uum, is an Assistant Professor, Department of Medicine, U of Western Ontario, London, Ontario, and has a practice located in London. Joining him was Rachel Gow, an MSc candidate at the University.

Rachel is studying cortisol levels in hair. This will eventually develop into a research study to which Addisonians may be able to contribute by submitting hair samples. We will hear about it in due course. We will also be made aware of the results of the study and learn what practical application for Addisonians may come from the results. Hair is already used for tests for nicotine, estrogen, mercury, sedatives, etc. Hair grows approximately 1 centimetre per month and retains the information with respect to cortisol levels that existed in the body during that period. Thus, the longer the length of hair sample, the further back in time one can identify the cortisol levels

Dr. Van Uum and Rachel Gow also gave a structured presentation with a lengthy question and answer period. The comments below should not be taken as medical advice; however, they may help you formulate questions to discuss with our individual doctors:

- while cortisol is produced by the adrenal glands, it is controlled by the brain (hypothalamus, pituitary)
- cortisol regulates blood pressure, has a role in response to stress, regulates carbohydrates, helps in control of inflammation
- difficulties in diagnosis of Addison's
- not uncommon to have related autoimmune diseases
- be aware that other conditions may occur such as B12 deficiency, hypothyroid, to name a couple
- Correct cortisol dose was discussed and of course the outcome is that there is not one answer. It depends on weight, how we feel, etc. Some discussion revolved around the idea of comparing cortisol levels with those of family members when looking to find the right dose. Bottom line is that there is no simple answer.
- compounding pharmacies are a means to get a specific dose preparation if it is not readily available at your regular pharmacy.
- we will get quicker absorption of our steroids without food.
- cortisone suppositories are a possibility instead of an injection in an emergency.

\*\*\*\*

- one member told of having a crisis on an airplane and was lucky that a Doctor was on board but an emergency landing was still required. It was suggested that the Society write a letter to Airlines asking that Solu-cortef be kept on board for such emergencies. Dr. Van Uum would consider also writing such a letter. *(Editor's note: It is highly recommended that every Addisonian have an emergency kit with solu-cortef for just such circumstances. The Addisonian has the responsibility to carry emergency medication, which could then be used on airplanes, in trains, in restaurants, or wherever the crisis occurs. For more information on emergency kits, please see our website at <http://www.addisonsociety.ca> - Emergency Procedures and Injection Kit.)*
- 100mg cortisone injection will buy you about 8 hours. If stuck in a long wait at emergency and suffering vomiting and/or diarrhea you may choose to inject yourself to buy that time.
- If flying, be sure you have a letter re Addison's and carry the Injection Kit with you in your carry-on baggage.
- it is possible to have an Addisonian crisis happen once per year. More often might suggest something else is going on - such as hyperthyroid problems, etc. Possibly the steroid dose should be re-evaluated.
- B12 deficiency can result in anemia and/or possible nerve damage. We are susceptible to B12 deficiency particularly if we have 2 or more autoimmune conditions such as Addison's, hypothyroid, diabetes mellitus. B12 screening every two years is recommended.
- The issue of refrigeration of Florinef was discussed very briefly. Dr. Van Uum considers steroids very stable and refrigeration should not be a major concern.
- Take vitamins separate from prescription meds by at least a half-hour. Meds in AM and vitamins in PM was another recommendation where possible.
- Advancing age is not normally considered a reason for our Addisons to change. If it is getting worse with age, it may be a secondary situation developing.
- grey fog in head usually suggests too high cortisol level.
- avoid licorice
- stress may be physical or mental - know how to respond with medication - find the minimum level that works for you.
- Addison's is probably under-estimated and/or under-diagnosed.

Submitted by Harold Smith and Jennifer Kerr

The meetings for 2009 for the Southern Ontario Support Group

- **May 9, 2009** in Mississauga (Erin Mills United Church location to be confirmed).
- October 3, 2009 in Brantford at the Elgin Street Police Station. Please note that the Brantford meeting will also be the Annual General Meeting.

For further information on Southern Ontario Support Group activities or meetings, contact Harold Smith at [hsmith9995@rogers.com](mailto:hsmith9995@rogers.com) or (519) 742-9995.

....

### **Eastern Ontario Support Group**

The next meeting will be held Saturday, **May 9**, 2009, at noon, at Robbie's Restaurant, St. Laurent Blvd, Ottawa, Ontario.

The Eastern Ontario group is looking for someone to act as contact, and to organize future meetings. If you can volunteer, so that our meetings may continue, please contact the Liaison Secretary at [liaisonsecretary@addisonsociety.ca](mailto:liaisonsecretary@addisonsociety.ca) or at the national address shown on the front of this Newsletter.

### **Québec Support Group**

If you wish to start a local group in the area, please contact the Liaison Secretary at [liaisonsecretary@addisonsociety.ca](mailto:liaisonsecretary@addisonsociety.ca) or at the national address shown on the front of this Newsletter.

### **Atlantic Support Group**

The Atlantic Canada Support Group is looking for a volunteer to act as contact point. If you can do this, please contact the Liaison Secretary at [liaisonsecretary@addisonsociety.ca](mailto:liaisonsecretary@addisonsociety.ca) or at the national address shown on the front of this Newsletter.

---

## **Medical Q & A**

---

There is now a very large and wide-ranging set of questions on both daily living and very situation-specific issues that have been answered by our medical advisor. To review these questions, please go to the Canadian Addison Society website under Education (<http://www.addisonsociety.ca/faq.html>), or see previous issues of the newsletter.

**Q:** My calves are discoloured with splotchy dark pigmentation, like a dark splotchy tan. My skin is very thin and I bleed/bruise very easily. Is it the steroids that cause this, or is it the Addison disease itself?

**A:** Without knowing anything about your health situation, I cannot be specific in my response. The pigmentation with Addison's disease is usually generalized, so blotchy pigmentation only on the legs would be unusual. Thin skin with bruising and bleeding could be a symptom of too much glucocorticoid. Bleeding into the skin can leave behind an iron residue from the red blood cells which can result in a brown pigmentation.

**Q:** I am a 25 yr old female and have had Addisons since I was 12. I am on 20mg of hydrocortisone a day and 0.15 mg of florinef a day. It has come to my attention that my long-term steroid use and the disease itself make my immune system weak. As such, it seems my body can't launch a response to a foreign "bad guy" like herpes. I'm concerned I contracted it

....

but fear that my IgG test results might be falsely negative because of Addisons. Do you have any info on this?

**A:** I don't have any specific information about herpes susceptibility, but I will give you my general opinion. The dose of cortisol and Florinef that you are on are reasonable. Some individuals require less and some require more cortisol, but if your weight is stable, you are probably on an appropriate dose. This suggests that you are taking about the same cortisol as you would normally be making if you did not have Addison's disease, so you are really not compromising your immune system. You should be able to deal with most infections in an appropriate way. If you get a flu shot, you should have a normal antibody response. If your antibody response is not appropriate, you may be getting too much cortisol.

**Q:** I'm a 41 yr old male that was diagnosed with Addison's just over a year ago. I take 0.1 mg Florinef and 5 mg of Prednisone each morning. My work requires periodic shift work, where I am required to switch to a 12-8 a.m. time slot for 7 days. What can I do make this shift easier? I have tried moving the times I take the meds to match my waking hours (on suggestion by doctor). This almost resulted in me having to go to the hospital. Throughout a week of nights I go through periodic episodes of being quite nauseated. The idea of double dosing for a week doesn't seem right. Is there something more I can do beyond not doing the shift?

**A:** Shift work always requires some trial and error to get things right although I think everyone suffers a little when we change shifts. Since cortisol is one of the hormones involved in changing our diurnal changes, Addisonians may actually have an advantage because they can move their cortisol dosing to fit their schedule.

I am assuming that your usual shift is from 8 to 4 or 7 to 3 and the change is to the 12 to 8 shift and the afternoon shift is not a factor. On the day shift, you take your cortisol and Florinef when you wake, eat your breakfast and go to work. I am not sure if you take a second dose of cortisol later in the day. When you are working the 12 to 8 shift, you probably go to bed when you get home at about 9 a.m., and rise at 3 or 4 p.m.

You can try either taking your cortisol and Florinef when you wake up or about an hour before you go to work. The second dose can be taken at the lunch break at work or after you get home. You can see which works best for you both working and sleeping. The days you change over, the doses will be a little closer together or a little farther apart and you can adjust these depending on how you feel.

The key is that you are doing the thinking for your adrenals.

**Q:** I was diagnosed with Addison's disease 2 months ago. I was put on 25mg of hydrocortisone (15mg in morning and 10mg in evening) and 0.05mg of florinef. Since becoming unwell, I have experienced muscle cramping and joint pain. Is this to be expected or is there anything I can do to help alleviate this problem? As well, I would like to become

\*\*\*\*

pregnant and am wondering if there are any extra measures I should take to ensure a healthy pregnancy.

**A:** I was not sure from your question whether the muscle cramps and joint pain began before or after you began taking the cortisone. It is rare but some individuals get muscle pain when they start taking cortisone and it usually passes with time. If this is the case, you could try cutting back on your cortisol for a day or so, then go back to your current dose.

If the pains began before starting the cortisol and did not improve on medication, you should have your doctor look at your joints to see if there is evidence of inflammation and check your blood electrolytes and calcium to be sure these are normal.

You should be sure your treatment for adrenal insufficiency is stable before trying to become pregnant. Once it is stable, there should be no adrenal factors that would interfere with you becoming pregnant. Your cortisol requirement may go up a little during pregnancy so you may have to increase your dose by 1/2 or 1 tablet daily.

You should always check with your doctor before you make any changes in your medications.

**Medical Questions and Answers - Dr. Donald Killinger, MD, PhD, FRCPC**, Medical Advisor for The Canadian Addison Society, will answer your questions about Addison's disease. Send your question to Dr. Killinger directly from the webpage <http://www.addisonsociety.ca/faq.html#>, by emailing [liaisonsecretary@addisonsociety.ca](mailto:liaisonsecretary@addisonsociety.ca) or c/o The Addison Society (see address on front of this newsletter). Questions and answers that may be of interest to everyone will be published in the newsletter and on the website.

\*\*\*\*

THE CANADIAN ADDISON SOCIETY  
STATEMENT OF INCOME & EXPENSES  
FOR THE PERIODS ENDING DECEMBER 31, 2007 AND DECEMBER 31, 2008

Cash on hand and in banks	January 1, 2008	January 1, 2007
	\$20,865.16	\$18,394.25
Income		
Dues Received – National	\$2,955.00	\$2,599.85
– Support Groups	520.00	385.00
Donations	1,901.91	2,871.14
Interest	629.12	659.55
	<u>6,006.03</u>	<u>6,515.54</u>
Expenses		
Memorial Plaque	-	-
Newsletter	856.81	1,163.46
Web Site	188.95	174.90
Secretarial	1,200.00	1,200.00
Annual Meeting	308.85	126.14
Postage, stationery and supplies	850.88	132.71
Telephone	1,006.72	1,024.74
Support Group Expenses	335.51	146.36
Bank Charges	70.18	76.32
	<u>\$4,817.90</u>	<u>\$4,044.63</u>
Cash on hand and in banks after adjusting for O/S cheques	December 31, 2008	December 31, 2007
	<u>\$22,053.29</u>	<u>\$20,865.16</u>



....



# **The Canadian Addison Society** **La Société canadienne d'Addison**

193 Elgin Avenue West

Goderich, Ontario N7A 2E7

Toll free number: 1-888-550-5582

Email: [liaisonsecretary@addisonsociety.ca](mailto:liaisonsecretary@addisonsociety.ca)

<http://www.addisonsociety.ca>

**Membership in The Canadian Addison Society is \$25.00 due January 1<sup>st</sup> of each year.**

New Membership  Renewed Membership  + Plus a Contribution

Name: \_\_\_\_\_

Address: \_\_\_\_\_

Postal Code: \_\_\_\_\_ Telephone: \_\_\_\_\_

E-mail Address: \_\_\_\_\_

How do you wish to receive the Newsletter?

I will read it on the website at [www.addisonsociety.ca](http://www.addisonsociety.ca)

by mail

If you **DO NOT** want your name to be made available to other Addisonians in your area, please sign here.

\_\_\_\_\_

You may also direct \$5.00 of your annual fee to one of the local support groups below. Please check a box of your choice.

\$25.00 to go to The Canadian Addison Society

**OR**

\$5.00 to Eastern Ontario Support Group – ON + \$20.00 to Society

\$5.00 to Southern Ontario Support Group – ON + \$20.00 to Society

\$5.00 to Saskatchewan Support Group – SK + \$20.00 to Society

\$5.00 to Alberta Support Group – AB + \$20.00 to Society

\$5.00 to BC Lower Mainland Support Group – BC + \$20.00 to Society

\$5.00 to Vancouver Island (Victoria) Support Group – BC + \$20.00 to Society

\$5.00 to Vancouver Island (Nanaimo) Support Group – BC + \$20.00 to Society

\$5.00 to Atlantic Provinces Support Group (NB/NS/NF/PEI)+ \$20.00 to Society

+ Contributions are also gratefully accepted. A tax receipt will be issued for contributions over \$10.00.

Please make cheque or money order payable to The Canadian Addison Society and send c/o Treasurer, 193 Elgin Avenue West, Goderich ON N7A 2E7

Revised: September 2007