The Canadian Addison Society
La Société canadienne d'Addison

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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.

2011 Annual General Meeting:

The 2011 Annual General meeting of the Canadian Addison Society was held Saturday, October 1, 2011, in Brantford, ON. Minutes will be put on the website as soon as available, and will be included in the next Newsletter (Jan 2012).

News and Announcements:

- It is with sincere regret that we advise you of the death of Greeta McKague. Greeta was a founding member of the Canadian Addison Society. In 1993, she knew of 15 people in the Brantford area; by 1996, the Society had 98 names across Canada. Greeta held positions including President, Editor and Director since the Society was formed in 1997, and had only just retired as a Director from the Society this year. We thank her for her years of dedication and advocacy for Addison's Disease. Her insight, knowledge and dedication will be sorely missed. We shall truly miss her input.

- **Please remember that membership renewals are due in January. Take a moment to fill in the form attached to this newsletter and send it in.**

Cortef:

- Recently, several members (including us) found that their pharmacies did not have any Cortef on hand, and had a bit of trouble getting it. We could only get part of our prescription filled. According to the pharmacy, who talked to the manufacturer, they only do a run of manufacturing every couple of months, as there is not enough need to produce constantly. Each change in production requires 'retooling' of the machinery, so can't be done just for a small run. (This is also how production runs for most drugs are done. Remember the answers when they were doing the H1N1 vaccines? This is no different.) They were to do another run in September (and have done so). This is why we NEVER let our supply slip below several hundred, and why all the advice on Addisons websites, in our Q&As, and in our newsletter tells us to always have at least a 3-month supply at home.

Submitted by Steve McKenna

Personal Experiences:

How do you write something when everything is so fresh and you feel sorry for yourself? Pity parties are not my usual self-talk. But there are those days when I want to hide away and run as far as I can from anyone and everyone.

In 2000, I had my large bowel removed and half my stomach. It was a rough go but the worst part was that I developed sepsis and was in intensive care for six weeks on life support, fighting for my life. My heart rate was high and, had I not been a long-distance runner, I would not be sharing my Addison’s experience today.

One of the problems I experienced after my surgery was chronic and explosive diarrhea, and there were many other recovery problems. It took a few years to get things under control - my whole life had changed. I lost weight, and had to learn to drink lots of Gatorade and eat everything I could, in order to put weight on and keep it on. It was another struggle to say the least. There were many days when my body weight went down 8-10 pounds. Most of that was fluid but nevertheless, it was what it was. Through all of this, I worked very hard at my running and developed really good butt muscles holding in everything that was liquid. I seemed to be getting better but there were those days that I wanted to tell the world to leave me alone.

In 2005, I moved from the Toronto area to Edmonton to be with the love of my life. My energy was good and my running was not great but it was okay. I felt like a new person. My wife and I renovated our house and did a lot of work to make it comfortable for both of us. During this period, I began to get a lot of abdominal pain and developed some real nasty adhesions from my previous surgery. I was given a choice of some real good-feeling painkillers by mouth or a low dose of duragesic by patch. I found the patch worked best and became normalized to it. I had no doubt that, if I had taken the pills, it would be a matter of time until I had to increase them and eventually my thinking and feeling would be down the drain. I found the duragesic allowed me to function and I didn't have to keep popping pills.

Part way through the renovations, I found myself running out of energy. It was a real weird feeling and, as much as I wanted to keep going, I just didn't have any energy whatsoever. I started to crave, and couldn't get enough of, sugar and salt. My body craved salt and everyone said I was eating way too much salt.

In 2010, I noticed that, no matter how much I ate, I could not keep my weight on and I lost about 30 pounds in six weeks. I went from 185 to the mid 150's in no time at all. I was always tired and drained. I had no doubt that the cause was from not having a large bowel to absorb fluids. I increased my fluids, and kept up my food intake but to no avail.

Finally after a long drawn out attempt to find out what was going on, and after a variety of blood tests and ACTH tests, I was diagnosed with Primary Addison's. Can you believe it - 59 years old, a retired pilot and avid shark diver and lo and behold another blessing to learn to live with!

My internist started me with Cortef 25mg. per day. I took 10mg in the morning and 10 mg at lunch and 5 mg in the evening. I was also put on Florinef .01 mg twice weekly. The first week was heaven and then everything went downhill again. For the first month, I was getting that crash that we all hate and no energy to do anything. During this period, we found out my Iron was so low that I had to go through an iron infusion over three days with 48 hours in between each infusion. During this period, I was only getting about 2-3 hours of sleep a night.

After a month, I found the cortisol to be so unpredictable that I had to see my internist and we came to the conclusion that I was just not absorbing the pills. So we started a new dosing routine. I found that if I took one 10mg pill at 4:30 in the morning and went back to sleep, it took and helped. The next dose was 10mg at 8:30 in the morning and it was by injection. Then at 2:00 p.m., I took another 10mg by injection, and depending how I felt at 4:30 p.m., I took either 5mg by pill or nothing.

It has been two months since I started the injection routine and I have had perhaps two crashes where I just had nothing to give. One month ago, I started 200 mg of long acting testosterone that should also help with my iron. I also started a new medication – DHEAS - which has really helped with my sleeping. I take 25 mg in the morning and 25 mg. in the evening. I will keep you posted on the DHEAS.

So there it is - who would have thought that just turning age 60 I would be learning to live with Addison's. I am hopeful that I can return to my running and return to a quality of life I can be comfortable with. I carry my Alberta Addison's protocol and my emergency kit everywhere I go. My family doctor has been great and is a partner in my health care. I think my wife likes giving me the injection in the butt a little too much but it is a small price to pay for everything she has gone through with me on my journey.

Things are coming along slowly and I am sure there will be some ups and downs, but it is getting there. I also found that my emotions are all over the place but I hope that the testosterone will help to deal with the feelings. The other medication I take is a B12 injection once a month.

I also found that reading everything I can and trying to learn as much as I can allows me some comfort that I am not alone on this journey. I would like to thank all of you who took the time and courage to share your story with the Canadian Addison Society as I have found it very helpful and really supportive.

All the best.

M. Scott

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I was diagnosed with Addison's in April 2004. I was just finishing up my first year in medical school, but had been feeling nauseous every morning and weak during the day with little energy for months. Working in a hospital, I just figured I had a virus that wouldn't quit and sucked it up. During March break, however, I went to Montreal with friends, and not wanting to be a downer, I would hesitantly get up from bed to go shopping with them and then pray we would go to shoe stores (because I knew shoe stores would have a place for me to sit down and catch my breath while they shopped). The day I got back from the trip, it began - nonstop vomiting to the point of pulling muscles and breaking blood vessels in my face, weakness to the point of having my family dress me for the ER trip and my brother half-carrying me to the car, and a long admission to hospital, the details of which are foggy at best as I went into shock. It was a month before they even realized I had Addison's.

Since I had so many labs out of whack and since my dad is a well-known physician at the hospital (and is East Indian), they assumed my dark skin was hereditary. What they didn't know was that my mother is as white as a ghost, and I was now much darker than normal (my family just assumed I had been fake tanning for the last couple of months which of course I hadn't been!!!!). It also turned out I had Graves' disease simultaneously (severe hyperthyroidism) which was helping my body run on empty and was ultimately the reason I survived a cortisol level of 4 nmol/L (or 0.1 mcg/dL)! It's been 7 years and now I'm the doctor, and the way I've always thought about it is “yeah, it's pills for life, but now I'm a skinny, tanned girl on a HIGH-salt diet with huge zest for life - could be worse.”

Submitted by S. Kassum

Highlights from Local Meetings:

Vancouver Island Support Group

The Vancouver Island Group met October 1st. Of the 17 people attending, 5 were spouses or family members and four travelled from up-island communities.

Those attending brought forward various questions or experiences they wished to discuss.

- One woman is experiencing low blood pressure. She will soon visit her endocrinologist to review her treatment and possibly adjust her Florinef dose. Difficulties finding good quality DHEA has exacerbated her condition.

- A woman has been told her pituitary gland is not functioning. There are very few Addisonians with pituitary complications. She continues to take her adrenal replacement. http://www.pituitary.org.uk/content/view/19/28/, http://www.pituitary.org/disorders/addisons_disease.aspx

- Going to the dentist requires taking extra cortisol replacement for at least three members present. After taking extra medication, one woman still had an hour-long adverse reaction from the anaesthetic injections. Speculation as to the reason ranged from an allergic reaction to the freezing to the needle hitting a nerve. We are advised to let the dentist know that we have Addison's and what replacement medication we are taking. http://www.addisons.org.uk/comms/publications/surgicalguidelines-bw.pdf

- One lady regularly has an upset stomach after eating her cereal at breakfast. One solution that worked for her was to take an extra 1/2 pill (5mg) of Cortef before bedtime. Suggestions offered were to try protein with breakfast, such as an egg. Kellogg's Vector cereal has protein. Supplements like Glucerna or Ensure may help.

- A raw food diet was explained by one member who feels her health has improved during the month she has tried it. The diet avoids meat, dairy products, fish, and sugar. About 50% of her food was cooked over the first month, including bread, quinoa and other grains. There are beneficial active enzymes in raw foods such as vegetables and fruits. Juicing vegetables and fruits and making smoothies add to the variety of this vegan diet. Sea salt is preferred over salt, and honey instead of sugar. Taking B12 supplements are necessary, however. She was convinced to try it after visiting an elderly relative who changed to a raw food diet after several heart attacks, and is now looking very healthy.

- When to take our medications and whether to keep to a set schedule was discussed. Most people take their medications for Addison's in the morning with breakfast and usually cortisol replacement again at noon with lunch, late afternoon, or with dinner. Some studies have determined taking meds 3 times each day is optimum, but many Addisonians are comfortable with two doses daily. Certainly, it is advisable to take meds with food. Taking a pill with meals is easier to remember than between meals. Members should review their dosing schedule with their doctors, keeping it to convenient times of day where possible.

- One woman experienced vision problems, seeing floaters and bright lights in one eye. Checking promptly with her GP, he found she had a detached retina requiring immediate surgery. (A detached retina is age related and not associated with Addison's.) All 3 eye surgeons in Victoria were unavailable, so she was referred to Vancouver General Hospital. A detached retina was confirmed in the left eye and a tear in the right, which was quickly fixed with a laser. A gas was administered to the left eye to push the retina back into place, allowing it to reattach (she was required to sleep sitting upright for 3 nights), then laser treatment to finish. She has had 2 more tears in her right eye since, all fixed with lasers. http://en.wikipedia.org/wiki/Retinal_detachment

- A question about night sweats was asked by the woman with a pituitary disorder. One woman suggested having the thyroid function checked. Our medications may cause sweating and pituitary disorders may be the reason (excessive growth hormone). http://www.pituitarysociety.org/public/faq/pituitarytumour(general)faq

- A member plans to get a shingles vaccine, which is available at some pharmacies and doctor's offices for a fee. http://www.healthlinkbc.ca/healthfiles/pdf/hfile111.pdf

Evidently flu vaccines are now available. Check with your doctor http://www.gov.bc.ca/FluBC/

There is now an endocrinologist for adults in Nanaimo, Dr. Rustom Guzder, tel: 250-740-6926.

The room for meeting dates in 2012 has not been booked yet.

Submitted by Jim Sadlish

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

BC Lower Mainland Support Group

The next meeting will be November 5th 2011 from 1:00 am to 3:00 pm, in the Neil Russell Room, 3rd floor Columbia Tower (to the right of the elevators), RCH, 330 E Columbia Street, New Westminster BC. This room is wheelchair accessible.

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

Alberta Support Group

For information on this support group, contact Ginny Snaychuk at ginray@shaw.ca or (780) 454-3866 in Edmonton, or Peter Little at bettypeter66@gmail.comor (780) 918-2342 in Edmonton.

Saskatchewan Support Group

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

South/Central Ontario Support Group

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

Eastern Ontario Support Group

Attendance at our meeting on Oct 15, 2011 was very disappointing, with only 3 Addisonians attending. The regional rep will try to determine the cause of the trend to lower attendance and consider what changes may be needed to future meetings. Nevertheless, we had an excellent presentation done by our Newsletter editor, Patricia Hehner, who walked us through the many resources available on the Canadian Addison Society website (note: a written walk through will be contained in an upcoming newsletter).

Submitted by Steve McKenna

The next meeting will be the weekend before the May long weekend, on Saturday, May 12, 2012, at Robbie's restaurant on St. Laurent in Ottawa, starting at noon. For information on Eastern Ontario Support Group activities or meetings, please contact Steve McKenna at steveandpat@rogers.com or 613-523-7648.

Québec Support Group

Our representative in Québec is Marie-Josée Normand, in Montréal. If you wish to contact her, she can be reached at (514) 376-2712, by email at marijonormand@videotron.ca or through the 'Local Groups' page of our website.

Notre représentante au Québec est Marie-Josée Normand, à Montréal. Si vous désirez la rejoindre, vous pouvez communiquer avec elle au (514) 376-2712, par courriel au marijonormand@videotron.ca, ou bien par l'entremise de notre site-web.

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 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/related/FAQApril2011.pdf), or see previous issues of the newsletter.

Before submitting a question to our medical advisor, please consult the wealth of Q&As on our website. Many questions have already been answered.

Q: I am 54-year-old woman, diagnosed with Addison's Disease in 1993. Fortunately, over the years, I have remained very stable. However, in spite of my active healthy lifestyle, including regular weight bearing exercise, I have been recently diagnosed with osteoporosis of my lumber spine. I take 6mg Prednisone and 0.1 mg Florinef. For years, I have taken 1200 mg calcium (cal/mag supplement) and Osteoforte. I am concerned about the emerging research revealing an association between what was once considered a "recommended" daily dosage of calcium (approx 1200 mg) and an increased risk of hip fracture and cardiovascular disease. Given this evidence, what are the current dosage recommendations for calcium and vitamin D for those living with Addison's Disease and osteoporosis?

> **A:** The amount of calcium recommended for daily intake is about 1000 mg daily so you don't have to worry about what you have been taking. The recommendation for Vitamin D is 1000 IU daily. I am not sure what is in the Osteoforte but some tabs have 50,000 U. These are not usually used for regular Vitamin D intake, but can be used on a monthly basis.
>
> There has been some interest in calcium intake and heart disease but the incidence is very low, so at present there is no reason to worry about your calcium. There has been no information about calcium intake and hip fractures. You may have read about the incidence of a specific type of hip fracture in individuals taking medication to treat osteoporosis. These drugs are Fosamax and Actonel.
>
> One thing you may want to check with your endocrinologist is whether you are taking a little too much prednisone. On the basis of how you feel, it is difficult to know, but there are some reports suggesting that we may be over-treating our patients and one result could be a tendency for osteoporosis. One way to check this is to measure ACTH in the morning before taking your prednisone. It should be higher than normal, to indicate that the previous dose of medication has been metabolized before taking the next dose. Your morning ACTH should be over 10 pmol/l and possibly up to 30 or 40 pmol/l

Q: My husband has type 1 diabetes and was diagnosed with primary Addison's in 2011. What regime of hydrocortisone and Florinef should he be on? We are presently not monitoring blood pressure. Should we be? He has an insulin pump and sensor as well as hypoglycemic unawareness. A day ago, our endocrinologist, at my behest, told us to split the dosage of hydrocortisone because the patient was going low at night and very high in the morning. My husband is also using ramipril 10 mg at night and that lowers blood pressure and also protects the kidneys. Why does he take both florinef and rampiril?

> **A:** Your idea for splitting the dose of hydrcortisine was a good one. We often recommend taking it three times a day. I am not sure what dose he is now taking, but an average dose of hydrocortisone would be between 20 and 30 mg daily. A 20 mg

> dose could be 10 mg, 5 mg, 5 mg, or a 25 mg dose could be 10 mg, 10 mg, and 5 mg. The Florinef is usually 0.5 or 1.0 mg daily.
>
> The ramapril could be for one of two reasons. Since he has diabetes, it is often given to protect the kidneys. It may also be given to treat high blood pressure. It seems counterintuitive since the Florinef causes salt retention and helps to maintain blood pressure, but some individuals seem better if they are taking Florinef to maintain a sodium balance. You can monitor his blood pressure if you wish, but if he is seeing his doctor regularly it can but followed by his doctor.

Q: I have had Addisons for 12 years and am 80 years of age. Due to chronic back pain and hip bursitis, my GP has advised me to take morphine, as nothing else works; pain relievers are not permitted due to kidney failure and high blood pressure. I have been housebound for 6 years and the pain is so very bad I get breathless at any exertion. Is the drug morphine safe for an Addisonian to take?

> **A:** There is no specific concern regarding the use of morphine or morphine analogues in individuals with Addison's disease, but it is important to remember that you may need added cortisol during periods of stress. Pain is very debilitating. I am not an expert on pain management, but the appropriate use of analgesics is very important if the pain is going to be a long-term problem. I hope that you have been to a pain clinic or discussed the situation with someone who is familiar with pain management.

Q: I had fluorescein angiography + laser for diabetic retinopathy. I took an extra half daily dose of prednisone (2.5mg) in preparation. The laser surgery was painful and resulted in my glucose rising from 11.2 pre-surgery, to 18.6, a few hrs after surgery. It took me 12hrs to get my glucose back on track, with 17 extra units of insulin, throughout that time frame.

I have to have more laser surgery and am wondering if my sugars rose due to stress, as I wasn't expecting the laser to hurt. Should I take more steroids next time, to buffer that stress?

> **A:** You did the right thing by increasing your prednisone by 2.5 mg before your last laser surgery. Be sure your eye specialist is aware of your discomfort during your previous surgery. There would be no problem taking a 5 mg tablet before your next surgery if your feel very stressed, but remember that taking the extra prednisone can cause your sugar to go up. If this happens again, there is no reason you cannot handle it the way you did last time with extra insulin. Having your sugar a little high for twelve hours will not cause further problems.

Q: Two weeks ago I was taken off osteoporosis medication and calcium supplements and I think my body may be reacting to the change. I have been feeling faint, dizzy, short of breath and very tired yet my sleep is restless. My mind has also become sluggish. My situation hasn't improved over time; in fact I feel it is worse. Is this a normal reaction for my body to have after being taken off a medication even if the medication doesn't have anything to do with Addison's? Should I increase my dose of Cortef to help my body deal with the stress?

> **A:** I am not sure what to say about your symptoms. I cannot see why coming off your calcium and vitamin D should have such a major effect on you. Vitamin D is a fat soluble vitamin so it is stored in fat tissue and is released over a long period of time. Stopping calcium would not normally have any immediate effect. I am not sure what other medication you are on, but Fosamax and Actonel don't generally provide any withdrawal when it is discontinued. If your doctor could check you out, he/she could do some tests to check your cortisol level, and your electrolytes to see if they are OK. I don't think this is a situation requiring added cortef unless the stress is severe.

Q: I suffer from osteoarthritis in my neck and back and was wondering if Boswellia (from aryuvedic medicine) would be helpful. Would there be any contraindications with my meds? I am on prednisone and florinef, atenenol, synthroid, and norvasc.

> **A:** I don't know anything specific about Boswelia. It has been reported to be helpful in treating arthritis and asthma, but there are few real studies that have tested the effects. There is therefore no information about side effects or drug interactions. You can give it a try, but watch for both effects and side effects. It is made from the tree resin and apparently is the source of frankincense in the Christmas story in the bible.

Q: Is it recommended that Addisonians get vaccinations that contain live viruses? I was thinking of getting a Shingles/ Zostavax Vaccination. Every time I used to get the Flu shot, I would have a mild case of the flu and got sick for a week or more after.

> **A:** We usually suggest that individuals with Addison's disease react normally to vaccinations such as flu shots. Some people in the general population react the way you do with a mild illness. I have not discussed Zostavax with any of our Addison's people, but my feeling is that it should be comparable to other vaccines. I will try to get some further information for you but there may not be any.

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 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.

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Membership in The Canadian Addison Society is $25.00 due January 1st of each year.

New Membership ☐ *Renewed Membership* ☐ **+** *Plus a Contribution* ☐

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☐ *I will read it on the website at* ***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.

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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 Québec Support Group – QC+ $20.00 to Society*
☐ *$5.00 to Eastern Ontario Support Group – ON + $20.00 to Society*
☐ *$5.00 to South/Central 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 Support Group – BC + $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: October 2010