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/Adrenal Insufficiency management program. Please note that the Society does not endorse the information provided by guest speakers.

News and Announcements

COMING SOON! Watch our website for the coming additon of ***PayPal*** for ***Membership payment and Donations.***
(You do not require a PayPal account to use PayPal)
CanadaHelps.org, our current DONATION system when using Credit Cards, will also remain with us.

PayPal

CAN YOU HELP? A gentleman in Quebec with both Addison’s and Haemophilia is looking for someone else in Canada with the same conditions to communicate with and share experiences. Please email admin@addisonsociety.ca if you are able to help and we will make sure the two parties are connected.

Editor’s Comments

We have had several positive comments regarding some of the subtle and not so subtle changes in design and layout that have been made to the Newsletter. Obviously we are experimenting by shaking things up bit and to find some fresh ways of presenting the information to you. Your comments on what you like would be welcome.

Don’t be shy, we really do want those photos so members and other readers may put a face to a name. If you are a contributor to the Newsletter in any way, please join us by putting your face next to your article or information for the benefit of our readers. Derek did it. Harold did it. Even I did it. You can as well.

Have you had an experience with Adrenal Insufficiency either as the patient, caregiver, family, friend, nurse, doctor or anyone else? Please consider sharing your story for our **Personal Experiences** section, for the benefit of others. You may do so anonymously. You may reach me at newsletter@addisonsociety.ca.
Thanks, Carrie

Youth Advisory Council

When I was first introduced to the idea of an Addison's youth council, one issue brought to my attention was the occasionally low participation rate of younger Addisonian's at local support group meetings. There are likely several reasons for this phenomenon. Perhaps it's simply not a high priority at this time in their life. It's also possible that many younger people prefer to gather information in other ways (of course, this may apply to overall engagement in the society as much as it does attendance at local meetings).

First, I think it's great that in this day and age there is more than one way to get answers to many of the important and timely issues surrounding Addison's. I've spent a great deal of time googling symptoms, searching for stress management tips and simply reading trivia myself. It's also one of the reasons we are in the process of expanding the society's online presence, by revamping the website, and establishing formal Facebook and Twitter profiles.

That said, I think there is a lot of value that can be gained from attending meetings. Both frequent and occasional participation in the support groups can be a tremendously positive experience. I'm sure that I don't need to tell anyone that adrenal insufficiency is not exactly the most common ailment out there. Attending meetings can be a great way to get information around common activities and life events (how do you deal with illness? how do you handle intense work outs? how do you manage your cortisol when flying through time zones or doing shift-work?) Being able to talk to people who have already experienced similar stresses and challenges is an invaluable resource. Considering that Addison's is a disease that can be very individual and relies a lot on someone understanding their own body, I've found it very helpful to hear what other people do to recognize when they need to make an adjustment, and what strategies worked best for them.

Conversely, if you are feeling particularly great and have a routine that works well for you, it can be great to share that with others. I always appreciate people at meetings who set a positive example and are willing to provide answers and insights based on their experiences. I'd be curious to hear from anyone with ideas for how they (or someone they know) would be more motivated to attend meetings. What factors most affect your decision? Is it Location? Duration? Relevant speakers and topics? Please let me know! youthadvisorycouncil@addisonsociety.ca Thanks, Derek.

President's Comments

We are saying goodbye and a big Thank You to **Steve McKenna** who is retiring from his volunteer roles as a Director of The Canadian Addison Society as well as the Regional Representative for Eastern Ontario. Steve has made a large contribution in both roles with the Society. On behalf of the members of the Society we offer a very large Thank You!

The Board of Directors have appointed Derek Burpee to fill Steve's Director Position until the Annual Meeting which is scheduled for September 26, 2015. Derek is the Chairperson of the Youth Advisory Council.

Steve also leaves a big hole in the Regional Representative role in Eastern Ontario and we are actively seeking a volunteer to take on this important role. If you are interested please contact the writer or our Vice-President, Roger Steinmann.

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It remains busy for your Executive and Board Members as we continue to move forward on many fronts. At the time of writing we had concluded discussions with PayPal and our Webmaster as we move forward to add this feature as an alternative method for submitting donations. In addition, current members will be able to pay their annual member dues using their credit card, through the PayPal system. New members will be able to pay their initial dues in the same manner. No, you do not have to have a PayPal account to use this payment method. This has been a long time coming and we hope you find this new feature to be as convenient as anticipated.

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Adrenal Insufficiency Awareness Month We recently received an email asking why we did not promote this event as done by a UK Addison's group. We were previously aware of at least one of the Facebook groups in the US that do some promotion of a similar cause. NADF in the USA has in the past, promoted April as **Addison's Disease Awareness Month**. This was considered by our Society several years ago but did not meet with enthusiastic support at that time. However it is the right thing to do. In fact any type of awareness promotion of our cause helps it to become better known. Baby steps are better than no steps.

So we will look at the Society's options to promote **April is Addison's/Adrenal Insufficiency Awareness Month** in 2016 as part of our Community Awareness Campaign. If you have ideas of what you personally and/or your group could do in your Community during April 2016, please forward to your Regional Representative, Director, or to me at president@addisonsociety.ca.

President's Comments - *Continued*

Residual Adrenal Function in Autoimmune Addison's disease

Canadian Addison Society Past President **Judy Stanley** has drawn to our attention this study undertaken in the UK.

Now we should not get too excited about this as only 1 of 13 subjects was successful in stopping all treatment for Addison's. A layperson's interpretation is that the subjects were treated over a 20 week period with tetracosactide (ACTH $_{1-24}$) therapy. This is apparently a synthetic version of ACTH. Not being Medical Doctors we will not delve deeper at this time but we do support and applaud this promising yet preliminary study.

The conclusion was that autoimmune Addison's disease is amenable to a regenerative medicine therapy approach.

The real good news is that someone somewhere is actually studying such potential treatments that may help some Addisonian's. One of thirteen is better than none of thirteen. We applaud this effort and will watch for follow-up studies.

Thanks, Harold

Personal Experiences

From my diagnosis in 1980, I was taking 50 mg of Cortef and 0.05 mg of Florinef per day. I was experiencing numerous symptoms such as weight gain, higher blood pressure, stomach issues, sleeping issues and a considerable bone loss.

About 6 years ago, my new endocrine specialist successfully reduced my dosage to 25 mg of Cortef and 0.05 mg of Florinef and it is our hope that I will eventually get down to 15 mg of Cortef and 0.05 mg of Florinef as a stable dosage.

In August 2013, I developed an ischiorectal abscess and immediately went into an Addisonian flare-up. The surgery was minimal but I spent 7 hours in recovery with low blood pressure.

April 2014 while working in an extremely stressful and overwhelming job, I developed another ischiorectal abscess only this one was much worse. I didn't recognize the signs although I should have (blurry vision, dizziness, dehydrated, diarrhea, extreme pain, constant backache, cravings for salt, some fever) and subsequently went into a severe Addisonian crisis.

I was rushed to hospital and underwent surgery, once they got me stabile enough. My blood pressure was 54 over 27 and they could not get intravenous into me. I just wanted to sleep and I was not aware of what was going on.

Finally had surgery and was left with a gaping open wound for several months. They tried many antibiotics until they found 2 that had less allergic reactions. I eventually went home with double medications for several months and a high protein diet to help heal better.

In October 2014 I started to wean back from the higher dosages back to my normal 25 mg of Cortef and 0.05 mg of Florinef.

The motto of my story is: even though you may be a long term Addisonian such as myself, one needs to be vigilant and recognize the signs and symptoms that may save your life such as lowered blood pressure, blurred vision, dizziness, dehydration, pain, fever, vomiting, etc. All of these symptoms can put you into a flare-up very quickly which may require medical intervention. I suffered these symptoms for 3 weeks.

You also need to recognize that as an Addisonian, you may, over time develop other autoimmune issues. I have rheumatoid arthritis and severe allergies to all sorts of medications, foods, pollens, trees, environmental items now, that I did not have 20 years ago. I have been able to stave off severe bone loss and am now considered no longer osteoporotic. I am not able to take bone building drugs, or calcium. Again, I have allergic reactions to these items. I do eat considerable dairy products, exercise daily and keep myself strong.

I keep a positive attitude and I think that is the best advice that I could give - keep a smile and be positive.

Debra

Support Group Meetings

Vancouver Island Support Group – Victoria

Submitted by Jim Sadlish

The Canadian Addison Society Vancouver Island support group met Saturday afternoon, February 28th, with 7 people attending, two traveling from Nanaimo. The meeting was held at the home of a Victoria member.

Attracting younger members to the Canadian Addison Society is a current focus of the national executive and the initial discussion topic. Thoughts voiced were: 1) Members present would not have considered attending meetings when they were young adults. 2) Young people communicate, use forums and gather reliable information online using smart phones and computers. 3) Discussing a chronic disorder within a group or joining a society to learn and support others is not a priority when life at a young age is so full of exciting activities and challenges.

A member dealing with multiple serious chronic health problems imparted some very positive news to the meeting. A new Isagenix diet regime agreeable to her celiac condition enabled her to lose 75 lbs, putting less stress on her osteoporosis-weakened bones. In preparation for a CT scan for abdominal pain she was given a suppository. Observing the result, she discovered almost-whole tablets of Cortef, undissolved! Clinical analysis confirmed this. With the new knowledge that she was not digesting her tablets, she now grinds all her pill medications into powder then takes them in Fruit Lax. Getting back to feeling normal now that she is receiving the full benefit of her replacement medication, her brain is functioning better and she can now travel to visit relatives.

Timing of hydrocortisone doses - A man recalled the advice of a prominent Toronto endocrinologist to take the afternoon dose at the 'low time', when you feel drowsy after lunch. Having his dose at 4:00 led to night time insomnia, but taking his Cortef at 2:00 improves his night's sleep.

Emergency medication - A review, Diagnosis and Management of Adrenal Insufficiency, states that "an alternative to intramuscular injections, which some patients are hesitant to give promptly, subcutaneous injections can be used, generating similar pharmacokinetics to intramuscular injections." Subcutaneous injection is an injection in which a needle is inserted just under the skin into the fat layer between skin and muscle.
http://www.eje-online.org/content/169/2/147.short

One woman finds licorice helps to raise her blood pressure. She also uses nettle tea for the same purpose. Another man enjoys licorice as a snack. The medical advisor to the CAS in the Frequently Asked Questions page advises that raw licorice increases the effectiveness of cortisone; but is not standardized, so strength and quality vary greatly. Because the impact of licorice is on the conversion of cortisone to cortisol, its use would not avoid any unwanted side effects of simply increasing the cortisol medication intake. http://www.eje.org/content/165/5/761.full

Wakefulness at night is a recurring issue with most of us. Some use melatonin with their doctor's approval, but it does not consistently work. Melatonin may give you dreams, morning grogginess or small changes in blood pressure. Another woman manages to get back to sleep after mid-night wakening by listening to peaceful music. Pillow speakers are available to avoid waking partners.

Even with a flu shot, one man contracted the flu twice over the winter. Vertigo symptoms in a few people this winter, some thought may be the result of an inner ear virus. Dizziness can also be caused by low blood pressure.
http://www.mayoclinic.org/diseases-conditions/low-blood-pressure/basics/definition/con-20032298
A woman recalled her condition prior to diagnosis when pregnant. She could not stand upright for any length of time and had to bend over waiting for a traffic light or sit on the floor while in a bank line-up.

Cortisol Day Curve - Our September 2014 meeting report related that a member's condition improved after her endocrinologist reduced her hydrocortisone dose based on the results of a Cortisol Day Curve test. These tests are not a standard procedure now in North America or most of Europe because they are "of limited value in the monitoring

Vancouver Island Support Group – Victoria *continued*

of glucocorticoid replacement.". Please see: http://onlinelibrary.wiley.com/doi/10.1111/j.1365-2265.2006.02473.x/abstract;jsessionid=844E09CB257B94705D999DE62FCC05FC.f03t04?deniedAccessCustomisedMessage=&userIsAuthenticated=false
Also, in the CAS Frequently Asked Questions page the medical advisor discusses the Cortisol Day Curve.
http://www.addisonsociety.ca/files/pdfs/FAQNovemberb2011.pdf

Nanaimo Meetings – A woman living in Nanaimo would like to see support meetings resume in that area. Victoria meetings at members' homes are working fine, so with a few interested members in the Nanaimo area, meetings there are possible. Anyone in the area willing to meet, please reply and we will get the ball rolling.

The next meeting in the greater Victoria area is May 30th and will include emergency injection practice. If anyone with medical training can assist by demonstrating this procedure, please reply. We already have practice vials for everyone. Syringes will be purchased. If a medic is not available, we will still proceed using the injection instructions available on the CAS website: http://www.addisonsociety.ca/index.php/emergency-documents/injection-kit

Please refer to our group website for directions to the May 30th meeting at 1348 Lands End Road in North Saanich. http://vancouverislandaddisonsgroup.weebly.com/meetings.html 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 Sharon Erickson at ericksons@shaw.ca.

BC Lower Mainland Support Group For further information on this support group please contact Judy Stanley, bugbee@shaw.ca.

***The next meeting* of this group is scheduled for Saturday, June 6, 2015,** from 1:00 to 3:00 pm at the Royal Columbian Hospital, Neil Russell Room, 330 East Columbia Street, **New Westminster**

Alberta Support Group For information on this support group, contact Ginny Snaychuk at 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 elizabethhill10@hotmail.com
The Saskatchewan Addison's Group will be meeting either in May or June 2015 in Saskatoon (it is not yet decided when or where). Please contact Elizabeth Hill by email if you wish information when it is decided.

South/Central Ontario Support Group For further information on South/Central Ontario Support Group activities or meetings, contact Roger Steinmann in West Montrose at rdsteinmann@ehtel.ca or (519) 575-6590 or Harold Smith in Kitchener-Waterloo at hsmith81@hotmail.ca or (519) 742-8170.

The next meeting of the South/Central Ontario Group is scheduled for **Saturday May 2, 2015** at the Erin Mills United Church, Lower Hall Meeting Room, 3010 The Collegeway, Mississauga ON L5L 4X9
Registration at 12:30 pm, Meeting from 1:00 to 4:30 pm. This location is accessible by Public Transit (please check Saturday schedules).

Eastern Ontario Support Group For information on Eastern Ontario Support Group activities or meetings, please contact Steve McKenna at steveandpat@rogers.com or 613-523-7648.

The next meeting of this group is scheduled for **Saturday May 9th**, 2015 (the weekend before the May long weekend in the usual location at noon).

CAS Members located in Quebec would be most welcome at our Ottawa meetings.

Québec Support Group For information on the Quebec Support Group please contact Fiona Vickers. Fiona may be reached at fiona.f.vickers@gmail.com or 514-882-2613.

Atlantic Support Group Holly Mclean is the Regional Representative for Atlantic Canada. She lives in northern New Brunswick. You may reach Holly at hquilter@nb.sympatico.ca or 506-546-1687

Medical Q & A's

There is a very large and wide-ranging set of questions on both daily living and situation-specific issues that have been answered by our medical advisor over the years. Before submitting a question to our medical advisor, please consult the wealth of Q&A's on our website. Many questions have already been answered.

To review these questions and answers, please go to the Canadian Addison Society website under Education http://www.addisonsociety.ca/files/pdfs/FAQNovemberb2011.pdf see previous issues of the newsletter.

Question #1: I was diagnosed with Addison's 26 years ago. I was wondering if it would be a good idea to have the shingles vaccine. I take prednisone and Florinef. Thanks, Vern

Response: Hi Vern, There is no problem with taking the shingles vaccine. Your immune system should respond appropriately.

Question #2: I am going to need a knee replacement. I have Addison's. I was diagnosed in 1975 and have been on 7.5 mg of prednisone and 0.1 mg of Florinef since. I also have hypothyroidism and osteopenia for which I take 35mg of Actonel weekly. I also have osteoarthritis. My thigh muscles have atrophied greatly and I don't understand why as I am active and try to exercise as much as I can. I am 65 and worried about my increase chances of infection and my ability to get back to normal with Addison's. Can you offer any advice? Thanks very much, Sandra

Response: Sandra, There is nothing special re knee replacement for patients with Addison's disease vs the general public. You should be as active as you can to strengthen the muscles around the knee before surgery. For the surgery, you will need intravenous **Solu-Cortef** before the anaesthetic and perhaps more during the surgery depending how long the procedure lasts.

The anaesthetist usually looks after this during surgery. But it helps if he/she talks to your endocrinologist to discuss doses before the operation. You will also need extra cortisol for a few days following surgery depending on how you are feeling. This usually involves doubling or tripling your daily dose then gradually tapering off over about a week. Be sure your endocrinologist talks to the anaesthetist before the operation.

Medical Questions and Answers – Dr. Donald Killinger, MD, PhD, FRCPC, and 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#,

Or by emailing liaisonsecretary@addisonsociety.ca

Or c/o The Canadian Addison Society, 2 Palace Arch Drive, Etobicoke, Ontario M9A 2S1

Questions and answers that may be of interest to everyone will be published in the newsletter and on the website.

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If you DO NOT want your name to be made available to other Addisonian's 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. ** Tax receipts are issued for donations over $15.00.

- ☐ **$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 South/Central Ontario Support Group – ON + $20.00 to Society**
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- ☐ **$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**
- ☐ **$5.00 to Quebec Support Group + $20.00 to Society**

Please mail your payment to

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c/o Treasurer,
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Optional (for newsletter mailing purposes if you wish to provide this information)

Endocrinologist Name____

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ER Director of Hospital and Hospital Address______________________________

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Revised: January 2015