The Canadian Addison Society
La Société canadienne d'Addison

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In this issue

Distribute to:

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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

The answer to the Fall season's most asked question:

"It is flu season...it is safe for individuals with adrenal insufficiency to have their annual flu shots."

Editor's Comments

newsletter@addisonsociety.ca.

Have you had an experience with Adrenal Insufficiency either as the patient, caregiver, family, friend, nurse, doctor or any other role? Please consider sharing your story for our **Personal Experiences** section, for the benefit of others. You may do so anonymously. Please send to me at the email address shown above.

Please see the attached which features Gail McArthur's personal story,

President's Comments

president@addisonsociety.ca

Solu-Cortef Recall

We understand some members that had been in possession of recalled Solu-Cortef Act-O-Vials are still experiencing difficulties in obtaining the replacement product. There should be no reason for this as the replacement product has been available in the marketplace in Canada since late August. Your pharmacist may have to contact their source if they have not yet received the replacement product. Everything based on the assumption they ordered it for you. The following currently appears on our website:

> Solu-Cortef replacement product now available in the marketplace!!
>
> **Please see the Society's Summer 2016 Newsletter for details on the recall.**

Seeking Regional Representative Volunteers

The Society is seeking members interested in becoming our volunteer Regional Representative in several regions in Canada. We are seeking Representatives in the following regions, some of which are replacements for retiring members and others are new assignments.

Edmonton, Calgary, South Central Ontario, Quebec City.

The duties of the Representative may be viewed on our website or by following this link http://www.addisonsociety.ca/pdfs/duties-of-the-regional-representative-nov-2016.pdf

The Canadian Addison Society is a 100% volunteer organization.

If you have interest in taking on one of these important volunteer positions, please contact the writer at president@addisonsociety.ca

Support Group Contact Information & Meeting Reports

B.C. - Vancouver Island Support Group

Meeting Minutes – October 22, 2016 1:00 to 3:05 PM

Eight people attended our Oct 22nd meeting which was again hosted by Allison. We discussed two stories where a stressful personal situation turned into near Addison's crisis. The stories were similar, in each case the person involved was dealing with a very stressful (emotionally difficult) situation. The result was light headedness, general weakness and abdominal distress. It may also create a feeling of panic or anxiety. We are reminded that additional stress dosing is required in these situations.

We took a few minutes to review the correct way to open and use Solu-Cortef. Instructions for use are on both the Canadian Addison Society and Vancouver Island Addison's web sites.

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B.C. - Vancouver Island Support Group *continued*

A modified release hydrocortisone product (Plenadren) has been available in the UK for several years. The pill has a soft outer shell which dissolves quickly and a hard inner center that provides a slow release of the remaining hydrocortisone. This one pill a day design is intended to more closely mimic the body's natural cortisol production. It's not yet licensed in Canada but we will keep you updated on this product.

Several of our members have polyendocrine syndrome which is broadly defined as an autoimmune disorder on more than one endocrine organ. This might include someone with both Diabetes and Addison's disease for example. Several of the members of our Vancouver Island group might be considered as polyendocrine. Please contact me if you would like to link up with others who suffer from this syndrome.

We ended the meeting with a good laugh over our widely varied salty food cravings. Clearly, everyone has a favorite food to help with this! It's also the flu season, so you may want to consider a flu shot.
Our next meeting is planned for February 2017 (date TBA). In the meantime, stay heathy!
Derek

For further information on the Vancouver Island Support Group, please contact Derek Clarke at vancouverislandaddisons@gmail.com or (250) 857-4320.

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 at, bugbee@shaw.ca

Alberta - Edmonton Region Support Group

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

We are searching for a volunteer to take on the Regional Representative role in the **Edmonton** Region. If you are interested, please contact either Ginny Snaychuk at ginray@shaw.ca or Harold Smith at president@addisonsociety.ca.

Alberta - Calgary Region Support Group

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

We are searching for a volunteer to take on the Regional Representative role in the **Calgary** Region. If you are interested, please contact either Ginny Snaychuk at ginray@shaw.ca or Harold Smith at president@addisonsociety.ca

Saskatchewan Support Group

For information on the Saskatchewan Support Group, contact Elizabeth Hill at (306) 236-5483 elizabethhill10@hotmail.com

The next meeting is expected be held in the Regina area – date and location have not yet been determined. …

Ontario - South/Central Support Group

The South-Central Ontario Support Group met in Woodstock, Ontario on Saturday, October 1, at The College Street United Church. There was a fabulous turnout of about 50 people including several first timers whom we were all glad to welcome. Many travelled for hours to attend.

The group hosted the Society's ***Annual General Meeting*** and we were very pleased to have Elizabeth Hill join us via video link. Elizabeth is a Director of the Society, located in Saskatchewan.

The minutes of the AGM may be found by following this link. http://www.addisonsociety.ca/pdfs/annual-general-meeting-2016-minutes.pdf

Following the Annual meeting business portion, our Special Guest Speaker was Stan Van Uum, MD, PhD, FRCPC Program Director Endocrinology and Metabolism Program, Associate Professor Endocrinology & Metabolism, Clinical Pharmacology, Dept. of Medicine, Western University, London, Ontario. Dr. Van Uum as usual hosted a lengthy and valuable Q&A session with the group.

An **Emergency Injection Training Clinic** was also a key part of the October 1 program.

We are searching for a volunteer for the Regional Representative role in the **South-Central Ontario** Region. If you are interested, please contact Harold Smith at president@addisonsociety.ca.

For further information on South/Central Ontario Support Group activities or meetings, please contact Harold Smith in Kitchener-Waterloo at hsmith81@hotmail.ca or (519) 742-8170.

Ontario - Eastern Support Group

The Eastern Ontario Support Group met on Saturday, October 15, 2016, at Robbie's Restaurant in Ottawa. There were ten in attendance.

The first item presented at the meeting was an update of the "vial of life", a pilot project sponsored by the *Fédération des aînés et des retraités francophones de l'Ontario* to help Paramedics quickly find medical list of patients in emergencies. The new "vial of life" should hopefully be available at our next meeting in May 2017.

We followed by doing a quick round table and welcomed a new member who has had Addison's since 2000, Kenny accompanied by his supportive wife. He is struggling to control his Addison Syndrome and is searching, with the help of his family doctor, for an endocrinologist. He has had to be transported by ambulance to the hospital numerous times when he was in crisis and has encountered a lot of misunderstanding at the hospital and paramedics on how to treat him. The hospital protocol letter drawn up by Dr. Silverman at the Ottawa Hospital plus the emergency kit with 250 mg of Cortef were helpful tools for him. Both Kenny and his wife were pleased to have discovered our support group and to learn about Addison's and to find out that many shared similar problems in the past.

I informed the members that during the Annual General Meeting which took place on October 1, 2016, in Woodstock, Ontario, that the members voted in favour of the motion to change the Membership from $25 annual dues program to a $25 one-time Lifetime Membership. This is an excerpt from the information provided to all members in the Notice of the Annual General Meeting regarding Lifetime Membership proposal:

Continued

Starting in 2017, a member renewing their membership, or anyone joining for the first time upon paying the $25 fee would become a life member without needing to renew in subsequent years. This Membership is in effect immediately.

When facing a crisis or things are approaching a problem, members indicated that there was brain fog. Members discussed the document entitled “Management of Adrenal Insufficiency, Frequently Asked Questions”, May 14, 2016, and we all agreed that adding 5 m of Cortef to head off colds / flu or facing unwanted stress was very helpful, as was resting, taking naps during the day.

We also talked at length about how important it is to have an emergency kit while travelling. The kit should include a letter from your endocrinologist indicating you have Adrenal Insufficiency and what are the symptoms when you are having a crisis; the Hospital Protocol in both official languages; a few syringes with doses of 250 mg of Cortef, as it is easier to fill up 100 mg in that syringe; a few alcohol pads; a print-out from your pharmacy of the list of medications you are taking; etc… Be sure to wear a Medic Alert bracelet.

Anne-Marie Willems and I will be looking to have a special guest at our next meeting in May 2017 and we hope that you will be able to attend.

For information on Eastern Ontario Support Group activities or meetings, please contact Ghislain Hardy, email ghislain2406@live.ca or telephone (613) 601-3671. *Those located in Quebec, near Ottawa, would be most welcome at our meetings.*

Quebec - Montreal Region Support Group

The next meeting of this group is scheduled for Sunday, December 4, 2016, at 12.30 pm. The meeting location is PF Chang's, 5485 Rue des Jockeys, Montréal, QC H4P 2T7.

For information on Montreal Region Support Group activities or meetings, please contact Shelley Saklatvala, email shell326@hotmail.com or telephone (514) 991-0294.

Quebec - Québec City Region Support Group

We are searching for a volunteer to become our Regional Representative for a Quebec City Region Support Group. If you can assist in this volunteer role please contact Harold Smith, president@addisonsociety.ca. In the interim, if you are trying to connect with the Society for support please call our Montreal Area Regional Representative, Shelley Saklatvala at (514)-991-0294 or you may also call the Society via our Toll Free number 1-888-550-5582 or email info@addisonsociety.ca or president@addisonsociety.ca.

Atlantic Canada Support Group

For information on the Atlantic Canada Support Group activities or meetings, please contact, Holly Mclean email hquilter@nb.sympatico.ca or telephone 506-546-1687. Holly lives in northern New Brunswick

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 or refer to previous issues of the newsletter available on the website.

Question 1 :
A few weeks ago, I had a small TIA. With all the testing, I have no signs of a mini stroke. I saw a neurologist who put me on baby aspirin. As a person with Addison's disease should I be taking the aspirin?

Response 1 :
Sorry about the TIA. Aspirin is a common treatment for stroke prevention. There is no reason that you should not take this medication.

Question 2
Recently I had to have a colonoscopy. One day prior to the exam an IV was inserted in my arm and I was given my hydrocortisone every 8 hours. Each dose was 100mg. They kept this schedule until one day after the procedure finishing today with the last 100mg. bag of hydrocortisone I haven't felt this well in months. I am not experiencing the nausea, lack of energy, and generally feel like my old self again. I slept through the night and awoke bright and cheerful. The doses that I have been on is 10mg, 10mg, 05mg every day with 1/2 Florinef every other day. I haven't felt nearly as well as I do now after having the larger doses for the past three days.
Can I safely increase my dosage to 20mg, 20mg,10mg every day to see if I can maintain how I am feeling now?

Response 2
You are asking a question that your endocrinologist should be answering. The dose of cortisol that you are on (25 mg daily) would be an average dose and whether you should be on a higher dose depends on how you feel and other factors such as your weight, blood pressure, blood sugars and possibly a morning ACTH. You should discuss this question with your endo. The suggestion that you have made is a doubling of your present dose and that would be too much of an increase and would probably result in side effects such as weight gain, thinning of the bones and possible increase in blood sugars in the future.
.
The fact that you felt well on 300 mg of cortisol daily is not surprising. Most of us would feel excessively energised even if we did not have an adrenal problem if we were given that dose of cortisol suddenly. That is not a good yardstick to use for comparison. Be sure to discuss this with your endocrinologist.

Question 3
How do I know if I am having a crisis? I am not getting help from my endocrinologist. I have no idea as to when I should increase my dosage of cortisol and have been flying by the seat of my pants. Any help would be appreciated.
I have chills, sweats, nausea, anxiety but no fever. No energy and very lethargic.

Response 3
It does not sound as if you are having a crisis although I am not certain what is causing your symptoms. When someone does not respond to appropriate replacement treatment. The first things that comes to mind are: Is the diagnosis correct? What is the basis for the diagnosis? and could there be some other problem associated with the adrenal problem that requires investigation and possibly treatment. Try to see your endocrinologist to sort out these questions. It is best to go through your family doctor to do this.

You can get some information on what to do in stressful situations form the Canadian Addison's web site but it will not be specific for your situation.

Medical Questions and Answers

Dr. Donald Killinger, MD, PhD, FRCPC, Medical Advisor to The Canadian Addison Society
Dr. Killinger will answer your questions about Addison's/Adrenal Insufficiency. Please send your question to Dr. Killinger directly from the webpage or this link http://www.addisonsociety.ca/index.php/education/faqs/ask-a-question
By emailing info@addisonsociety.ca ? Via Canada Post to The Canadian Addison Society, 2 Palace Arch Drive, Etobicoke, ON M9A 2S1
Questions and answers that may be of interest to everyone may be published in the Newsletter and on the website.

Journey to Crisis and Understanding:
My SAI Story, from Gail McArthur, Vancouver, BC

On June 1, 2016, I had an adrenal crisis. The nausea started the previous evening; a familiar feeling, but alarming, as this was worse than the mild episodes I'd been having over previous months. By about 2 am the upper abdominal chest pain had started; I hadn't felt that for a while, either. This time, unlike previous episodes, it didn't go away, but got steadily worse, feeling almost like being in labour, only in the wrong part of my 65-year-old body!

By 6 am I was vomiting….and I HATE vomiting, and will do anything I can to avoid it. I'd had mostly fluids in the last 20 hours, as I hadn't eaten much the day before. I thought maybe I'd be OK after the first episode, but no such luck. Got up to find some Zofran, and felt so dizzy I thought I would pass out, and was afraid my jelly legs wouldn't hold me up.

By 7 am the pain had me moaning and in tears, I was still vomiting every time I moved, I had a killer headache and I was beginning to think I might need help. I live alone, so decided to message my AIC Facebook buddies for their suggestions. They both said "get to emergency". Called my RN daughter, who said "call an ambulance", which I did. I was on a 60-mg

dose of prednisone, dealing with an asthma flare, and knew I wouldn't be able to keep it down. And I knew from my own research that not getting the prednisone down could be a problem. I had been diagnosed previously with "temporary" adrenal insufficiency, a result of the frequent high doses of both inhaled and oral steroids, so I knew that I needed to be able to get my prednisone onboard – and keep it down.

My daughter had reminded me to take the prednisone I keep in my purse with me in the ambulance. I had no Solu-Cortef emergency injection kit, as my endo said it was only for camping trips, and as I was SAI, not likely to ever have a crisis. Thank goodness I was given IV gravol in the ambulance; once it started to work its magic, I managed to swallow and keep down that 60-mg prednisone. Within an hour the nausea was almost gone, and the pain was down to a 4/10 from a 9/10 and within two hours of taking my prednisone it was gone.

I was given no IV fluids or steroids in ER; they had tested my cortisol about 2 hours after I'd had my prednisone, and because it showed up in bloodwork, they'd dismissed my protestations that I had SAI, and ignored my pleas for IV fluids. Eight hours later they sent me home, saying they couldn't find anything wrong with me, and maybe I'd been right about it being a "low cortisol" episode. I shudder to think what would have happened to me if I hadn't had that prednisone in my purse! At least they did include that possibility in the report my G.P. received from the ER.

I knew I had adrenal insufficiency, as my new asthma doctor had listened to me, a year earlier, and tested me am cortisol, which came back with an annotation: abnormally low. None of the other specialists I'd consulted had ever suggested low cortisol as a cause for all the mysterious, insidious symptoms that often left me bed bound, had melted 30 lbs off my body, sapped me of both body and brain energy, and produced the following symptoms:
*extreme fatigue - I couldn't do the simplest of housework tasks without needing frequent breaks;
*terrible sweating episodes whenever I was on my feet for more than a few minutes,
*lack of appetite (strange for me) with frequent nausea and big D
* muscle cramps all over my body,
* blurry vision
*periods of low blood pressure that made me dizzy every time I stood up,
*air hunger that was very different from my asthma,
* alarming short term memory issues and what I now know to be called "brain fog"
* elevated TSH after being stable on the same dosage of synthroid for 25 years

I was dismissed by my neurologist (dissed might be a more appropriate verb!) when I told him that my seizures, after being stable for 25 years, had increased in both frequency and intensity, and were occurring along with all these other mysterious symptoms. He said there was no possible way the new seizure activity would be related to the other symptoms, and reminded me that I was now an older woman. I found a new neuro PDQ.

Continued

But here's the rub. Neither of the two endos I'd seen felt I needed a medic alert bracelet or emergency injection kit. The first endo, as I'd passed the stim, despite continuing low am cortisol, wrote a report saying I wasn't "Addisonian" but should consider supplemental steroids should I have surgery or become seriously ill. But – she didn't tell ME that – I only found that by reading the report online! I sought a second opinion, and the new endo assured me that once I got my asthma under control, I'd be able to taper completely off prednisone and my adrenals would recover and get back to work. Neither mentioned the possibility of adrenal crisis: I learned about that through reading stories and files on the ADSG Facebook page!

When I finally did get down to 5 mg prednisone, feeling like crap, my endo had me withhold my 5 mg prednisone for 24 hours (but still used my steroid inhalers for asthma). My cortisol result was 23, against a reference range of 150 – 500. Endo left phone message saying "no adrenal recovery", but in a month, let's try a month of alternating daily doses of 5 mg/2.5 mg. My GP suggested that was too big a drop for me, since every attempt at tapering more than 2.5 mg at a time was resulting in breakthrough seizures. Said GP gave me a script for liquid prednisone, so I could measure out whatever amount worked best for me. I didn't get a chance, as after about three weeks on 5 mg/day I picked up a nasty virus, got a chest infection with asthma flare and was back on the prednisone merry-go-round yet once again. So much for tapering!

My endo did confirm – two weeks after the fact - that I'd had a crisis on June 1, but seemed surprised. He said it was probably a combination of my chest infection, asthma flare, family stress and the cold sore that turned up the next day (you think?!). But he still wouldn't give me a script for Solu-Cortef, as I could "call an ambulance "if it ever happened again. And he referred to Solu-Cortef as a "pen" – I doubt he's ever seen the vial! And no – I shouldn't break my prednisone into doses per day as that would interfere with my adrenal recovery.

I do now have an emergency injection kit, thanks to my GP! Even though he didn't recognize my symptoms as cortisol insufficiency when I first started complaining about them, he has consulted with my new asthma doctor and is learning along with me how to manage my various health issues considering this diagnosis. He told me that taking my own prednisone during "the event" probably saved my life! He agreed that our local hospital ER likely had never dealt with such a crisis. He approved of the ER protocol that I'd found on the Canadian Addison's Society website, printed, and shared with him. I now have a "green file" stuck on my fridge, that includes my health history, meds and emergency protocol for adrenal crisis. When I requested a script for HC to supplement my prednisone, to provide faster coverage if I start to go low, he agreed that was a good idea, he gave it to me right away.

And yes – I'm waiting to hear back from the new, freshly minted endo who has just moved into my community. My GP was happy to send in the referral!

My story doesn't end here, as my experiences, combined with similar stories of other AI patients, have turned me into an activist! I research online daily, collaborate with my AIC/AIU friends, and am in the process of forming a support group of other AI patients in my small community in B.C. I do most of this from my couch now, with my trusty laptop, in the hope my experience might help other folks facing a similar AI journey.

In fact, this journey has inspired me to join the Canadian Addison's Society and my local "Lower Mainland" branch, and I hope to become as active as my health will allow in supporting the wonderful work of these organizations. And I have a very gratifying new development to add to my narrative: AIC has recently merged with Adrenal Insufficiency United (AIU), and I'm now on the Board of Directors! As a member of AIU, I'm involved in two projects: 1) continuing to research and report out on the growing issue of steroid induced adrenal insufficiency, and 2) exploring the issues faced by all AI patients in their senior years, and the overlapping topic of issues faced by AI patients living alone. So – I'm doing my best to turn this lemon (SAI) into juice, through research and advocacy. Now I have even more reason to keep myself healthy!

With thanks to my daughter, who really "gets it" and my AIC girlfriends who knew what was happening to me, what to do about it, and kept me alive to fight another day! *Gail McArthur*