The Canadian Addison Society
La Société canadienne d'Addison

Offering support for those with Addison's disease
and other forms of Adrenal Insufficiency

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December 2018 **FALL/WINTER Edition** ISSUE NO. 90

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. Please note that the Society does not endorse the information provided by guest speakers. Meeting minutes/notes are prepared by non-medical volunteers. Readers are advised to consult their own doctors before making changes to their Addison/Adrenal Insufficiency management program.

News and Announcements:

We have exciting EMS news to report…

We are extremely pleased to share the latest **EMS news from Newfoundland & Labrador** as of Sept 25, 2018. Following are the intros and links to media reports both print and video, all of which announce and/or discuss the implementation of the new potentially life-saving EMS protocol for *suspected adrenal crisis*. We are very grateful to all that helped to make this new protocol a reality.

The Telegram – Wed, September 19, 2018

Newfoundland and Labrador paramedics' ability to administer hydrocortisone a life saver, says patient

It may be a play on her last name, but Paula Courage has bravely dealt the effects of Addison's disease since being diagnosed about nine months ago.

Addison's disease is a medical disorder in which the body produces insufficient amounts of certain hormones produced by the adrenal glands. The condition puts her at risk of an adrenal crisis that could make her really ill, possibly unconscious, and can even become fatal if she is not administered hydrocortisone in short time.

EMS news from Newfoundland & Labrador *continued*

An announcement Tuesday by Eastern Health that paramedics in Newfoundland and Labrador are now able to administer hydrocortisone at the scene brings a high level of comfort to Courage and others in her situation.

The province is the first jurisdiction in Canada to bring in the new protocol. For the video links please note the start and end times of the article within the video.

NTV Evening Newshour Early Edition - Tue, September 18, 2018

LIFE-SAVING MEDICATION TO BE ADMINISTERED BY PARAMEDICS: Paramedics in the province that are now able to administer a shot that could save lives. ["Dr. Brian Metcalfe"]

WATCH HERE [02:55-07:00]

NTV Evening Newshour - Tue, September 18, 2018

THE CARTER FILE: A milestone in our health care system today; paramedics will now be able to administer a life-saving drug. ["Dr. Brian Metcalfe"; "Dr. Carole Joyce"; "Paula Courage"]

WATCH HERE [28:50-31:16]

Editors 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 forward to newsletter@addisonsociety.ca

The AGM Minutes are available on the website

http://www.addisonsociety.ca/pdfs/annual-general-meeting-minutes.pdf

Re: The Election of Directors and Officers

The Notice of Meeting indicated one Director Position was up for election for a one-year term. No nominations were submitted prior to the meeting. During the meeting, Harold Smith was nominated for the position and agreed to accept the nomination with the understanding this will be his final year as a Director as well as President of the Society. The nomination was moved, seconded, and approved by a show of hands.

President's Comments

president@addisonsociety.ca

Attendance for the 2018 Annual General Meeting (AGM) was very positive again this year. We appreciate the effort of those who made it to the meeting. We do also understand that as a national organization, most members are not within reasonable travel distance. Others may be limited due to health.

While everyone is welcome to read the minutes, Society members should make a point to do so. I would direct you to the PRESIDENT'S MESSAGE. On page two, I reference the need for a qualified member to step forward prior to next year's AGM and consider allowing your name to stand in nomination for Director and President.

We require a member that is both interested and qualified, to express interest. If this is you, please contact me directly. The time is now to learn of this opportunity and to determine if you would be both qualified and comfortable assuming this position. http://www.addisonsociety.ca/contact-us.html

Merry Christmas and Happy New Year!

We send our Best Wishes to all for the upcoming Holiday Season.

Support Group Contact Information & Meeting Reports

B.C. - Vancouver Island Support Group

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

BC - Lower Mainland Support Group

Canadian Addison Society Meeting October 13th, 2018 at the Coquitlam Library 575 Poirier St Coquitlam BC.

There were 15 attendees and a presenter. The meeting started at 1:10 p.m.

Geoff Metcalfe chaired the meeting, welcomed everyone, reviewed the agenda and introduced the speaker Ole Olsen. Ole has wide experience as a paramedic and is currently a Paramedic Practice Leader with B.C. Emergency Health Services.

BC - Lower Mainland Support Group *continued*

On September 5th, Ole met with the Emergency Licensing Board to discuss how to help Addison's patients in administering Solu-Cortef. This requires an increase in their scope of practice. This necessitates a change to the existing legislation which is 40 years old and outdated. Within the paramedic community at this time Addison's Disease is very topical because the sister of a paramedic died recently of non-diagnosed Addison's disease and Ole was very supportive of the need for change.

The changes that are needed are slow in coming. Various levels of bureaucracy have to be satisfied in order to move forward. Ole was confident and hopeful because change is in fact on the way. He also said that the letter writing has been helpful, and he suggested that further lobbying in the future should be considered by us.

Ole discussed the roles of the three levels of paramedics. They are Primary Care, Advanced Care and Critical Care. He felt that as a starting point the Advanced Paramedics would be trained and add steroid injection to their scope of practice.

He pointed out that if we call emergency services it should be clearly stated that the patient has Addison's Disease and is steroid dependent. There was also discussion that AI patients may require similar treatment.

Several questions were posed:

Will firefighters be able to administer our shots in an emergency? Ole said he would have to check on this. He thinks higher level "First Responder Licences" will be allowed to give us a shot in the future but perhaps not the lowest level licence.

Ole will be speaking with the doctor's association about clearer communication channels as patients are delivered to the emergency ward. Geoff took the floor and thanked Ole for his time and then reported on activities since the last meeting.

1. Registration form for Addison's patients is not going forward at this time.

2. Dr. Brian Goldman of the CBC radio show White Coat Black Art will be contacted by Gail McArthur re: getting more education on adrenal insufficiency to the general public.

3. 12 members wrote letters recommending that the law be changed to allow emergency responders to administer Solu-Cortef. It looks like it helped as the province has plans to change the law.

4. Still a need for more letters to be written so Gerry Ott may be sending us a second boilerplate letter we can use.

5. The AGM is being held today in Ontario and we should have a new president as Harold Smith is stepping down after many years in office. There was agreement that he has done an admirable job and will be thanked. *(Ed note: there were no nominees for the President position and Harold agreed to stay on for one final year).*

6. New group for younger members has not panned out.

BC - Lower Mainland Support Group *continued*

Helpful advice from audience:

1. Gail said there is an excellent resource for us on Facebook under 'adrenal insufficiency support'. The program is called backpack and offers a good place for information and discussion.

2. A suggestion was made that when we travel, we should carry injection directions in the language of the country we are visiting.

3. Google Pfizer is a resource to obtain good photos of how to prepare the Solu-Cortef shot. Pictures would help a lot in any language or if someone is unfamiliar with the procedure.

4. A salt replacement recipe may be available on the Addison's website, so you can make your own drink, Gatorade not recommended due to high sugar and potassium.

Judy Whittaker then took the floor to help us all practice how to give ourselves a Solu-Cortef shot.
1. She stressed how important it is to call 911 after injecting.
2. Clear plastic zippered pouches are available to purchase at Save-On Drugs. They are ideal for making up injection kits.
3. Several kits may be required, always keep one in your car and one on your person plus another in your home for emergencies.
4. She stressed that bold signage should be prominently displayed in the cases so, if an emergency occurs, a first responder or other person will understand to look inside for our drugs.
5. A good printable information sheet is available at www.addisons.org.uk. Fill out the details and include with each injection kit.

For further information on this Support Group please contact Geoff Metcalfe at calfe579@telus.net or 604-533-0579.

Alberta - Support Group

Meeting of the Alberta division of the Canadian Addison Society in September 29, 2018 in Innisfail.

New Research:
The first item we discussed was a newly discovered research project by the Physician Learning Centre in Edmonton which is to develop a 'tool kit' for all adrenal insufficiency patients in the province. We were small in numbers, so it was easy to agree that we want to be in the loop on this project. There was a sample questionnaire which we all answered, and I will be in touch with the project leader to see how we can be involved or receive results.

Injections:
After lunch we practiced injections, although one of the three in attendance carries dexamethasone so does not have to worry about mixing in an emergency. She's also one of the few who had actually had to use her injection.

Ambulance Care:
We then discussed ambulance protocol - there is no real progress in Alberta to date. The protocol is still under medical review.

We also discussed the exact wording on our injection prescriptions - two said 'as directed' and one 'for emergency use'. I had a chance to hang out with an advanced service paramedic last week, so we discussed the injection issue. He said that my current label (the emergency one) would make him think of something like a bee sting. He suggested changing it to 'In case of illness or trauma, inject to prevent or treat adrenal crisis' and you can add 'patient has Addison's or adrenal insufficiency' - whichever diagnosis applies.

He knew what Addison's was and he knew what an Adrenal crisis was, although he said they didn't run into an Adrenal crisis very often (highly believable).

Then Laura Bishop pointed out that most, if not all ,of us are able to register our driver's licenses with AHS with all relevant health information - and paramedics will have access to that because they look through your possessions for ID. That is something which needs further investigation.
I passed out a handout showing the scope of the Alberta Healthy Living Program, but we did not discuss details. That's something in reserve for when we can bring in a speaker, but it's important because the better one's general health is, the easier the AI is to manage. We then had a discussion around goals for meetings in 2019, considering the poor attendance at this one. The next meeting is set for May 25, 2019 in Airdrie – location to be determined.

Last but not least, thanks to the Fireside restaurant in Innisfail for giving us the use of the room and serving a lovely lunch.

For information on this support group, contact Rosemary Brown at 403-391-1507 or rhdbrown52@outlook.com

Saskatchewan Support Group

For information on the Saskatchewan Support Group, contact Elizabeth Hill at elizabethhill10@hotmail.com

Ontario - South/Central Support Group

The South-Central Ontario Support Group met in Woodstock, Ontario on Saturday, October 13, 2018 at The College Street United Church. There was a good turnout of about 40 people. The group also hosted the Society's Annual General. The minutes of the AGM may be found by following this link:

http://www.addisonsociety.ca/pdfs/annual-general-meeting-minutes.pdf

An Emergency Injection Training Clinic was, as always, a key part of the Support Group part of the day.

The Q&A and sharing part of the meeting was interesting as always. We always learn a great deal from sharing our stories with each other. Thank you for coming out, for listening and for sharing.

For further information on the activities or meetings of the South/Central Ontario Support Group, please contact Becky Sparks in Sarnia at rebeccalouisepacker@gmail.com, 519-402-2833.

Ontario - Eastern Support Group

We are searching for a volunteer to take on the Regional Representative role in the **Ottawa** Region. If you are interested, please contact Harold Smith at president@addisonsociety.ca

Quebec - Montreal Region Support Group

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 at hquilter@nb.sympatico.ca or telephone 506-546-1687. Holly lives in northern New Brunswick.

Medical Q & A's

Question 1

I was just put on Cipralex and I am on my 10th day of taking the Med and I am very sick with this pill. I am nauseous, no energy, want to sleep all the time and am quite depressed. As I thought about this medication, I realized that the purpose of the medication is to reduce the cortisol which causes the stress. Am I correct? Therefore, the Cortef I am taking for my Addison's is being reduced because of the Cipralex. Therefore, should I be taking the Cipralex? Should my cortisol be changed to reduce my anxiety and depression and stop the Cipralex?
I am presently taking 12.5 mg in the morning, 5 at noon and 2.5 at dinner.

Response 1

Sorry you are having problems with your medication.
The Ciprolex is designed to decrease your anxiety. As you suggested, cortisol secretion is increased in response to stress and anxiety. The Ciprolex may decrease the need for increased cortisol secretion if it helps your stress, but it does not have a direct effect on cortisol secretion. Your dose of cortisol does not need to be changed because of the medication.
The side effects of Ciprolex are nausea and fatigue, so your symptoms may be due to the medication rather than its effect on cortisol.

Question 2

I am a 25-yr. old female that has been diagnosed with Addison's Disease for about five years now, it is well managed for the most part, I take 6mg of Prednisone in the morning (occasionally increasing to 7mg if sick or stressed) along with 0.05mg of Florinef. I have been quite active for the years I have had Addison's and frequent the gym on a regular basis with very minimal issues (only once did I have a severe ankle sprain, and experienced dizziness, nausea and cold sweats but did not go into a full-blown crisis). My question is, in the last four months I have taken interest in the martial art Muay Thai, it can be quite intense and have found myself sometimes taking an extra mg of prednisone before sessions however I have just started to spar and take more advanced classes which have increased chances of injury and stress. I very much enjoy Muay Thai and don't want to stop and I don't want Addison's to control my life, however I would like to know if the risk is too high and if the recommendation is to find a safer sport. Or what the recommendation is to better take care of myself while I continue with the sport, and would I ever be able to safely take the opportunity to do amateur fights? Thank you so much for your time and I'm sorry for the long essay. Kind Regards

Response 2

I am glad that you're Addison's disease has been well controlled and that you have the enthusiasm to participate in a sport that you enjoy. It sounds as if the episodes can be physically challenging and it is appropriate for you to take extra steroid before these episodes. The prednisone seems to be working well for you on a regular basis, but it may not be the best for stress dosing because of its longer duration of action so it may not give you the benefit when you want it. We tend to use hydrocortisone for stress dosing, it reaches a peak in about 30 min and comes back to pre-treatment levels in 2 to 4 hrs. In general, a 5 or 10 mg dose would support a normal increase in physical activity. You have to try different doses depending on what you are doing and for how long.

It is important to remember that the Addison's disease is not a factor in whether you get injured, so no amount of steroid will protect you from this. If you participate in activities that carry a risk, your chance of injury will be the same as other participants provided you are properly prepared. If you enjoy what you are doing you should carry on, but if you are concerned about getting injured, then perhaps a less hazardous sport would make you feel more comfortable.

Question 3

I was diagnosed with SAI in late March this year (2018) while in hospital admitted with what we now know was Adrenal Crisis symptoms.

The cause is unknown and there is no attempt being made to find one. I was told that my adrenals are capable of producing cortisol and that my pituitary is capable of producing ACTH but that the "message" from the pituitary to the adrenals is getting lost somewhere.

From my own reading I have learned that the message is of course ACTH but that "lost" does not adequately describe the potential problem and that the Hypothamus/CRH has not been addressed, nor am I certain as to the condition of the pituitary. My Endocrinologist is only concerned with managing the SAI. I am concerned regarding the cause but need more information to even suggest an avenue for investigation. My efforts to that effect are hindered by adjusting to, as they say, "My new normal", and yet not knowing what normal should be.

One concern, of the many that I have, is the symptoms that I am experiencing as the appropriate replacement dose for me is determined. The hospital gave me 20/20 mg at 8:00 and 5:00 and I was discharged with no education or instruction of any kind other than to take it for the rest of my life.

As I read article after article in the various journals, I discovered that I was on too high of a dose and that perhaps I should be splitting it up three ways. I was on 40 mg daily for 4 weeks after discharge and then lowered to 30 mg per day for one week and then to 20 mg all within the first 6 weeks.

I experience flushing, intense heat and headaches daily as well as a feeling of tightness under my tongue (as you would with nausea but with no or very little increased saliva production and no further progression). Is this something you have come across? Might it be an indication of excess or deficient cortisone or the cortisone itself or something else? It is not something that is of the norm for me, but I have experienced it across the 30 mg and the 20 mg daily dose changes and my current dose of 35 mg as I developed acute conjunctivitis and was advised to stress dose for five days and then return to 20 mg. The five days ends after tomorrow.

I am 52 yr. old woman possibly menopause could be responsible for the flushing, but it does seem to concur with the time period of 4 hrs after a dose prior to the next. Changing from two doses to three has not stopped the symptoms.

Although the changes did happen rather quickly, and might that figure in?

Thank you for having a look and seeing what if any suggestions or history you may be able to offer to help me discern what is going on and how to resolve the symptoms.

Response 3

It seems like a lot of things have happened since March!
Your diagnosis is an interesting one and I would like to see the lab tests that led to the diagnosis. There are situations in which the receptors for ACTH do not work well resulting in decreased hydrocortisone output.

I would have to know more about the initial investigation to know if this could be the type of situation you are dealing with.

Your dose of hydrocortisone has varied from 20 to 40 mg a day. I would be surprised if this would be responsible for the flushing episodes. Were you having flushing before the diagnosis and treatment began? A change in your overall metabolic situation could change your response to other things that are going on. You should try to be on a stable dose of hydrocortisone for a period of time because changes in the steroid dose can make you feel somewhat different. The 35 mg dose should be satisfactory for the present so stay on it to avoid frequent changes.

You did not mention your levels of sodium and potassium. I assume they are Ok, but you could check this with your endocrinologist.

You should review this information with your endocrinologist to get a better perspective. This is a rather complex situation and your endocrinologist may be trying to gradually educate you about your problem.

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. Send your question to Dr. Killinger directly from the webpage or use this link http://www.addisonsociety.ca/ask-a-question.html

By emailing info@addisonsociety.ca or by 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/or on the website.

Personal Experiences

Adventure in Cuba!

My husband and I travelled to a resort south of Holguin, Cuba in December of 2016. We were looking forward to a relaxing two-week holiday there. My husband had been previously diagnosed with Addison's Disease several years before that. He had not experienced any symptoms before this trip. When we arrived at the resort the temperature was in the mid-thirties Celsius and he appeared tired and sluggish within the first day. He did not attribute it to anything other than the heat and did not take any extra meds. On the second day he fainted while having breakfast at the outdoor cafe. There was no doctor at this resort, only a nurse as it was considered a three-star location. We were driven to an adjacent resort where a doctor gave my husband a shot of hydrocortisone and sent him back to our resort.

Everything seemed fine until that evening when he began to feel ill and he could not urinate. We had not taken a thermometer with us and only after begging the nurse on duty did she lend me her old glass one with reassurances that if I didn't return it her salary would be docked for it. My husband's temperature was elevated and by the middle of the night I had to phone the switchboard and request a doctor.

He arrived from the adjacent resort, gave my husband a shot for his pain and said he would have to go by ambulance in the morning from the adjacent resort into Holguin. In the morning we waited several hours at the resort for the paperwork to be readied and another doctor to examine him. This doctor was well respected by others at the resort and was working there part time to top up his salary from his hospital job. He diagnosed my husband as having a prostrate issue.

We then left for the hospital in Holguin in an antiquated van which was their version of an ambulance. My husband was admitted to the 'tourist' wing of the hospital. Finally, at nine o'clock at night a resident catheterized him, by then he was in agony from the wait. He had his own nurse who was very efficient and spoke good English. I was able to sleep in a small bed in his room. The hospital was in horrible shape outside of our wing and the medical staff did what they could with lack of equipment and resources.

While my husband recuperated, I dealt with the insurance issues. We did not pay up front but used a Cuban insurer as a third-party link with Canada. It was five days before the doctor signed the 'fit to fly' form for my husband. We returned by cab to our resort, picked up our belongings and flew out the next morning. Other than the prostate diagnosis we never found out if his Addison's had any connection to the prostate issue or if the high Cuban temperatures contributed to his symptoms.

We took this experience as a wake-up call to not become cavalier while travelling anywhere away from home and to be better prepared for any situation. We have done a number of trips since then and my husband has not been ill again.