



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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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

CORONAVIRUS

Please see the information on the website BULLETIN BOARD on the Home Page or follow this link:

<http://www.addisonsociety.ca/>

The Canadian Addison Society has endorsed ISMP Canada's 5 Questions to ask about your medications. Please refer to the link below. We have also posted information on the Addison Society Bulletin Board:

Regional Representative news:

We are very pleased to share that Sheri Thiffault, is now the Regional Representative for the South/ Central Ontario Support Group. Please do refer to the Personal Experience section in our Newsletter to read about Sheri and her family's experience with a child with Adrenal Insufficiency. Thank you, Sheri, for sharing your story & we are so pleased to have you as our newest Regional Representative.

For more information on upcoming meetings please click on the following link: <http://www.addisonsociety.ca/support-group-meetings.html> .

Thank you, Sheri for helping the society by stepping up to these very important responsibilities.

**Youth Ambassador for Canadian Addison Society:**

As part of the 30th Anniversary of the United Nations Declaration of the Rights of the Child on November 20, 2019, the Addison Society had representation via a Youth Ambassador, Kyle Yeates, attend the UNICEF Summit in Toronto. The CRC document continues to be used to support the rights of children to access essential medicines and healthcare across the globe.

A day of learning how to advocate for child and youth was experienced by Kyle at the summit with many takeaways.

As our youth ambassador, Kyle is available as a contact to any youth who would like to connect with him regarding adrenal insufficiency. Kyle is a physics student at Laurentian University who he himself commented that when he was first diagnosed (via crises at 18 years of age); "It would have been great to be able to talk to someone else who had experienced a new diagnoses". Kyle is a physically active young man, recently registering in the 64 Km Mattawa River Canoe Race (and Portage), for July 2020.

Kyle can be contacted at: <mailto:kylegyeates@hotmail.com>



President / Editors

Comments

newsletter@addisonsociety.ca

A warm hello to all as I step into the role of President of the Canadian Addison Society. What a time to take on this role! I hope this note finds you healthy, practicing social distancing/ and better than that... staying at home, as we navigate this uncertain time with the coronavirus and all that comes with that.

I was in self quarantine myself as I returned from a trip to Africa recently. (more to come when the time is right, I will share in that I brought with me on this trip meds for Adrenal Insufficient children who attend a clinic in Ghana set up by the Canadian organization GPED out of Vancouver) <https://www.globalpedendo.org/>

While in Africa I fell ill (not related to coronavirus, but as a precaution, was understandably held by the state to do a coronavirus test, only allowed to start my journey home (early) once a negative test was returned. I am a small business owner and while quarantined, my staff locked the store doors until we are again safe to open. My son is Adrenal Insufficient, so as a mom, I check on him incessantly to make sure "he is feeling ok". Like each and everyone of us, I appreciate these are challenging times personally, emotionally, financially, and physically. I also know that this will eventually be managed, and life will go on to a new normal. We need to all work together to move through this very challenging time and so importantly, stay healthy.

This is all uncharted territory. How will the coronavirus affect those with Adrenal Insufficiencies? What do we do? What do we not do? We are trying to gather information as it comes out. It's also imperative to ensure that information is fact based and the most recent guidance available.

We will be posting information on our Canadian Addison Society Website under the Bulletin Board. Do reference there, as updates become available, we will post.

As of today, we are NOT experiencing drug shortages in Canada for Hydrocortisone and Florinef. In saying that, DO ensure you have enough medicines at hand should you need to up-dose. Our suggested amount is to have three months of medicines at hand. Have your emergency kit and emergency letter available. (content breakdown is listed on the website). Keep hydrated and ensure you have salty snacks and electrolytes at hand for those who salt waste.

We are hearing from various sources that those with Adrenal Insufficiencies are NOT more likely to fall ill with coronavirus. We also have heard that those who have Adrenal Insufficiencies and HAVE coronavirus are faring well. There have been incidences shared with us that patients are up dosing and staying home while combatting the illness. We are still early in the pandemic and of course everyone with Addison's is different from each other.... However, this is positive news to hear that the cases thus far, are faring "well". Please do visit the Health Canada Website for up to date coronavirus information.

All our support meetings are on hold. Below the dates are listed, however, with the pandemic at hand will not be going forward. Do check the website for any updates as perhaps remote meetings are a thought.

More to come in the coming days and weeks. As always, do have an [Emergency Kit](#). Have a jewelry identifier indicating the need for immediate stress dose of hydrocortisone for suspected adrenal crises. Stay well, stay home and be healthy

Support Group Contact Information & Meeting Reports

***ALL SUPPORT MEETINGS ARE PRESENTLY ON HOLD
DUE TO THE RISK OF SPREAD OF CORONAVIRUS.***

B.C. - Vancouver Island Support Group

There has been some interest shown in the Vancouver Island area for an upcoming support group meeting. Derek Clarke the regional representative is planning to send out an email to gauge interest for a new location for a group in the near future. For our Vancouver Island support group members, do watch for an email from Derek!

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

The Lower Mainland group will be holding a meeting at 1pm ~~18th April 2020~~. It will be at the Coquitlam Public Library 575 Poirier St Coquitlam BC.

There will be a guest speaker, Dr Holmes who is division head of Clinical Chemistry at St Paul's Hospital Vancouver. He will be speaking of his experience with Addison Disease particularly in respect of diagnosis.

Thanks go to our member Doris Loughheed who was able to secure Dr Holmes for us.

For more information on the BC Lower Mainland support group and to rsvp your attendance at the upcoming meeting please contact Geoff Metcalfe at: calfe579@telus.net

BC- Northern BC Support Group

We are very pleased to add Tyanna Trottier as our new regional rep in Northern BC. More to come as Tyanna works to build a support group in this region! For more information on the newly created Northern BC support group please contact Tyanna Trottier at: 250-845-9446. tyannatrottier@gmail.com

Alberta - Support Group

The fall meeting for Alberta was held in Rocky Mountain House in October 5. Attendees came from Edmonton, Calgary, Red Deer, and Drayton Valley.

The guest speaker was Renee Nuttall from the Alberta Healthy Living Program where she wears the hats of both a health educator and exercise specialist. She went over all the programs available (free) to help us live healthier lives. Her information is specific to the central zone, but all programs are province wide and may be accessed at aha.ca/decentralizing. Tabs for the other zones will be found there. We tried a balance exercise and strength exercise out of the supervised exercise program, and a problem-solving exercise from Better Choices Better Health.

Following lunch, we discussed the Specialty Treatment Protocol program which already exists in Alberta. It is in place for paediatric AI patients in Calgary at the present time. Our goal now is to expand it to adults and province wide. This STP (or personal care plan) is attached to your health care number so is available to any medical personnel as soon as you are identified.

I have spoken with the head of the program, who agrees that expansion of the program is reasonable. It became apparent that one of the problems is going to be finding us, as the way this program works in Calgary is that all pediatric patients are seen at the endocrine clinic at Children's and the clinic submitted their information. When you move to the adult world, we are much more scattered. I have been asked to stay in touch with the team which is working on this.

We would remain largely responsible for our own emergency care - to carry our own Solu-Cortef, wear our Medic Alert ID, and identify ourselves as much as possible. There are various means to have additional information available - the health app on iPhones, cards or letters on our person or in our Green Sleeves, and so forth. I feel the more the better as you don't want to be reliant on one option.

We had a short conversation around the Green Sleeve program and how it relates to emergency services. This is a coded goals of care plan to be kept on top of your fridge where paramedics will look for it. It is now required for hospitalization. Because the paramedics will collect it, it's a good place to keep any other information you want them to be aware of.

We practiced emergency injections at this meeting - everyone injecting into an 'injectable' supplied to me by Pfizer in my anticoagulant kit from my knee replacement. Since Pfizer also donated the practice vials to the CAS, we owe them a thank you for this experience.

None of us felt that the vials would be very easy to use in an emergency- not to mix and not to draw up the liquid. Ginny Snaychuk gave a short report on someone in the USA who is working on an auto injector which would be similar to an epi-pen and therefore require hydrocortisone which is stable as a liquid. Just because it's there doesn't mean it would be licensed in Canada but at least we would know it exists

A date of May 30 was picked for the spring meeting and current plans are to hold it in Red Deer. Therese Kehler is going to find a suitable location.

The Alberta group of CAS will hold their spring meeting in Red Deer on ~~May 30th, 2020~~. Plans are to follow the same format of meeting as previous Alberta Meetings, with start time at 11am in a restaurant that will let us use a meeting room provided we eat, lunch at noon, and wind up by about 2pm.



A photograph from the Alberta Injection training at the Support Group Meeting.

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

Saskatchewan - Support Group

On May 25, 2019 Regina's Addison's met at Dolores (Tom) Cameron's house. There were 6 Addison's, 2 parents of a young man with Addison's and 2 spouses. 2 of the Addison's were Twins!!! Elizabeth Hill, Saskatchewan Addison's Representative Face-Timed using Messenger with the group. It was a lively discussion: introducing ourselves to each other; how long we had lived with Addison's disease and medications; other health conditions and which physician you see: Endocrinologist or Physician.

It was encouraged to join the C.A.S. and "be counted in the Saskatchewan Addison's population. With more Addison's we can show the Saskatchewan College of Paramedics how important it is for the Advanced Care Paramedics to carry or assist us when an Addison is in a crisis either by administering Solu-Cortef or assisting us with the administering of it.

We discussed the valuable information on the websites of the C.A.S., The National Addison Disease Foundation (USA) and The Rare Disease Foundation. The value of wearing a Medical Alert bracelet or necklace and keeping all medication current with Medical Alert.

It is of importance that a family member or a significant other knows your medications in case of an emergency so they can inform Emergency personal or physician of them. Having all your medications written down correctly in your wallet also assists E.R. staff in getting medical assistance quicker.

Dolores had C.A.S. send her Act-o-vials and she bought syringes, needles, alcohol swabs and oranges so all could follow Elizabeth along with the demonstration of how to draw up and inject. Of course, it is easier than it looks and the group requests more practise in the future.

The meeting was a huge success in using FaceTime Messenger. IT is an excellent way to connect Addison's from the north and south ends of Province. Highly recommend it when "in person" is not possible.



Submitted by Dolores Cameron and Elizabeth Hill

The Saskatchewan Support Group is presently looking for a Regional Representative. Please contact Elizabeth Hill elizabethhill10@hotmail.com

Ontario - South/Central -Support Group

The next meeting for the Ontario- South/Central Support Group will be as follows:

Saturday, ~~May 23rd, 2020~~

Erin Mills United Church, Lower Hall (Elevator available)
3010 The Collegeway, Mississauga, ON

Registration 12:30-1:00pm and Meeting 1:00-4:30pm

Guest Speaker: Michael Roffey - Coordinator Paramedic Practice. Sunnybrook Centre for Prehospital Medicine.

Topic: Prehospital Treatment for a Patient with Suspected Adrenal Crises

Mr. Roffey will be discussing the following:

-Brief overview of Paramedicine in Ontario. Education and training surrounding Adrenal Insufficiency. Treatment for Adrenal Insufficiency. How to plan and prepare in case of an emergency. What to expect if 911 is called, and how to assist paramedics.

Can you help us at this meeting? Room set up and tear down requires volunteers. It is always appreciated if you can bring a small snack for the snack table to make our Coffee and Conversation break more enjoyable for all. Please feel free to take home any of your snack contribution that may be left over.

We look forward to seeing many of you in Mississauga on ~~May 23rd~~. Safe journey!

For further information on the South-Central Meeting please contact Sheri Thiffault thiffaultsheri@gmail.com

Ontario - Eastern Support Group

The Fall meeting was a great success and we had a several members (new and old) join us in Carleton Place. Many of the new members were so happy to have found a support group to connect with. Interesting stories were shared. The injection clinic was a great success, as well. Since the Fall meeting there have been 4-5 additional new members reach to be included in correspondence for future meetings. It appears the Eastern Ontario Group is gathering new momentum with a Spring Meeting date being worked on at the present time.

For information regarding the next Eastern Ontario/ Western Quebec activities or meetings please contact David Sparks at davidsparks04@gmail.com

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 Shelley Saklatvala, email shell326@hotmail.com or telephone 514-991-0294.

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've had Addison Disease for 12 years. I take 10mg hydrocortisone in a.m. 10mg at dinner and 5mg at bedtime. Also take Levothyroxine 100mcg, and Fludrocortisone 0.1mg, Perindopril 4mg in a.m. and at dinner, and amlodipine 5mg.

I've had three attacks requiring an injection of Solu-Cortef since Sept 2018. Each one different, the first started with extreme vertigo, the second was extreme diarrhea for three days and last Fridays was a sudden onset (under ten minutes) of vomiting, diarrhea and extreme abdominal pain.

My long-time doctor has retired and my new one is right out of university setting up her practice. I She is prescribing a switch from hydrocortisone to 5mg Prednisone twice a day.

I don't know of anyone who takes Prednisone exclusively. I have heard that it can affect the amount of Fludrocortisone I take. Anything else I should know before I decide to change my routine?

What is your advice? Should I switch as she prescribes or perhaps try what others do by adding a tiny amount of prednisone midday to ensure long term drug coverage?

I consider myself well-tuned to my body and take extra precautions if I feel an attack coming on, however, these three took me completely by surprise. Also, I am wondering if there might be an unrelated cause that needs investigating as all three attacks presented differently.

Continued

Response 1

I am surprised that you have had these episodes. The medicine routine you are on is ideal. Your doctor probably wants to switch you to prednisone because it is longer acting. There have not been a lot of studies comparing prednisone and cortisol in the treatment of Addison's disease but the Endocrine society which provides guidelines for the management of Addison's disease generally recommends using cortisol in divided doses. I don't think anyone would criticize your doctor for suggesting the use of prednisone, because there are many patients are using that medication who are doing well. The general feeling however is that cortisol is the preferred choice.

I think you should review your treatment with your new doctor and see if she/he can give you some information about why they feel that prednisone may work better for you.

The episodes that you have had must have been caused by some external factors such as a viral infection, food poisoning or allergic reaction. You should see if you can get some information about this rather than changing your cortisol replacement since which seems to be ideal. Episodes of adrenal insufficiency are due to factors which cause you physical or emotional stress. You may want to adjust your cortisol dose a little, but these episodes are unlikely to be related to the dose of glucocorticoid replacement. You also have to be sure you use the stress dose of Solu-Cortef before you get so ill.

Question 2

Hello, I am sick (cold, cough, fever and nasal bleeding) I had catherization both nasals... I need to return if I'm bleeding again like the day of the catherization. (Still bleeding because of the vomiting for the headaches or any other reason). I Went to the hospital with fever 39.1 at 1am...at 6 am I received a dose of fludrocortisone.

I felt better but today I feel sick again. I'm vomiting, I'm having pain on my lower back (kidneys?) Terrible headaches, and no eating. Is this a reason to return to the hospital? I went already 4 times and still feeling sick.

Response 2

I am not sure what the problem is with your nasal bleeding, but with the fever, you have an infection so your doctor should arrange a culture and you may need an antibiotic.

Have you been taking your stress doses of hydrocortisone (cortisol)? I am not sure what your regular dose of cortisol is, but you should at least take an extra 10 mg tablet until the problem settles down. You should check with your endocrinologist about the stress dose for this situation, and to be sure there are no other factors that need to be looked into.

Continued

Question 3

Please tell me a procedure after a crisis.

I crashed and released from hospital to take 3 hydrocortisone 3 x day. For 2 days then go back to my regular 2 a day.

I did that last night and this morning going back to normal. I am in fear of crashing again. I am dehydrated, have severe back and abdominal pain. I feel like my intestines are eating me alive. As well, my kidneys hurt.

Response 3

Before we discuss your crisis situation, I would like to be sure that you have an endocrinologist who knows your situation and has advised you on how to deal with stress situations. If not, this is an important first step. There are endocrinologists who are familiar with Addison's disease and should be a resource you can turn to when you have a problem. Your family doctor can refer you to the endocrinologist.

The usual way to deal with a stress situation, if you are at home and can keep food down depends on the degree of stress. For a flu like illness, you should double up on your cortisol medication for a few days until the problem has resolved then go back to your previous dose stepwise over the course of about a week. you are probably also on Florinef to control your salt situation. You probably do not have to change the dose of Florinef, but occasionally your dose of this medication may need to be increased, but if you are uncertain about the dose., you should check with your endo. For more severe stresses, you need larger doses of cortisol for longer periods, and if you cannot keep down food, you should go to emerg. Information about this can be found on the Addison's web site.

You must get an endocrinologist who you feel comfortable with. It will give you a feeling of comfort that you are not on your own. Let us know how you make out and look at the frequently asked questions on the website for information and forms you can fill in to take with you to the emergency department, It will show the emerg doctors that you know what to expect for appropriate treatment.

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

I would like to take this opportunity to introduce myself, my name is Sheri Thiffault and I am the new Regional Representative for South/Central Ontario Support Group. I have two daughters one is 11 years old and the other is 7 years old. The story I am going to share with you is that of my oldest daughter Taylor.

Her story started back when she was 6 years old.... I remember so clearly, leaving the doctor's office for her 6-year checkup and she was crying because she would be the only grade 1 student still in a car seat. She was not yet 40 lbs and therefore, could not be moved into a booster seat. This was at the end of July and by the end of August she had put on 5 lbs which seemed like a lot to us however, we chalked it up to a growth spurt, plus the doctor was not concerned about it.

This continued throughout her grade one school year, her weight would go up and down. She was having headaches, was tired a lot and breaking out in hives. We were back and forth to the family doctor and it was always watch what she is eating, or the symptoms would no longer be present when we finally got into see the doctor, so there was nothing for him to see and to evaluate at the time. This continued for months.

It really hit home for me when she was invited to a trampoline birthday party. I watched her and in the first few minutes of jumping she did not look well. She could not keep up with the other kids and was really struggling. I tried calling the family doctor after the weekend was over and could not get her an appointment for weeks. So that week I took her back to see the pediatrician at the walk-in clinic that we had seen in the past. She listened about her symptoms, examined her and took her blood pressure. Then took it again, which it was at that moment I knew something was wrong. She told me we needed to take her the emergency room as her blood pressure was very high and needed to be tended to right away. She explained that Taylor's symptoms sounded like something called Cushing's Syndrome and gave us a letter stating that, for us to give when we arrived at the emergency room. When we arrived at SickKids emergency department, they took her in basically right away. They gave her something to take care of her blood pressure and testing began. Taylor had elevated blood pressure, an 8-month history of weight gain in face and abdomen (that would come and go), hyperphagia and fatigue. Taylor was admitted to Endocrinology at SickKids Hospital with possible Cushing's syndrome, to continue testing. The features of Cushing's she had included a full face with plethoric cheeks, fatty hump between the shoulders and enlarged abdomen.

While preparing a monthly photo journal for the doctors at SickKids I remember thinking 'how could I have not seen this sooner' and done something about this sooner. It was amazing to see the changes her body went through in less than a year. Seeing her everyday made it difficult for us to see it, yet those who did not see her as frequently could see it.

They confirmed that yes Taylor did have Cushing's Syndrome and that they thought it to be originating in the adrenal glands. Over the course of time Taylor had a variety of tests completed at SickKids, yet they still could not figure out what was causing it as they found no tumors on her adrenal glands.

In March of 2016, after Taylor's endocrinology team at SickKids had been in contact about Taylor's case with a specialist at the National Institute of Health (NIH) in Bethesda, Maryland. It was decided it was best if we took her to see them for further review. Once we arrived things moved quickly, and a diagnosis was confirmed.

Taylor was diagnosed with Cushing's Syndrome from primary pigmented nodular adrenal disease. She had bilateral laparoscopic adrenalectomy in April 2016. She started on her replacement doses for adrenal insufficiency of hydrocortisone and fludrocortisone.

continued

Almost 4 years later and Taylor is doing fabulously. She sees her endocrinologist at SickKids every 6 months. She had been returning yearly to the NIH for follow up but at our last visit in November 2019 it was decided next visit would be in 2 years.

Taylor loves dance and currently dances competitively. She does jazz, contemporary, hip hop and musical theatre and dances 5 nights a week. She is in grade 6 at school and is doing well. She enjoys spending time with friends, being outdoors, listening to music and of course electronics.

We are grateful for all the wonderful people who we met and got us through this difficult journey. We are also grateful for those we have met after diagnosis, especially those at the Canadian Addison Society. After attending our first meeting, I knew I needed to get involved in some way. At the time, I never would have thought it would be as the Regional Representative for the South-Central Ontario area, but I am looking forward to this new chapter and hope I can fulfill the role as well as those previously.