



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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SUMMER Edition

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Distribute to:

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:

Drug Shortage Status Inquiry (Reply from Health Canada, Courtesy of Mr. Ali Ehsassi, MP)

As of August 21, 2019

- Health Canada recognizes the significant impact that drug shortages can have on patients and is committed to doing its part to address them when they occur. • According to www.drugshortagescanada.ca, the following information is being reported:
 - o For SOLU-CORTEF products, as of August 5, 2019, Pfizer Canada Inc. has resolved their shortages for the 100 mg, 250 mg and 1 g strengths. Currently, there are no actual or anticipated shortages being reported for SOLU-CORTEF products.
 - As there are no shortages currently reported for SOLU-CORTEF products, intervention such as the use of an Interim Order is not being considered.
 - o For CORTEF products, Pfizer Canada Inc. is not currently reporting any actual or anticipated shortages.

continued

o For FLORINEF, Paladin Labs Inc. is currently reporting an actual shortage with an estimated shortage end date of September 23, 2019. Paladin has implemented a measured national allocation strategy to conserve existing supply.

- Regarding the recently resolved shortages of SOLU-CORTEF products and the current shortage of FLORINEF, Health Canada has been engaged with the companies and will continue to monitor the situation and take action as required.

- When a critical national shortage occurs, Health Canada works with stakeholders across the drug supply chain to coordinate information sharing and identify mitigation strategies. Factors such as whether the shortage is national in scope, whether alternative supplies are available and whether the product is considered medically necessary are all considered in determining the potential impact and any necessary actions by Health Canada.

The Canadian Addison Society will continue to contact Health Canada and political representation in the event of future shortages.

Florinef Shortage Update

At the time of writing, Paladin Labs continue to say they do have inventory of Florinef in limited quantities and are shipping allocated quantities on a regular basis as stated above.

Regardless we continue to hear of situations across Canada where patients have been unable to have their Florinef prescriptions filled at their usual pharmacy.

We also hear from patients who have had their prescription filled without issue. The writer had such an experience and received a prescription refill in late July, without any indication of a supply issue.

The Health Canada Drug Shortage Report states that Paladin does have “Limited Inventory. Stock available on allocation”. We suggest that you consider asking your pharmacy to call other distributors as clearly some of them have Florinef inventory. Alternatively try pharmacies of other chains, or independent pharmacies.

<https://www.drugshortagescanada.ca/shortage/87124>

The following link will take you to the website of The Canadian Society of Endocrinology and Metabolism where a message on this topic may be found:

<https://www.endo-metab.ca/53-front-page/237-florinef-shortage>

Regional Representative news:

We are very pleased to share that David Sparks is now the Regional Representative for the Eastern Ontario Support Group. David was diagnosed 4 years ago- the fall of 2015, as he was starting veterinarian school. After bouncing between several different doctors, he finally was diagnosed by a doctor and ER triage nurse who noticed his odd “bronze” skin color and immediately tested for Addison’s. He has been thankfully stable since his diagnoses. David now works as a veterinarian in the Ottawa area and lives outside Carleton Place with his wife, daughter and six dogs.

For more information on upcoming meetings please click on the following link:

<http://www.addisonsociety.ca/support-group-meetings.html> Eastern Ontario as well as nearby Quebec members are encouraged to support the group by attending this meeting.

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

**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

**President’s
Comments**

president@addisonsociety.ca

This issue of the Newsletter is a bittersweet experience for yours truly as it is my final “President’s Comments” contribution. The Society’s Annual General Meeting on September 28 will see my time in this volunteer position come to an end as my retirement from the Board of Directors becomes effective.

It has been a very rewarding experience over the last many years, first as Regional Representative, then Director, and over the last number of years as Director and President.

The Society has made many advancements during this time and there are many, many, dedicated volunteers across Canada that have made significant contributions of time and talent to make it all possible. Without their support and assistance, regardless of their role, the Society would not exist. Thank You!

To the incoming administration, I wish the best for you in your guidance of the Society going forward.

Support Group Contact Information & Meeting Reports

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

B.C. Lower Mainland Support Group Meeting April, 13, 2019 Minutes

Held at: Coquitlam Library 575 Poirier St Coquitlam BC. There were 19 members and speaker Ms. Prabh Mann R Ph. a pharmacist from Shoppers Drug Mar in attendance. The meeting started at 1 p.m.

Geoff Metcalfe chaired the meeting, welcomed everyone and reviewed the agenda. Juvena Burns introduced Ms. Mann and gave us a summary of her accomplishments. Ms. Mann is Juvena's pharmacist and she was pleased to be asked to speak with our group. She stated that a pharmacist's professional goal is good patient care and safety.

Ms. Prabh Mann's objectives in her presentation were as follows:

What is Addison's Disease: She showed us a chart explaining the complex interactions between the hypothalamus, the anterior pituitary and the adrenal cortex.

Treatment Options:

She listed the various drugs used to treat Addison's with quantity comparisons. She said pharmacists have the authority to switch drugs if there is a shortage or a recall. Her power point noted which drugs are short acting (i.e. Hydrocortisone 4-8 hours); intermediate acting (prednisone 12 – 24 hours and which are long acting (Dexamethasone – used only for certain indications based on clinical experience). She stressed making very small adjustments to medications to avoid trouble.

- A member stated that we can request unopened bottles of hydrocortisone (100 pills) to ensure we can trace the lot # if there is a drug recall.
- A member suggested keeping a drug supply six months in your home.
- A member asked about the shelf life of Florinef. Once placed in weekly pill boxes the drug is no longer refrigerated. Ms. Mann wasn't sure but believes that only really high levels of heat would cause rapid deterioration of Florinef. However, she recommended that Florinef be stored under refrigeration.

Drug Interactions:

- Some antibiotics, antifungal and estrogen drugs will increase corticosteroid in blood levels.
- Phenobarbital, phenytoin, rifampin will decrease blood levels.
- Short term use of antibiotic or high dosage of corticosteroids pose no major risk.
- Cholesterol drugs may increase joint pain and GI upset.

Food Drug Interactions

- Grapefruit juice can increase glucose, blood pressure

continued

BC - Lower Mainland Support Group *continued*

Drug to Drug Interactions

- St. John's Wort should not be taken at same time as regular meds.
- Activated charcoal reduces absorption of cortisone.
- DHEA not recommended for females as it is a male drug
- Some theoretical evidence that probiotics, melatonin, selenium, ginseng turmeric increase drug potency.

Possible Future Treatment Options for us to look forward to:

- Delayed release corticosteroids
- Implanted pumps
- Gene therapy

A member spoke about receiving immune system injections (IVIC) on a regular basis as their doctor did blood tests and discovered she was in need. Ms. Mann agreed that a blood test was available for people who may suspect low immunity problems. Ms. Mann will answer any further questions via her email at prabh@shoppersdrugmart.ca. If members wish to have her dispense their drugs, she can be reached at 604-395-1410. Geoff thanked her for her interesting and informative presentation.

Solu-Cortef injections Practice. At 2:15 Judy Whittaker took the floor and distributed equipment so everyone could practice preparing and administering Solu-Cortef. We were advised to always take the shot when in doubt. When feeling terrible never lay down and delay giving yourself a shot.

Progress on Paramedics being able to give Solu-Cortef injections.

(Ed. Note: This article is B.C. specific only).

Gerry Ott took the floor to give us an update. He said without concerted effort on all our parts to continue to write letters and contact our MLA's this project will not move forward. Legislation must be enacted to make the changes which we urgently need. We should contact as many persons of influence that we can including Health minister Adrian Dix.

He shared Tom Shypitka's (MLA for Kootenay East) speech to the BC legislature about the importance of paramedic's ability to save a life by injecting Solu-Cortef and urged us to write to Tom to congratulate him for speaking on our behalf.

Contact info is:

Tshypitka@leg.bc.ca mail will go to him directly.

tom.shypitka.MLA@leg.bc.ca, will go to his secretary

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Our previous letter writing campaign needs to be followed up with very personal letters – not boilerplate – to have any effect. Contact your own MLA and get them involved. Find your MLA at www.leg.bc.ca/Pages/BCLASS-Member-Search. Gerry told us that people at the Health Authority will change in December so write soon. Addison's patients are not the only steroid dependent group. There are a good number of other conditions which would require emergency injection, and this obviously increases the demand for the changes.

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BC - Lower Mainland Support Group *continued*

Gerry Ott will be forwarding information that we can include in our letter writing.

Members of the Canadian Society of Endocrinology and Metabolism and the Canadian Paediatric Endocrine Group are also writing letters.

Gerry reminded us to request a Green Sleeve from the Health Authority to keep our medical information in. The Green Sleeve should be placed on our refrigerators for use by paramedics. Take it with you on holidays and when going to the hospital.

Geoff Metcalfe thanked everyone for coming and adjourned the meeting at 3:10pm. A member thanked the organizers for a very well prepared and run meeting.

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

Alberta - Support Group

The Alberta group of CAS held their spring meeting in Airdrie on May 25. Once again, we had great cooperation from a local restaurant which allowed everyone to enjoy a tasty buffet while having the use of a private meeting room from 11am - 2:30pm. There were six new members in attendance. I was unable to attend this meeting in person because of having a knee replacement on May 22 so I am very grateful for the efforts of those who ensured it ran well in my absence.

The main focus of the meeting was all things pharmaceutical - a session ably led by our in-house pharmacist Dallas Foulston. The presentation covered a quick review of primary adrenal disease (Addison's), secondary disease (pituitary) and tertiary disease (hypothalamic), then a quick review of the 2 main glucocorticoids we use for replacement, and the differences between them (potency, mineralocorticoid activity, biological half-life), then what glucocorticoids do (very brief rundown) including metabolism and immune effects. then we covered speed of absorption and when it matters, including food versus empty stomach, sublingual absorption, and subcutaneous versus intramuscular hydrocortisone. then talked a little about fludrocortisone and mechanism of action, then about refrigeration of the Canadian product and implications for travel (all 3 US brands are heat stable from my understanding). Lastly, I spoke about 3 different natural products (DHEA, melatonin and vitamin B12). There were lots of questions asked and answered so the discussion around the table was very good.

One question which came in after the meeting was "whether the Cortef pills, when split, degrade as a result and if so, how long before they become less effective". And the answer: "the tablets once split don't degrade any faster. The Cortef tabs are meant to be split (they are scored) and have no special coating that is protecting the integrity of the tab."

There was input from the significant others (all male, plus two parents). One husband expressed his relief at being in a room full of people who understand what he and his newly diagnosed wife are going through. Those who accompanied members had a good discussion together.

Continued

Alberta - Support Group *continued*

There is starting to be some localized interaction separate from the main group. Those in the Calgary area who have regular coffee/pizza meet-ups reported on how it helps us - also that we have a Messenger chat where

those of us who might be facing a weekend alone or are feeling ill etc. can report in and have the rest of us able to check up with them. We also started a chat to report exercise goals and so on.

Those from north and Edmonton talked about having similar coffee meetups. It is especially good for those newly diagnosed to get a chance to chat with those who have had AI longer. Obviously, members who live in smaller centres or more remote areas do not have the same opportunities for interaction, but small groups could still organize on messenger for support as above if they wished.

Topics for future discussion that arose:

1. positive best experiences since being diagnosed. Some cited travel, others just happy at having learned how much is too much and how to balance activity and rest.
2. It seems some of those who have secondary AI struggle a bit to feel well and could perhaps use extra information and support so that maybe something to bring up next meeting or we could suggest resources via the FB group. Possibly a small cyber group among the SAI patients would be an option.
3. We could each tell a story or two about how we coped with different stressful situations that triggered or almost triggered a crisis (like surgery, food poisoning, etc.).

The date for the fall meeting is Saturday October 5 in Rocky Mountain House. The main presenter will Renee Nuttall speaking about the Alberta Healthy Living program.

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

Saskatchewan - Support Group

While the Society does not typically promote commercial businesses, Elizabeth Hill, a Society Director, has submitted the following information regarding a car belt accessory which she believes will be of interest to those with Primary Adrenal Insufficiency/Addison's.

https://www.etsy.com/ca/listing/630790838/addisons-disease-help-belts?ref=shop_home_feat_5

On the same site you will also find accessories with the term Adrenal Insufficiency. Follow this link.

https://www.etsy.com/ca/search?q=adrenal%20insufficiency&ref=auto-1&as_prefix=adrenal%20insufficiency

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 September 28th
College Avenue Church
22 Wilson Street
Woodstock, ON

Please note: This meeting will include the AGM which will be a brief business session.
Members may refer to the Annual General Meeting mailing they received this past week.

Registration: 12:30 and the meeting will start at 1:00pm (to 4:30pm)

Guest Speaker: Dr. Stan Van Uum

Dr Van Uum is the Assistant Professor in the divisions of Clinical Pharmacology and Endocrinology and Metabolism at the University of Western Ontario (Western). Dr. Van Uum's clinical practice is located at St. Joseph's Health Care, London, and is focused on endocrinology, with a interest in pituitary and adrenal diseases, and secondary hypertension.

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 Woodstock on September 28th. Safe journey!

For further information on the South-Central Meeting please contact: Harold Smith.
president@addisonsociety.ca

Ontario - Eastern Support Group

The Eastern Ontario Support Group met in Bells Corners, ON, this past Spring for a meeting which saw 3 new members attend and one past member along with several family support members. The meeting was a great success, and all members enjoyed sharing diagnosis stories and discussing challenges and success-tips for living with Addison's. The ever-present injection clinic was educational and very constructive as always.

The group is in a place of transition as new members join while older members are proving challenging to re-recruit. The Fall meeting is tentatively slated for Sept. 28 in Carleton Place, ON and will include a video feed of the AGM and of the keynote speaker from that meeting. All members welcome! See you all there. Further details to follow on website and by email as the date approaches.

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 was recently diagnosed with breast cancer both DCIS and invasive. I had a successful partial mastectomy surgery with clear margins to remove the cancer from both my breast and one sentinel axially lymph node. The pathology is Stage II, pT2 pN1a, hormone receptor positive and HER2 negative. I will be doing adjunct radiation therapy and hormone therapy, but the medical oncologist is recommending chemotherapy as well. My concern is how the chemo will affect me because of my Addison's. I know from lived experience that my reactions to just about everything are not that of a typical person simply because I am taking replacement glucocorticoids. The opinion of the medical oncologist is that because I take replacement medications my response should be just like anyone else but I have never found this to be true in any other situation so I have no reason to believe it suddenly will be in this instance. The oncologist freely admits he has never treated an Addisonian with chemo before so therefore he really has no idea how I might respond. Also, my endocrinologist has never had one of her Addison's patients treated with chemo so, she too, has no experience of what may happen. I am very concerned about the potential side effects of chemo with my having Addison's and feel that the risk to my life as well as my overall quality of life even long term is not worth the risk. I would appreciate any insight or experience that could be shared as a medical professional with experience with Addison's and, hopefully, specifically as it relates to cancer treatment. Thank you so much. I look forward to your response.

Response 1

I understand your concerns, particularly since you have had some experience with difficult responses in the past. The suggestion of your oncologist to have chemotherapy would have been made on the basis of studies which have shown that this approach would provide you with the best long-term outcome for your type of cancer. When someone who does not have Addison's disease is treated with chemotherapy, it is a stress to their system, and their adrenals respond by increasing cortisol secretion to respond to the stress. This response will be different in different people, but the adrenal response will be appropriate for each person,

In your situation, the oncologist would have made the suggestion for chemotherapy with your best interest in mind. If you decide to go ahead, you would have to anticipate what would occur in someone with normal adrenal function and alter your cortisol treatment accordingly. This should start with a discussion between the oncologist and the endocrinologist to review what sort of effect the chemotherapy generally has, because different chemotherapy has different effects and then come up with a plan for increasing your cortisol to deal with your chemotherapy. I am not sure what type of chemo you will be getting, IV, oral daily, Oral weekly etc. The plan should include a cortisol increase with each treatment and the amount can be adjusted to help you deal with the situation. for example, you could double the daily dose on the days of your oral treatment or get IV Solu-Cortef on the days of your IV treatment. The magnitude of the increase will depend on how you respond. Good luck with your discussions with your endocrinologist. Let us know how things go.

continued

Question 2

Can having the flu vaccination cause someone with Addison's to have an Addison's Crises?

Response 2

It is recommended that everyone get a flu shot and that includes individuals with Addison's disease. The risk of complications is very low and is the same in individuals with Addison's disease as in the general population. Feeling unwell for a day after the flu shot is not uncommon and serious side effects occur about one in a million individuals. People with Addison's disease should monitor how they feel after a shot and respond as they would in any stress situation if it occurs.

Question 3

I have had Addison's disease for 36 years. I am in good health otherwise. Should I update some of the vaccinations I had as a child. I am especially concerned about the measles that seem to be spreading.

Response 3

Great question. Vaccination is so important, and it is a shame that there are people who jeopardize their health and the health of others by not getting vaccinated

Adults should get tetanus and diphtheria vaccine every 10 years and, for hepatitis A and B particularly if they are travelling, for shingles if they are over 50 and pneumococcus if they are over 60.

The effect of vaccines you got as a child, measles mumps chicken pox, rubella can wear off so you should check with your family doctor about what you have had and when you had it to see if you should get a booster.

In this regard, individuals with Addison's disease are like everyone else.

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

Hello All,

My name is Carolynn Yeates and I thought I'd share Kyle's story. Kyle is my now 20-year-old son with Addison's Disease and Hashimoto's. (Dual Diagnoses a year ago).

When Kyle was 14, he approached his dad and said: "I think I have a brain tumor. Something is wrong and I can't seem to understand what is going on at school like I used to". Dad's response: "Stop playing so much video games, focus more on schoolwork, and you'll be fine". At 15, Kyle's athletic abilities really started to decrease. He was upset and our response to him: "Kyle, not everyone is an athlete". As Kyle continued to lose weight... I encouraged him to "eat a sandwich". (More than once). In grade 12, we were called into a meeting with the school principal and two of his teachers. They were concerned about Kyle in school as he was obviously trying, but not succeeding as he should for the amount of effort. They let us know that he had been emotional in class and that was concerning. We didn't understand why he was struggling, and we worried about his mental state.

Skip ahead to University. Kyle is a Physics major in his first year. He did go into the clinic at school to report he wasn't feeling "right". Appreciating that "right" is hard to discern, the physician suggested he exercise more, eat better and get more sleep. School did not go well. We had that conversation with Kyle; "Maybe Physics isn't for you". For all those years Kyle continued telling us that something was wrong. We didn't listen.

Kyle's health was declining at a quicker pace. He stayed at school and when he returned in April he was a shadow of himself. We went into our family doctor and she quickly deduced he had Hashimoto's. He was put on meds for that. Within a week he could no longer walk and forming a sentence was a challenge. I rented a wheelchair for him just to get him from point A to B. He could not get out of bed. It had been a while since he took a shower. It was a quick decline with us ending up in our local emergency room. Our family physician had done more blood work and called to direct us to the hospital immediately. She told us to bring a copy of the bloodwork. His sodium at that point was at a 0, while his potassium was a 6. We were sent home from that visit with the instructions to drink less water and follow up with our family physician. He had probably drunk too much water and it caused his sodium loss was the explanation. (He HAD been drinking a lot...).

Next day our family doctor called us before we called her. I advised her we were back at home. She directed us to go immediately back to the hospital. She would call ahead this time. Arriving at the hospital with Kyle he was now vomiting and unable to communicate at all. Thankfully our doctor called ahead, and we were very well received. We were told Kyle had Addison's Disease. When I told him what he had (once he was back to his old self following the administration of IV Fluids and steroids), his first words were: "Can you get me back into school?". (He had failed out sadly).

Skip forward a year post diagnoses. Kyle is back in University. A Physics major which he loves. Doing very well. He has struggled with moments such as exam time and is working on adjusting managing his having Addison's. Is this a time he needs more sodium and hydrate, or is it an up-dose time? He's working on it and figuring it out quite well. He is physically active and "works out" regularly. He scuba dived for the first time, post diagnoses. He now rock climbs. Free Hand. He has gone back woods camping and lives in a messy house with 5 other students. He is doing as any 20-year-old should be doing at this point in their lives.

continued

Personal Experiences *continued*

