



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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SPRING 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:

**It has been mentioned in some of the online support groups that there is a Florinef shortage in the US. This is not an issue for us in Canada.*

Newsletter Editor news:

Some Newsletter readers will be aware that our Editor Stacey Doherty has advised she is unable to continue in this important role. We are very grateful to Stacey for the effort she has put forward in tackling this important position. On behalf of the Society members and other reader's, thank you Stacey! Many look forward to receiving the Newsletter and your contribution of time and talent has been appreciated by all.

We are now pleased to introduce member Carolynn Yeates who has stepped forward to take over the Newsletter Editor role, at least for the immediate future. This Newsletter issue is Carolynn's first. Welcome Carolynn.

Regional Representative news:

Although Carolynn resides in Central Ontario, she is a frequent visitor to eastern Ontario and has also volunteered to act as a 'temporary' Regional Representative for the Eastern Ontario Support Group until such time as we are able to confirm a Rep, from the area. As a result, Carolynn has been very busy to insure the group has its first meeting in some time, on May 4. Please follow this link for details on the meeting. <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, Carolynn, for helping the Society by stepping up to these very important responsibilities.

**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 forward to newsletter@addisonsociety.ca

**President's
Comments**

president@addisonsociety.ca

Website updates:

We are excited to advise of the very recent upgrades to our website. While the general appearance has not changed dramatically, with the leadership and talent of our webmaster we have significantly improved accessibility of several of the most visited sections of the site. In addition, a Bulletin Board feature now appears front and centre on the Home Page. This BB content will change as news of interest to all, comes to our attention. In addition, we hope our French Speakers find the site a little more user friendly as more of the site may now be translated to French using a third-party service for instant translation.

Canadian Addison Society telephone:

If you have recently contacted the Society through our 1-888 telephone number, you will be aware that we have introduced a bilingual answering service. We are assured that all calls will be answered by a real, live human, not a recording. While the answering agent will be able to assist with basic inquiries in English or French, a few key Society admin individuals will make themselves available as much as possible for a direct live patch when required. This includes one Society French Speaker. If we are not available, we will receive immediate electronic contact information of your call. We assure you of contact within 24 hours. Please be aware that we are all volunteers. Also be aware that we are not a 24/7 medical hot line. If urgent medical assistance is required, you should use your own judgement and consider either contacting your Healthcare Provider(s) or proceed to the nearest Emergency Department for care.

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

The next meeting for the BC- Lower Mainland Support Group will be as follows:

April 13, 2019 at the Coquitlam Public Library
575 Poirier St. Coquitlam, BC

Guest Speaker: Prabh Mann. Pharmacist and Certified Educator of Patients.

Ms. Mann will be discussing the various medications that Addison's patients must take and how they can interact with other medications and supplements.

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

Alberta - Support Group

The next meeting for the Alberta group is as follows:

May 25th – 2019
Pasta La Vista. In Airdrie.
(Conveniently located just in the west side of the QEII)

Similar format as previously. Individuals are responsible for the purchase of their own lunch. We will have a separate room, and programming will be both before and after the meal.

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

Saturday May 4th at Erin Mills United Church (Lower Hall)

3010 The Collegeway. Mississauga, ON.
SW corner of Winston Churchill Blvd & The Collegeway.
S of 403.
Free Parking and Public Transit avail.

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

Speaker at the meeting to be confirmed. Watch the website for updates.
<http://www.addisonsociety.ca/support-group-meetings.html> *article continues...*

Ontario - South/Central Support Group...continued

This year Erin Mills Church is holding a Garage Sale (not associated with the Canadian Addison Society), in the parking lot on Saturday morning. We expect that this will be finished by our start time, but feel free to come earlier if you would like to shop!

Can you help us at this meeting? Room set up and tear down requires volunteers. It is always appreciated if you are able to 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, May 4. Safe journey!

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

The next meeting of the Ontario Eastern/ Western Quebec Support Group will be as follows:

Saturday May 4th at Bells Corners United Church
3955 Old Richmond Road
Nepean, ON K2H 5C5

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

Please do contact our interim Regional Representative: Carolynn Yeates at carolynny@rogers.com or 705-431-8437 to confirm your attendance.

We are searching for a volunteer to take on the Regional Representative role in the **Ottawa** Region. If you are interested, please contact carolynny@rogers.com or 705-431-8437

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.

In the interim, if you are trying to connect with the Society for support please call 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.

Question 1

I am presently taking an anti-depressant. I am just seven weeks in, and still struggling. I saw my doctor yesterday and he increased my cortisol medication for my Addison's. This morning I woke up very depressed. More so than I have been. Is not the purpose of an anti-depressant, to decrease the cortisol and now I have MORE cortisol in my body? Should I go back to what I had been taking previously? Thank You.

Response 1

The problem of depression and anxiety is complex, and it is known that specific medications can affect these behaviors, but the underlying causes are not well understood. It is true that stress increases cortisol levels, and chronic stress can increase cortisol level chronically, but changing the dose of cortisol replacement would be unlikely to affect anxiety and depression. The drugs currently used for treating depression affect the uptake of serotonin and generally do not affect cortisol secretion and blood levels.

Question 2

My 14-year-old has been on prednisone (range 3-5mg) for the past 12 years to treat an inflammatory condition. We just found out she has Secondary Adrenal Insufficiency. In August she was tested, and her morning cortisol level test results were 21 nmol/l. We now have to stress dose in case of sickness and have been taught how to administer Solu-Cortef. However, yesterday she missed her usual dose that she usually takes at 8am. She took it after school at 5pm. I asked her if she had any symptoms and she said she felt fine all day. No low cortisol symptoms. She did gym class etc. My question is: Can someone with Adrenal Insufficiency function without any symptoms if they missed a dose? Would she normally have low cortisol levels? Thanks

Response 2

The dose of 3-5mg of prednisone a day would be enough to replace most of the cortisol that your daughter's adrenal is making but probably not all. Her adrenal may be able to secrete a certain amount of cortisol under basal conditions but may not be able to respond to a stressful situation as an injury or infection. The less prednisone she requires to treat her inflammatory condition, the less suppression of the adrenal will take place. As long as she requires the prednisone for her inflammatory condition, you would have to assume that her response to stress may be decreased and she would require added prednisone to deal with the stress. It is possible that her adrenal function is satisfactory for day to day situations, but she would only need added prednisone to respond to more demanding situations. You would have to review this with her endocrinologist before making any decisions.

Question 3

I have Polyendocrine Failure (Schmidt's Syndrome). For my Addison's, I typically take 20mg of hydrocortisone in the am and 10mg around 1:30pm. For a sustained amount of time, (off and on for 2 years), I have taken 25mg (and 30mg for stress doses) in the morning, 10mg at 1:30 and then another 5mg around 5pm. I had started to get a buffalo hump, weight gain around my stomach, and easy bruising. Last week, my blood pressure spiked and has stayed elevated. My ACTH was very low, (less than .1) and my glucose was high. It is possible to get Cushing's Disease Syndrome temporarily from taking too much hydrocortisone. I understand that Cushing's Disease is basically the opposite of Addison's, but I wasn't sure if the Syndrome could be triggered by taking too much cortisone for Addison's as well? Thanks.

Response 3

You have pointed out a very important point about cortisol doses in treating Addison's Disease. The lowest dose of cortisol that makes you feel well is the right dose for you. Stress dosing should be reserved for situations where there is a true stress which can be both physical or emotional. If we take extra cortisol frequently, we can develop symptoms of too much cortisol which is Cushing's Syndrome. The fact that your ACTH level is low, is an indication that you are taking more cortisol than you need. In general, if you measure your cortisol first thing in the morning before taking your cortisol, your cortisol will be low, and your ACTH level will be high.

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 there,

My name is Jessica Slaney-Grant and I am from St. Lawrence, Newfoundland. In 2010, my mom was diagnosed with Addison's Disease. I recently got married and at our wedding we decided in order to get myself and husband to kiss we would set up a donation box and people would have to make a donation to this very generous cause. We were very grateful for all the lovely people at our wedding and we were fortunate enough to get \$650 in donations. This is the one I just made. I just wanted to include a little recap of our story to go along with the donation.

Back in 2008, we began to notice that my mother was becoming ill. We went to several doctors all over the province and no one was able to help her. She began to deteriorate into nothing. She was this very bright vibrant person who was becoming a couch potato with no energy and no desire to enjoy life. She was sick. After being told many times that my mother was anorexic and that we needed to feed her and force her to eat, things were very frustrating for my entire family. I went from having a very healthy mom who loved coming to watch me play sports, perform in drama and was very involved in my school life, to a mom I had to visit in the hospital all the time, who lost close to 100 pounds and to a woman I had to take care of every day. Let's jump ahead to May 2010. Being a 16-year-old girl, getting very excited for her high school prom, my dreams of what my prom would be started to fall apart very fast. My mother didn't know many things or people for a few months at this time, we knew that there wasn't much more time with her. We were ready to say our goodbyes. We were told that there was nothing else that could be done for my mother. She was going to die. This was when a girl who was getting ready for her prom, was now getting ready for a funeral. We were very fortunate that a doctor who was working at the clinic in St. Lawrence was celebrating a prayer week for his culture. He went to his office and prayed that something would break through for her. He wanted something to work for her. He prayed for a fix! He then came to our family, knowing that she only had about a week to live and tried one medication. This was supposed to make my mother hyper and hungry and instead she slept. She had no idea who we were, she didn't eat, drink or wake up. This was when the magic happened. He knew that my mother's adrenal glands were not working. He knew how to fix this. And this is exactly what he did. We went from having 190-pound women to 94-pound women. But only TWO short days after being medicated, it was like my mom returned to her normal self. She wanted to jump over the moon. With lots of family support, and medical support, she was going to be fine!!!! Let skip now to 2018! My mom is 100% back to her old self with the help of some medications which we can handle. With many prayers and thanks, I went from a 16-year-old girl who thought my mother wouldn't make it to my prom, to a 25-year-old girl with her walking me down the aisle.

Thank you so much for promoting and helping people be aware of this scary disease. It is people like you who raise the awareness and may help a family get through it like our family did!

I have attached a few pictures of her at my prom and then her at my wedding!

