The Canadian Addison Society
La Société canadienne d'Addison

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PLEASE NOTE: The content of this newsletter is intended for basic information only and not as personal medical advice. Readers are advised to consult their own doctors before making changes to their Addison management program. Please note that the Society does not endorse the information provided by guest speakers.

News and Announcements

We are very pleased to officially welcome **Rick Burpee** as the Canadian Addison Society's new **Secretary/Treasurer** effective February 1, 2015.

Presidents and Directors come and go with elections, but the Secretary/ Treasurer position provides that essential continuity to The Canadian Addison Society year after year. Rick has just retired from his "Day" job as President of the Canadian Electricity Association and it is our very good fortune that he is both willing and most able to take on this very important role for the Society, on a volunteer basis.

Rick and spouse Denise, have been dedicated Society members attending Support Group Meetings in South Central Ontario for many years in support of their son Derek who has Addison's Disease.

Denise, as a retired RN, BScN is also deeply involved as the leader of the group's Emergency Injection Clinics which are a feature of every meeting of this large group. Derek, as a young Addisonian is about to embark on a new venture for the Addison Society as the first Chairperson of the newly formed Youth Advisory Council. As such, he will be connecting with young people with Adrenal Insufficiency, across Canada.

The Burpee family are clearly heavily invested in support of The Canadian Addison Society. On behalf of all members we thank each of them for their willingness to step forward and participate as volunteers in taking the Society forward into the future

Addison Society Office Relocation

After many years in Goderich, Ontario, The Canadian Addison Society is relocating its office to Etobicoke, Ontario. This is the result of the retirement of Irene & John Gordon. Our new Secretary/Treasurer. Rick Burpee is located in the Etobicoke area. As you may expect, there are many logistical matters being attended to and many volunteer hours invested in order to achieve what we hope will be a seamless transition. Please note that the Society's 1-888 Toll Free Phone number will not change.

New Logo & Website… *have you seen it?*


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The Canadian Addison Society

Welcome to The Canadian Addison Society

Welcome to our new look. We hope you like it!!

News

Donate Now to The Canadian Addison Society

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Rare Disease Day

Membership Info

Meetings

Newsletters

We are excited to have our new design website www.addisonsociety.ca officially up on the web, as of January 5, 2015. This is the first redesign in recent memory, if ever, and it was well overdue. The content is virtually identical to the old site and we will be making additions and improvements to that content over time. One important last minute improvement was the addition of the International English/French translation buttons. The webmaster is still fine tuning this as some small discrepancies appear in the translation but we hope many will find this new feature to be helpful.

Other coming improvements include increased Educational information. We were very fortunate to have been the recipient of a recent donation from Pfizer Canada which supported this website redesign and will be instrumental in the development of further Educational information during this year, promoting increased awareness and knowledge of Addison's/Adrenal Insufficiency with Patients, Educators and the Medical Community in Canada. All part of our Community Awareness Campaign.

The Canadian Addison Society Youth Council

We are pleased to announce the formation of a new Committee within The Canadian Addison Society to represent youth with Adrenal Insufficiency. This committee, in the planning phase was to be named The President's Youth Council. It was announced at the AGM last September in Brantford, Ontario. At that time the first Chairperson of this Youth Council, Derek Burpee was introduced.

Derek has been busy since that time working with the President and the Executive to establish the committee objectives and mission. While Derek is the first chairperson, the group will establish its own succession plan to insure the chair role is rotated on a formal and scheduled basis. The committee will be working to attract members from across Canada.

Attention Members:

Please remember to renew your annual membership in the Society for 2015

$25.00 is due in January

Your membership fees are important to the ongoing operation of the Society and our ability to continue making resources available to members. You will find the necessary membership renewal form at the end of this newsletter, or online at www.addisonsociety.ca.

Thank you for your continued support.

President's Comments

You will have noticed from previous articles, that it has been a very busy 4 months at The Canadian Addison Society since the Annual General Meeting in September. As you have just read, Rick Burpee is ready to take the reins of his appointment as our new Secretary/Treasurer and in another article you were introduced to the new Youth Council which has become a reality. In addition, the Society has just introduced a new modern version of our logo as well as the complete revitalization of the Society's website.

These are huge accomplishments achieved in a short period of time, primarily by volunteers plus our new webmaster and designer. Thank you to everyone that may have had a hand in bringing these changes and new ideas to fruition. They are all done with the view to offering support to more folks with Addison's and Adrenal Insufficiency in general. They also contribute to our Community Awareness Initiative whether the Community is one of Patients, the Medical Community, The Educational Community and others. Each community is important, each from a different perspective possibly, but all in support of patients with Adrenal Insufficiency.

Newsletter Editor

Another call for photos please to fulfill requests we have received to add more photos to the Newsletter so members may put a face to a name. Please remember to identify who is in the photo.

Please consider sending me your articles about your experience either as the patient, caregiver, family, friend, nurse, doctor or anyone else with a connection to Adrenal Insufficiency. Each of you has a story that may support and help someone else understand what is happening to them.

You may reach me at newsletter@addisonsociety.ca. Thanks, Carrie

The Canadian Addison Society Youth Council

As you have probably heard, we are in the process of establishing a new group within the Society this year: The Canadian Addison Society Youth Council. Our mission is to increase the participation of young people with adrenal insufficiency in the society by ensuring it's relevant to their needs and interests.

Along with identifying existing barriers to youth participation, one of our first efforts will be to increase The Canadian Addison Society presence on social media. Establishing (and maintaining) official Twitter and Facebook pages will hopefully allow us to reach more people, while also providing new, less formal ways to interact with the Society.

If you are under the age of 35 and interested in joining the Youth Council, please let me know! I will be the first to admit: it took me a while before I was comfortable attending meetings or interacting with the Society at all. Little did I know just how much information and support it would give me over the following years. I'm so grateful I finally decided to get involved and I'm hoping this committee can help do the same for others. I'm excited to be chairing this new pursuit and looking forward to hearing from anyone with ideas or suggestions.

Happy New Year!
Derek
derekburpee@gmail.com

Support Group Meetings:

Vancouver Island Support Group – Victoria

Submitted by Jim Sadlish

The Vancouver Island support group will meet **Saturday, February 28th**, at 1706 Sheridan Avenue in Victoria. For directions to the meeting please see http://vancouverislandaddisonsgroup.weebly.com/meetings.html

For further information on the Vancouver Island Support Group, please contact Jim Sadlish at vanisleaddisons@gmail.com or (250) 656-6270. For information on Central Island activities, please contact Sharon Erickson at ericksons@shaw.ca.

BC Lower Mainland Support Group

Submitted by Judy Stanley

A letter has been sent to the BC Minister of Health from the BC Lower Mainland Support Group regarding Paramedics being allowed to inject patient's Solu-Cortef in a Crisis. Paramedics in BC can administer injections for various conditions i.e. diabetes, heart conditions but not Addison's. Administration of Solu-Cortef which could save a life but would do no harm if injected. We are waiting for response for further action.

As the Lower Mainland communities are so dispersed we will be setting up local meetings for members to discuss items regarding Addison's. They will report back on their concerns to a general meeting.

The next meeting of the BC Lower Mainland Support Group will be scheduled for **May or June, 2015**. Please watch the upcoming meetings page on the website at www.addisonsociety.ca.

For further information on this support group please contact Judy Stanley, (604) 936-6694 or bugbee@shaw.ca.

Alberta Support Group

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

Saskatchewan Support Group

For information on this support group, contact Elizabeth Hill at (306) 236-5483 kesahill@sasktel.net or elizabeth.h@pnrha.ca.2

South/Central Ontario Support Group

Submitted by Roger Steinmann and Harold Smith

The next meeting of the South/Central Ontario Group is tentatively scheduled for **Saturday May 2, 2015** at the Erin Mills United Church, Lower Hall Meeting Room, 3010 The Collegeway, Mississauga ON L5L 4X9 from 1:00 to 4:30 pm (registration at 12:30 pm).

This location is accessible by Public Transit (please check Saturday schedules).

Watch the "Upcoming Meetings" page on the website www.addisonsociety.ca for confirmation of the date and details on the agenda and speaker.

For further information on South/Central Ontario Support Group activities or meetings, contact Roger Steinmann in West Montrose at rdsteinmann@ehtel.ca or (519) 575-6590 or Harold Smith in Kitchener at hsmith81@hotmail.ca or (519) 742-8170.

Eastern Ontario Support Group

Submitted by Steve McKenna

Next meeting: **Saturday May 9th**, the weekend before the May long weekend in the usual location at noon.
Any ideas or suggestions as to what to do or who to invite?

CAS Members located in Quebec would be most welcome at our Ottawa meetings.

For information on Eastern Ontario Support Group activities or meetings, please contact Steve McKenna at steveandpat@rogers.com or 613-523-7648.

Québec Support Group

For information on the Quebec Support Group please contact Fiona Vickers. Fiona may be reached at fiona.f.vickers@gmail.com or 514-882-2613.

Atlantic Support Group

Holly Mclean is the Regional Representative for Atlantic Canada. She lives in northern New Brunswick. You may reach Holly at hquilter@nb.sympatico.ca or 506-546-1687

Medical Q & A:

There is a very large and wide-ranging set of questions on both daily living and situation-specific issues that have been answered by our medical advisor over the years. Before submitting a question to our medical advisor, please consult the wealth of Q&A's on our website. Many questions have already been answered.

To review these questions and answers, please go to the Canadian Addison Society website under Education http://www.addisonsociety.ca/files/pdfs/FAQNovemberb2011.pdf see previous issues of the newsletter.

Question #1:

I was first instructed to take 20 mg of Cortef in the am and 10 in the evening – this was awful. I woke up, took my Synthroid, waited an hour, took the Cortef, half hour later took the Florinef and then waited until 6pm to take the 10mg of Cortef - It was a terrible day, I was sore, ached everywhere, couldn't think or function and then was up all night.

I am newly diagnosed with Addison's and have been reading everything I can on the Addison's site and made a judgement call. I am on day 3 of new medications, Cortef in doses of 15 mg am 10 mg lunch at 5 mg at 5:00pm and Florinef ½ tablet in the am. In addition, I was put on Synthroid in July and told to take this first thing in the am on an empty stomach, and wait 1 hour before eating or drinking and 4 hours before I had calcium/magnesium, due to the absorption of the medication.

Medical Q&A-continued

Question #1: continued

I took the Synthroid 1 hour before I got out of bed and took the Cortef as soon as I woke up with yogurt and granola and then took the Florinef 1 hour later. I felt fine and this worked well. However, Monday I did not wake up in time to take the Synthroid before getting out of bed, so I took it when I got up, waited and hour and took my Cortef and Florinef but I could not get going for hours due to being tired, sluggish and just having no energy. It wasn't until after my dose at 12:30, that I was able to get to work at 1:30 in the afternoon. By 4 pm I was lethargic, tired, and my eyesight got blurry again.

I know it takes some time to work out the medications with their dosages and timings, but I was hoping you could give me some insight of what you would recommend. I tried the same timing today as I did on Sunday, but I have had low energy and feeling very tired all day and not thinking clearly. I went to my GP yesterday and he did some blood work on my electrolytes and thyroid as they were not tested since October.

I hope I have provided enough information to aid in receiving a recommendation from you. The endocrinologist told me I could take the Synthroid at night but I must take the Cortef first thing when I wake up, When I had the prescription filled, the pharmacist told me it must be taken in the morning first thing. I was also told that taking it in the evening may mean that eventually I will have my dose increased. As it has been a cumbersome week trying to figure out these timings I thought I would write to ask for your feedback.

My husband found a study on taking it during the evening and the success they found with it. I attached the link below. Would you recommend that I adjust to the evening or keep on a morning schedule as I have been? And what is the best time to take the Florinef. The doctor forgot to write a time on the prescription and the pharmacist wasn't sure what to tell me. I haven't heard back from them, so went with what I have read on the Addison's site about taking it in the am.

Also, I am allergic to many antibiotics and medications (anaphylaxis) and have had to take prednisone in the past to avoid an allergic reaction – do you have any recommendations on what to do if I were to have to take an antibiotic now that I have Addison's and am on the Cortef, and Florinef? Thank you so much for your help and feedback.

Response:

I am sorry that you are having so much difficulty with your medication. It really does not have to be such a problem. The biggest problem seems to be with the Thyroxin which should be taken at a time when you are not taking calcium or iron because the thyroid can be bound by the iron and be poorly absorbed. I know that everyone is told to wait 4 hours after taking the thyroid to take calcium containing foods. These are general guidelines but somewhat unrealistic.

You can take Cortef, Florinef and Thyroxin all at the same time when you wake up in the morning, wait about an hour while you get ready for your daily activities and then have your breakfast. Take your Cortef at noon and again later in the afternoon as you have been doing. Don't take your Cortef too late or it may make it difficult to get to sleep.

Review this with your endocrinologist so she/he can give you their opinion and if it is Ok give it a try.

Medical Q&A-continued

***Question #2*:**

I developed secondary adrenal insufficiency after taking a corticosteroid nasal spray for 3 years. The adrenal insufficiency was not diagnosed for 2 years following that, and I now have been on 30mg of Cortef for a year. Despite the Cortef, which does help with my energy level later in the day, I am not able to wake up in the morning before 11am. My blood cortisol levels at 8am are between 58-138, and they seem to drop and then come back up to that level again or a bit higher around 11am. If I try to get up at an earlier time and take my first dose of Cortef then, I feel nausea and am unable to remain awake until 11 no matter how hard I try. I have also tried combining my daytime dose of Cortef with 2.5 mg of Prednisone at bedtime, but this did not improve my morning cortisol level. Is this a common symptom of adrenal insufficiency, and is there anything I can do to get my mornings back?

Also, since my adrenal function did not recover during the 2 years after I stopped taking the nasal spray, and now another year that I have been on Cortef, is there a chance that it will ever recover? I did try to wean off Cortef recently by cutting back my dose by 2.5mg per week, but I felt so much worse that I was not able to sustain this process and went back to my full dose after 2 weeks. Should I plan for not being able to improve much from this point?

Response:

Your problem is one we see with increasing frequency because of the popularity of inhalers and the lack of adequate warnings about this problem. Getting off the puffers can be difficult but it is usually possible. It is interesting that you were off the puffer and not on cortisol for two years. That is about the time it often takes to gradually get off of the cortisol dependence. Why did you go on to cortisol after two years on no medication? Let us go back and see what has taken place:

You started using the puffer for a non-adrenal problem so your adrenals were working well at the time. You were probably using the puffer as directed twice daily- one or two puffs. The output of cortisol from your adrenal glands is stimulated by a hormone from the pituitary gland (ACTH). Each pulse of ACTH results in a pulse of cortisol from the adrenal. These pulses are more frequent starting about 4: AM so the maximum cortisol level is achieved around 8: AM. The pulses are less frequent during the day and evening so that at midnight, cortisol levels are quite low. There is cortisol inside the cells so we feel fine.

There is absorption of the glucocorticoid from the puffer. If this is used for a short period of time, the adrenal is not suppressed. With time, the pituitary is being exposed to the glucocorticoid from the puffer so it does not have to stimulate the adrenal so both the pituitary and the adrenal become suppressed.

You have to go through a prolonged period during which you are on slightly less glucocorticoid than you need so the pituitary starts to stimulate the adrenal to make cortisol. At present, you are on 30 mg of cortisol daily. This is a slightly supraphysiological dose of cortisol so there will be no real stimulation of your pituitary. The addition of prednisone adds more glucocorticoid but is not measured in the cortisol assay so does not show higher levels of cortisol when cortisol is measured in the morning.

Medical Q&A-continued

Response: continued

You should review the situation with your endocrinologist and get on a dose of cortisol on which you feel comfortable. This would probably be taking the cortisol three times per day e.g. 15mg AM, 10mg at lunch and 5mg at bedtime. You may try taking the AM dose about 4: AM so when you get up at 7 or 8, your cortisol level will be at its peak. You can then cut back by 2.5 mg a day each week starting with the supper dose. You may feel that you are not feeling quite so well for the first few days but this passes. Theoretically you can carry on with this until you are off added cortisol.

I must emphasize that you must review your situation with your family doctor and endocrinologist so they are aware of your problem and your attempt to improve it. They may have other approaches. If you follow a prolonged course, your adrenal function will return.

Medical Questions and Answers – Dr. Donald Killinger, MD, PhD, FRCPC, and Medical Advisor for The Canadian Addison Society will answer your questions about Addison's disease.

Send your question to Dr. Killinger directly from the webpage http://www.addisonsociety.ca/faq.html#,

Or by emailing liaisonsecretary@addisonsociety.ca

Or c/o The Canadian Addison Society, 2 Palace Arch Drive, Etobicoke, Ontario M9A 2S1

Questions and answers that may be of interest to everyone will be published in the newsletter and on the website.

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<u>Please check a box of your choice.</u> ** Tax receipts are issued for donations over $15.00.

☐ $25.00 to go to The Canadian Addison Society <u>OR</u>
☐ $5.00 to Eastern Ontario Support Group – ON + $20.00 to Society
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☐ $5.00 to Saskatchewan Support Group – SK + $20.00 to Society
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☐ $5.00 to BC Lower Mainland Support Group – BC + $20.00 to Society
☐ $5.00 to Vancouver Island Support Group – BC + $20.00 to Society
☐ $5.00 to Quebec Support Group + $20.00 to Society

Please mail your payment to The Canadian Addison Society c/o Treasurer,
2 Palace Arch Drive, Etobicoke, Ontario M9A 2S1

<u>Optional</u> (for newsletter mailing purposes if you wish to provide this information)

Endocrinologist Name____

Endo's Full Address/Postal Code____

ER Director of Hospital and Hospital Address_______________________________

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Revised: January 2015