



The Canadian Addison Society La Société canadienne d'Addison

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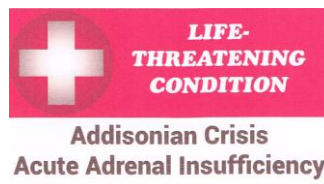
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PLEASE NOTE:

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/Adrenal Insufficiency management program. Please note that the Society does not endorse the information provided by guest speakers.

News and Announcements

New Member Card



We are very pleased to advise members that our newly designed Member Card is ready and attached for your immediate use. On this initial version, in order to put this into member's hands as quickly as possible, you will have to fill in your own name and the year to which your annual dues are paid. If unsure we suggest you either contact us to confirm the year or simply use 2016 as the default year.

Our Secretary-Treasurer, Rick Burpee, plans to have this form fully integrated electronically with PayPal by year-end so that when you pay your annual fee by PayPal, it will automatically generate a new Member Card for you with your name and the year already filled in. This new card would then be sent to you by return email. For those paying by cheque, manual preparation of your new Member Card will be required. It will then be forwarded to you by email.

Upon receipt you will cut and fold as per the instructions printed on the form resulting in a wallet size document that expresses more of an urgency and includes instructions not represented on our current card. The instructions include elements derived from the Hospital Protocol featured in our Emergency Documents section of the website.

We have had very positive responses from everyone that has reviewed this document including from the medical field. We hope it will assist you in your efforts to impart that very necessary, critical and potentially life-threatening, sense of urgency needed, with Paramedics/Triage/ER Nurses/ER Physicians.



Editor's Comments

newsletter@addisonsociety.ca

Brazilian Addisonian seeks Canadian Addisonian Pen Pal to compare common experiences

We have received a request from an Addisonian in Brazil seeking correspondence with an Addisonian in Canada who may also have hemochromatosis and possibly rheumatoid issues to compare experiences. Please contact Cristina Fischer directly via email: cristinaft@osite.com.br.

Personal Experiences

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 send to me at the email address shown above. Thanks, Carrie.



President's Comments

president@addisonsociety.ca

Membership Renewal for 2016 past due

We hate to raise this matter however If you have not yet sent in your membership renewal for 2016, we ask that you please do it now. You can check the Home Page of the website <http://www.addisonsociety.ca/> for options on using your credit card through PayPal or you may still use the traditional hard copy/via Canada Post method. Both options are available to you. Please also look at your options to pay for one, two, or five years. We are most appreciative of your ongoing support.

Progress at the Society continues...

We are excited to launch our newly designed Member Card in this issue of the Newsletter. We hope you like it and that it works for you. This is another major step for the Society and follows the launch last fall, of the new information brochure which has been very well received. Prior to that, our newly designed website was launched in January 2015 and has proven very effective and helpful to those seeking information and/or support. These are huge achievements for an organization that functions as the result of the efforts of volunteers only. Busy times at the Society continue.

Support Group Contact Information & Meeting Reports

B.C. - Vancouver Island Support Group

Meeting Minutes – 20 February 2016 (revised March 10) – Vancouver Island/Victoria Support Group

Five members of the Vancouver Island Support Group met on February 20 in Victoria. Although the turnout was lower than expected an in depth discussion of numerous adrenal insufficient issues took place. Our apologies to anyone who didn't receive an email advising of the meeting. The email and contact transfer from Jim to Derek didn't go as smoothly as expected. The meeting was hosted by one of our local members and our thanks go out to Allison.

Replacement hydrocortisone levels continue to be an item of large concern to the Addison's group. It's always interesting to note that no two people have the same Cortef requirements.

Jim updated the group on the use of Strontium as a dietary supplement. Strontium is an earth metal that is usually consumed in tablet form as strontium chloride. A special form of strontium called strontium ranelate can increase bone formation and prevent bone loss when used in postmenopausal women with osteoporosis. It's not known if strontium contained in dietary supplements has these effects. It had been rumored to have been helpful in building bone density and increasing collagen and cartilage in bone joints. It seems very clear now that products contain either strontium citrate, strontium gluconate or strontium lactate should be avoided.

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B.C. - Vancouver Island Support Group – continued

Health Canada now recommends you do NOT use a strontium-containing product if you have, or are at high risk for heart disease, circulatory problems, or blood clots. Risk factors include: a history of heart disease, heart attack, stroke, peripheral arterial disease, high blood pressure, high blood fat levels, diabetes, taking prescription hormone drugs, or if you are temporarily or permanently immobilized. As always, if you have any cardiovascular risk factors, read the label of products you are taking to know if they contain strontium.

Several of the people present noted that they have had abdominal pain when nearing an Addison's crisis. Victoria Endocrinologist Dr. Richard Phillips has confirmed that abdominal pain is a well-recognized symptom of impending adrenal crisis. He also notes that some (people) are mistaken to have an acute abdomen.

Some question of the link between Addison's disease and Diabetes took place. Diagnosis of more than one endocrine disorder is often referred to as Schmidt's syndrome.

Our next meeting is planned for May. Date and details to be advised via email.

Addison's Abstract February 20, 2016

- 1) Diagnosis and management of adrenal insufficiency Authors- Irina Bancos, Stefanie Hahner, J. Tomlinson and Wiebke Arlt, Birmingham, UK
<http://www.sciencedirect.com/science/article/pii/S2213858714701421>
- 2) Beneficial effects of replacement therapy with modified-release hydrocortisone in patients with adrenal insufficiency Authors- Valentina Morelli, Erika Messina & Anna Spada University of Milan, Italy <http://www.endocrine-abstracts.org/ea/0037/ea0037EP53.htm>
- 3) Is DHEA replacement beneficial in chronic adrenal failure? Authors: Katherina Lang, S. Burger-Stritt & Stefanie Hahner, University Hospital of Wuerzburg, Germany <http://www.sciencedirect.com/science/article/pii/S1521690X14001195>
- 4) Comorbid Latent Adrenal Insufficiency with Autoimmune Thyroid Disease Author - Yamamoto T. of Yao Tokushukai General Hospital, Yao, Japan - Full Text <http://www.karger.com/Article/FullText/433532>
- 5) Management of adrenocortical insufficiency with continuous subcutaneous hydrocortisone infusion: long-term experience in three patients
Authors- A. Khanna, D.W. Ray 1 <http://www.ncbi.nlm.nih.gov/pmc/articles/PMC4482159/>
- 6) Adrenal Dysfunction Author- Phyllis W Speiser, Pediatrics, New York <http://www.omicsonline.org/open-access/adrenal-dysfunction-2161-1017.1000164.pdf>
- 7) Focus on Vitamin D and the Adrenal Gland Authors - G. Muscogiuri, B. Altieri, M. Penna-Martinez, K. Badenhop, Naples, Rome and Frankfurt. https://www.researchgate.net/profile/Giovanna_Muscogiuri/publication/272833995_Focus_on_Vitamin_D_and_the_Adrenal_Gland/links/552b7550cf29b22c9c1ad99.pdf
- 8) Improvement of anthropometric and metabolic parameters, and quality of life following treatment with dual-release hydrocortisone in patients with Addison's disease Authors- Roberta Giordano, Tilde Manetta <http://link.springer.com/article/10.1007/s12020-015-0681-z>
- 9) Steroid replacement in primary adrenal failure does not appear to affect circulating adipokines
Authors- Marta Fichna, Marek Ruchala, Poznań, Poland <http://link.springer.com/article/10.1007/s12020-014-0388-6>
<http://link.springer.com/article/10.1007/s12020-014-0388-6/fulltext.html>
- 10) ACTH Stimulation Tests for the Diagnosis of Adrenal Insufficiency: Systematic Review and Meta-Analysis Authors- N.S. Ospina, M Hassan Murad, Mayo Clinic
<http://press.endocrine.org/doi/abs/10.1210/jc.2015-1700>
- 11) BONE MINERAL DENSITY IN PATIENTS WITH ADDISON'S DISEASE ON REPLACEMENT THERAPY WITH PREDNISOLONE
Authors: David D ChandyMD, DMEesh BhatiaMD- Institute of Medical Sciences; Lucknow, India <http://journals.aace.com/doi/abs/10.4158/EP151014.OR>
- 12) HEALTH CANADA
<http://healthy Canadians.gc.ca/recall-alert-rappel-avis/hc-sc/2015/55524a-eng.php>

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

For information on Central Island activities, please contact Sharon Erickson at ericksons@shaw.ca.

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Support Group Contact Information & Meeting Reports *continued*

BC - Lower Mainland Support Group

The next meeting is scheduled for Saturday, June 4, 2016, from 1.00 – 3.00 pm, in the Neill Russell Room, Royal Columbian Hospital, 330 East Columbia Street, New Westminster. An Emergency Injection Training Clinic will be part of the afternoon program.

For further information on this Support Group please contact Judy Stanley at, bugbee@shaw.ca

Alberta - Edmonton Region Support Group

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

We are searching for a volunteer to take on the Regional Representative role in the **Edmonton** Region. If you are interested, please contact either Ginny Snaychuk at ginray@shaw.ca or Harold Smith at president@addisonsociety.ca.

Alberta - Calgary Region Support Group

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

We are searching for a volunteer to take on the Regional Representative role in the **Calgary** Region. If you are interested, please contact either Ginny Snaychuk at ginray@shaw.ca or Harold Smith at president@addisonsociety.ca

Saskatchewan Support Group

For information on the Saskatchewan Support Group, contact Elizabeth Hill at (306) 236-5483 elizabethhill10@hotmail.com

The next meeting may be held in the Regina area - TBA.

Ontario - South/Central Support Group

The Spring meeting of this support group is scheduled for May 14, 2016 at the Erin Mills United Church, Lower Hall, 3010 The Collegeway, Mississauga. Registration opens at 12.30 pm and the meeting begins at 1.00 pm with adjournment at 4.30 pm. The agenda will include Guest Speaker, **Dr. D.W. Killinger**, Medical Advisor to The Canadian Addison Society. In addition, an Emergency Injection Training Clinic will be part of the agenda. <http://www.addisonsociety.ca/index.php/community/support-group-meetings>

For further information on South/Central Ontario Support Group activities or meetings, please contact Harold Smith in Kitchener-Waterloo at hsmith81@hotmail.ca or (519) 742-8170.

Ontario - Eastern Support Group

The next scheduled meeting for this group is Saturday, May 14, 2016, the weekend before the Victoria Day long weekend. Our Guest Speaker will be **Marie-Lyne Caron, Pharmacist, Jean Coutu.**

<http://www.addisonsociety.ca/index.php/community/support-group-meetings>

For information on Eastern Ontario Support Group activities or meetings, please contact Ghislain Hardy, email ghislain2406@live.ca or telephone (613) 601-3671.

Those located in Quebec, near Ottawa, would be most welcome at our meetings.

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Support Group Contact Information & Meeting Reports *continued*

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 are able to assist in this volunteer role please contact Harold Smith, president@addisonsociety.ca. In the interim, if you are trying to connect with the Society for support please call our Montreal Area Regional Representative, Shelley Saklatvala at (514)-991-0294 or you may also call the Society via our Toll Free number 1-888-550-5582 or email info@addisonsociety.ca or president@addisonsociety.ca.

Atlantic Support Group

For information on the Atlantic Canada Support Group activities or meetings, please contact, Holly Mclean email hquilter@nb.sympatico.ca or telephone 506-546-1687. Holly lives in northern New Brunswick

Medical Q & A's

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/FAQNovember2011.pdf> see previous issues of the newsletter.

Question #1:

I have several doctors. I am also the bearer of hereditary hemochromatosis. I also have problems with my joints and hypoglycemia reactive. I think reading will help me to feel better and know that I am not alone in this health problem. I wonder about appropriate food because I have a lot of sweating and discomfort, postural hypotension

Response for question #1:

I am sorry to hear that you are having difficulties which do not seem to have been resolved. You have been diagnosed with hemochromatosis. This is a disorder in which you have too much iron in your body and it is deposited in tissues that are not normal sites for iron deposition. One of these sites is the pancreas and damage to the pancreas can lead to diabetes. You did not mention what treatment you are receiving, but this would be one area you should discuss with your doctors. A second site where iron can be deposited in hemochromatosis is the pituitary. This can lead to damage to the pituitary gland which controls the output of hormones from many of our hormone producing glands such as the adrenals, thyroid and ovaries. If the adrenal glands are affected, it can lead to some serious problems. It would be important to discuss the hemochromatosis with your doctors to see if it could have affected these other tissues. Best of luck with your discussions.

Question #2

Does Addison's Disease cause memory issues on short term memory?

Response for question #2:

Any serious illness will cause a person to focus on their health so they may not be paying attention to the things they are doing or what other people are saying. Because of this, they may not remember these events as accurately or at all. This is not a function of a specific disease, it has more to do with the severity of the problem and the person's response to it. Addison's disease is no different and does not cause memory loss but some people feel very unwell for a long period before their diagnosis is finally made and during that time their focus may not be on what is going on around them so their recollection of events may be faulty.

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Medical Q & A's *continued*

Question #3

I have just recently been diagnosed with Addison's after 9 months, one of which was spent in hospital, with no diagnosis given at that time. However, I am now on my meds and feeling much better. My question: now I have very bad upper back pain. Is this normal or does everyone get this from the meds?

Response for question #3:

I am sorry you went through such a long session before your diagnosis was made. I am not sure whether I have good news or bad news for you. The good news is that I do not think your back pain is due to the treatment medication. The bad news is that I am not sure what might be causing this problem.

I do not know anything about your situation, but you should tell your endocrinologist or family doctor about the pain, mentioning what it is like, what makes it worse, what makes it better and exactly where it is in your upper back. She/ he may want to do an X-ray of your back or a bone density to get more information. There may also be some blood tests depending on what is found. I am sure it will get resolved but you must be sure to stay on your medication

Question #4

How would one find out the appropriate amount of cortisone to take for physical activities and mental stress? Can you explain why the endocrinologists do not acknowledge mental stress as a factor for low cortisol? Why do they continue to want a person on the lowest dosage known to man, when the patient keeps saying "but I can't function on this"? In short, why do the endocrinologists not acknowledge quality of life as important and why do they not listen to patients?

Response for question #4:

Our gauge as to how much cortisol you should take is.... The lowest dose that makes you feel well. The reason doctors want you to be on the lowest dose possible is that high doses of cortisol can have negative effects on bone and body fat composition,

There is no rule for how much extra cortisol to take with stress, it depends on the degree of stress, usually starting with 1/2 extra tablet per day.

Mental stress is hard to assess and much depends on the individual response.

Medical Questions and Answers

Dr. Donald Killinger, MD, PhD, FRCPC

Medical Advisor to The Canadian Addison Society

will answer your questions about Addison's/Adrenal Insufficiency.

Send your question to Dr. Killinger directly from the webpage or this link

<http://www.addisonsociety.ca/index.php/education/faqs/ask-a-question>

Or by emailing info@addisonsociety.ca

Or via Canada Post to

The Canadian Addison Society, 2 Palace Arch Drive, Etobicoke, Ontario M9A 2S1

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



The Canadian Addison Society
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Toll free: 1-888-550-5582
www.addisonsociety.ca

Membership in The Canadian Addison Society is \$25.00 due January 1st of each year.

* indicates a required field

***New/Renew:**

- New Membership
 Renew Membership

***Length of Membership:**

- 1 Year (\$25)
 2 Years (\$50)
 5 Years (\$125)

***+ Plus a Contribution:**

- Yes
 No

*Name:
*Address:
*City:
*Province:
*Postal Code:
*Phone:
Fax:
E-mail Address:

***How do you wish to receive the Newsletter:**

- Mail me via Canada Post
 Email Me

***Do you want your name to be made available to other Addisonians in your area?**

- Yes
 No

*** You may also direct \$5.00/year of your annual fee to one of the local support groups. (check one)**

- | | |
|--|--|
| <input type="radio"/> No Thanks | <input type="radio"/> \$5.00 to Ontario: Eastern |
| <input type="radio"/> \$5 to Alberta | <input type="radio"/> \$5.00 to Ontario: South/Central |
| <input type="radio"/> \$5 to Atlantic Provinces | <input type="radio"/> \$5.00 to Quebec: Montreal Region |
| <input type="radio"/> \$5 to BC: Lower Mainland | <input type="radio"/> \$5.00 to Quebec: Quebec City Region |
| <input type="radio"/> \$5 to BC: Vancouver Island - Nanaimo | <input type="radio"/> \$5.00 to Saskatchewan |
| <input type="radio"/> \$5 to BC: Vancouver Island - Victoria | |

†Contributions are also gratefully accepted. A tax receipt will be issued for contributions over \$15.00.

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The Canadian Addison Society
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Optional (for newsletter mailing purposes if you wish to provide this information)

Endocrinologist Name:
Endocrinologist Address:

Hospital Name:
Hospital Address:

ER Director of the Hospital: