



The Canadian Addison Society La Société canadienne d'Addison

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JULY 2017

SPRING/SUMMER Edition

ISSUE NO. 86

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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:

The Canadian Addison Society is pleased to introduce our new Newsletter Editor, Stacey Doherty. Stacey is a member of the Society, an Addison's patient and a participant in the South-Central Ontario Support Group. We welcome Stacey to her new volunteer role and look forward to her Newsletter initiatives in future editions.

The Society's Annual General Meeting will be held Saturday, October 14, 2017. The location is College Avenue Church, 22 Wilson Street, Woodstock, Ontario N4S 3N4. Details may be found on the Society's website <http://addisonsociety.ca/support-group-meetings.html>



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

If you live in Ontario and you or a family member have Adrenal Insufficiency you will be excited to learn of a breakthrough regarding Paramedic pre-hospital treatment available as of July 17, 2017.

Primary and Advanced Care Paramedics are currently undergoing or just completing training to assist them in recognizing **suspected adrenal crisis**. In these emergency circumstances, authorized Paramedics can assist and/or administer YOUR emergency hydrocortisone (Solu-Cortef) injection. You will then be transported to hospital for further treatment.

If in doubt, you may wish to confirm timing and status with the Paramedic Service in your area. It should be noted that the onus is clearly on the patient to *never be without your emergency kit*. Hydrocortisone will not be carried on Ambulances.

We wish to thank the many medical doctors that supported this important advocacy initiative, as well as the Ontario Ministry of Health staff and management for listening to our story and responding favourably to our request for emergency pre-hospital intervention by paramedics.

In Nova Scotia and Newfoundland Adrenal Insufficient patients may be registered by their GP or other clinician, with their local Paramedic Service.

The Canadian Addison Society continues its advocacy for pre-hospital treatment of Adrenal crisis and is in discussion with the provinces, territories and Health Canada on behalf of all at risk for Adrenal crisis.

Support Group Contact Information & Meeting Reports

B.C. - Vancouver Island Support Group

Meeting Minutes – 13 May 2017 1:00 to 3:20 PM – Vancouver Island/Victoria Support Group

Twelve members and spouses of the Vancouver Island Support Group met on May 14th in Victoria. It was terrific to see such a nice turn out! Attending our meeting for the first time were two people with secondary adrenal insufficiency. It was also our first opportunity to learn from one of the group about Sheehan's syndrome, also known as Simmond's syndrome. It is generally defined as postpartum hypopituitarism (decreased functioning of the pituitary gland), caused by blood loss and hypovolemic shock during and after childbirth.

We took time to discuss everyone's wellbeing; especially those who were new to the group. One of our group members is currently receiving laser therapy and will keep us up updated on her progress with it. Laser therapy is thought to help stimulate tissue regeneration. It is not available everywhere and unfortunately is not usually covered by medical plans.

The group had an opportunity to look at two new products that were clearly of interest to people with Addison's. The first product is a medical alert bracelet by a company called Identify Yourself. This company provides a trendy new style of alert bracelet and importantly they allow users to create their own medical info text. Their products can be purchased at www.identifyyourself.com

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Support Group Contact Information & Meeting Reports *continued*

B.C. - Vancouver Island Support Group *continued*

The other interesting product is a red emergency kit case labelled for use by someone with Addison's disease. It comes in various sizes and is available through www.zazzle.com. As you know, we encourage all Addison's sufferers to carry an emergency injection kit. This case is bright red and easily identifiable. We believe the kit to be an excellent idea but is probably a bit overpriced at \$25 US.



Near the end of the meeting Jim and Shirley Sandish were presented with a gift and card of thanks. As most of you know, Jim has been the heart and soul of Addison's on Vancouver Island for many years. They will be moving to a smaller island nearby so attending regular meetings may be difficult for them. Thank you, Jim!!

Our next meeting will be hosted by Klaus and Erika and will take place in early October - Date TBA. Take care of yourselves and enjoy your summer!

Addison's Abstracts May 13, 2017 Meeting

1) Management of glucocorticoid replacement in adrenal insufficiency shows notable heterogeneity – data from the EU-AIR Author - Robert D. Murray

<http://onlinelibrary.wiley.com/doi/10.1111/cen.13267/full>

2) An analysis of the relationship between serum cortisol and serum sodium in routine clinical patients Author - Eleanor McLaughlin

<http://www.sciencedirect.com/science/article/pii/S2352551717300197>

3) Clinical Characteristics of Patients with Adrenal Insufficiency in a General Hospital Author - Ye Yeon Lee, Daegu, Korea

<https://synapse.koreamed.org/search.php?where=aview&id=10.3803/EnM.2017.32.1.83&code=2008ENM&vmode=FULL>

4) Doping Status of DHEA Treatment for Female Athletes with Adrenal Insufficiency Author - Handelsman, David J

http://journals.lww.com/cjsportsmed/Abstract/2017/01000/Doping_Status_of_DHEA_Treatment_for_Female.12.aspx

5) Study of Prevalence and Predictive Factors of Adrenal Insufficiency in Patients Admitted to Medical Intensive Care Unit in a Tertiary Care Hospital of North Karnataka Author - Durgaprasad M. Kabade1

http://www.ijcmr.com/uploads/7/7/4/6/77464738/ijcmr_1281_mar_8.pdf

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

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

Support Group Contact Information & Meeting Reports *continued*

BC - Lower Mainland Support Group

Minutes of Lower Mainland Branch (CAS) General Meeting

April 22, Russell Room, Royal Columbian Hospital. Chair Geoff Metcalfe. Recorder Gail McArthur.

Meeting called to order by Geoff Metcalfe at approximately 1:00 pm

Geoff reviewed the agenda highlights which included a guest speaker, update on para-medical emergency injections, a practice session for emergency injections and recognition of retiring Representative Judy Stanley.

1. Guest Speaker Dr. Lindsay Adrian – Dr. of Naturopathy a specialist in auto-immune disorders
Dr. Adrian's Presentation: "Consideration and Support for Addison's Disease", was backed up with a series of slides.

Highlights included:

*issues that need to be monitored:

- regulating sodium retention and blood pressure
- loss of aldosterone

*Slide: "Factors Affecting the Adrenals"

"emotional stress, diet, body issues, toxins, lifestyle; anything we ingest including caffeine, is a burden on the liver and can have a negative effect on our adrenal glands"

*Slide: "Circadian Rhythms":

To maintain Circadian Rhythms, it was suggested that a higher dose of cortisol should be taken in the morning and a lower dose in the afternoon. When there is a higher dose later in the day it can disrupt the Circadian Rhythms. Dr. Adrian recommended melatonin to aid sleep.

Question from group: "is melatonin regulated?" Answer: It was de-regulated a few years ago.... now available anywhere and should be good quality, but fillers are not regulated. Compounding pharmacies can make it. Melatonin is good for the brain, it's an autoimmune support, and has several good qualities.

Research Article: Mitchell Henry, Ian Louis Ross, Wolf and Thomas: University of Cape Town: "Impaired Quality and Efficiency of sleep impairs cognitive functioning in Addison's disease" www.elsevier.com/locate/payneuen was the link in the slide, additional information is at [www.psyneuen-journal.com/article/S0306-4530\(16\)30629-1/abstract](http://www.psyneuen-journal.com/article/S0306-4530(16)30629-1/abstract)

*Slide: DHEA and Sex Hormones

DHEA was discussed and Dr. Adrian suggested that it would be helpful for people with Addison's, however, this drug can only be prescribed by a physician.

The article below supports this theory.

<https://www.researchgate.net/publication/316041534> The role of dehydroepiandrosterone on functional innate immune responses to acute stress

DHEA is available in Vancouver through Kripps Pharmacy, in 50mg doses and DHEA levels can be tested through either salivary or blood serum tests.

Dr. Adrian stated that patients with autoimmune diseases are less likely to develop cancer!

Ed. Note: Please discuss with your Endocrinologist and/or Family Doctor before making any changes to medications and treatments.

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Support Group Contact Information & Meeting Reports *continued*

BC - Lower Mainland Support Group *continued*

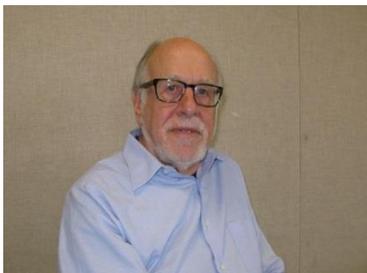
2. Legislation re: Ambulance/Para-medics and Solu-Cortef: Gerry Ott gave an update on the work being done to get our ambulances to carry Solu-Cortef, and/or to allow paramedics to administer our own emergency vials. The need for change in legislation which would allow this is currently before the Minister of Health, Terry Lake, for approval. However, the election and the fentanyl issue have moved it back. A board has been setup to review a number of situations that might require paramedics to administer meds, including ours. It might soon be possible for paramedics to assist us using our own medication. Ontario does – but didn't need legislation, so it was a different process for them.

Gerry reiterated the importance of wearing medical alert bracelets and carrying the CAS information card. This was a great introduction to #3 on the agenda:

3. Gerry demonstrated the injection of emergency Solu-Cortef. The group then practiced the procedure.

4. A Tribute to Judy Stanley was made by Moh Thauberger. Judy has retired from the position of Lower Mainland Representative which she had held for many years. Judy has devoted much time and energy to the Society and Moh expressed our gratitude for this. There was a discussion regarding future meetings. One of the members present works at RCH, and told us that parking will be an issue for another 3 years during construction. Judy shared the history of meeting at the hospital, which was chosen for its central location at the time.

Meeting was adjourned at 3:00pm. The next proposed meeting will be in September with a link up to the Society's AGM in Ontario.



Pictures from Left to Right: Geoff Metcalfe; Moh Thauberger (on left) and Judy Stanley following Moh's tribute to Judy; New member Juvena Burns on the left with our speaker Dr. Lindsay Adrian.

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

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.

Support Group Contact Information & Meeting Reports *continued*

Saskatchewan Support Group

We have a very close group of Addison ladies here in Saskatoon. We have amazing gals in our group and we support each other. Some of us frequently contact each other by phone or by private group on messenger. We discuss all aspects of Addison's.

We meet for coffee as a group as often as we can at a local restaurant. These coffee times are so very important to us. We laugh together, shed tears and support and pray for each other. We are so blessed to have this group. Some of the gals are dealing with great trauma and personal loss. So important to have such a good group. *Jeannette Weber*

We are trying to arrange the next main support group Saskatchewan meeting in Regina sometime in November. It will be posted on the CAS website.

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

Ontario - South/Central Support Group

This is a condensed version of the notes taken at the South/Central Ontario Support Group meeting of May 13/17 held in Mississauga, Ontario.

Self-introductions included Society members and family/friends. Discussions took place regarding diagnosis (primary vs. non-primary adrenal insufficiency), dosing and medication regimens, adrenal crisis events, advocacy initiatives, etc.

Approximately 40% of participants indicated a diagnosis of primary adrenal insufficiency. Several causes were relayed for adrenal insufficiency (genetic, corticosteroid use, cancer (adrenal/kidney), pituitary tumours, etc.). Over 90% of participants have experienced an adrenal crisis.



Deputy Chief McMurrugh
Halton Paramedic Service

Deputy Chief Peter McMurrugh of the Halton Paramedic Service reviewed the new Ontario paramedic medical directive (Suspected Adrenal Crisis) which comes into effect July 17, 2017. Deputy Chief McMurrugh noted the N/A descriptor for symptoms in the Ministry of Health directive. Discussion included the following topics: base hospital training programs, implementation timeframe of the directive and different base hospitals, paramedic levels (basic, advanced, critical), Canadian Triage and Acuity Scale (CTAS) priority levels, patient communication with local paramedic services (flagging of address and registration regarding the need for emergency hydrocortisone injection), fridge vial program used by Halton Paramedic Services. DC McMurrugh will provide more information to Harold regarding this program.

The emergency injection training session included questions related to: choice of injection site, syringe safety, importance of regular training (for patients and family/friends). Many positive comments were shared regarding the benefits of regular training.

The treasurer conveyed the Society's assets and increasing membership base. The implementation of PayPal has been very beneficial. The 1-800 number has seen requests for information in both French and Cantonese. The largest source of donations has been from "In Memoriam" contributions.

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Support Group Contact Information & Meeting Reports *continued*

Ontario - South/Central Support Group *continued*

Harold discussed the brochure campaign potential in hospitals and endocrinologists' offices. This is an important route for patients to learn about the need for emergency hydrocortisone and for support from the Society.

The Society continues to advocate on a national level including each province and territory to allow paramedics to administer hydrocortisone (Solu-Cortef) for suspected adrenal crisis. In some areas where paramedics may not be available, first responder (volunteer paramedics, nurses, teachers, etc.) training may be required. The Society is advocating for increased awareness of emergency physicians in Canada. The awareness program in the education community for schools is another upcoming initiative.

Appreciation to all volunteers was expressed. The society is 100% volunteer and functions ONLY because of volunteers offering their time and talent

The next meeting of this group will be in Woodstock, Ontario, October 14, 2017 and will include the Annual General Meeting business. A speaker has not yet been confirmed. Please watch this website page for developments <http://addisonsociety.ca/support-group-meetings.html>

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 OR Becky Sparks in Sarnia at rebeccalouisepacker@gmail.com, 519-402-2833.

Ontario - Eastern Support Group

The next meeting of this group is scheduled for October 14, 2017. The location will be Robbie's Italian Restaurant, 1531 St. Laurent Blvd., Ottawa, ON K1G 1A1. We will be looking to have a special guest at this meeting and hope that you will be able to attend. Watch the Society's website for any developing plans for this meeting.

For more 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.*

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 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 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 diagnosed in February of this year and I am on a regime of 10mg, 10mg, 0.5mg, of Cortef daily and Florinef 0.1mg every other day. I am not feeling well as I have extreme nausea, diarrhea, anxiety and lack of energy. I have been unable to talk to or see my endocrinologist for over 4 weeks. I have tried doubling my doses for 5 days at a time, which seems to help but I have no idea if I should be doing this. I also have been experiencing cold chills, and sweats but I don't have a fever. It feels like I am cold from the inside.

Response 1

Sorry you are going through a difficult time. Your dose of Cortef sounds satisfactory. You should be feeling better on this medication.

Did you have these symptoms before starting your Cortef or do you think the medication is causing some of your problems? You should review the circumstances with your family doctor to be sure that there are no other things going on such as colitis which can be associated with Addison's disease.

I do not know anything about your tests so I do not know what else could be complicating your situation but your endocrinologist would be the person to discuss this with. Your family doctor is your advocate and she/he can call the endo for you to see if you can get an appointment. If this does not work, you could ask your family doctor if there is another endocrinologist that might see you.

Question 2

I have had primary Addison's, for about 7 yrs. now and my health is stable. Managed with 20mgs of Cortef and 0.05mg Florinef.

I am going to Liberia in November and need to have the yellow fever vaccine to enter the country. Public health informed that people with auto-immune disorders may be contraindicated to have this vaccine and that the steroid meds may not mesh with the vaccine. She was not sure if Addison's was one of those.

Went to my past endo who would not give advice as I was no longer a patient. Went to the GP, who had no idea, and started to google it (not reassuring as I could do that). He will try to ask the endo, but said the endo does not respond to their calls. Tried the pharmacist who said that would be a lot of work, and did not want to find out the answer for me. Seems a rather simple question...but hard to get someone willing to answer it.

Response 2

Individuals with Addison's disease are not compromised from an immunological standpoint so they can generally receive appropriate vaccines. The Center for Disease Control states that individuals on physiological doses of steroids for replacement purposes can get the Yellow fever vaccine. The vaccine may however have some side effects and you should seek the advice of a physician who is involved in a travel clinic to find out more about the vaccine before making any decisions, these doctors can usually be found at University Clinics, so depending on where you live you could contact the Department of Medicine at the University to contact the appropriate individual. I have not had any experience with the Yellow fever vaccine so it is important to speak to someone who has.

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

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 on the website.

Personal Experiences

To the Newsletter Editor,

My name is Rev. Larry Paul and I am submitting a personal experience for my wife, Evelyn Paul. I am doing this on her behalf, and with her permission, as she is currently in Perth Community Care Centre, a Nursing Home near our home in Perth. Evelyn has had Addison's Disease since she was 14, and now 78. The onset of the disease seems to have come from stress over two summers when three of her older sisters were married, and her father suffered some form of depression plus in, his eyes, the loss of his daughters. Evelyn worked in the hayfield with him those summers, but he didn't talk to anyone. This stress ended in her being diagnosed with Addison's Disease, by her family doctor and taken to the Ottawa Civic Hospital where she was in the care of specialists, and through cortisone, her life was saved.

Through our years together, she gave birth to our three children, helped me in my career in the Presbyterian ministry, and became an excellent Grade 1 teacher. In the mid '90's she and 8 others formed the Addison's Society in Eastern Ontario, by meeting in our home.

Fast forward to the years 2013 - to 2016, when in another stressful time, she lost two sisters, her brother, and two brothers in law. It was, in a way, a repeat of her original family losses and stresses and in May 2015 she entered hospital for what turned out to be an Addisonian crisis, and we almost lost her with mix-ups over cortisone. She had some memory loss and dementia and she entered the Nursing Home in July 2015. Her care has been good there, and our family visits her often to keep things current and just to be with her. She had a fall and is now in a wheelchair, as physiotherapy was not too successful, mostly due to the dementia. In the above time period, her going through the deaths was made more difficult because I was going through recovery of childhood sexual assault, and was often not easy to live with. This roughly corresponds to the summers of stress caused by her father's condition.

However, she is doing well apart from the dementia which has been labelled 'Lewy Body', but even that has not taken over her mind completely. Her sister Janet, a retired Canadian geriatric nurse consultant and I have become aware of the new brain research through the writing of Dr. Norman Doidge and brain plasticity; also, Janet saw an interview with Maria Kennedy about connections between Addison's (hormones and inflammation) and dementia. McGill University is embarking on major work with dementia and have an 80-million-dollar grant for 7 years to bring different professions together, with the lead being the Montreal Neurological Hospital; and a research team from Australia (Queensland Brain Institute) making use of noninvasive high- frequency ultrasound to clear a path for blood proteins to enter the brain and clear out clusters of lesions that cause memory loss and cognitive decline in Alzheimer's and other dementias.

I guess I think Evelyn could be the beneficiary of some treatment for her dementia. Janet and I feel like we are circling in on something, but are not sure what. Any ideas along this line would be very helpful.

Sincerely, and with thanks for your great newsletter.

Rev. Larry Paul

P.S. Evelyn and I started Grade 9 in Carleton Place High School, and I remember her, and where she sat, and what she wore one day, a blue and green outfit. I remember her skin was brown, and that was from the first summer (1952) when her two sisters were married. I remember she was, and is, very pretty, but we didn't get together until the end of High School. I remember that others said of her, 'she has personality', which I found to be very true! In fact, she has been the best thing (person) to happen to me my whole life since we started going together. That was in 1957 and this August we will celebrate 55 years of marriage (August 25, 1962).