The Canadian Addison Society
La Société canadienne d'Addison

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ISSUE NO. 74 **APRIL 2014**

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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:

FINAL REMINDER: Please remember to renew your membership in the Society - $25 was 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 http://www.addisonsociety.ca/membership.html.

We thank you for your continued support.

President's Comments

As a follow-up to my Newsletter article in January, **Rare Disease Day** on February 28 appears to have been a great success around the world. Every event held, regardless of size, contributes to the focus on Rare Diseases that is required for more progress

As The Canadian Addison Society is now an Affiliate Member of CORD (Canadian Organization for Rare Disorders) we were represented by CORD at their Gala event in Ottawa in early March with slides taken from our website and brochure, being part of their Audio/Visual presentation.

According to CORD'S position, these events help to bring the cause of Rare Disease's to the attention of our Parliamentarians who need to move faster to approve the Orphan Drug Regulatory Framework to allow testing on Orphan Drugs and Treatments to be in line with the timeline in the USA and Europe. You may learn more about this by visiting CORD's website at www.raredisorders.ca.

You may also wish to visit their website to learn of the significant work done by this very special organization on behalf of many with rare disorders. They speak with a loud voice when lobbying for improvements in the care of those of us with rare disorders.

Possibly next February 28, members of this Society will consider holding local events to raise awareness of RARE DISEASE DAY and raise a few dollars for the Society as a bonus. It does not have to be a major event, the smallest of events works.

We have had a few changes on the Board of Directors since the Annual Meeting last fall. Don Archi resigned his Vice-President position and Joan Southam resigned her position as Director. Both of these individuals have made a huge contribution to the Society going back to its very inception. We are indebted to them and thank them for their contribution over many years.

Gerry Ott of British Columbia has agreed to act as our fill-in Vice-President until the Annual Meeting, Fall 2014. We thank Gerry for agreeing to step into this important role.

Submitted by Harold Smith, President

Newsletter Editor:

Please send me your articles about your experience with Addison's either as the patient, caregiver, family, friend, nurse, doctor or anyone else with a connection to Addison's. 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

Support Group Meetings:

Vancouver Island Support Group - Victoria

The Canadian Addison Society Vancouver Island support group met March 1st in Victoria at Esquimalt Serious Coffee. Nine people attended with one travelling from Ladysmith. Although we had reserved the mezzanine meeting space at Serious Coffee, other patrons encroached on our privacy during the meeting. As a result of this intrusion a couple have invited members to their home for the next meeting where discussion would be more private. Please see below for the date of the next meeting and directions.

Vancouver Island Support Group - Victoria - *continued*

A woman member recounted her experience when she went into crisis after falling in the bath and suffering whiplash. She has experienced nausea and a churning stomach for the last month and a half. Doctors are stumped by the nausea symptoms after two CT scans. She has doubled her Cortef medication, started a gluten-free diet, and uses almond milk as an alternative to dairy. Gravol has not worked for her. She has always been healthy apart from Addison's.

During one bad bout of nausea her husband administered Solu Cortef. However, the medication did not alleviate her crisis symptoms because it was not adequately mixed to give her the extra boost of medication that she required. Solu-Cortef injection instructions from Pfizer say to *"Press firmly down on the yellow top to force the diluent into the lower chamber. Gently mix the solution without shaking it. Turn the vial upside down a number of times. Do not shake the vial. The solution is initially cloudy but then clears."* Another member suggested trying a wrist band product to relieve nausea: http://www.sea-band.com/ca/

Another woman member started vomiting while visiting family near Duncan, B.C. From her previous medical history she knew to get to a hospital and an ambulance was called. Arriving at Emergency at the Cowichan District Hospital in Duncan, she presented her emergency letter plus a letter from her endocrinologist, and a hospital protocol letter. The hospital staff refused to act on the emergency letters and insisted on consulting their own specialist, whose instructions were to wait until the patient could keep fluids down then give her oral replacement medication.

They hooked her up to intravenous fluids and Gravol. It took about 7 hours before she could keep hydrocortisone down. Hospital staff would not administer Solu-Cortef intravenously because their specialist said it was not necessary. She was released when her system stabilized. The next day, she had diarrhea and again called an ambulance returning to the same ER in Duncan. She patiently explained the seriousness of her adrenal condition to the nurses, asking that they please administer Solu-Cortef by IV. They would not. They instead gave her Gravol intravenously again.

Back at home, 3 days later, she received a call from VIHA to give her an appointment to have an ultrasound scan. She explained that she didn't live in Duncan, so the person changed the location to the Saanich Peninsula hospital. When our member asked the purpose of the scan they wouldn't say. They asked if she had had any surgery in her stomach area. When she said she had her gallbladder out their technician said that the Duncan hospital should have taken down her history. They went ahead with the ultrasound scan anyway.
No problems were found. Perhaps we should all carry a medical history of surgeries, etc.

Another member in Nanaimo Regional Hospital ER with crisis symptoms was asked multiple times before they would treat if she had completed a Living Will.

One woman uses Pedialyte to promote electrolyte absorption. Another athletic woman prefers Gatorade instead of water for rehydration. Travelling to hot climates? An endocrinologist suggested that his patient increase her Florinef dose a few days before departure.
Most of us with adrenal insufficiency tweak replacement doses to manage stress in our day to day lives, with our doctor's approval. One woman splits her Florinef dose, taking a half tablet at 6:00 am and the other half tablet at 6:00 pm which has reduced swelling in her fingers, alleviated feeling dehydrated by evening and stopped morning headaches. As a swimming instructor she developed intolerance to chlorine. Since leaving this occupation she has developed yeast infections in her arms and feet. To help improve from this condition, she was advised that people taking steroids should not eat a lot of simple carbs. She also takes magnesium regularly for leg cramps.

Trouble sleeping is a common problem for many with Addison's. Tryptophan is used by one woman as a sleep aid, but works for only a few hours. Another takes sleeping pills. Hot chocolate, warm milk, or hops before bedtime or lavender in the bedroom, were other suggestions to help get sleep.

One member living alone uses the services of the Lifeline medical alert system. She carries a device with a personal help button which works within the range of her property. When the button is activated, the service telephones the client to ask the nature of the concern. If there is no response to their call, an ambulance is summoned. In one event when the member reported having the flu, three people on her contact list were telephoned in the middle of the night and asked to assist. In future, she will request that an ambulance be called instead.

There was a request to set up a laptop and use Skype to enable an interested Courtenay woman to join in the meeting discussions. There happened to be a laptop among members present, but no one had experience using Skype. Most of us have never had a need to learn about Skype or interest in setting up an account. With a direct internet or WiFi access, Skype video may be free to connect with one person. This may be a feasible method to connect to members living too far away to attend meetings, but will require someone knowledgeable to coordinate ahead of time. If you can offer suggestions or help out with this idea, please contact by reply email or through the website.

The next support group meeting will be held May 31st at 1706 Sheridan Avenue, Victoria. See our group's website for directions: http://vancouverislandaddisonsgroup.weebly.com/

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.

Submitted by Jim Sadlish

BC Lower Mainland Support Group

The next meeting for this group is scheduled for Saturday, June 21, 2014, 1.00 pm to 3.00 pm. The meeting location is The Royal Columbian Hospital, Columbia Tower, 330 E. Columbia St., New Westminster, B.C., (Neil Russell Room, 3rd Floor (to the right of the elevator). Parking is available and the location is accessible by Skytrain.

Judy Stanley reports that the group has determined that they will meet twice per year in future. 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.

South/Central Ontario Support Group

The next meeting of the South/Central Ontario Group will be **Saturday May 10, 2014** 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 on Saturday transit schedules.

Our Speaker will be

Brad Bowie, PCP,
Community Relations Officer,
Peel Regional Paramedic Services

The fundamentals of EMS are fairly constant across Ontario so come and listen, learn, participate, regardless of where you live and particularly those in Peel region.

In addition to our speaker and local business matters, we will again have an **Emergency Injection Training Clinic**. If you have attended one of these before please do not assume you are now an expert. Come and repeat the experience as often as possible.

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

Submitted by Harold Smith

Eastern Ontario Support Group

Kingston Meeting January 2014

The Eastern Ontario Support Group held a special meeting in Kingston on Saturday Jan. 25, 2014, with 5 Addisonians *(including one from Montreal)* and 3 family members. As many of those in the Kingston area cannot make the regular meetings in Ottawa (held in May and October), they were happy to have a meeting held in their area. A big thank you has to go out to member, Kelly Cole, who allowed us to meet at her home. Due to severe winter weather, attendance was down.

Item discussed at the meeting include

- The Canadian Addison Society website now has an internal ‘search’ function to assist in manoeuvring around the site. Additionally, there are interesting FAQ’s on the New Zealand and Australian sites as well as those on the CAS site. Also the UK site’s ‘Crisis Management’ document as well as the ‘Owner’s Manual’ are worth a look. Also mentioned was Endocrineweb.com, a site written by doctors for patients. This site also stresses the need for a Medic Alert Bracelet.
- The January 2014 Newsletter was now on the site.
- Rare Diseases Day is Feb.28, 2014. This is an initiative to create worldwide awareness of rare diseases, promoted in Canada by CORD (Canadian Organization for Rare Disorders), of which the Society is a member. For more info, see Society web site and link to CORD site.
- VP - Don Archi resigned as Vice President of the Society. A director from B.C., Gerry Ott, has assumed the duties until the next AGM. If anyone wants to put their name forward, they should contact our secretary, Irene Gordon.
- GET A FLU SHOT if you haven’t already.
- There is now an official form from the Ottawa Hospital, on the website called Ottawa Emergency Letter, from the Endocrine and Diabetes Centre. It covers both current meds and emergency requirements. Fill it in and take to you doctor for them to sign! Then put it on your fridge as paramedics will first look on your refrigerator for medical information. For privacy and safety reasons, they cannot, and will not, look in your wallet or around your house for medical info. They recommend it be put on the fridge and, if you don't want everyone to see this information, fold the paper and label it properly with your name and what it is (ex: Medical Information for: *John Smith*).
- One member shared a frightening story. The person had flu which precipitated a crisis. Paramedics refused to listen to the patient’s knowledge of their Addison’s, and disputed whether they should transport them to the hospital because ‘they only had the flu’, without realizing the danger the patient was in. Additionally, the hospital did not treat the patient very well at all, in spite of having an advocate. This is all possibly due to the medical profession’s (and associated profession’s) apparent lack of knowledge of the seriousness of the condition. The person is following this up with higher levels in the hospital. If this happens to you (let’s hope it never does), be sure to contact the ER head, hospital administration, president, emergency services, etc. directly to let them know their people may be risking our lives with this type of behaviour.

Eastern Ontario Support Group -*continued*

- Emergency Kit – We reviewed what the kit should contain (*vial of Solu-Cortef, needle, swab, alcohol wipe and emergency letter*) and reminded everyone that there can be a very real need for an Emergency Kit, even if your doctor isn't convinced (flu, accident, etc.). Reminded everyone to call an ambulance –and to bring the Hospital Protocol Letter. If your local hospital doesn't have one, contact the hospital emergency admin and have them add one to their Protocol List for your hospital. There are items on the Society's web site that outline all these things as well as providing Emergency Letters in various languages for travel.
- There was considerable discussion generated by one member whose endo (from the Ottawa Hospital) has not offered to prescribe solu-cortef in case of an emergency. The member intends to pursue this further, with documents from our website. Of the 5 Addisonians, 4 had full emergency kits, and all had used them at one time or another.
- Injection demonstration – Everyone participated in a practice session opening the emergency vials, filling syringes and giving shots to fruit. Family members of Addisonians should know how to do injections as they are most likely to be administering them in case of a crisis.
- CAS Pamphlets – Provided everyone with a copy of the CAS pamphlet; suggested they download copies and to give/leave at your doctor's or local pharmacy, with their permission of course.
- Membership Form & Dues - reminded members to send in 2014 membership form and dues, or just your dues if renewing.

Lastly, Kingston members indicated that they wanted to share contact information to stay in touch with locals who share this condition, and perhaps have future Kingston meetings. I can administrate this from Ottawa and let them decide what they'd like to see happen.

Next Meeting

The next meeting for the Eastern Ontario Support Group is scheduled for Saturday, May 10, 2014, 12.00 pm to 2.00 pm at Robbie's Restaurant, 1531 St. Laurent Blvd., Ottawa, Ontario.

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.

Submitted by Steve McKenna

Québec Support Group

Welcome to our new Regional Representative in Quebec 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 now 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. To review these questions, please go to the Canadian Addison Society website under Education (http://www.addisonsociety.ca/related/FAQNovemberb2011.pdf), or see previous issues of the newsletter.

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.

Question:

As a person with Addison's should I be taking the drug Prolia as prevention for osteoporosis just because I have been taking cortisone for many years? *From Susan*

A response from our Medical Advisor…

Answer:

Hi Susan.

It is recommended that individuals on cortisone or prednisone for diseases such as arthritis, colitis etc should take medication to protect their bones. These people are on high doses of these medications and that is why they can get into trouble with osteoporosis. Individuals with Addison's disease take physiological levels of cortisol so are not at risk for osteoporosis. This does not mean that you are less likely than the general population to get osteoporosis.

You should get your bone density checked and if it is low, your Family Doctor or your endocrinologist can help you decide whether you need medication. Prolia is one of the newer preparations and is injected twice a year. There are some older preparations such as alendronate or residronate which are commonly used to prevent steroid induced osteoporosis. These are oral preparations. All of them are very good.

Talk this over with your endocrinologist. The advice will depend on what steroid you have been taking, what is your bone density and what preparation she or he prefers in your situation.

Medical Questions and Answers – Dr. Donald Killinger, MD, PhD, FRCPC, 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 Addison Society (see address on front of this newsletter).

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

The Canadian Addison Society
La Société canadienne d'Addison

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Goderich ON N7A 2E7
Website: www.addisonsociety.ca

Membership in The Canadian Addison Society is $25.00 per year, due January 1st.

*New Membership☐ Renewed☐ 1yr☐ 2yrs☐ 5yrs☐ ** Plus a Contribution ☐*

Name:____

Address____

Postal Code:________________ Telephone:____________________

E-mail Address:____

How do you wish to receive the Newsletter? (please tick one box)
☐ I will read it on the website at www.addisonsociety.ca or ☐ by mail

If you DO NOT want your name to be made available to other Addisonians in your area please sign here____

You may also direct $5.00 of your annual fee to one of the local support groups below. Please check a box of your choice.

- ☐ *$25.00 to go to The Canadian Addison Society OR*
- ☐ *$5.00 to Eastern Ontario Support Group – ON + $20.00 to Society*
- ☐ *$5.00 to South/Central Ontario Support Group – ON + $20.00 to Society*
- ☐ *$5.00 to Saskatchewan Support Group – SK + $20.00 to Society*
- ☐ *$5.00 to Alberta Support Group – AB + $20.00 to Society*
- ☐ *$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*

*** Tax receipts are issued for donations over $15.00.*

Please mail your payment to The Canadian Addison Society c/o Treasurer, 193 Elgin Avenue West, Goderich ON N7A 2E7

Optional (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: April 2014