



The Canadian Addison Society La Société canadienne d'Addison

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July/August 2015 **SUMMER EDITION** ISSUE NO. 79

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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. 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

It's Here!!!!

PayPal for **Membership payment and Donations by Credit Card.**
(You do not require a PayPal account to use PayPal)

CanadaHelps.org our current **Donation** system for Credit Cards



Please visit our website Home Page to access both payment systems.
www.addisonsociety.ca

The Annual General Meeting (AGM) of The Canadian Addison Society will be held on **Saturday September 26, 2015** in Woodstock, Ontario. The venue will be College Avenue Church, 22 Wilson Street, Woodstock, Ontario. *More details to follow.* Please mark this important date on your calendar. If you live within a reasonable distance we need your support at this meeting.



Editor's Comments

For the convenience of those readers that may be in a medical facility or an association office setting, we have added a "Distribution Box" at the top of the front page. This may promote and simplify the circulation of this Newsletter to others in your facility who may have an interest in following us. Please help us by providing those others the opportunity to become aware of our Society for the sake of Adrenal Insufficient patients with whom they may connect at some point in the future.

Have you had an experience with Adrenal Insufficiency either as the patient, caregiver, family, friend, nurse, doctor or anyone else? Please consider sharing your story for our **Personal Experiences** section, for the benefit of others. You may do so anonymously. You may reach me at newsletter@addisonsociety.ca.

Derek has been on vacation during the Newsletter preparation period and his Newsletter contribution will return in the fall edition.

You may contact Derek Burpee directly at youthadvisorycouncil@addisonsociety.ca

Youth Advisory Council



President's Comments

CAN YOU HELP?

A gentleman in Quebec with both Addison's and Haemophilia is still seeking someone else in Canada with the same medical conditions to communicate with and share experiences. Please email admin@addisonsociety.ca if you are able to help. We will connect the two parties.

AGM

We are looking forward to the **Annual General Meeting** this September in Woodstock, Ontario. This is a new venue in order to accommodate a larger attendance as well as the availability of WIFI which was not available to us in our previous location in Brantford, Ontario.

While not yet a guarantee, we will attempt to create a video link with another Support Group meeting in another region of Canada so they may join the AGM portion of the meeting as a trial. Wish us luck as we venture down the technology road, on a tight budget.

Personal Experiences

I have been an Addisonian for a little over a year now. I have to say that life has completely changed for me. When I started to get sick a few years ago, the doctors were testing me for all sorts of things. They did a blood test for my cortisone levels and they were fine. So they looked at everything else but couldn't find out what was wrong. It started with all over pain, my arms legs back, neck and head. So I was told, it could be Fibromyalgia, and I was sent home with some pills. The pills caused the skin to fall off my fingers. If there is a side effect, I find it. Then I was told I have Irritable bowel, my bowels were sensitive and acting up. As a result I had a colonoscopy and everything looked perfectly fine.

...continued

Personal Experiences *continued*

Then the headaches started, they were so severe that I was in bed for 3 weeks. I had temporal arteritis and it was treated with prednisone pills. It made me really sick, but having those pills made me so happy, I felt so good, no pain, no nothing. I had to reduce the intake of the pills after a while, when my headaches were gone. Things were great, I felt so good.

I had some other tests done and I found out that my thyroid was not good and I had to take pills for that, I didn't notice much change with these pills. One day I woke up and I couldn't hold my balance and I stumbled to the living room to my husband, who said I looked terrible.

First thought was that it was because I wasn't taking prednisone any longer. But this was almost a week later, why now? Then a few days later I felt like I was going to die. I was so sick, and really I was feeling as if it was my last day. So my husband took me to the hospital and they took me in right away. They did all sorts of tests and then I finally had an answer. Addison's disease.

My specialist doctor told me that if I had waited one more day I would have been in a coma. The doctor studied at the same school as Doctor Addison did, more than a century before. Things started to fall in place. For three years prior I had seen so many doctors for different things, including my last year with Addison's. I gained a huge amount of weight, about 60 lbs. Because of pain in my legs and back I have a hard time walking and I still can't really hold my balance.

But you know what? I am happy, I take one day at the time. I am a mom and a wife and I love my life. I use a walker now because I don't want to fall on my face.... and I feel great, I really do. Pain is a mindset I tell myself...then I get my walker and I walk around the block. I am 47 years old, I have 2 beautiful daughters 9 and 12. And a husband that loves me ...so yes...my life is good. Addison's disease is just something I have, it doesn't have me.

Sandra

Support Group Meetings

Vancouver Island Support Group – Victoria

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.

The Canadian Addison Society Vancouver Island support group met in North Saanich near Victoria on Saturday, May 30th. Seven people attended this meeting which focused on the emergency injection procedure.

In an Addisonian crisis, if getting to a hospital emergency department immediately is not possible, a Solu-Cortef injection is the next option (some members have used dexamethasone injections). Few of us have actually used the Solu-Cortef injection during crisis. Therefore, it is crucial to know how to load a syringe and have our advocate informed about the procedure. After injecting Solu-Cortef it is advisable to still reach Emergency, as the medication will not last indefinitely and further treatment will be necessary.

...continued

Vancouver Island Support Group – Victoria *continued*

Each person at the meeting used a non-medicinal practice vial supplied by the Canadian Addison Society originating from Pfizer Canada, the manufacturer, plus a syringe purchased from a local pharmacy. Instructions were followed from Pfizer. http://www.hypofysis.se/upload/file/solu_cortef_injection.pdf and from the CAS website: <http://www.addisonsociety.ca/index.php/emergency-documents/injection-kit>

The following particular points during the procedure seemed significant to those in attendance:

1) The vial has a yellow cap. Place the vial upright on a table. Press the yellow cap down firmly with the palm of your hand. The whole yellow cap moves down the vial, breaking the rubber seal between the liquid and the powder.

2) Pfizer, the manufacturer, instructs us to gently mix the solution, without shaking, by turning the vial upside down a number of times. The solution is initially cloudy but then clears and should have no granules left.

3) After removing the small round plastic tab covering the rubber stopper in the yellow top of the vial, Pfizer's instructions state to place the vial on a firm surface with the yellow cap up, then insert the needle through the centre of the rubber stopper. Invert the vial and, keeping the tip of the needle below the fluid level, withdraw the correct dose.

Note that the two sets of instructions, from Pfizer and the CAS website, differ slightly. Please refer to whichever one you prefer using, but it is advisable to not shake the vial to mix the liquid and powder medication, to avoid getting air bubbles. The two instructions also differ in whether or not to inject air into the vial before withdrawing the medication. The following video may also help you: https://www.youtube.com/watch?v=nuJ9Wj_eb4U
Another site for injection information from the Netherlands:
<http://www.addisoncrisis.info/emergency-injection/emergency-injection-cortico-steroids-solu-cortef-act-o-vial-two-chamber-ampul/>

Other topics of discussion at the meeting:

A woman's endocrinologist increased her Cortef dose because she has been feeling very tired in the early morning. She also plans to take a bit extra medication before attempting vigorous hikes.

Another woman is experiencing thinning hair, with no new hair growing in. She wondered if DHEA may be the cause so has reduced her dosage and will consult with her endocrinologist.

A man travelling in Europe had difficulty getting over jet lag and felt dizzy whenever he laid down. Low blood pressure, inadequate rehydration in the dry air, lack of sleep or inadequate Florinef dose seemed to be the cause. A few days after returning home, all symptoms resolved and he was back to his normal Florinef dose with no dizziness.

A member had surgery to replace an arthritic hip. Her endocrinologist coordinated her care with the surgeon and the anaesthesiologist. Everything went smoothly and the new hip feels great.

Bill Eastman, a long-time member of this group passed away peacefully on April 11. His widow, Yasuko, said that his mind was sharp right up until the end. Bill attended meetings regularly then later would write to express his appreciation and give encouragement. We will miss Bill.

The next meeting in Victoria will be held at a member's home this fall. There will also be a fall meeting in or near Nanaimo. We will advise the dates and locations of these meetings a month beforehand.

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

Canadian Addison Society Meeting (Lower Mainland BC) minutes Saturday, June 6, 2015 - minutes taken by Judy Whitaker. Judy Stanley chaired the meeting.

10 members attended the meeting and 12 sent regrets. Thanks to everyone for their replies or acknowledging the email. It's the only way I know if they were sent or arrived!

Self-Introductions were made with a brief history related to diagnosis. The ongoing delays in receiving a diagnosis are frustrating to all involved.

Two new members were welcomed and assisted with information relating to managing their disease and the importance of MedicAlert Bracelets with Membership in MedicAlert.

Discussions were held on Stress, High temperatures and Humidity in managing Addison's and the need for supplemental Cortisone to manage these symptoms with the awareness of Physicians to provide for the extra dosing in the medication orders. Also, Electrolyte replacements during high outside temperatures are valuable to stabilize the sodium levels in the system. Samples and discussion of various forms of replacement were made. Members were advised to check out the UK Addison's Web Site, as it holds great information about Addison's.

Emergency Kits were demonstrated by various members with the contents including injectable Solu-Cortef. In an emergency, Members were advised when calling for an ambulance to request a Life Support Ambulance as this one would be able to establish an IV during transfer if required.

Self-Injection Practice Session: led by Judy Whittaker - President Harold Smith is looking to update the CAS website using current information from Pfizer. Please note, do not shake vial but gently mix sterile solution with powder before using. We really appreciated the vials supplied by Pfizer Canada for demonstration and training purposes.

Satellite Meetings: Members have volunteered to assist and leading the group of approximately 17 in the Langley, Surrey, Delta, White Rock and Richmond areas who find it difficult to attend the regular quarterly meetings on Saturday afternoons in New Westminster. Please note: **Privacy Laws** require that members agree to have their email circulated for meeting information. This is for member use only and not to be circulated or used for any other purpose.

In the future, we hope to cover North Vancouver, also Pitt Meadows and areas East – Maple Ridge to Abbotsford etc. The Satellite Meetings will report by minutes and it is anticipated that eventually they may replace the current CAS BC Lower Mainland meetings in New Westminster.

Update on progress on Paramedic Proposal: Gerry Ott stated the follow up has been delayed, but expects contact in the next few weeks with the head of the BC Medical Program for Paramedics.

The next meeting of the CAS BC Lower Mainland Group will be the AGM Saturday, September 26, 2015. Meeting site to be updated once finalized

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

The Saskatchewan Addison's group met in Saskatoon at one of our group's condo meeting room. The meeting went over the scheduled 2 hours with lots of information being shared. There were 4 Canadian Addison Society members and 5 Addisonian's. The room was full with spouses and family members supporting them. 3 were recently diagnosed with Addison's.

A young boy accompanied by his parents and siblings. He felt alone in the beginning of his Addison's journey but soon learnt he was not. He would like to talk to other young people with Addison's under the age of 20 years. The group's discussion was around how difficult it was to get diagnosed, how we could assist each other living with Addison's, the benefit of joining the Canadian Addison Society, how to pay and being forgetful was cited as problem areas; the different medications and varying amounts each of us take, and whether or not to carry the Injectable Hydrocortisone. The group felt another lesson in how to administer the injectable form of steroid in an emergency was important especially for the family member or friend who will possibly be administering the injection. It was also suggested that it would be nice for an endocrinologist to come to a meeting for questions and answers.

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

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

This group met May 2 in Mississauga, Ontario. Total attendance was 42. The Meeting was called to order by Harold Smith with a welcome and then proceeding to the Self Introductions of all attending- There were at least 8 new people present. Sharing of personal stories was quite lengthy due to the size of the group and was very informative. Members' stories included: Addison's, Secondary Adrenal Insufficiency, Cushing's, and Adrenal Cancer. Two members shared their experiences of recent 911 calls. Both families shared how quickly things can change from unwell to Crisis (minutes) and the need to be ready, prepared and comfortable with using the Emergency Injection Protocol.

Harold officially welcomed Rick Burpee to his first meeting after taking over the roles of Secretary and Treasurer of the Society, as previously held by Irene and John Gordon. Rick is a recent retiree from the Executive world and brings both a wealth of work experience and some new-found free time.

Derek Burpee, head of the newly formed Youth Advisory Council, presented ideas of the planned Facebook and Twitter accounts to be managed by his group as vehicles to reach more of the Adrenal Insufficient youth. Derek is still hoping more youth will come forward to join his efforts. Justin Raczynski has put his name forward to be part of this new initiative.

At this time our Guest Speaker, Dr. Roger Cheng, was introduced. Dr. Cheng proceeded to explain the role of ISMP in the Medical Community and the role each of us could play in reporting Medication Incidents.

Guest Speaker

Dr. Roger Cheng RPh, BScPhm, PharmD
Project Leader Institute for Safe Medication Practices Canada (ISMP Canada)
Partner in the Canadian Medication Incident Reporting and Prevention System



...continued

South/Central Ontario Support Group *continued*

- About ISMP Canada – An introduction to ISMP Canada, and that the goal is to reduce preventable harm from medications.
 - Medication Errors: Significance of the Problem – Roger presented about the incidence rate of serious medical errors and that medication errors can lead to significant patient harm.
 - Addison's Disease: Specific challenges as related to medication safety – Roger presented about specific challenges as related to Addison's disease as related to medication use, that guidelines mentioned the need for more education for health care professionals in this focused clinical area. Roger also mentioned the importance of consumers to get involved in their medical care.
 - Key medication safety tips throughout your "medication journey": Roger shared medication safety tips at different stops of the "medication journey" – At the doctor's office, at the pharmacy, at the over-the-counter aisle, at home, at the hospital...etc.
 - What can we as consumers do? -- Roger presented about the importance of reporting medication incidents so that we can learn from them in a systematic manner, and to prevent their recurrence.
- Please see the Reporting Form at:** https://www.ismp-canada.org/err_index.htm.

At this point of the meeting our **Emergency Injection Clinic** was held on how to use the Solu-Cortef Injection kit under the leadership of Denise Burpee with Carrie Morrell assisting. This may be the single most important item on any Addison Society Support Group meeting agenda.

Meeting Adjourned at approximately 4.45 pm.

The next meeting of the South/Central Ontario Group is scheduled for **Saturday September 26, 2015** at College Avenue Church in Woodstock, Ontario. Registration will be open at 12:30 pm, Meeting from 1:00 to 4:30 pm with the AGM portion beginning at 1.00 pm and then continuing as the Support Group Meeting for the balance of the afternoon. This is a new venue for the group. Check the website regularly for further detail updates. <http://www.addisonsociety.ca/index.php/community/support-group-meetings>

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

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

The Eastern Ontario Support Group met on Saturday, May 9th, at Robbie's Restaurant in Ottawa for lunch. There were nine in attendance with six others sending their regrets due to illness or unforeseen circumstances. We welcomed a newly-diagnosed member from Montreal (Shelley), and her very supportive friend, who both were very interested to learn what Addison's is all about. Even though she'd only been diagnosed a few months earlier, she already had an emergency kit. Nicely done.

On the topic of emergency kits, I had a discussion with my endocrinologist at the Riverside Hospital in Ottawa, about the lack of consensus among Endos in his office at the clinic on the topic of whether or not emergencies kits were needed. Of course, I support the 'need one' side of the topic and urged him to bring it up at the next staff meeting. To date, I have not heard from him on this topic but look forward to finding out at my next appointment which is only weeks away. I wonder if this issue is the same with others within the CAS. We advised the group of this on-going discussion and mentioned that we (the Society) may have to go the Canadian Medical Association with our concerns on this topic.

Still with the emergency kits, my wife, Patricia (former Newsletter Editor), led the always popular demonstration on how to inject a 'very ill' orange. Using the very handy demonstration vials provided by our Society, she went through the procedures with everyone having a chance to inject their very own orange. Also, distributed injection instructions to those who wanted them and noted they are on the web site as well.

One member asked if being Addisonian would affect her ability to be an organ donor. The discussion in the group concluded that a person with Addison's Disease could be a viable organ donor – when the time comes!

...continued

Eastern Ontario Support Group *continued*

A member, Lorrain Kirby, told us about a phone App that is available. Here is what she emailed me on this topic:

“Further to our discussion at the meeting today, I checked on iTunes and the iCortisol app (for iPhone and iPad) is \$2.99 on this <https://itunes.apple.com/us/app/icortisol/id550088042?mt=8> It is sponsored by the UK Pituitary organization – here is the link to their website page and an excerpt about the app. Apparently it can be configured to remind you about other medications in addition to the Cortef. <http://www.pituitary.org.uk/information/living-with-a-pituitary-condition/useful-products/hydrocortisone-phone-app/>”

The app is designed to be quick and simple to use and includes the following features:

- *A smart reminder system so you don't forget a dose of hydrocortisone. (Reminders are highly configurable allowing you to set simple alarms or reminders that only trigger if you have not taken enough hydrocortisone).*
- *A logging system which keeps a record of each dose you take and allows you to quickly review how much of each drug you have been taking. This log can be exported which can be sent by e-mail (to yourself or your endocrinologist) and opened using any standard spreadsheet program.*
- *Quick reference information about how to take hydrocortisone and scenarios when you may need to take more hydrocortisone i.e. sick day rules (e.g. illness, medical investigations).*
- *Advice when travelling away from home.*
- *Hydrocortisone in an emergency, including information about how to give a hydrocortisone injection and instructions for ambulance and A&E clinicians.*

I really like the app and found it useful; hopefully others will too.”

We also discussed the suggestion that we all should be carrying the hospital protocol from the Ottawa General Hospital as it may speed up the process if/when one is in need. Also mentioned that emergency letters are available on the CAS site in a number of languages.

As previously noted, I am stepping down as the representative of the Eastern Ontario Support Group but, fortunately, we have a couple of people who have volunteered to take up the task. The main person is Ghislain Hardy, a life-long Addison's patient who is well versed on the topic. As well, Anne-Marie Willems has agreed to assist Ghislain when needed in running the support group. I will be forwarding Ghislain my electronic and paper files that I've accumulated in this position shortly and will assist them in any way they require in the future. As well, he is bilingual which is of great assistance to some members in our area. A great big THANK YOU goes out to Ghislain and Anne-Marie for taking on this task. I hope that you will do what you can to support Ghislain with the group by attending meetings and providing suggestions for guest speakers or other items as required. For myself, I'd like to say thank you to those who have helped, inspired and supported me with the Eastern Ontario Support Group and I look forward to seeing you at the next meeting which is usually scheduled for the Saturday after Thanksgiving (October 17, 2015). The location will remain the same at Robbie's Restaurant in Ottawa unless otherwise notified. From my side of things, it has been a privilege to be the contact for the Eastern Ontario Region and I wish you all a great summer and good health.

Signing off,
Steve McKenna

Québec Support Group For information on the Quebec Support Group please call our Toll Free number 1-888-550-5582 or email info@addisonsociety.ca or president@addisonsociety.ca.

We are currently speaking with a possible volunteer for the role of Regional Representative for a Support Group in the Montreal region. We are also seeking a volunteer to fill a similar role in the Quebec City region. If you are able to assist in one of these volunteer roles please contact Harold Smith, president@addisonsociety.ca.

In the interim, Quebec members that may be within practical driving distance are most welcome at our Ottawa meetings held by the Eastern Ontario Support Group. You may contact the Regional Representative, Ghislain Hardy, for more details. ghislain2406@live.ca or telephone (613) 601-3671.

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'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 lymphoma Crohn's and Addison's I have heard that Crohn's and Addison are connected, how ? Can all three be connected?

Thank you

Kind Regards, Helen

Response for question #1:

Helen

Addison's disease and some types of colitis are autoimmune disorders so can occur in the same person. Some types of thyroid disease are also autoimmune and are frequently seen with Addison's disease.

Autoimmune means the individual is producing antibodies that are directed toward a specific cell protein in the individual's body. Normally, these antibodies are destroyed by the body but in these cases the surveillance system to detect these antibodies is not as efficient as it should be and these antibodies survive and cause problems. The lymphoma is not generally associated with this type of autoimmune disorder, but there are different types of lymphoma and there are always exceptions.

Question #2

I just had an ACTH test completed. The results showed that my cortisol level is down. I have now increased my Cortef to 30 mg from 25 mg. my doctor has also prescribed Teva-escitalopram 5 mg. I took the new meds today and feeling very nauseous. Should I wait for the Cortef to kick in before taking any more of the antidepressant? Could the lack of cortisol be the problem of the trembling, nausea, ear ringing, low energy and anxiety/depression?

Thank you. Susan

Response for question #2:

Hi Susan

I am not going to be much help to you because I don't know enough about your situation. I hope that you have discussed you situation with your endocrinologist who can review the sequence of events. If you had an ACTH test while taking cortef it would not be very helpful.

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Medical Q & A's, *continued*

Question #3

I'm wondering what the chances are of someone being misdiagnosed with Addison's.

What would happen to someone taking 30mg of hydrocortisone daily who didn't actually need it?

How long can someone with Addison's generally go without taking hydrocortisone before having an adrenal crisis?

Is there any way of testing for Addison's when you are already being treated for it?

Thanks, Tamara

Response for question #3:

Tamara

You have asked some very interesting and important questions.

Because some of the early symptoms of Addison's disease such as weakness and fatigue are non-specific, a diagnosis of Addison's is occasionally made without proper testing and the individual is started on hydrocortisone or another steroid. They initially feel better because of non-specific effects of the steroids but since the underlying problem is not

Response continued for question #3:

treated they continue have their original symptoms. There is then an ongoing process of changing steroid doses to try to correct the situation but since they are not treating the original problem the individual continues to feel unwell.

Once someone is on steroids for any length of time it is difficult to test for Addison's disease without gradually withdrawing treatment.

Taking 30 mg of hydrocortisone if you do not need it would do 2 things.

1. It would suppress the individuals adrenals if they were on it for more than a few weeks so if they suddenly stopped taking the hydrocortisone they could have adrenal insufficiency i.e. weakness, low blood pressure and possibly death if the situation was not recognized.
2. They may develop signs of too much steroid such as weight gain, rounding of the face and easy bruising.

An individual with true Addison's disease would go into a crisis in about 48 hrs without replacement. This is a rough estimate. It could be sooner or could be later.

Medical Questions and Answers

Dr. Donald Killinger, MD, PhD, FRCPC Medical Advisor to The Canadian Addison Society
will answer your questions about Addison's disease.

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 liaisonsecretary@addisonsociety.ca

Or via Canada Post

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

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



The Canadian Addison Society La Société canadienne d'Addison

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email: admin@addisonsociety.ca
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