THE CANADIAN ADDISON SOCIETY
La Société canadienne d’Addison

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

Annual General Meeting Report:

The Canadian Addison Society ***Annual General Meeting*** was held Saturday, September 27, 2014 at the Brantford Police Services Building, Community Room, 344 Elgin Street, Brantford, Ontario. The Financial Review documents that were presented by Treasurer John Gordon are attached for your information. Meeting Minutes are as follows:

The Annual General Meeting was called to order at 1.00 pm by Harold Smith, President of The Canadian Addison Society.

President’s Report – Harold summarized the last 12 months of the Society. Since last year’s Annual, Vice President Don Archi found it necessary to resign and Director Gerry Ott graciously agreed to fill in as VP for the balance of the year. Director Joan Southam also decided to “pass the torch”. It was noted that both Joan and Don offered support and service for many years and the Society is indebted to them. Their names appear on the original Constitution and By-Laws passed exactly 17 years ago – September 27th 1997.

Also, a special tribute to Irene and John Gordon was shared as they retire from their volunteer roles as Treasurer (John) and Liaison Secretary (Irene). “What could we possibly say that would adequately express our appreciation for their tremendous and continuous daily volunteer contribution and service to the Society over the last 15 years?” A “Certificate of Appreciation” and a token of thanks on behalf of the Board and all members (past and present) were presented.

Rick Burpee was introduced as the Society’s new Secretary/Treasurer effective immediately although it will be January before Rick will be in a position to take on his new volunteer role. In the interim, John and Irene will carry on. This is not the first time the Society has faced such a significant transition of Officers and Directors. Going forward, we will reset the future course of the Society within the mandate established by our Constitution.

- It was noted that The Society joined **CORD- the Canadian Organization for Rare Disorders** last year.
- Also as part of the **Community Awareness Campaign** the Society has started sending Newsletters to --YOUR Endo, Director of ER at YOUR Hospital as well as other associations, as requested by you.
- The Brochure Holder Campaign is ongoing.

Minutes of the 2014 Annual General Meeting-continued

Personal stories are powerful and welcomed in the Newsletter but accuracy and a reminder that this is not a complaint forum was shared.

It was noted that upcoming changes to the Website, Newsletter and Brochure Design will reflect a bolder, more powerful, and recognizable identity.

Adoption of Minutes from 2013 Annual General Meeting- Presented by Irene Gordon, Liaison Secretary
Moved by: Denise Burpee **Seconded by**: Rick Larocque and **CARRIED**
THAT the Minutes of the 2013 Annual General Meeting be adopted as circulated.
(Reminder that only paid up members may vote) A show of hands **CARRIED** the vote.

Financial Review - Presented by John Gordon, Treasurer--Financial Statements presented for the periods ending December 31st, 2013 and September 30, 2014. Balance in the bank at September, 2014 is $46,037.34.

It was noted that many members have taken advantage of membership renewal for longer periods so membership revenues will fluctuate.

Nomination/Election Lead by: Irene Gordon, Liaison Secretary. All positions are 3 Year Terms:
President: Harold Smith
Vice President: Roger Steinmann (absent due to illness)
Directors at Large:
Gerry Ott
Elizabeth Hill
Derek Clarke
Heather Raczynski
(Stephen McKenna's term does not expire until 2016)

There were no other candidates and the Motion was put forth to close the Nominations.
Moved by: Rick Larocque Seconded by: Jack Mayos A show of hands **CARRIED** the vote.

SLATE OF OFFICERS & DIRECTORS FOR 2014/2017

Officers
President: Harold Smith
Vice President: Roger Steinmann
Secretary / Treasurer: Rick Burpee

Directors at Large
Derek Clarke (BC)
Elizabeth Hill (SK)
Gerry Ott (BC)
Heather Raczynski (ON)
Stephen McKenna (ON) (***2016***)

REGIONAL REPRESENTIVES:

- New Regional Representative for Quebec: Fiona Vickers has graciously accepted to assist the Society and those with Adrenal Insufficiency in Quebec. Fiona may be contacted at: 514-882-2613.

OLD BUSINESS and NEW BUSINESS
It was noted that due to time constraints, old and new business would be deferred
2015 ANNUAL GENERAL MEETING: Vancouver B.C. (BC Lower Mainland Group to host- *to be confirmed*)

Annual General Meeting Adjourned at 1:40pm

THE CANADIAN ADDISON SOCIETY

STATEMENT OF INCOME & EXPENSES
FOR THE PERIODS ENDING DECEMBER 31, 2013 AND SEPTEMBER 30, 2014

Cash on hand and in banks	**January 1, 2013**	**September 30, 2014**
	$37,875.11	**$42,229.95**
Income		
Dues Received - National	**$3,075.00**	**$3,611.93**
- Support Groups	**595.00**	**635.00**
Donations	**5,255.87**	**3,513.53**
Interest Earned on Investments	**409.24**	**401.54**
	9,335.11	**8,162.00**
Expenses		
Memberships - other organizations	**50.00**	**0.00**
Advertising & Publicity	**0.00**	**473.02**
Newsletter	**1,164.98**	**1,071.30**
Web Site	**526.14**	**768.34**
Secretarial	**1,200.00**	**600.00**
Annual Meeting	**94.82**	**-**
Postage, stationery and supplies	**618.60**	**385.48**
Telephone	**1,107.19**	**892.56**
Support Group Expenses	**203.64**	**133.33**
Bank Charges	**14.90**	**30.58**
	$4,980.27	**$4,354.61**
Cash on hand and in banks	**December 31, 2013**	**September 30, 2014**
	$42,229.95	**$46,037.34**

THE CANADIAN ADDISON SOCIETY

Analysis of cash on hand & in banks as at September 30, 2014

Equitable Trust -	
The Canadian Addison Society - $14,568.41 @1.35% due November 4, 2014	
- $21,182.16 @1.45% due June 9, 2015	$35,750.57
TD Canada Trust -	
The Canadian Addison Society	4,557.81
Quebec Support Group	210.00
Eastern Ontario Support Group	790.98
South/Central Ontario Support Group	2,297.18
Saskatchewan Support Group	255.00
Alberta Support Group	599.60
Lower Mainland (Vancouver) Support Group - British Columbia	806.20
Vancouver Island Support Group - Victoria	770.00
Total	$46,037.34

News and Announcements:

We recently received a request from Janet in the Ottawa, Ontario region whose sister is an Addisonian and also suffering with Dementia. ***Janet is looking to connect with any Addisonian also suffering with Dementia.*** Please contact Janet via email at twojays58@hotmail.com.

Please remember to **renew your membership** in the Society - $25.00 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. Thank you for your continued support.

President's Comments

There was a tremendous and gratifying attendance for the Annual General Meeting and on behalf the Board Members (past and present) we thank all of those that were able to attend, and for making it a most successful day. We recognize that many members across Canada who would like to be able to participate are unable to do so, due to location. We are working to find an acceptable and workable system that would allow us in the future, to broadcast the day's activities so that more members will be able to participate through some means of a video link. Stay tuned as we investigate options that may be within our means.

Staying with the AGM topic, I wish to thank past Directors and Officers for their service and at the same time welcome some new members. I look forward to the next three years and personally wish to thank members for their support. We have a somewhat refreshed Board and Executive Committee and look forward to a full agenda over the next three years.

The President's Youth Council is in its formative stage. I am very pleased to report that Derek Burpee has accepted my request to head-up this initiative and he is busy preparing a draft proposal of the Council's mission and objectives. All of this will of course, be within the Addison Society's Constitutional mandate. Stay tuned!

Team Gordon Retires

One of the major events at this year's Annual General Meeting was the recognition of Irene and John Gordon for their volunteer service and contribution to The Canadian Addison Society, for over 15 years, on the occasion of their retirement from their important roles.

Directors and Presidents come and go but Irene and John have been on the job for our members and non-members, every day.

Denise Burpee presented Irene with Flowers and on behalf of the Board of Directors and all members, past and present, Irene and John were presented with a framed "***Certificate of Appreciation*".**

To conclude, they were presented with a **Gift Card** of consequence to buy a gift so they may remember this special event, in recognition of their amazing service.

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L to R - Harold Smith, John Gordon, Irene Gordon

Newsletter Editor:

You will see a few photos in this edition as a direct result of the requests we have received to add more photos to the Newsletter so members may put a face to a name. Not everyone will be thrilled with their pic but here we go.

Please continue to send me your articles about your experience either as the patient, caregiver, family, friend, nurse, doctor or anyone else with a connection to Adrenal Insufficiency. Each of you has a story that may support and help someone else understand what is happening to them. As noted above, members are requesting a few photos so please send us what you may have. Please remember to identify who is in the photo.

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

Support Group Meetings:

Vancouver Island Support Group – Victoria

This group met Saturday afternoon, September 27, with 10 people attending including 3 spouses. One member travelled from Duncan, BC and another from Ladysmith, BC.

When to take medications while travelling was one question asked. A frequent flyer advised that he follows the sun by taking his breakfast dose after sunrise and the lunchtime dose at mid-day. Some people know from experience that they must increase their dose before leaving to avoid feeling unwell during travel, while others carry on with a normal dose. Several travellers increased their Florinef dose before and during trips to hot climates with good results, including a better appetite.

On other topics, members discussed their experiences from passing out due to low blood pressure caused by illness, pre-diagnosis diabetes symptoms, food poisoning and serious infection. One individual advised us to stay around people if you feel faint so they may assist you if you should collapse. A few have unintentionally locked themselves in bathrooms before fainting.

Vancouver Island Support Group – Victoria (continued)

It was suggested that using a blood pressure cuff monitor at home can identify low BP so you know when to seek medical assistance. Both cortisol and aldosterone play a role in maintaining blood pressure. Low blood pressure is one of the symptoms of a potential adrenal crisis.
http://endocrine.niddk.nih.gov/pubs/addison/addison.aspx

A concern of many is how endocrine disorders may impact their children in the future. We know that endocrine diseases can occur within families. Katherine White of the UK Addison's Disease Self-Help Group wrote a 2007 research paper based on the results of her group's international survey.
http://www.endocrine-abstracts.org/ea/0013/ea0013P114.htm

Not sleeping for one member is a real concern and shared by many of us. She has tried numerous sleep aids that have not helped. One woman uses melatonin to sleep successfully, although it was pointed out by others that melatonin instructions warn against taking it for anyone with an autoimmune disease. Another suggested using valerian and one takes magnesium supplements with calcium before bed. One woman finds dimming the lights later in the evening readies her for sleep.

Increasing glucocorticoids because of stress was discussed. Two members coping with bereavement increased meds for an extended period then gradually reduced their doses to return to their normal dose.
One found that extra hydrocortisone gave her migraine headaches which she had never previously experienced.
Many in the group said they will increase for a stressful occasion and with illness as recommended by doctors.
A woman scheduled for an operation received help from her endocrinologist to arrange for a hydrocortisone drip throughout the procedure and still required two more hydrocortisone injections afterwards as her blood pressure was very low.

The emergency Solu-Cortef injection kit was used in one household when a woman collapsed in the kitchen. Her husband called for an ambulance then he administered the Solu-Cortef injection. A form with her medical information was given to one medic while the other aided his wife. The actions of the paramedics seemed slow to the husband, getting his wife off the floor and into the ambulance. In the ambulance one paramedic called the doctor at the hospital then instructed the other medic to put the woman on IV. Emergency staff were waiting at the hospital and the woman received treatment very quickly on arrival.

It was recommended that you download the medical information form to complete and place on your refrigerator as Paramedics typically look there. http://www.addisonsociety.ca/related/EmergencyFillinForm.pdf

You may also wish to print off the Peel Regional Paramedic Services for Addison's Disease emergencies at the end of the CAS July 2014 Newsletter:http://www.addisonsociety.ca/newsletters/Newsletter2014July.pdf

A member wrote to relate her daughter's medical experience for the group. Some time after being diagnosed with Addison's she started getting a pain in one eye. A brain scan showed an enlarged pituitary gland was pressing on her optic nerve. No treatment was recommended. She also suffered from fatigue and tachycardia (faster than normal heart rate at rest). She saw a number of doctors who had no answers for these symptoms. She had asked several doctors for a Cortisol Day Curve test but was told these were not done in Canada. Then a new endocrinologist in Nanaimo actually asked to do a Cortisol Day Curve test. "The results were quite staggering."

Although she was on the correct dose 'by the book', her day curve test results showed she was taking twice as much hydrocortisone as she needed! Her dose was gradually lowered. She realized that many of her symptoms were caused by taking too much hydrocortisone. Now she no longer has eye pain and believes the swelling has gone down. She has more energy and is able to work part time, even the tachycardia has improved. "Because of the day curve test and lowering her dose, her quality of life has greatly improved."

Vancouver Island Support Group – Victoria (continued)

Our next Victoria meeting should be late February 2015. Is any member in greater Victoria willing to host this meeting? If so please reply. Members will be informed of the date and location in the February meeting notice and on the website. We would like to practice the emergency injection at the Spring meeting (May/June) and would greatly appreciate the help of an experienced, medically trained person to demonstrate this procedure. We now have practice vials as supplied by CAS as provided by **Pfizer Canada**.

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

Saturday, October 4, Royal Columbian Hospital, New Westminster, B.C. *Attending: 11, Regrets: 4*

Welcome by Moh Thauberger:

Self-introductions by all –Most of the members related a slow deterioration – months to years of fatigue, intestinal symptoms – ending with a life-threatening crisis before a diagnosis was made.

Member Klara Dickey's passing on July 2nd was given special mention.

Maggie Metcalfe: Personal Preparedness Plan:
There is a fairly new medical program with the hospitals called the "Personal Preparedness Plan". Maggie had good success setting up her plan with the ER Dept. at Langley Hospital. Now, when she presents at Emergency in any hospital in Fraser Health, her file will have a flag, indicating that she is to be seen by a physician within 20 minutes
It is up to each of us to make a plan with the emergency department at our local hospitals. A first step is to contact the Medical Director in the Emergency Department to discuss it and fill out the appropriate forms—one of which shall be completed by your doctor.

Judy Whittaker: Addison's in Canadian Medical Association Journal:
The CMA is a bi-weekly publication to physicians presenting articles on health care—trends, new developments, etc. As we all know, Addison's Diagnosis is frequently misdiagnosed with often severe traumatic consequences to us as patients. e.g. Psychiatric Consult, Anorexia, Hypochondria, etc.
It is our wish to have Addison's disease written up in the CMA to assist our GPs to recognize the signs and symptoms of Addison's. To this end Judy W has submitted a letter to Dr. Anne Priestman and Dr. C. Wallace to assist us with this request.

This seems an opportune time for such an article, as Addison's Disease has just been added to the National Organization of Rare Diseases—NORD (USA) https://www.rarediseases.org/
Just type in Addison's Disease, or look under "A". You will find an excellent description of the signs and symptoms of Addison's.

BC Lower Mainland Support Group-continued

Gerry Ott: Advisory Council
The Council came together almost by accident several months ago. Members meet every six/eight weeks to discuss issues and projects pertinent to the Addison's group. Current topics are on the issues related above, plus following on work with Paramedics in BC, the 2015 AGM, and increasing member involvement.
The Council is comprised of six members: Judy Stanley, Gerry Ott, Judy Whittaker, Maggie and Geoff Metcalfe, Moh Thauberger

Satellite Meetings –
Because we now have only two general meetings a year in the Lower Mainland, and a very long time in between the Fall and late Spring meetings, we invite members to get together by geographic locations in between general meetings, to discuss the current group issues, to promote greater involvement, as a social time and to support each other. One or two council members will attend each meeting.
Members signed up will be contacted to arrange a get-together, probably after the New Year. Anyone else who would like to attend a meeting in your area, or if you would like to form a group, please contact Judy Stanley: bugbee@shaw.ca

I will contact those in your catchment and pass on phone numbers or email addresses as permission is given.

National Issues http://www.addisonsociety.ca
2014 AGM held in Ontario, Sept 27th, the minutes are not yet available
The new executive is: President: Harold Smith, Vice-President: Roger Steinmann,
Secretary/Treasurer: Rick Burpee

Gerry Ott relinquished his Vice-President position to become a director for BC, to allow him to concentrate his efforts at a local level.

Membership Renewal:
The national executive is looking to make this available on-line for payments. It is not available yet, Memberships are due the end of each year and renewal forms can be found at http://www.addisonsociety.ca/membership.html Early renewal means more for the holidays.

Gerry had ordered Electrolyte Replacement for some of the members. Because the minimum order was very large, the extras were made available to the group. This is excellent to use to replace electrolytes during hot weather, or whenever we feel they are depleted.

Emergency Letter:
Available on-line from the UK site: addisons.org.uk On the right hand side, Click on What to Do In An Emergency, printed in red letters. On the left click on Emergency Crisis Letter. The top choice is English. There is also a wallet card just above it, which can be printed.

Moh Thauberger: 2015 AGM planning -
There are several locations available at minimal cost, which have hard-wiring in place for stable internet connection. That will allow us to have Skype or some other method by which groups across the country may join the meeting. Further planning will take place at the satellite and Advisory Council meetings.

John and Irene Gordon were Treasurer and Secretary for 15 years—truly dedicated to helping all of us. We circulated a Thank you card to them for members to sign to send to them.

Judy Whittaker: Self-Injection Practice Session:

BC Lower Mainland Support Group-continued

Price Smart Foods in Coquitlam donated new syringes and a safe disposal unit to our group. A very sincere thank you to Price Smart. The syringes will be put to good use at the Spring meeting. Due to time restraints we were not able to complete the practice session today.
Members are encouraged to carry their Emergency Cortisone Injection Kit with them.

Judy Stanley: Thanks to those who took the meeting for me and such excellent notes. So much was accomplished in such a short time! Reminder: Flu season will be with us soon so please update your flu shot for the year.

Submitted by Judy Stanley

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

This Support Group meeting was held in conjunction with the Society's *Annual General Meeting* and therefore was a somewhat shortened version. Please refer to the *Annual General Meeting* notes as printed elsewhere in this Newsletter or you may also see them on the Society's website at www.addisonsociety.ca.

SELF INTRODUCTIONS: Sharing of our personal Adrenal Insufficiency journeys has become the highlight of our meetings for many who attend. Total attendance at this meeting was 36.

EMERGENCY INJECTION CLINIC: Denise Burpee, BScN- conducted our **Emergency Injection Training Clinic.** It was reported that no one found it necessary to use their injection kit since our last training session. Reminder of the importance of carrying the kit with you as it could be 20-30 min or longer for the pills to take effect, if at all depending on your situation, and may be too long in crisis situations such as: vomiting, diarrhea, loss of consciousness, or accident.

GUEST SPEAKERS: Dr. Stan Van Uum and Dr. Christine Ibrahim from Western University reported a preliminary summary of the findings of the ***ADEQUATE Study*** and its potential application for the *future benefit* of those with Adrenal Insufficiency.
The results were discussed and many, many questions were fielded. At this time unfortunately we are unable to print specific findings here just yet, in order to maintain the ability of the study to be officially published. We look forward to the final copy, and getting it out to you, the medical community and the general public.

South/Central Ontario Support Group-continued

Items discussed were:
- A general overview of Primary Adrenal Insufficiency
- A novel diagnostic tool that measures cortisol in the hair
- The preliminary results from their study titled,

"ADrenal insufficiEncy, QUAlity of life, and Treatment in the Emergency room (ADEQUATE Study)".

This study looks at the survey results from 134 persons with adrenal insufficiency. Their main objectives were to:
a) Assess individuals' education around adrenal insufficiency and stress dosing;
b) Address the use and perception of emergency rooms and hospitals;
c) Assess the barriers to care;
d) The use and perception of medical alert identifiers;
e) A quality of life survey.

The initial results were quite fascinating, in particular, raising some concerns about the effectiveness of the Medic Alert Identifiers and Cards. We thank both Doctors for sharing their knowledge, their time, and their ongoing support for those living with Addison's and other forms of Adrenal Insufficiency.

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

Submitted by Harold Smith

Eastern Ontario Support Group

The Eastern Ontario Support Group held a second special meeting in **Kingston on Saturday, August 9th**. Meetings for the Eastern Ontario Support Group are usually held in Ottawa twice a year but, due to popular demand, a summer meeting in Kingston was arranged. We met at the home of our member, Kelly Cole, who was kind enough to have us congregate there. Not as many people as expected showed up but we had a very good meeting with those that did attend.

Emergency Kits - After the introductions were made, we again noted and discussed the subject of some Endocrinologists not wanting to prescribe emergency kits and deem them unnecessary. This is contrary to what most Endos think as well as the potential needs of Addison patients in our opinion. A week later I brought this up with my Endo in Ottawa. He confirmed there was no standard on this subject but would bring it up at the next staff meeting in his office at the Riverside Campus of the Ottawa General Hospital. We wondered if this was the case in other areas of Canada as well. In the opinion of those gathered at the meeting, if a patient wants an emergency kit, the doctor should prescribe it.

Ottawa Hospital Protocol – Passed around this protocol for treating those with Addison's Disease that is in place at the Ottawa Hospital (written by Dr. Silverman). Suggest you ask if there is one in the local hospital? If not, suggest they talk to the head of the hospital, the head of emergency services and to use the Ottawa version as a template. Also noted that this is a great item to be kept with Addisonian's at all times, wherever they live.

Spouses/Family – it was suggested that we get input from the spouses and/or family of Addisonian's asking for them to relate their personal stories about living with someone who has the condition.

CAS Brochures – Noted that we have a CAS brochure available on our site that outlines what Addison's Disease is and tells of the Society. Advised that it can be printed from the CAS web site and left at your GP or Endo's offices. If you would like a lot of these, let me know and I'll have the CAS secretary send them to me on your behalf.

CAS AGM: Advised of the next Annual General Meeting for the Canadian Addison Society to be held Sept.27th from 12:30 to 4:30 pm in Brantford ON. Noted that they'd be welcome to attend.

Endocrinologist – Asked if they would like their endocrinologist to receive the CAS Newsletter? If so, they need to contact me or the CAS Newsletter editor, Carrie Smith. If you DO NOT have an Endo, contact the Ontario College of Physicians and Surgeons to find one in Ontario.

Cool Vest – I brought along my cool vest to show everyone what it is like and also to show how exciting it is to put on at first. The brand name is 'Cool Sport' and I bought it on-line from California. The cost was around $170, which I felt was worth it so I could finally participate in some hotter summer weather activities without fearing potential detrimental effects.

Web Site – Suggested that they take the time to go through the links provided on the CAS site, there are some other organizations that have interesting things going on that are worth the read, especially the 'Owner's Manual' on the UK web site. Also, there are various groups on Facebook dealing with our condition.

On the topic of other web sites and other Addison Groups, it was suggested that the CAS join each of the major societies across the world so we, as a group, could read their newsletters and support those in other countries.

Emergency Injection Practice – this demonstration was repeated by popular demand. Patricia Hehner, our former Newsletter Editor, ran us through the procedure. One point to make, ask your pharmacy for the 250 ml vial of Solu-Cortef as it is then easy to fill the syringe with 100 ml of the liquid in an emergency situation.

CAS Membership – please be sure to keep your membership up to date as it assists in many ways, including personal support, meetings, web site and much more. Also asked for members to let us know if you change address, phone number or email information.

Our Next Meeting: the next meeting for our region will be on Saturday October 18 at Robbie's Restaurant in Ottawa from noon until 2:00 pm.

In regard to other meetings in Kingston, I mentioned that it is a long drive to and from Ottawa to Kingston and asked, "Could you run your own meetings?" Those present felt they could do this as needed. Also, others there did not want to make the journey to Ottawa meetings for the same reasons. I can co-ordinate the meeting from Ottawa and send any items to Kelly Cole for meetings in their city. Thanks to everyone for understanding.

October 18 2014 Ottawa Meeting

The Support Group met Saturday, Oct.18th at Robbie's Restaurant, in Ottawa. The fourteen attendees introduced themselves along with how long they've had Addison's or, if they were not Addisonian, who they were with. We also introduced our guest speaker, endocrinologist Dr. Mark Silverman, the doctor who wrote the Ottawa Hospital Addison's Protocol for the Emergency Department.

The meeting started by noting an item in a recent National Adrenal Diseases Foundation (NADF in the USA) newsletter that a product called *CORTISLIM*, was being sold to promote weight loss by blocking cortisol - which they falsely claimed was the cause of weight gain. The creator of this product was charged with false advertising by US's Federal Trade Commission. This type of product obviously should be avoided by Addison's patients.

Eastern Ontario Support Group-continued-

Dukoral - over-the-counter oral vaccine to help ensure a safe and happy vacation. It is used to help prevent traveler's diarrhea and is taken orally in two doses prior to departure date. Not everyone had heard of this. Dr. Silverman agreed that it is a good idea to use in when travelling to many locations.

Dr. Mark Silverman began his presentation by giving a bit of history on his becoming an endo and then took questions from the group. Some of the questions put forth included:

- Why is there no standardized policy on emergency kits for Addison's patients within the endocrinology world? Some doctors are on-board while others say it's not worth it and will not prescribe the medication. Why is there no consistency on this very serious subject?
- Consistency again with type of medication prescribed (some say must take Dexamethasone while other say Prednisone or Cortef)?
- Drug duration and when to take extra (Solution – think for yourself)
- Does Addison's make arthritis worse?

The prominent general theme was 'Everyone's different. Take a dosage and follow a schedule that works for you.' It's better to increase for a short while when you didn't need to, than not increase when you should have.

Dr. Silverman noted that dogs are 100 times more likely to have Addison's; many of us have heard stories about how easily a pet was diagnosed and wondered why it's so hard to diagnose people. Indeed, he thinks on average an endo would normally be testing 8-10 people a year for Addison's – not all will have a positive diagnosis, but you won't find the ailment if you aren't looking for it.

A suggestion was made that, for emergency kits, 250mg vials be prescribed as it is easier for an inexperienced person to get the required 100mg to inject rather than trying to get all of the 100mg of Solu-Cortef out of the 100mg container. Dr. Silverman thought this was a good idea.

The discussions were lively and lengthy. The group was very happy to have had the opportunity to speak with Dr. Silverman in an open forum setting.

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

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

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

Submitted by Steve McKenna, Eastern Ontario Support Group

Québec Support Group

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

Atlantic Support Group

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

Medical Q & A:

There is a very large and wide-ranging set of questions on both daily living and situation-specific issues that have been answered by our medical advisor over the years. Before submitting a question to our medical advisor, please consult the wealth of Q&A's on our website. Many questions have already been answered. To review these questions and answers, please go to the Canadian Addison Society website under Education (http://www.addisonsociety.ca/related/FAQNovemberb2011.pdf), or see previous issues of the newsletter.

Question #1: My daughter is adrenal insufficient and is on 25 mg cortef per day. She has a bladder infection. I doubled her dose on Tuesday, she started antibiotics Wednesday evening.
How long should I continue the double dose?

Response: "You should talk to the doctor who started her on the antibiotics since she/he will know how severe the infection is and the age and general health of your daughter. In general, the increased dose should carry on until the symptoms improve."

Question #2: I developed secondary adrenal insufficiency after taking a corticosteroid nasal spray for 3 years. The adrenal insufficiency was not diagnosed for 2 years following that, and I now have been on 30mg of Cortef for a year. Despite the Cortef, which does help with my energy level later in the day, I am not able to wake up in the morning before 11am. My blood cortisol levels at 8am are between 58-138, and they seem to drop and then come back up to that level again or a bit higher around 11am. If I try to get up at an earlier time and take my first dose of Cortef then, I feel nausea and am unable to remain awake until 11 no matter how hard I try. I have also tried combining my daytime dose of Cortef with 2.5 mg of Prednisone at bedtime, but this did not improve my morning cortisol level. Is this a common symptom of adrenal insufficiency, and is there anything I can do to get my mornings back?
Also, since my adrenal function did not recover during the 2 years after I stopped taking the nasal spray, and now another year that I have been on Cortef, is there a chance that it will ever recover? I did try to wean off Cortef recently by cutting back my dose by 2.5mg per week, but I felt so much worse that I was not able to sustain this process and went back to my full dose after 2 weeks. Should I plan for not being able to improve much from this point?

Response: Your problem is one we see with increasing frequency because of the popularity of inhalers and the lack of adequate warnings about this problem.

Getting off the puffers can be difficult but it is usually possible. It is interesting that you were off the puffer and not on cortisol for two years. That is about the time it often takes to gradually get off of the cortisol dependence. Why did you go on to cortisol after two years on no medication? Let us go back and see what has taken place:

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

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

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

Medical Q&A-continued

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

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

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

Send your question to Dr. Killinger directly from the webpage http://www.addisonsociety.ca/faq.html#, or by emailing liaisonsecretary@addisonsociety.ca or c/o The 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

193 Elgin Avenue West
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