



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.

Clarification of Presentation included in July 2013 Newsletter:

In the last newsletter, there was a presentation to the South/Central Ontario support group by Scott Clack of the Touchstone Naturopathic Center in Oakville. The slides of his presentation were included at the end of the newsletter. Our advisor, Dr. Killinger, indicated there was information in the presentation which was incorrect and could lead to significant problems if any of our members acted on this information and discontinued their prescribed medication.

- It is suggested that various stressors, environmental toxins and nutrition deficiencies can cause Addison's disease. There is no evidence to support any of these causes for Addison's disease.

- There is a description of naturopathic treatments for Addison's disease, none of which would provide any specific benefit for a patient with adrenal insufficiency.
- Some "supplements" for adrenal glands are given and once again there is no evidence that any of these supplements will specifically improve adrenal function.
- There is no evidence that melatonin or ashwaganda improve adrenal function. Licorice acts on the kidney to block the enzyme which protects the aldosterone receptor and is of no help in the treatment of adrenal insufficiency. It can cause high blood pressure in individuals with normal adrenals. Yams were used by some companies in the commercial biosynthesis of cortisol but cannot be converted to cortisol by the body.
- Intravenous vitamins or formulations of homeopathic preparations have no role in the treatment of adrenal insufficiency.

The Society does not endorse the views of any of the speakers at local or annual meetings. We remind members that it is essential that each member assess the views put in front of them and discuss their implications with their medical doctors. We apologize for any confusion which may have occurred.

Minutes of the 2013 Annual General Meeting:

The Annual General Meeting was held Saturday September 28, 2013 in Brantford, Ont. It was called to order at 1:00 p.m. by Irene Gordon, Liaison Secretary of The Canadian Addison Society standing in place of the President. There were 22 members and guests in attendance.

1. Welcome
2. **President's Message** - presented by Irene Gordon. Judy Stanley has had to retire 1 year early for health reasons. Huge thanks for all she has given to and done for the Society during her tenure. (Addendum #1).
3. **Adoption of Minutes from 2012 Annual General Meeting: Moved by:** Don Archi
Seconded by: Joan Southam and **CARRIED**

THAT the Minutes of the 2012 Annual General Meeting be adopted as circulated.

(Reminder that only paid up members may vote)

4. Thank you to Lesley James for her efforts as Secretary to the South/Central Ontario Support Group. Lesley has retired from the position due to other obligations. Heather Raczynski has kindly volunteered to step into this role
5. Special thanks to Justin Raczynski and his school Holy Trinity for their fundraising efforts on behalf of the Society.

6. **Financial Report-** John Gordon

- a) Financial Statements presented for the periods ending December 31st, 2012 and Sept 30, 2013. Balance at Sept 30, 2013 is \$42,089.85. (Addendum #2)
- b) It was **Moved by:** John Gordon **Seconded by:** Denise Burpee and **CARRIED** that a further \$5,000 of Cash on Hand be invested in a GIC with Equitable Trust coming due November 6th, and the investment period be extended to 270 days @ 1.65%. Page 2 of the financial report was also discussed.

Moved by: John Gordon **Seconded by:** Lesley James and **CARRIED**

THAT the financial report be accepted as presented and discussed.

7. **Membership update-** Irene Gordon

- a) Paid up Members - 134 members
- b) Canada Helps Donation button is now on Web Site – a small percentage of donations are kept by Canada Helps for services such as issuing of Tax Receipts. Only donations are handled using this process, not membership fees.
- c) Memberships are due every January 1st. Reminder of the importance of membership fees and discussion that membership can be paid several years at a time if you so wish. You may also designate \$5 of that \$25 to your own Local Support Group with the remaining \$20 going nationally. This \$5 would be applicable for each year your total payment covers. Be sure to tick off the related local support group box on the membership form.
- d) It is sad to report that 2 of our members have passed away. Our sympathies go out to the families of Stephanie Leger and Robin Whittemore.

8. **Nomination/Election:** It was noted that 2 Executive Positions have been vacated.

Nomination for Harold Smith (ON) for President was put forth. There were no other candidates and a Motion was presented to close the Nominations.

Moved by: John Gordon, **Seconded by:** Jack Mayos, **CARRIED**

THAT Harold Smith is elected President by show of hands.

Nomination for Don Archi (ON) for Vice President was put forth with the proviso that Don agreed to take the position of Vice President for 2 years only with the goal to find and mentor the next Vice President. There were no other candidates and a Motion was presented to close the Nominations.

Moved by: John Gordon, **Seconded by:** Denise Burpee, **CARRIED**

THAT Don Archi is elected Vice President by show of hands.

SLATE OF OFFICERS and DIRECTORS FOR 2013/2014 *(for information only)*

President	Harold Smith (ON)	Directors:	Derek Clarke (BC)
Vice President	Don Archi (ON)		Elizabeth Hill (SK)
Treasurer	John Gordon (ON)		Stephen McKenna (ON)
Liaison Secretary	Irene Gordon		Gerry Ott (BC)
			Joan Southam (ON)
Newsletter Editor	Carrie Smith (ON)		



Harold Smith – President
Irene Gordon – Secretary
John Gordon – Treasurer
Joan Southam – Director
Don Archi – Vice President

It is imperative that we acknowledge and thank each of the following individuals for their dedication to the organization, their willingness to give of their time and sharing a wealth of knowledge with others. Our most sincere thanks go out to each of the following:

Retiring President - Judy Stanley (BC) (remaining as Regional Rep)

Retired Vice President - Jim Sadlish (BC) (remaining as Regional Rep)

Retiring Director/Newsletter Editor – Patricia Hehner (ON)

REGIONAL REPRESENTATIVE OPENINGS:

- Alberta
- Quebec (looking for a more interactive member)
- Welcome to Holly McLean of New Brunswick as the contact person for Atlantic Canada.

9. OLD BUSINESS from AGM 2012

Increasing Membership - President reported that the board will be discussing issues related to maintaining and increasing members with an objective of developing a recommendation that can be brought to the 2013 Annual General Meeting.

Action to date: Although there has been some sharing of thoughts, nothing concrete has been developed and therefore no recommendations at this time.

10. 2014 ANNUAL GENERAL MEETING – (to be determined)

11. NEW BUSINESS: Moving Forward - Where do we go in the future?

12. UPDATE ON BROCHURE HOLDER PROGRAM: It was reported that there are approximately 5 holders still needed to be circulated. Heather Raczynski reported that the holder recently taken to Sick Kids Hospital in Toronto is on display.

Meeting adjourned at approximately 4pm.

ADDENDUM #1

PRESIDENT'S UPDATE

I would like to thank the Executive and Directors for making my five years as President so enjoyable. Due to personal reasons I am resigning a year early but know I leave the Society in good hands.

A lot has changed in the 36 years since I was diagnosed with Addison's Disease. Originally I joined the National Organization for Rare Diseases (NORD) in the USA as there were no Addison's groups at that time. They referred people who wanted to connect with others with Addison's. I wrote to fellow Addisonians around the world, we all wanted more information.

The first person I met 10 years after diagnosis was from California and 2 years later from Oklahoma, what a feeling it was to actually meet in person. 5 years later in 1993 I was contacted by someone in Vancouver who NORD gave my name to and the numbers have grown since. After the computer was mass produced, communicating was easier, now we have Skype where we can actually see and talk in real time, the next 35 years will vastly improve communication for us. I look forward to the advances with technology the Society applies.

Thanks again to all those who are so dedicated to the Canadian Addison Society.

Judy Stanley

THE CANADIAN ADDISON SOCIETY
STATEMENT OF INCOME & EXPENSES
FOR THE PERIODS ENDING DECEMBER 31, 2012 AND SEPTEMBER 30, 2013

Cash on hand and in banks	January 1, 2012 \$34,452.18	January 1, 2013 \$37,875.11
Income		
Dues Received - National	\$3,310.92	\$2,560.00
- Support Groups	430.00	485.00
Donations	5,405.81	3,747.12
Interest Earned on Investments	334.68	254.18
	<u>9,481.41</u>	<u>7,046.30</u>
Expenses		
Advertising & Publicity	395.50	0.00
Newsletter	1,657.28	967.68
Web Site	217.03	201.14
Secretarial	1,200.00	600.00
Annual Meeting	224.00	0.00
Postage, stationery and supplies	982.56	154.13
Telephone	1,077.24	737.90
Support Group Expenses	294.53	160.76
Bank Charges	10.34	9.95
	<u>\$6,058.48</u>	<u>\$2,831.56</u>
Cash on hand and in banks	December 31, 2012 <u>\$37,875.11</u>	September 30, 2013 <u>\$42,089.85</u>

THE CANADIAN ADDISON SOCIETY
 Analysis of cash on hand & in banks as at September 30, 2013

Equitable Trust -

The Canadian Addison Society - \$14,373.91 @1.35% due November 6, 2013	
- \$15,820.06 @1.35% due September 16, 2013	\$30,193.97

TD Canada Trust -

The Canadian Addison Society	7,059.75
Quebec Support Group	170.00
Eastern Ontario Support Group	682.41
South/Central Ontario Support Group	1,932.04
Saskatchewan Support Group	185.00
Edmonton Support Group – Alberta	499.60
Lower Mainland (Vancouver) Support Group - British Columbia	662.08
Vancouver Island Support Group – Victoria	705.00
Total	\$42,089.85

New Ottawa Hospital Emergency Letter:

The Ottawa Hospital now has an official form for doctors and Addisonians to use as a generic emergency response letter available to all doctors and patients. It can be found on our website at <http://www.addisonsociety.ca/emergencylett.html> (click on Ottawa Emergency Letter in the box on the right side of the screen).

News and Announcements:

- We regret to inform you that Robin Whittamore of the South/Central Ontario support group passed away on July 23, 2013. His wife was kind enough to say that, although he had only been a member of the Society for a short time, he put great store by the good information he obtained from us.
- There has been a change to the home page on the Society website to now include the ability to send e-mail directly to any one of the Executive Committee. Just click on the envelope icon next to the name. Please feel free to contact any of the Executive to share your views and ideas.
- Remember to renew your membership in the Society - \$25. due in January. Your membership fees are necessary if we are to continue making resources such as this newsletter available to you. You can find the necessary form at the end of this newsletter or online at <http://www.addisonsociety.ca/membership.html>.

Newsletter Editor:

After ten years editing the Society newsletter, I am passing this role on to Carrie Smith, a member of the South/Central Ontario support group and daughter of an Addisonian. You can reach Carrie at csmith041441@yahoo.com. Welcome, Carrie!

New Vancouver Island Support Group Website:

A quick reference for basic information about Addison's disease and local support meetings is the purpose of a new Vancouver Island support group website. Newly diagnosed people often ask about finding an endocrinologist, or when the next support meeting is scheduled, but they should also be aware of the precautions we, with adrenal insufficiency, must take. This website offers a simple source for emergency forms and injection instructions as well as links to learn more about living with Addison's. The site replicates material already available on the Canadian Addison website, but offers a regional perspective, allowing the posting of permanent notices for scheduled meetings and the need of a leader to facilitate mid-island meetings, plus a link to locate the Victoria meeting place. In all, the new website offers a package of critical knowledge to assist both new and established members. Have a look: <http://vancouverislandaddisonsgroup.weebly.com/>. Of course, there is also a link to the new

site from the Society website - under the "Links & Resources" section "Canadian Addison Online Support Groups".

Personal Experiences:

Now that I'm menopausal, I have noticed my fatigue levels are decreasing.

I was 33 when I was diagnosed and in a state of crisis. Over a 2-year period, I had seen 8 specialists who kept telling me that I was depressed. No one did a blood test. So I was diagnosed in emergency, bright orange, with tachycardia and I weighed 92 lbs.

On a recent visit to my endocrinologist, we were discussing whether or not I should start HRTs and the subject of DHEA came up. I've read enough medical journals to know of its potential benefits to Addison's patients. I have had the prescription filled at a compounding pharmacy and the benefits have been huge! No more muscle pain (particularly in my legs) and increase of energy, and I feel more alert.

DHEA is not recommended to just anyone due to the possible links to cancer but this is not the case of Addison's patients It's a great supplement for me. I also take bio identical HRT's which have been very beneficial to my overall health.

Highlights from Local Meetings:

Vancouver Island Support Group - Victoria

The Victoria support group met October 5, 2013, in Victoria at Esquimalt Serious Coffee. Four people and 3 spouses attended with 2 travelling from Qualicum.

The launch of a new, regional website for the Vancouver Island support group was announced: <http://vancouverislandaddisonsgroup.weebly.com/>. This website provides links to emergency forms and helpful Addison's information sites plus upcoming meeting dates and meeting reports. It has links to the Canadian Addison Society site, a source of abundant information.

A founding member of our group dealt with a number of serious health issues this year including infections and major surgery. Her daughter, acting as advocate, wrote to offer meaningful tips for members. Victoria General Hospital did not have a supply of the needed cortisol replacement medication in stock. Ordering from an outside pharmacy may take up to 24 hours. It seems prudent to carry medications with you when going to the hospital. If you are admitted to hospital, ensure that the 'house doctor' is aware of the stress dose for Addisonians. That is, increasing the glucocorticoid dose 3 times for 3 days for a major illness, surgery or fracture. Also check that nurses give you this stress dose.

Emergency injection practice demonstrations in future will be enhanced by using Act-O-Vials, containing no medication. These will be supplied through the Canadian Addison Society.

A Pacific Blue Cross website assists finding the best price for medications in pharmacies near you: <http://www.pharmacycompass.ca/>. It was noted that some pharmacies do not keep a large stock of our cortisol replacements, frequently having to order in more to fill prescriptions.

In distress with pre-crisis symptoms and vomiting with flu, a woman was driven to Comox Emergency. With the busy state of the ER, the triage nurse glanced at our member's Emergency Letter then asked her and her husband to sit in the waiting room. They were told that all the beds were filled with heart attack and stroke cases. They waited 1 1/2 to 2 hours before treatment with saline drip and Solu-Cortef. Calling an ambulance may help in getting treated sooner.

A woman asked if others experienced dizziness taking Florinef. One side effect of fludrocortisone is in fact dizziness: <http://www.drugs.com/cdi/fludrocortisone.html>.

Another has lost weight since she was taken off medication that proved unhelpful for her burning feet. It was suggested that she might ask her endocrinologist for a hypoglycemia test to rule out diabetes <http://www.mayoclinic.com/health/burning-feet/MY00409/METHOD=print&DSECTION=all>.

If you are concerned about how much Vitamin D to take, ask your doctor to include it with your regular blood tests.

Discussing cortisol replacement, one woman takes Cortef first thing in the morning before coffee and breakfast. Others are more cautious and heed the advice to take with food, printed on the medication labels by pharmacists. Evidently, Cortef may be taken with, or without food unless you have a stomach upset or irritation, according to this source: <http://www.drugs.com/cdi/cortef.html>. During a day of intense stress another woman needed 100 mg Cortef to maintain stability.

Submitted by Jim Sadlish

The next Victoria meeting of the Vancouver Island support group is scheduled for March 1, 2014, at Serious Coffee in Esquimalt.

For further information on the Vancouver Island Support Group, 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.

BC Lower Mainland Support Group

The BC Lower Mainland Group met May 25, 2013. Six members brought a variety of foods that we all appreciated.

After serving for twelve years, Moh resigned the position of Education Coordinator. We thank her for her dedication and great job in obtaining guest speakers. If anyone can take over the Education position or even volunteer to approach a speaker for one meeting, please let me know. I would also like someone to take notes at meetings as I can no longer do this.

Dr. Donald Killinger, MD, PhD, FRCPC, Medical Advisor for The Canadian Addison Society again advised that dexamethasone is not our best choice for use in an Addisonian crisis, as it has very little salt retaining activity and thus does not support blood pressure. However, a preloaded syringe with 4 mg dexamethasone is a reasonable emergency kit for use when travelling (<http://www.addisonsociety.ca/related/FAQNovember2011.pdf> under Addisonian Crisis / Emergency).

Dr. Killinger also answered my question for the timing of taking cortisol and thyroxine:

- Normally, cortisol levels are at their peak when we wake up in the morning. You should therefore take your cortisol as soon as you wake to get it into your system as early as possible. It is absorbed quite quickly. The studies that have been done comparing twice daily cortisol with cortisol three times daily have tended to favour three times daily in terms of patient satisfaction.
- Thyroid medication should be taken on an empty stomach to avoid having it bound to calcium or iron in the diet. Thyroid levels do not fluctuate like cortisol so timing is not such an issue but avoiding taking it with food products that may interfere with its absorption is important. For this reason most people take it first thing in the morning and have breakfast 1/2 to 1 hr later.

Professor Simon Pearce, Consultant Endocrinologist Royal Victoria Infirmary, Newcastle, UK was able to get funding after several years for 'Rescue of Addison's Disease Study'. The study had limited success - 1 of 6 remained well with no treatment after 18 months. The report can be found below.

- Simon H. S. Pearce et Adrenal Steroidogenesis after B Lymphocyte Depletion Therapy in New-Onset Addison's Disease J Clin Endocrinol Metab. 2012 Oct; 97(10):E1927-32. doi: 10.1210/jc.2012-1680. Epub 2012 Jul 5.
<http://jcem.endojournals.org/content/97/10/E1927.abstract>.

I phoned UBC - there are no endocrine studies at the moment but they will contact me if one comes up.

NADF is initiating a Global Addison's Awareness Campaign. This year, due to short notice, we were unable to participate. It occurs in April and it would need to be an effort from each local.

Submitted by Judy Stanley

Our next meeting will be Saturday, October 19, 2013 from 1:00 – 3:00pm, in the Neil Russell Room, 3rd floor Columbia Tower, Royal Columbian Hospital, New Westminster BC (to right of elevator). For those travelling by bus: exit Sherbrooke Street or SkyTrain to Sapperton Station.

Trevor Lesmeister M.ED., RRC will be our guest speaker. Trevor is a Vocational Rehabilitation Consultant and Registered Clinical Counsellor for OrionHealth www.orionhealth.ca. He will arrive early and start his talk at 1:00 pm followed by a Q&A period. The talk will cover:

- Introduction and my role as a Voc Rehab Consultant
- Vocational Rehabilitation – What is it and how can it help
- The need for a supportive employer
- Resources for support (e.g., OT, Private Agencies, Insurance Companies, ICBC, Non-Profit employment programs)
- What to do when a person can no longer work (e.g., applying for disability benefits, volunteering, etc)

A short meeting will follow. We should be receiving a shipment of Act-O-Vials which we can use to provide injection clinics with members and hopefully, if received in time, we can demonstrate after the guest speaker. The vials do not contain any ingredients for an Addison Crisis.

For further information on this support group or any upcoming meetings, 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, or Peter Little at bettypeter66@gmail.com or (780) 918-2342 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 group's Sept 28, 2013 meeting was incorporated in the Society's Annual General Meeting.

- Emergency Injection Clinic: Denise Burpee, RN and BSc in Nursing, conducted emergency injection training. It was reported that nobody needed the injection since the last emergency injection training session. Remember the importance of these injections, as it

could be 20-30 min for pills to take effect - too long in a crisis situations (vomiting, diarrhea, loss of consciousness, or accident).

- Dr. Scott Clack – Some issues with the May 2013 presentation handout were brought to Harold’s attention. Harold does not feel there was any suggestion from Scott Clack that he could cure you of Addison’s or that he could take you off steroids. On the contrary, his presentation was focused on improving our quality of life while living with Addison’s.

(Ed. Note: please see more detailed information under the heading ‘Clarification of Presentation included in July 2013 Newsletter’ earlier in this newsletter.)

- Harold shared that the positive meeting with Dr. Wicket that gave hope of training and changes at both Grand River and St. Mary’s Hospitals in Kitchener-Waterloo has come to an apparent dead end. More follow-up will be done in an attempt to learn if anything at all has been changed.
- Heather Raczynski shared that training of the EMS in Simcoe County will begin in October. It will still need protocol to change in order to ensure the emergency injection will be administered.
- An image of a person with a pump being used, taken from Facebook, was discussed as a possible future method of administering medication. It is currently being recommended by an endocrinologist in Arizona, USA.
- Dr. Stan Van Uum and Dr. Donald Killinger, both endocrinologists, are on board with The Canadian Addison Society, showing great support.

It was noted that we are an orphan disease – a recent movie “the Butler” and The Doctors T.V. show have both mentioned Addison Disease.

- Members shared their journeys and concerns

Submitted by Harold Smith

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 watch the "Upcoming Meetings" page on the website www.addisonsociety.ca for details on the agenda and speaker.

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.

Eastern Ontario Support Group

The next meeting will be noon Saturday, October 19, 2013, the weekend after Thanksgiving, at the usual location (Robbie's Restaurant on St. Laurent Blvd in Ottawa).

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

Québec Support Group

Our representatives in Québec can be contacted at centresantedentaire@bellnet.ca.

Atlantic Support Group

The Atlantic Canada Support Group is pleased to welcome Holly Mclean as the regional representative and leader. She lives in northern New Brunswick. You can 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 very 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&As on our website. Many questions have already been answered.

Q: My son is newly diagnosed with Addison's. He likes to play hockey but has not done so in awhile due to being sick for the last 3 months. He is now on Prednisone (5 mg) a day. He played hockey (medium intensity) the other night and is still feeling fatigued. Should he take a bit more prednisone before doing that type of exercise? If yes, how much? For the fatigue he feels now, should he take a bit more for the next day or two?

A: Your questions are very specific so you should discuss these with your endocrinologist. In general, individuals who are participating in strenuous activities take extra cortisol or prednisone before participating in the activity and after the event they are usually fine. The amount of extra steroid will depend on the activity. This type of situation requires some trial and error in collaboration with your endocrinologist to work out the best arrangement for your son. There is no single answer so your son will find out what works best for him as he tries

different approaches. In general though, extra steroid replacement is required to deal with extra activity.

Q: I am wondering if DHEA plays a large role if I am not producing it? I do not know much about it. Should I have my doctor test for it and would taking a supplement help if the test came back abnormal?

A: The role of DHEA in the treatment of individuals with adrenal insufficiency continues to be controversial. There have been a few studies which have approached the topic and the results generally have not shown much or any benefit. There was one article which suggested that DHEA may improve sexual interest but that article is controversial. DHEA is not officially available but some pharmacies may make it available. I generally do not recommend it. Low doses are usually without side effects but doses of 25 mg or more can cause facial hair, acne or voice changes.

Q: I was diagnosed with Addison's about 18 months ago. Since then, I have been taking Prednisone: 5mg in the morning and 2.5mg in the afternoon. I recently had a trip to NYC - it was a stressful trip and the weather was very hot (over 100 degrees F each day) and when I came home I crashed. I have had symptoms for over a week now and I have been doing everything I can think of to improve. I have taken extra doses of supplement, lots of milk, drinking boost and I even increased my prednisone slightly. Do you have any ideas how I might manage better so I don't keep "going off the rails"?

A: The exhaustion after a trip to New York may not be too unusual if you did not take extra steroid to deal with the added stress. In a normal situation, the adrenal gland responds by secreting cortisol in proportion to the stress the body is going through, both physical and emotional. You have to do the thinking for your adrenal and take added steroid at the time of, or preferably before the added stress. The amount you require depends on the degree and duration of the stress. You should review this with you endocrinologist to discuss the doses.

Q: I was diagnosed with Addison's disease in early June 2013 and have been on 30mg Cortef and 0.5mg Florinef daily since. My T4 Free count over the past two months is as follows: May 23 = 11; June 7 = 12; June 18 = 8; July 23 = 5. The last two results have been flagged as abnormally low. Is there a relationship between this declining count and my Addison's Disease or as a consequence of my medication?

A: I doubt if it is related to your medication although it depends on how ill you were when starting the medication. Thyroid disease can be associated with adrenal disease but you need more information to determine what is going on. You should get your TSH (thyroid stimulating hormone) measured along with the free T4 and thyroid antibodies. Your family doctor or your endocrinologist can help you with this.

Q: Is there any way to find a list of recommended endocrinologists in each province? I have been to a few already and am still not satisfied with treatment. I know it is partly due to complications from other conditions. My family doctor is more inclined to look at me as a whole and consider changing doses according to how I feel, so I may forego the specialist in the future.

A: There is no list of recommended endocrinologists to treat Addison's disease. My suggestion would be to contact the section of the Addison Society that is in your area and find out who is looking after different people in the area and see who is happy with their endocrinologist. You could then get your family doctor to refer you to that endocrinologist.

Q: I have had many issues with hormones, excess adrenaline and hypothyroid symptoms my whole life. My health has been an ongoing battle trying to find health and answers. Last year I was finally diagnosed with hypothyroidism and put on a natural thyroid hormone. I was given herbal formulas for adrenal help but now I am pregnant and I was taken off all adrenal supports. I have had a total collapse. I can't get off the couch or take care of my kids. In researching it seems that my issues may stem from undiagnosed Addison's disease. My questions: How do I get an American doctor to diagnose me? How do I get someone to put me on the right herbs, hormones etc if most western doctors won't treat pregnant women due to the lack of evidence for safety?

A: I am not sure where you live but there must be good doctors in your city or town. I think you should avoid herbal formulations for treating adrenal insufficiency and if the doctors you are seeing have been giving these to you, you may want to avoid them as well. You should ask to see an endocrinologist who can review your symptoms and lab work to decide what investigation and treatment you require.

Q: I was diagnosed with Addison's about 2 years ago. I take 30 mg of Cortef and 0.05 mg of Florinef a day. I've been in the hospital 3 times this year. I've had to quit jobs because I just couldn't handle working and taking care of my family anymore. My muscles are tightening up again, I'm finding it hard to walk up and down my stairs at home and I am very tired, and can't keep up with my children anymore.

I have been given the OK to double my dose of medication when needed, and have done so but it doesn't seem to help. Is it normal for someone with Addison's to be on disability as I am thinking that would be my next step?

A: It seems that you have had a difficult time since you have been diagnosed with Addison's disease. In general, when someone with adrenal insufficiency is started on replacement treatment, they feel much better. It often takes a while to get the medication adjusted but the individuals feel well.

You have been in hospital 3 times in the past year. It would be important to know what caused your problems at those times. It is also interesting that doubling your dose of cortisol did not help you when you were feeling unwell. I do not know what was happening at the time but an extra dose of cortisol will generally improve things if you are cortisol deficient and can keep the cortisol down. Under these conditions, I feel it is best to go back to the findings at the time of diagnosis to be sure that there is not another problem which is confusing the issue. This is best done with your endocrinologist to determine if you had high ACTH levels along with low cortisol and a tendency for skin pigmentation before getting your first cortisol treatment. Once you are on treatment, it is very difficult to review the diagnosis. Discuss your situation with your endocrinologist and review your original diagnosis.

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#>, 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
Goderich, Ontario N7A 2E7
Toll free number: 1-888-550-5582
Email: liaisonsecretary@addisonsociety.ca
<http://www.addisonsociety.ca>

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

New Membership Renewed Membership + Plus a Contribution

Name: _____

Address: _____

Postal Code: _____ Telephone: _____

E-mail Address: _____

How do you wish to receive the Newsletter?

- I will read it on the website at www.addisonsociety.ca
 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 Québec Support Group – QC+ \$20.00 to Society
 \$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

+ Contributions are also gratefully accepted. A tax receipt will be issued for contributions over \$10.00.

Please make cheque or money order payable to The Canadian Addison Society and send c/o Treasurer, 193 Elgin Avenue West, Goderich ON N7A 2E7