



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
www.addisonsociety.ca

ISSUE NO. 69

JANUARY 2013

In this issue:

- Minutes of 2012 Annual General Meeting
- Membership Renewals
- Email Chat String for Young Addisonians
- Highlights from Local Meetings
- Medical Qs & As
- UBC Faculty of Medicine: *Doctor, Patient and Society* & the *At Home Interview*

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.

Minutes of 2012 Annual General Meeting:

The AGM meeting was called to order on Saturday, October 13, 2012 at the Victoria General Hospital, Victoria, BC by Jim Sadlish, Vice President. Fifteen people were in attendance; this included 4 members of the Executive and 5 Guests.

1. WELCOME – Introduction of Guests
2. PRESIDENT'S REPORT – presented by Judythe Stanley (Addendum #1).
3. ADOPTION OF MINUTES FROM 2011 ANNUAL GENERAL MEETING

Moved by: Ginny Snaychuk **Seconded by:** Jim Sadlish and **CARRIED**

THAT the Minutes of the 2011 Annual General Meeting be adopted as circulated.

4. FINANCIAL REPORT – John Gordon

- a) Financial Statements presented for periods ending Dec. 31, 2011 and Sept. 30, 2012 (Addendum #2)

Editor's note: the year-end financial statements have been appended to this newsletter as Addendum #2 instead.

Sept. 30, 2012 – Total Assets to date: \$36,643.56

Moved by: John Gordon **Seconded by:** Ericka Gothe and **CARRIED**

THAT the Financial Statements to September 30, 2012 be accepted as presented.

- b) Motion to invest a further \$7,000 in 90 day notes with Equitable Trust

Moved by: Marilyn (Moh) Thauberger **Seconded by:** John Gordon and **CARRIED**

WHEREAS it is the responsibility of the Board and Membership to approve all significant financial matters, the Treasurer, John Gordon, proposes that, on behalf of the Canadian Addison Society, he invest an additional \$7,000 in 90 day notes with Equitable Trust.

THEREFORE be it resolved that the Board and Membership approve, adopts, and authorizes John Gordon to invest an additional \$7,000 in 90 day notes with Equitable Trust.

5. REGIONAL REPORTS (refer to recent newsletter)

6. SLATE OF OFFICERS & DIRECTORS FOR 2012/2013 (For information only)

President -	Judythe Stanley (BC)	Directors:	Joan Southam (ON)
Vice President -	Jim Sadlish (BC)		Elizabeth Hill (SK)
Treasurer -	John Gordon (ON)		Stephen McKenna (ON)
Liaison Secretary -	Irene Gordon (ON)		Harold Smith (ON)
			Patricia Hehner (ON)
Newsletter Editor:	Patricia Hehner (ON)		Derek Clarke (BC)
			Gerry Ott (BC)
			Don Archi (ON)

Please Note: Jim Sadlish (BC) will be completing his term as Vice President this year, so we are looking for a replacement. However, Jim has agreed to stay on the Board as a member-at-large.

7. MEMBERSHIP UPDATE – Irene Gordon

- a) Paid Up Members - 140 paid members as of October 13, 2012.

- b) Canada Helps Donation Button on Web Site – advised those present that the donate button on the web site has begun to see online contributions.

8. OLD BUSINESS

- a) **2011 Recommendation:** to explore other less expensive communication options: i.e. Web Conferencing, SKYPE, and Teleconferencing. Begin with Teleconferencing or SKYPE and perhaps investigate video conferencing.

Although we haven't yet had a member come forward who has the expertise to do an in-depth investigation, a small review did take place in order to provide some idea of associated costs, pros and cons of applying this form of communication for membership at our meetings as well as the logistical difficulties and equipment requirements, etc. The fact that having professional "in the room" style of video conferencing would be exorbitantly expensive (i.e. \$5,000 or better) per meeting, means trying to find other possibilities for electronic communication. There are no "free" internet programs that allow for more than a one-to-one clean, clear, voice/audio connection. **SKYPE Premium** and **Cisco's WebEx** were investigated. Both programs have a cost attached to their video conferencing product that allows for up to a maximum of 25 individuals to connect. In both cases, the Society would be required to purchase a laptop and a video camera so that it can be moved across the country for the AGM every year. In the case of SKYPE Premium, every member who wishes to connect to the conference would be required to have their own computer and video camera as well as the free version of SKYPE downloaded, if they want to be seen at the other end. At least one computer (probably the Society's) must have the SKYPE Premium product downloaded on it (there is a monthly fee attached to this version of the program). The second product investigated, WebEx, runs along very similar lines, although once purchased, any individual can connect to the conference using any kind of computer, or electronic device that has internet connect. The costs associated with this program are based on a monthly fee as well. There is the option of teleconferencing (without the use of a web cam from the member), but still requiring a computer, at cost per individual connection per meeting, based on number of members who want to be connected, number of minutes/hours they need to be connected and a per minute charge. Any of these options assume that there will be an internet connection available in the meeting room in order to transmit meeting activities.

An alternative discussed during the meeting would allow for direct telephone connection should any of the Executive be unavailable at a particular meeting to respond to questions related to their roles. In particular, the Liaison Secretary or the Treasurer might be required to answer questions regarding finance and/or membership or web issues. Further investigation must take place, and Judy Stanley suggests the board discuss it and bring forth workable recommendations to the next Annual General Meeting in 2013.

- b) Update on Brochure Holder Program – Report attached (Addendum #3)

NEW BUSINESS

- a) **Web Master** - Marilyn (Moh) Thauberger raised the topic of the Web Master and the fact that CAS has not been charged for the work being done by him, on the web site. After determining that he has opted not to accept a fee for the “small” requests, it was suggested that Judy Stanley, in her role as President, write a letter of thanks to him for his efforts. Membership was also informed that he is working on a re-design of our web site (a paid project). Board members will be given a chance to review and familiarize themselves with the finished product prior to uploading to the internet.
- b) **Globe & Mail Article – October 4, 2012 – “Federal plan to help those with Rare Disorders”** – Judy Stanley advised members present of a recent article found in the Globe and Mail that reports the federal government is finally in a position to “create a national framework to improve access to orphan drugs”. Judy reports that she sent a note to CORD to acknowledge and congratulate them on their progress. A copy of this article will be made available in an up-coming newsletter for membership at large to review.
- c) **Increasing Membership** – Judy 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.

9. NEXT AGM IN 2013 – Brantford Police Station, Brantford ON September/October, 2013 (to be confirmed)

10. REFRESHMENT BREAK



11. GUEST SPEAKER

Dr. Manjoo's specialty is Clinical Epidemiology, understanding the associations of risk factors with disease at a population level. She is a general endocrinologist, but her special interest is with obesity, bariatric surgery (to achieve weight loss and improve cardiovascular risk factors), and metabolism in general. She also is working on a project with the Cree population in Northern Quebec, as they are at risk and develop a lot of diabetes and heart disease. Steroids are an important area for her. What is learned from one spectrum of disease can be related to another, and vice versa. Addison's patients are quite different from those with obesity and steroid excess. It is very interesting to look at the contrast. Knowing what to look for, doctors are now diagnosing more people with Addison's. Treatment requires a very fine balance. Without steroids we feel awful and with steroids we feel so much better.

There is a lot of current endocrine research in health related quality of life outcomes, or how patients subjectively feel. It is difficult to evaluate how a patient feels as there is an inherent bias. We are just beginning to understand diseases where hormones are replaced. There are objective heart outcomes like blood pressure and heart rate and subjective outcomes like quality of life, sleep and mood which are also important. It is much harder for physicians to look at the population-based research and bring it down to the individual level because individuals are so different. In new fields like pharmacogenetics, researchers are understanding that people don't react in the same way to the same drugs. There are subtle differences in the way enzymes process hormones. Doctors rely heavily on population based studies which may say treating 100 people on a particular drug, 75% may do well, yet not have any effect on 25%. It is difficult for doctors if a patient does not respond to the drug the way they should. How much can a doctor adjust treatment without causing harm? It is best to explain to the patient that there are a lot of things about Addison's disease and the replacement of hormones which doctors don't know. For example, in the setting of illness, we increase the dose of glucocorticoid replacement, but it is difficult to know exactly how much someone needs.

Dr. Manjoo was asked about the sustained release medication, Duocort, presently approved in Europe and the US. Would it be advisable for the CAS to apply to Health Canada for this replacement medication under their proposed orphan drug program? Dr. Manjoo agreed that it would, although doctors do not know if sustained release medication will be adequate or if another tablet will be required during the day. They won't know until it is used in practise. The aim is to adequately replace the steroids but not over-replace.

Another new area of interest for medicating is continuous subcutaneous infusion of hydrocortisone (a needle into the fatty layer of the skin), as with insulin pumps in diabetes. Slow released medication can be programmed for higher levels in the morning and lower levels at lunch to aid in fine tuning treatment.

What is latest knowledge of adrenal gland? Dr. Manjoo showed slides of the adrenal gland for review. The adrenal cortex is comprised of 3 layers. The outer layer of the adrenal cortex produces mineralocorticoids, mainly aldosterone for retaining salt. The middle layer of the adrenal cortex produces cortisol. The inner layer produces androgens including the male sex

hormone. The adrenal medulla is the core of the adrenal gland and is surrounded by the adrenal cortex. The medulla produces epinephrine and norepinephrine.

There are several causes of adrenal insufficiency: 1) Genetic - where particular enzymes are missing. 2) The destruction of the gland by antibodies (most common), when a large number of antibodies attack an enzyme responsible for conversion of one form of a steroid into another that produces cortisol in the adrenal gland cortex. The destruction continues to damage the rest of the cortex, in all 3 layers. The inner part of the adrenal gland survives intact. There may be some cortisol produced but not enough in Addison's disease. 3) Destruction of the gland as a result of hemorrhage or tumour or other infiltration.

There is an association in Addison's with other autoimmune diseases. Other endocrine glands may also be damaged by attacking antibodies. So patients with Addison's should be screened for hypothyroidism and hyperparathyroidism. The parathyroid glands may be affected resulting in low calcium levels. Other possible disorders are premature ovarian failure and hypogonadism - low testosterone in men and low estrogen in women. How are these autoimmune diseases grouped together? There is autoimmune polyglandular syndrome, type 1, which is related to mutations in the AIRE gene. The name for this is Autoimmune Polyendocrinopathy-Candidiasis-Ectodermal Dystrophy. It is slightly more prevalent in women than men and associated with hypothyroidism, chronic candidiasis infections of the mucous membranes, low sex hormones, and some gastrointestinal malabsorptions. Autoimmune polyglandular syndrome, type 2, is associated with autoimmune thyroid disease, type 1 diabetes, low sex hormone steroids, and, less commonly hypofunction of the pituitary gland. In those situations where adrenal insufficiency is caused by damage to the pituitary gland, the adrenals are still able to produce but if they are not stimulated for long enough they atrophy, shrivel up.

Primary adrenal insufficiency is the autoimmune destruction of the adrenal glands. In secondary adrenal insufficiency the pituitary is damaged and can't stimulate the adrenals. If detected early on, the adrenals could potentially be stimulated.

Regarding stimulating the adrenals, there are several advances in stem cell research and there may be a role for these in treating adrenal insufficiency. The problem is that the antibodies are still in your body and can attack those cells. Eventually, future research may look at switching on and off our immune responses.

A question was asked of Dr. Manjoo: Is collagenous colitis associated with Addison's? Type 1 is associated with malabsorption and abnormalities in the gut, so it is possible, but I am not aware of a well defined association.

Wearing a bracelet and carrying a card to explain your Addison's is very important, also having an advocate and friends who know how to use the injection kit. In crisis situations, two members use dexamethasone because it is simpler to use than the mixing required for Solu-cortef. One woman who injects dexamethasone into her thigh in a crisis asked about the extra time it takes to act. Dexamethasone taken intramuscularly takes a bit longer to act than Solu-cortef but lasts longer and is more potent. Solu-cortef is gone in 6 to 8 hours whereas

the dexamethasone lasts much longer. Having both emergency medications on hand may be worthwhile. However, if you are really ill, it is advisable to take the fastest acting medication, Solu-cortef, then go to the hospital. If you are dehydrated, absorption will not be as good through the skin. Nausea and vomiting can cause you to be depleted. In hospital, you are usually given saline solution. If you can tell when you are beginning to feel unwell, double up on cortisol replacement medication. Addisonians must have advocates to help when in crisis to explain the importance of getting to a doctor as quickly as possible, especially if they don't have a medic alert bracelet.

Hypotension is associated with Addison's. In a normal person, standing up quickly or when you are feeling hot or have infection, your blood vessels dilate, adrenaline starts kicking in and makes blood vessels constrict, which increases blood pressure and keeps circulation going. When you don't have enough glucocorticoid, the blood vessels don't respond to the adrenaline and noradrenaline in the normal way. Cortisol is needed to prime them and without cortisol the blood pressure stays low. In the intensive care unit when normal people have bad infections with much inflammation, the body produces substances that interfere with the ability of cortisol to interact with the blood vessels. That blocking gives rise to sepsis. So even normal people in the ICU may need a boost of cortisol.

Responding to a question about hyper pigmentation, Dr. Manjoo said it can depend on taking the correct amount of replacement, and taking them regularly. Exposure to the sun can be a factor. Ensure blood pressure and energy levels are good. In a period when you are under-replaced the ACTH will go up to try and stimulate the adrenal glands and also the melanocyte-stimulating hormones increase pigment in your skin. Some individuals are very sensitive to under-replacing.

Medical student interviews may be possible in the standardized patients program at the University of Victoria. Dr. Manjoo will pass the message on to the administrators of the Island Medical Program that the Vancouver Island support group would be interested in taking part in student interviews, as the Mainland group does with medical students at the University of B.C.

The issue of having too many steroids was covered by Dr. Manjoo. This is more likely to occur with the longer acting steroids - prednisone and dexamethasone. Some consequences of too many steroids are bone loss, hypertension, diabetes, mood swings, weight gain, Cushings, high lipids, or high cholesterol. These can happen if you over-replace. Studies have shown that steroids in replacement doses are not associated with bone loss. Several members are also diabetic. So if we are taking correct replacement doses, is genetics a factor? Genes can be affected by our environment, viruses, foods, etc. For instance, with obesity the type of calories are important and gut bacteria can have a huge influence over how much weight we gain or lose. Gut bacteria plays a big role in the immune system.

Dr. Manjoo was asked about taking hormone replacement for a woman dealing with menopause. Hormone replacement therapy is very tricky. From large studies doctors have learned that estrogen on its own tends to be better. The addition of progesterone seems to be more harmful. If you have a uterus, you have to take both, because treating with estrogen alone causes an imbalance between estrogen and progesterone which may cause pre-

cancerous changes in the endometrium. If you don't have a uterus, then you can take just the estrogen. There are not enough studies on taking progesterone alone. Hormone replacement therapy should not be used solely as a treatment for osteoporosis or preventing heart disease. It is used to treat menopausal symptoms only and should be used with the lowest dose possible.

A large meta-analysis concluded that taking very high doses of calcium could increase vascular disease. It seems reasonably safe to take up to 1200 mg of elemental calcium per day. Patients should count up the elemental calcium they are getting in their diet and add supplements to make up 1200 mg for each day. One theory to explain the association is that taking big doses at one time you can cause spikes of calcium in the blood stream, which may cause calcification of the vessels. Absorbing calcium in food is more physiological. Liquid or tablets should both break down in the stomach. Do not take calcium with iron because it interferes with the absorption of the iron and the absorption of the calcium. Calcium taken with oxalates tends to precipitate out in the gut. So take calcium supplements separate from iron, spreading it out during the day. Vitamin D is really important. Research suggests that vitamin D may be involved in fat cell growth. It plays a huge role in bone development and bone strength. It is usually safe to take up to 2000 - 3000 IU of vitamin D per day. However, if you are a small person, it is possible to develop high levels taking "regular" amounts. So start with a modest dose and have your vitamin D levels checked by your family doctor, and adjust your dose accordingly.

Most people now with Addison's live normal, healthy lives and die of other things. It is probably one of the most easily treated diseases with hormones being so available for replacement. If guidelines are followed and patients use their steroids and pay attention to their symptoms, they can live long, healthy lives. Patients are the ones managing this disease and doctors are there to help us achieve that.

Asked about how our medication can affect blood sugar levels, Dr. Manjoo said that it shouldn't, unless you are over-replacing your glucocorticoids. It should not cause hyperglycemia, even after prolonged use. The most common cause of diabetes is the accumulation of visceral fat which can put the pancreas under stress. So losing a bit of weight and exercising is very important. Everyone can develop diabetes. The question is what's the threshold, as some people have a higher threshold and others have a lower threshold. Even a 10 pound gain may be enough, if the pancreas cannot tolerate it. For example, it could be that having Addison's may affect some portion of the pancreas so that you don't develop type 1 diabetes but have a lower threshold for type 2. We shouldn't gain weight when going on replacement except to bring you up to a healthy weight after diagnosis. With improved appetite, you must watch your portion size, finding a balance with exercise to obtain a normal weight. You may have to talk with your doctor and adjust your dose. If you do gain weight, your dose of steroids will likely need to be increased, otherwise you may get symptoms of adrenal insufficiency.

Dr. Manjoo was given a hearty applause and a thank you by members and their families for her lively and very interesting talk.

ADDENDUM #1

CANADIAN ADDISON SOCIETY AGM 2012 MESSAGE FROM THE PRESIDENT

On behalf of the Executive and Directors I would like to welcome local and out-of-town members to the Canadian Addison Society (CAS) 2012 AGM. Special thanks to the Victoria Group for hosting again.

I would also like to thank the members of the Executive and Directors who have extended their terms as Director or agreed to stand for office. We offer kudos to John and Irene Gordon and Jim Sadlish for their dedication to the CAS. Special thanks to Pat Hehner who continues to produce our excellent newsletter.

Although our numbers are few, everyone who takes the time to renew their membership each year to support the CAS, is really appreciated. Prior to 1997, there was no society and only snail mail. Members often went years before ever meeting another person with Addison's. It was ten years after diagnosis before I met someone and she was from California, the next person was a few years later and she was from Oklahoma. Now I get several calls a year from newly diagnosed or those who have just found out about the CAS and want information.

The Canadian Addison Society has made many improvements over the years to our website. Regional Representatives provide contact through meetings to share information, and when possible arrange for guest speakers to present updated or new information to members attending those meetings. It's important to remember that we are a volunteer organization with many unpaid hours across the country in trying to help others cope with the disease.

Our membership dues pay many of the bills for the CAS and provincial groups. Charitable donations have restrictions attached for spending the funds, which must be used as outlined under the *Charitable Organizations Act*. We are not privy to information about doctors, so we cannot provide that service to our members nor can we offer any kind of medical advice. We do however have the benefit of Dr. Killinger, who kindly agrees to act as our Medical Advisor through the website. Anyone, member or not, can send their questions and they are always answered promptly with his medical expertise as an Endocrinologist.

We are endeavouring to increase awareness of Addison's among the medical profession, emergency personnel and government. Your dues support our efforts. All provinces have a large landmass with concentrated pockets of population, and miles of open spaces and tiny membership increase the limits of being able to hold meetings. Every group has travel restrictions even in densely populated areas where members are spread over a wide area. There are new methods of communication such as Skype for free using 'Video Call' but someone with more technical knowledge than I have would need to investigate it for use by the CAS.

Thanks
Judy Stanley

ADDENDUM #2

THE CANADIAN ADDISON SOCIETY
STATEMENT OF INCOME & EXPENSES
FOR THE PERIODS ENDING DECEMBER 31, 2011 AND DECEMBER 31, 2012

Cash on hand and in banks	January 1, 2011 \$28,818.15	January 1, 2012 \$35,283.86
Income		
Dues Received - National	\$4,160.88	\$2,479.24
Support Groups	570.00	430.00
Donations	6,204.13	5,405.81
Interest	267.17	334.68
	<hr/> 11,202.18	<hr/> 8,649.73
Expenses		
Advertising & Publicity	-	395.50
Newsletter	901.95	1,657.28
Web Site	201.14	217.03
Secretarial	1,200.00	1,200.00
Annual Meeting	70.57	224.00
Postage, stationery and supplies	874.86	982.56
Telephone	999.34	1,077.24
Support Group Expenses	325.62	294.53
Bank Charges	162.99	10.34
	<hr/> \$4,736.47	<hr/> \$6,058.48
Cash on hand and in banks	December 31, 2011 \$35,283.86	December 31, 2012 \$37,875.11

THE CANADIAN ADDISON SOCIETY

Analysis of cash on hand & in banks as at December 31, 2012

Equitable Trust -

The Canadian Addison Society	-\$14,225.69 @1.45% due February 4, 2013	
	-\$15,714.10 @1.35% due March 18, 2013	\$29,939.79

TD Canada Trust -

The Canadian Addison Society	3,459.43
Quebec Support Group	150.00
Eastern Ontario Support Group	617.41
South/Central Ontario Support Group	1,838.00
Saskatchewan Support Group	160.00
Edmonton Support Group - Alberta	474.60
Lower Mainland (Vancouver) Support Group - British Columbia	555.88
Vancouver Island Support Group - Victoria	680.00

Total	\$37,875.11
-------	-------------

THE CANADIAN ADDISON SOCIETY

ANNUAL GENERAL MEETING

OCTOBER 13, 2012

FINANCIAL INVESTMENT RESOLUTION

WHEREAS it is the responsibility of the Board and Membership to approve all significant financial matters, the Treasurer, John Gordon, proposes that, on behalf of The Canadian Addison Society, he invest an additional \$7,000 in 90 day notes with Equitable Trust.

THEREFORE be it resolved that the Board and Membership approve, adopts, and authorizes John Gordon to invest an additional \$7,000 in 90 day notes with Equitable Trust.

SIGNED:

_____	_____
_____	_____
_____	_____
_____	_____

ADDENDUM #3

August 18, 2012

Brochure Holder Program Status Report: *Part of the Community Awareness Initiative from the South/Central Ontario Support Group*

As part of the 2011 AGM meeting in Brantford, Ontario, our group presented the **Brochure Holder Program** concept. A few of the details presented are as follows:

'The initial objective of this campaign was, and remains, to reach as many endocrinologists as possible across Canada. To increase their awareness of the existence of The **Canadian Addison Society** and our mission, as well as the support role we may play to assist their current and future patients with Addison's disease.

By providing a brochure holder dedicated to our brochure, we have an improved chance of having our brochures displayed in a doctor's offices. At present, we must rely on the doctor's office staff to find a spot using someone else's brochure holder. This often results in our brochures being hidden behind others. In addition, when the quantity is getting low, or they are gone, there is no re-order mechanism. The dedicated brochure holder complete with re-order instructions, assists in reducing the risk of brochures not being re-ordered.'

While members were very supportive of the program intent as outlined above, a partial change in the distribution method for the initial test quantity of 50 kits was recommended and approved by the members. The change approved was intended to save mailing costs by having members distribute the entire test quantity of 50 kits. The initial plan was a mix of member deliveries and mail.

While the sentiment of saving Society funds was well intended, both as part of the initial plan plus the membership desire to include the entire 50 kits, the reality is that the program is still in phase #1, a year later.

Logistics was a huge problem in the distribution of the kits between meetings when dealing with our geographic area and members rather widely scattered, and still trying to avoid mailing costs. As stated earlier, the idea of member distribution was well intended but the practical application in implementation just didn't work.

A number of test kits were placed early by a few very dedicated members and feedback on their placement was received and documented quickly and efficiently. However it wasn't until the next Support Group meeting in May of this year that the balance, which was the majority of the 50 test kits, was finally placed in member hands.

At the time of writing, I am waiting for feedback on the placement of the kits taken by members at the May meeting and expect many are waiting for our Sept 29 meeting to submit this information. When details on the placement of all 50 kits is received and documented, it will be submitted to the National Office so a record may be kept of doctor's repeat requests for brochures processed by that office. Only then will we get a sense if the brochures themselves are getting picked up, handed to patients, or gathering dust.

To summarize, the program to date has, in my opinion, been totally ineffective only as a result of the distribution method employed with absolutely no reflection on the value of the original concept and intent. Had we accepted the mailing expense upfront of all 50 kits, we would have had a result at this time. However, I believe it will take another year before we may fairly evaluate the effectiveness of the initial program as it related to the original 50 test kits distributed. If we were to consider running a second test of possibly 25 kits, I would recommend we mail the entire quantity and do it immediately.

At this time, the initial 50 kit test program should be considered in a holding pattern pending receipt of placement details and repeat order activity analysis. Follow-up reports will be provided as information becomes available.

Harold Smith
Director and South/Central Ontario Regional Representative

Membership Renewals:

It's that time again. Please renew your membership for 2013. Fees of \$25.00 are due immediately. Please use the form attached to this newsletter or download the form from our website.

Email Chat String for Young Addisonians:

The NADF (US adrenal organization) has started an e-mail string called NADF Young Adults, targeting 18 to 29 years olds who would like to interact with Addisonian around their own age. If you are in that age group, and would like to correspond via e-mail with other cool young people, please send an e-mail to nadfmil@aol.com including your first name and adrenal condition.

Highlights from Local Meetings:

Vancouver Island Support Group - Victoria

The Canadian Addison Society AGM was held at Victoria General Hospital on Saturday, October 13, in Room 1814 next to the Cafeteria.

The next meeting of the Victoria group will probably be held Sat. Mar. 9, 2013, 1:00 pm to 3:00 pm.

For further information on the Vancouver Island Support Group, contact Jim Sadlish at vanisleaddisons@gmail.com or (250) 656-6270.

Vancouver Island Support Group - Nanaimo

The Nanaimo group met on Saturday, October 20th, at the Chase River Boys and Girls Club of Central Vancouver Island. Six people attended.

One woman, diagnosed in 1990, started on cortisone acetate and was then moved to hydrocortisone (10mg/5mg/5mg) and Florinef. She also takes Eltroxin for hypothyroidism. Her only everyday issues are tiredness, and insomnia due to the steroids. Overall, now retired, she looks and feels good, especially living in Port Alberni where it is less stressful and not a fast paced environment, more laid-back.

A member originally from Manitoba now lives in Nanaimo and was diagnosed in 1971. She takes cortisol acetate, 1 1/2 tablets per day, and if she has a stressful day she will take 1/2 tablet extra. Other meds are Florinef (1/2 tablet) as well as Eltroxin. Fatigue and tiredness are her only daily disturbances. She looks wonderful and very well for a woman of her age at 93! She mentioned a hormone called DHEA (dehydroepiandrosterone) that she got over the counter through a friend in the States. For more information on DHEA, go to

<http://en.wikipedia.org/wiki/Dehydroepiandrosterone> (and see information on our website FAQ November 2011 page 10).

One woman was diagnosed in 2004 when she became sick, throwing up, and quite dehydrated while on vacation. A seizure in the hospital waiting room put her into a coma. They ran tests then gave her cortisol to get her back home. She felt much better once meds were started. She takes 15 mg total of hydrocortisone (7mg/5mg/3mg) as well 1/2 pill of Florinef. She does feel tired at times. She has tried DHEA, but too much causes her side effects. She takes 1/4 pill every few days and has noticed more energy and improved muscle tone.

Another woman, diagnosed in 2005, felt she had this disease long before being diagnosed. Around the 1970s, through 3 pregnancies, she had many difficulties, always tired, hypoglycemia, as well as other medical issues. While on vacation, she could not handle the heat, felt exhausted, etc, and came home. The doctors ran tests and she was diagnosed. She takes 15mg of Cortef in the am and 5mg around 4pm. She did experience an Addisonian crisis about a month and half ago when she vomited for 2 hours. Again, tiredness is an issue for her.

One participant at the meeting mentioned that the booklet " Addison's Disease – An Owner's Manual", published by the UK Addison's Self Help Group, is a very good read <http://www.addisons.org.uk/info/manual/page1.html> (see link from our website <http://www.addisonsociety.ca/linksresources.html>).

A woman spoke about her daughter, diagnosed in 2006 with Schmidt's Syndrome, which consists of Addison's, type I diabetes and hypothyroidism. She takes Cortef 3 times per day - 5mg at 6am, 2pm and 10pm, as well as 1 1/2 tablets of Florinef, a full tablet in the am and 1/2 at bedtime. She takes 1 tablet Synthroid daily for the hypothyroidism. She controls blood sugars with an insulin pump and Alesse (low dosage birth control as a hormonal replacement- which has helped a great deal controlling blood sugars). This girl is apparently the youngest known case, and only case, of Schmidt's Syndrome in B.C. with the combination of Addison's and Type I diabetes, a very rare occurrence. Prior to diagnosis, she was at a diabetic camp where it was very hot that year and felt ill during the extremely hot weather. Upon coming home, she was sick on and off, throwing up for about 4 months, then for a whole month straight, threw up everything. It took that time and 22 emergency room visits before the right blood test was called for. This was due to the fact that for people of her age, 13 at the time, it is uncommon to get Addison's disease. The usual age of onset is 30. Once diagnosed, the meds were administered and she starting feeling better almost immediately. But again, tiredness is common with her too.

The mother's thoughts on hearing the conversations from the people attending the meeting and what she experiences with her own daughter are that Addison's disease is most definitely a hidden disease. It's not what you see as an outsider but its what these people are feeling inside, and at times it is difficult to explain what they are feeling.

We hope to schedule three meetings in Nanaimo for 2013 and will contact members when those dates are determined.

Submitted by Natasha Arntson

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

BC Lower Mainland Support Group

Ten people attended the Oct 27, 2012 meeting:

- Round table introductions and individuals' experience with Addison's
- Updates from the 2012 AGM
- Suggestion: when meds are updated in between prescription refills, contact the pharmacist to let them know so they can update their records
- Reminder: vigilance and advocacy are needed when an Addisonian is in hospital for something other than Addison's, e.g. surgery, as steroids are often neglected or forgotten by medical staff unless they are reminded
- *Therapeutics Initiative – Bringing Best Evidence to Front-line Clinicians* – UBC workshop based on numerous case scenarios and statistical evidence. The site <http://www.ti.ubc.ca/> includes workshop details, the bisphosphonates lecture, and the 'therapeutic letter' posted four times a year.
- The Cochran Library <http://www.thecochranlibrary.com/> is the best source of independent systematic reviews and can be accessed by the public.
- *UBC Annual Health Fair – 'allies in health'* – There were eight Patient Panel workshops. A variety of societies representing chronic conditions had tables to distribute pamphlets and talk to attendees. We will look into possibly manning an Addison's table next year and distributing information.
- Suggestions for topics for future meetings:
 - Paramedics and/or Firemen: as first responders, what are their parameters, what is needed from us, who goes where, what are they allowed to do for us, when does their responsibility start/end?
 - Long Term Disability: labour lawyer or someone from vocational rehabilitation
 - Alternative Funeral Services: Because only about 15% of people have a church funeral now, this company will present many ideas for a gathering or type of celebration of life outside the usual. They give ideas of different kinds of events, and how to personalize them.
 - Law Enforcement: how they react to people's behaviours, or to people who don't know how to ask for help, i.e.: person in Addison's crisis

The guest speaker was from the UBC Faculty of Medicine, describing how their yearly interviews with volunteer Addisonians from the Vancouver support group fit into their course *Doctor, Patient and Society* & the *At Home Interview*. This very interesting presentation will be included in the April 2013 newsletter.

Submitted by M Thauberger and Judy Stanley

The next meeting of the BC Lower Mainland Group will be Sat. Mar. 9, 2013, 1:00 pm to 3:00 pm in the Neil Russell Room, Royal Columbian Hospital, 330 E. Columbia St., New Westminister BC.

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

The Saskatchewan group met Oct.20th, 2012 at Saskatoon City Hospital, with 10 Addisonians and 4 spouses. Discussion was around the medications each Addisonian takes, who their GP or Endo is, emergency protocols, and increasing steroids. It was great to see new / previous members. Other Saskatchewan Addisonians could not attend due to travel or illness.

Submitted by Elizabeth Hill

For information on this support group, contact Elizabeth Hill at (306) 236-5483 kesahill@sasktel.net or elizabeth.h@pnrha.ca.

South/Central Ontario Support Group

The next meeting of the South/Central Ontario Support Group is tentatively scheduled for Saturday May 11, 2013 from 1 pm to 4:30 pm (registration from 12:30 pm) at the Erin Mills United Church (Lower Hall Meeting Room), 3010 The Collegeway, Mississauga, Ontario L5L 4X9 (accessible by public transit). Please check the "Upcoming Meetings" link on the Society website for more information closer to the date.

Submitted by Harold Smith

For further information on Southern Ontario Support Group activities or meetings, contact Harold Smith in Kitchener at hsmith9995@rogers.com or (519) 742-9995.

Eastern Ontario Support Group

The next meeting will be noon Saturday, May 11, 2013, the weekend before the long May weekend, at the usual location (Robbie's Restaurant on St. Laurent Blvd in Ottawa).

Submitted by Steve McKenna

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 are Georgia Kapralios and Dr. George Kambranis, whose son has Addison's Disease. They can be contacted at centresantedentaire@bellnet.ca. They can communicate in English, French and Greek.

Atlantic Support Group

The Atlantic Canada Support Group is looking for a volunteer to act as contact point. If you can do this, please contact the Liaison Secretary at liaisonsecretary@addisonsociety.ca or at the national address shown on the front of this Newsletter.

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: I would like to know if I should have a shingles vaccine.

A: In general, individuals with Addison's disease can get vaccines in the same way other individuals do. They should develop immunity normally. If you get a fever after the vaccine, take a little extra hydrocortisone for a day or so. Be sure to check with your family doctor if there are any other health problems that would prevent you from taking the vaccine.

Q: Is there anything safe I can take when I have a bad cold? I don't take Neo Citran as it has pseudoephedrine and makes my heart race. When I read the box of some cold and sinus pills, it states not to take if you have thyroid disease etc. I will double my pills, but was seeking more advice.

A: There is really nothing different to treating a cold whether or not you have Addison's disease. If you have a sensitivity to certain medications, as you seem to have, you must adjust for the sensitivity. Most of the cold remedies have pseudoephedrine or a similar medication because it shrinks the membranes in the nasal passages and decreases the running nose and sneezing. They do not

shorten the duration of the cold. You did the right thing by increasing your hydrocortisone.

You can try antihistamines as long as they are not combined with an ephedrine-like preparation. One problem is that some antihistamines tend to cause drowsiness. You can ask the pharmacist which ones cause the least drowsiness.

The reason that the instructions on the boxes of most cold medicines tell you not to take it if you have a thyroid problem is that people with an overactive thyroid already tend to have a fast heart rate and the ephedrine-like compounds in the cold remedy makes it worse. If you are on thyroid medication because of an underactive thyroid and the dose is right, there should be no problem with cold remedies.

Q: In your Oct 2012 newsletter, there was a line that said "Once you have Addison's Disease, you will never get a reliable test for Celiac Disease" but no more information was given. Why is it that you will not have a reliable test?

A: If you have Addison's Disease as part of a poly-auto-immune syndrome, then it is possible that you do not make IgA antibodies, which are used for the test. Thus, if you have Addison's disease and the test is positive for celiac disease, then you can trust the test results. However, if the test result is negative, then you can not rely on the test. Of note, patients who use a gluten free diet for several months may also have a negative test due to lack of exposure to gluten.

Q: I am scheduled for dental surgery. I take 7.5 mg prednisone and 0.1 mg of Florinef. I also have hypothyroidism, hypertension and osteopenia, for which I take Actonel.

The dentist is concerned about the Actonel since I have been on it for 10 years only taking small 3 month breaks. The doctors involved do not seem to agree on whether I should go off it.

I am extremely stressed about this pending work, and am further concerned about when I can return to my regular dose of prednisone. I take Xanax and my doctor has suggested Pristiq. I have tried other anti-depressants with so many side effects, I am afraid to try again. I am thinking of postponing the dental work again but know I have to face it. I am already stressed out, and by the time I am actually doing it, I will be a basket case. Should I increase the prednisone sooner than the day of surgery? Or should I start the antidepressant and wait till it takes effect before I go through with it?

A: Since there are several issues and I do not know all of your history, I will give you some pointers but you should discuss the situation with your endocrinologist.

The Actonel family of osteoporosis medications can be associated with bone problems in the jaw and its effect continues for a long period after it has been discontinued. There are other osteoporosis medications that you can take once the tooth problem has been sorted out, so I would stop the Actonel and get on with the extractions.

The prednisone dose should probably be increased now to 10 mg since you are under so much stress, but, on the day of surgery, the dose should be increased to about double your daily dose then tapered back to your regular dose over a few days depending on how you are progressing. I want to emphasize that you should discuss the situation with your endocrinologist before you get started. Don't be too concerned, you will be back on your regular dose of prednisone very quickly.

I am not the right person to ask about tranquilizer medication, I will leave that with you and your family doctor who knows you better than I do.

Q: My daughter has just given birth at 32 weeks in NYC. She has Addison's Disease and has been able to pump breast milk for the baby. Is there some difficulty with this disease and breast-feeding?

A: If your daughter is on appropriate adrenal replacement, there should be no problem breast-feeding.

Q: I was diagnosed with Addison's disease exactly 1 week ago today as a result of isolated ACTH deficiency. I started hydrocortisone replacement steroids immediately but, to be honest, I don't feel better in the slightest; in fact, I feel worse! I do not take Florinef. I also take eltroxin for thyroid. I feel like I'm way more tired and sleeping more and also I feel very weak and feeble! Does anyone know how long it takes to start feeling better on steroid replacement therapy? Would I have developed this recently or had this from birth? Would I have developed the thyroid or pituitary problems first?

A: The effects of hydrocortisone begin quite rapidly so if you are on the proper dose of hydrocortisone, you should start to feel better rather than worse. You should check with your endocrinologist if things do not improve.

The combination of thyroid disease and adrenal disease could be due to a pituitary problem that is affecting both TSH and ACTH resulting in thyroid and adrenal insufficiency. It could also be due to an autoimmune process affecting each gland separately.

Neither of these problems would have been present since birth. As you have further investigation to assess your pituitary function with lab tests and an MRI, your doctors will be able to determine what is causing the pituitary problem and

how it is related to your adrenal problem. They can also measure antibodies to the thyroid and the pituitary if an autoimmune process is suspected.

It is interesting to follow your story as new information becomes available so you will have to keep us up to date.

Q: Could an ulcer cause havoc for an Addisonian's medication? I currently have most of the symptoms of uncontrolled Addison's Disease, but am taking my Cortef and Florinef regularly. I will be going for a gastroscopy in due course. I have reacted negatively to every drug prescribed for me in the past few. I was wondering if an ulcer could stop the metabolism of my Cortef, as well as all the drugs I have been subscribed to over the last six months.

A: An ulcer would not interfere with the absorption of hydrocortisone but sometimes hydrocortisone can cause stomach irritation so some people take it with food to avoid this. I think that the gastroscopy is a good idea but the problem is a little more complicated because you do not seem to be getting the usual benefit from the hydrocortisone. You should review the situation with your endocrinologist to see if there could be other health problems complicating the situation.

Medical Questions and Answers – Dr. Donald Killinger, MD, PhD, FRCPC, Medical Advisor for The Canadian Addison Society, will answer your questions about Addison's disease. Send your question to Dr. Killinger directly from the webpage <http://www.addisonsociety.ca/faq.html#>, 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