The Canadian Addison Society
La Société canadienne d'Addison

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ISSUE NO. 51 **JULY 2008**

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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.

Annual General Meeting

The next Annual General Meeting will be Saturday, October 11, 2008, from 12:30 to 4:30 pm at the Victoria Hospital in Victoria B.C. If you will be able to attend from out of town, contact Jim Sadlish at 250-656-6270 or e-mail: wx699@hotmail.com, who may be able to arrange accommodation and other hospitality with Victoria members.

Victoria endocrinologist Dr. Richard Phillips will be our guest speaker. He requests medical questions beforehand from members to help him prepare the first half of his talk. For the second half, Dr. Phillips proposes to discuss the history of Addison's disease. Please send your questions to James Sadlish wx699@hotmail.com as soon as you can (but definitely by the first week of September).

Draft Agenda:

1. Registration and Call to Order

2.	President's Message	Athena Elton	5 Min
3.	Adoption of Minutes of 2007 AGM		5 Min
4.	Financial Report	John Gordon	15 Min
5.	Slate of Officers & Directors for 2008/2009 President Judythe Stanley (BC) Vice President Jim Sadlish (BC) Treasurer John Gordon (ON) Secretary Irene Gordon (ON) Directors Joan Southam (ON) Greeta McKague (ON) Ginny Snaychuk (AB) Stephen McKenna (ON) Newsletter Editor: Patricia Hehner (ON) Regional Support Group Representatives Needed: Eastern Ontario; Atlantic Provinces; Alberta; Québec		20 Min
6.	Directors Reports (where available)	For information	
7.	Membership Update		10 Min
8.	Web Site Update		15 Min
9.	New Business: Medical Information Card	Update	15 Min
10.	2009 Annual General Meeting – Brantford Police Station – Community Room Brantford ON September/October, 2009 (TBD)	For information	
11.	Break		20 Min
12.	Guest Speaker	Dr. Richard Phillips – Endocrinologist	1 Hr
13.	Question Period		

Announcements:

- We have been advised that Florinef should be refrigerated. There has been no change in its formulation. However, data indicates that it will remain stable for 24 months if kept in the refrigerator. It will remain stable for 30 days or more at room temperature (so no troubles when you travel). For more information on this, or if you want to check stability at room temperature for periods over 30 days, please contact the manufacturer, Squibb, at

1-888-550-6060. All pharmacists should be talking to their patients about this change and typing this information on the prescription bottle.

- As you can see, the Society needs volunteers in three regions - Eastern Ontario; Atlantic Provinces; Alberta – to come forward to help organize meetings and act as contacts in their local areas. Without such volunteers, local groups will likely cease, and the support groups may be lost to both long-time members and newcomers. **Please – if you have benefited from these groups and their exchange of information, seriously consider stepping forward so that those diagnosed in future can get the same help the Society has given you**.

- It is with real sorrow that we inform you of the death of Christy Lapi on April 6 2008. Our condolences go out to her daughters and other family members.

- Thanks to C-Diguer, the *Frequently Asked Questions* section of our website now has the questions sorted by topic, with hyperlinks, so that when you click on one of the subject lines, it takes you directly to that section in the document. It saves oodles of time trying to sort through all the questions. All questions of a like manner have been grouped together to make it easier to see what information is available.

- We've put a link to the Addisons Facebook page on the website http://www.addisonsociety.ca/linksresources.html (education - links and resources - forums/bbs/community support). Anyone who wants to access it will have to create an account with Facebook first, and it's only a matter of logging onto the site anytime they want to use it in future.

- Did you know – you can claim 50% of the cost of an air conditioner needed for a severe chronic ailment, to a maximum of $1000., as a medical expense on your income tax.

- A fill-in form version of the Emergency Medical Information Card that people can complete and then print off for themselves is on the website (in the benefit's section). A copy is also attached to the print version of this newsletter.

- If you currently receive print copies of this newsletter through the mail, and do not really need this format, please consider reading the newsletter on-line at http://www.addisonsociety.ca/newsletters.html. Printing and mailing costs for four newsletters a year eat up much of the money from your membership, leaving less for other purposes (advocacy, education). If you advise the Liaison Secretary at liaisonsecretary@addisonsociety.ca or 1-888-550-5582, we can remove your name from our print mailing.

Personal Stories

In 1979 I was diagnosed with hypothyroidism, followed by vitiligo in the mid-1980's, and finally with Addison's Disease in 1998 at the age of 32. Prior to my Addison's diagnosis, I had been feeling increasingly unwell for 8 years. It started with a strong craving for salt and feeling tired. By the end of the 8 years, I was extremely weak and exhausted, had trouble with stairs, vomited every day, was dizzy and itchy all over, and was very thin and in a lot of pain because every joint in my body was inflamed. My skin darkened significantly but because I had vitiligo, I had patches of very dark and very light skin. Overtop of this, I experienced an extremely high and unrelenting libido, which was anything but 'fun'. I cannot quite put into words what it was like to experience such exhaustion and intense libido simultaneously. I was too embarrassed to mention this symptom to any doctor, and silently endured it. I began to consider suicide to end my horrid existence.

I had been to a well-respected endocrinologist in Toronto and he warned that I might develop Addison's disease because of my other autoimmune problems. A few years later, when the strong salt cravings started, I told him that I thought I might be developing Addison's. He laughed and mocked me! He said "What are you doing? This?" as he pretended to shake salt into his mouth with an imaginary saltshaker. I was so upset and humiliated that I left his office for good. I went to my new GP, told her I was in danger of getting Addison's Disease, asked her to monitor me. In the end, it turned out she had no clue about the disease. I continued to request regular cortisol tests, until the point when she tersely told me that I had mental problems, was anorexic, and did not have Addison's Disease. She had put me on anti-depressants for 3 years and sent me to a psychiatrist (who determined I was not anorexic). I argued for one last cortisol test - and the results came back so low, that she said it must be a mistake and ran the test again. The results were even lower. By chance, she was talking to an endocrinologist (about another patient) and happened to mention my results. The endocrinologist sprang into action - and I was directed to go to her office immediately as I likely had only a matter of hours left to live. I started on the prednisone and florinef that day. But, because I was so far gone, it wasn't enough to turn me around and my heart began to beat erratically during the next two days. I ended up in emergency where the endocrinologist ran the hydrocortisone by intravenous, but I was still not recovering. She gently told me "we’re having trouble keeping you here" and asked for permission to triple dose me with steroids in an effort to shock my system back. I said 'sure'. At that point, I was welcoming the thought of death and being released from my suffering. But, I survived. And, over the next couple of days the pain, nausea, exhaustion and overactive libido started to dissolve away. I could not believe how wonderful it felt to be pain-free. It took about two years to fully recover from the whole experience. I gained 40-50 pounds during my recovery.

Since then, I have been very well. My daily meds include: 15-20 mg of hydrocortisone, 0.05 mg Florinef, 0.112 mg Synthroid and 1.5 mg Estradiol. I control my hypoglycemia through diet.

The support and understanding of my family has also played an important role in keeping me healthy.

Jen

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I have thought about telling my story many times over. It is still hard to think about it now. I was 37 years old and up until that point hardly ever sick. I started feeling weak and dizzy. My legs and arms often felt very weak. I went to my G.P. He told me I probably had a virus or inner ear infection. I continued feeling poorly. I now had more nausea, which resulted in vomiting infrequently, as well as weight loss. I went back to the same doctor who did blood tests. He said if I could bottle and sell my good blood, I would be rich. It was just a virus and would take time. I waited to feel better, I got worse instead. I lost 20 lbs in one month. I went back to see another doctor at the clinic. He seemed to think there was nothing to worry about. I continued my downward spiral. I was so weak and tired all the time. I had two children to look after. I forced myself to be normal. I went to a third doctor who also seemed to think it was in my head or was this infamous virus.

We had a vacation camping coming up and I decided, since they said it was nothing to worry about, we would take the family camping. I camped, I hiked, and canoed, all the time feeling so ill. It was my son's birthday and we decided to go out for a fancy dinner nearby, I forced myself to be okay again. The minute we left, I was sick. I started vomiting. I talked with my husband and we decide to cut the vacation short. We got home, thank God. I woke up the next morning vomiting constantly. We went to the local ER. The last thing I remember was telling my husband to get someone fast. I had intense pain in my chest, like a heart attack. Nobody thought it was my heart - I was too young. They brought me to a room where I continued to tell them I could not breathe and I had severe pain. My heart stopped beating. I had to be shocked. I was in critical condition. Nobody had any idea what I had. I was sent to the Sacré Coeur hospital in Montreal. My heart stopped twice on the way there. I was unconscious. My chances were slim to none. My family was told to prepare. I swelled up with fluid all over my body until I was unrecognizable. My heart and lungs were full of fluid. I had toxic shock and septic shock. I had to have emergency surgery. I had a tampanade of the heart. The fluid was around the sac of my heart. I was critical and in intensive care for six weeks. I needed to have two more lung operations to drain fluid. My kidneys failed as well and I was put on a special dialysis machine. Every day was critical. They still could not find my problem. It was Addison's disease, but with a difference. It affected my heart. No other disease was quite the same as mine.

Through hard work and intensive internet searches, my doctor and the team finally found two other people in the world at the time who had what I had, or had been diagnosed with it. I started treatment with prednisone and florinef and salt. I had also had to have a tracheotomy. I was holding my own. I got taken off the dialysis. My long struggle to come back took lots of time. I had total muscle atrophy. It was like I was paralyzed; only I could feel. I just could not move anything. I had to have physio every day. I had to be lifted to a wheel chair or other bed in order to move; it was like I was in a crane. I had intense pain all the time from my chest - a crushing pain. I thought I would die every night as I lay there. I cried constantly, especially when my family had to go home. I couldn't. I stayed there for 4 1/2 months. I was starting to walk with a walker. I went to our local hospital for another two weeks. I was let out but would continue physio at home and at a rehab to get my muscles back for four more months and then on my own for a year. I still had lots on pain in my rib cage area and chest. I was told my heart was okay and I was now covered by the cortef I was now taking. This changed my life and how I looked at everything. I try to appreciate every little thing, especially family and nature. I now know life can be taken away in an instant, no matter how old you are. That we should do the things we want to do now, not later - we may not get it. To prove to myself and everyone else I was going to be okay, I went to work after being a stay-at-home Mom. I had to travel for an hour twice a day, then work eight hours. It felt so wonderful to be able to walk, and do what other people do everyday.

That was eleven years ago. I am now 48 years old. I work out at a gym three times a week and have built up my stamina. I have been doing this for three years. I just finished getting my certificate to become a personal trainer specialist. It is something I really want to do. I know what it is like to feel weak, and to have to start from nothing and work your way back. I have done this several times in my life. I want to help people get in good health, no matter where they are starting from. I need to learn a lot more but I have time.

I had Addison's cardiovascular. Extremely rare. It could have been caught earlier. It was four months seeing three different doctors. No one did tests. I did not show dark skin, as it was summer. I had a tan by the time I crashed. I was young and looked to be healthy. Why did they look no further? What would my life have been like had they found it (Addison's)? I still remember so many horrible days and nights. But have gotten on with my life. I have had episodes where I am low in cortisone when I am sick. But over all, I am in better shape than a lot of people, and I never take it for granted.

Thank you for giving me the chance to finally tell my story. There is a lot more I could tell, have forgotten or left out. I hope people reading this can learn from it. - doctors, people who live with Addison's and their families.

I am doing alright.

Dale

Cooling vests

Like many Addisonians, I find the stress of hot or humid weather quite debilitating; it brings back all my symptoms. This summer, instead of hiding in the basement or running the AC full-time, I am trying to take back part of my summer life. I have been researching cooling vests – like those used by outdoor workers or motorcycle drivers. I have found several versions on the internet, and am currently trying one which uses a special gel pack which keeps me cool for quite a few hours without any chance of causing frost-bite (as ice packs do). If you have similar trouble in warm/hot weather, you may want to look into something like this. For me, it is “so far, so good”.

Submitted by Steve McKenna

Highlights from Local Meetings:

Vancouver Island Support Group

The Vancouver Island group met May 31st, at the Victoria General Hospital. Each Addisonian briefly described their diagnosis and the history of their treatment:

One woman consulted her doctor with abdominal complaints. This resulted in surgery to remove her gall bladder. However, her symptoms persisted until she was diagnosed with Addison's. After developing Type 2 Diabetes, her medication was changed to hydrocortisone. Managing her diabetes and taking adrenal replacement medication is difficult because glucocorticoids elevate blood sugar.

A new member sought medical help for left-side pain. A catscan revealed a large adrenal tumour. A quickly scheduled surgery removed a 2-pound tumour. Post-operative treatment included the anticoagulant heparin which caused a violent allergic reaction. As treatment, she has recently started taking Mitotane (Lysodren), a cytotoxic drug. It has a predilection for killing cells in a particular zone of the adrenal gland, thereby reducing function of that part of the gland. This lowers the blood cortisol concentration (also known as DDD, of the same family as DDT). She takes adrenal replacement medication as well.

One member's daughter experienced hives (swelling) after her grandfather died and questioned if this could be a precursor to Addison's. Two people present did have similar stress-related reactions prior to their Addison's diagnosis. Hives can be an indication that the immune system is under stress.

One week after childbirth, a woman went to Emergency with Addison's symptoms where medics found her potassium levels elevated. They consequently administered a series of enemas with the intention of reducing the potassium in her system. Following this regime, she was thankfully diagnosed with Addison's.

Recently returning to Victoria, a new member to this support group, a marathon runner, augments her regular medications when racing. She finds it beneficial to apportion both her cortisol and mineralocorticoid replacement into small doses throughout the run. She feels DHEA supplements are very helpful for improving her mental and physical functions. In Kamloops, before her Addison's diagnosis but already being treated for other endocrine disorders, she was so fatigued that she had to "crawl" into Emergency where health professionals found her blood pressure was "40 over pulse". The emergency physician, not able to diagnose the problem, declared it was "all in her head". Later, she was seeking help at Victoria General Emergency (when she previously resided in Victoria) and again was not initially diagnosed, until Dr. Duke luckily recognized her Addison's symptoms and prescribed replacement.

One family member observed that nearly every Addisonian attending the meeting was not diagnosed promptly, even though in most cases telltale symptoms were obvious. Some people dealt with the debilitating fatigue, salt craving, low blood pressure, joint pain, and abdominal aches for years, before medical personnel detected the cause. In some cases, the shutting down of essential body organs drew the attention of doctors to realize the seriousness of the undiagnosed disorder.

Several people described having strange symptoms such as numbness and tingling fingers before diagnosis. It was suggested that tingling fingers could be a sign of low sodium. Another person has no feeling in her hands on awakening. It takes about one hour after her morning meds dose before feeling returns to her hands. Evidently, these symptoms can occur with various endocrine disorders.

Many of those present require thyroid replacement and several have experienced or are being treated for other autoimmune conditions: pernicious anemia (B12 deficiency), vitiligo, ovarian failure, celiac disease, and diabetes.

Irregular heartbeat is a concern for a few people. A suggestion was made that their thyroid replacement dose may be too high. One woman was able to reduce her dose with her specialist's agreement, and so solved this problem.

One woman contends with diabetes along with Addison's and another deals with hypoglycemia. They find their morning cortisol replacement raises blood sugar levels. One actually finds it best to wake at 3:30am to take replacement. The preferred diet for diabetes is similar to the Atkins' diet, but it should be low in fat, low carbohydrates, low fruit, whole grains and lots of vegetables.

A naturopathic doctor recommended a collagen supplement for joint pain to one member, which helps. Also, she was told that Vitamin D is very important to people with Addison's. *(Editor’s note: Vitamin D is essential for bone health, especially important to help Addisonians avoid osteoporosis.)*

Two people noted that they are constantly hungry and yet both are slender.

Two members have taken the thyroid prescription drug Cytomel (liothyronine sodium), which evidently assists the conversion of T4 to T3. It seems to be quite controversial with doctors, as it can be tricky to determine a regular daily dose without possibly dealing with side effects such as hyperactivity and heart palpitations. One woman stopped taking it and the other finds it most beneficial now that she has found her optimal dose. (See http://www.rxlist.com/cgi/generic/liothyronine.htm).

Coffee is a favoured beverage of the majority of those attending the meeting. Evidently coffee may reduce the risk of Alzheimer's but is not so good for bone mineral density, as it could leach out calcium.

The marathon runner proposed a way to inform medics about Addison's disease. She regularly attends athletic events such as marathons, which also attract doctors and nurses who participate themselves. She has encountered many other runners and observers who wear T-shirts advertising their particular health concern, medical disorder or charity. A Victoria screen printer company was contacted to inquire about the potential cost of purchasing customized T-shirts. The quote for 25 plain T-shirts with a 3-colour logo and text was $250.00, including taxes.

Medically necessary eye examinations may be partially funded by the Medical Services Plan in B.C. (http://www.health.gov.bc.ca/msp/infoben/benefits.html#supp). One local optometrist's office said that the MSP will pay $45 once a year toward the cost of an eye examination if the patient is eligible, either taking certain medications or has a disorder such as diabetes. Addisonians take glucocorticoids, which could lead to cataracts or glaucoma. This optometrist's office ($80 fee) advised to compare the examination fees at various offices as there is quite a range, but the MSP supplement is still the same.

The *Vancouver Sun* of May 28, 2008 in the *Issues and Ideas* section printed an article about a drug watchdog organization. An independent body called the *Therapeutics Initiative* based at UBC reviews studies, assesses the benefits and harms of prescription drugs, and informs the public. There are 68 Therapeutics Letters available on their website (http://www.ti.ubc.ca/). You must register to access this information and also the websites of other watchdog agencies.

Endocrinologist, Dr. C. von Westarp, is leaving his office to work as a specialist for both Victoria general hospitals. Dr. Andre Moldoveanu will take over Dr. von Westarp's practice on July 14th. His address is Suite 215, 1900 Richmond Road, Victoria, phone 250-370-1110.

Addison's research:

Impaired subjective health status in 256 patients with adrenal insufficiency on standard therapy based on cross-sectional analysis.
J Clin Endocrinol Metab. 2007 Oct;92(10):3912-22. Epub 2007 Aug 7.
Hahner S, Loeffler M, Fassnacht M, Weismann D, Koschker AC, Quinkler M, Decker O, Arlt W, Allolio B.
http://www.ncbi.nlm.nih.gov/pubmed/17684047?dopt=Abstract

Dehydroepiandrosterone in adrenal insufficiency and ageing
Current Opinion in Endocrinology, Diabetes & Obesity. 15(3):239-243, June 2008.
Bhagra, Sumit; Nippoldt, Todd B; Nair, K Sreekumaran
Please Google the above title to access the abstract.

Replacement therapy for Addison's disease: recent developments
Authors: Lvs, Kristian; Husebye, Eystein S
Source: Expert Opinion on Investigational Drugs, Volume 17, Number 4, April 2008 , pp. 497-509(13) Publisher: Informa Healthcare
Please Google the above title to access the abstract.

Impact of Growth Hormone and Dehydroepiandrosterone on Protein Metabolism in Glucocorticoid-Treated Patients; The Journal of Clinical Endocrinology & Metabolism Vol. 93, No. 3 688-695
Morton G. Burt, Gudmundur Johannsson, A. Margot Umpleby, Donald J. Chisholm and Ken K. Y. Ho
http://jcem.endojournals.org/cgi/content/abstract/93/3/688

Adrenal emergency is a regular event for treated Addison's patients; Endocrine Abstracts (2008) 15 P308
Katherine White[1], John Wass[2], Alyson Elliott[1] & Wiebke Arlt[3]
http://www.endocrine-abstracts.org/ea/0015/ea0015p308.htm

Metabolic and cardiovascular profile in adult patients with addison's disease under conventional glucocorticoid replacement therapy; Endocrine Abstracts (2008) 16 P50
Roberta Giordano[1], Alberto Falorni[2], Marcella Balbo[3], Stefania Marzotti[2], Serena Romagnoli[2], Elisa Marinazzo[3], Ezio Ghigo[3] & Emanuela Arvat[1]
http://www.endocrine-abstracts.org/ea/0016/ea0016P50.htm

Glucose infusion affects memory function but not ACTH concentrations in patients with Addison's disease *May 2008*
Johanna Kuehn[1], Christian Hubold[1], Cecilia Loeck[1], Kerstin M Oltmanns[2] & Achim Peters[1]
http://www.endocrine-abstracts.org/ea/0016/ea0016P448.htm
[1]Department of Internal Medicine I, Luebeck, Germany;
[2]Department of Psychiatry and Psychotherapy, Luebeck, Germany.

Saliva and bloodspot cortisol: novel sampling methods to assess hydrocortisone replacement therapy in hypoadrenal patients in *Clinical Endocrinology* 2004
Authors: Wong
Conclusion - Bloodspot samplings provide a simple and convenient way for ambulant hypoadrenal patients on hydrocortisone replacement therapy to assess cortisol levels at multiple times in a single day. This may be useful in determining the optimal glucocorticoid dose for hypoadrenal patients.
http://www.blackwell-synergy.com/doi/abs/10.1111/j.1365-2265.2004.02062.x?cookieSet=1&journalCode=cen

Submitted by Jim Sadlish

The Vancouver Island Addison's support group will next meet at the **Canadian Addison Society AGM on October 11, 2008** in the Victoria General Hospital Lecture Hall at 1:00pm.

For further information or to contact the Vancouver Island Support Group, please contact Jim Sadlish at wx699@hotmail.com or (250) 656-6270. For information on Central Island activities, please contact Barbara Hunn at bhunn@shaw.ca or (250) 714-0036, or Sharon Erickson at ericksons@shaw.ca.

BC Lower Mainland Support Group

The BC Lower Mainland Group met May 24 for an appetizer meeting with 10 present.

Printouts were available on summer hydration, Emergency form, sheets for solu-cortef with sulphites (anyone wanting a copy please let me know) and a few copies of the Addison's Disease Owner's Manual were available for those attending. A simple rehydration formula is water, salt and sugar (see back issues).

Bill C51 was discussed by members. Anyone interested was advised to contact their local MLA for an update on the bill.

Reminder to members that the AGM is October 11th in Victoria. Anyone wanting to attend - I will be taking my car over and have room for three more people. One couple mentioned they would be attending but were planning on making a weekend of it.

Submitted by Judy Stanley

Arrangements are being made for Dr. Agniezka Zelichowska, endocrinologist to attend our fall meeting. Dates to be confirmed.

For further information on this support group or any upcoming meetings, contact Judy Stanley, (604) 936-6694 or bugbee@shaw.ca.

Alberta Support Group

The Alberta group met May 23, 2008.

- The Hospital Emergency Room Protocol has now been developed and finalized for the Capital Health Region of Edmonton. This has taken two years to complete and is in effect for all hospitals in the region. Information is attached to this newsletter.

  It would be desirable to have the same type of protocol implemented for all hospitals in Alberta, but we will have to wait to proceed with that plan until such time as the new changes are in effect for the various health regions.

- Ginny made everyone aware of the upcoming Annual General Meeting on October 11, 2008 in Victoria, B.C. She plans on attending. She will remain on the Board of Directors.

- Ginny would like someone to replace her as the Regional Representative for the Alberta Society. She has been actively involved for 11 years and feels it is time for 'new blood' and new ideas. Until someone else steps forward, she remains contact person..

- Some ideas for continuity of the Alberta Society were: set up a buddy system for newly diagnosed Addisonians; make more use of modern technology (emails, etc.).

- Ginny has sent letters to various pharmaceutical companies to enquire whether it would be possible to develop an emergency ‘epi pen’ for Addisonians. She has had no response.

- The Alberta Society has $264.60 designated for Alberta use, in the Canadian Society’s account.

- A new member discussed her frustration as a newly diagnosed Addisonian. She was given virtually no information apart from the instruction to take her medication and get a medic alert bracelet. When we are newly diagnosed with a chronic disease, it is a frightening thing and we want all the information we can get. Her family doctor phoned Ginny (also Ginny’s doctor) and asked if Ginny would call the newly diagnosed Addisonian and share information with her. He asked if it was normal for newly diagnosed Addisonians to experience not receiving any information about the disease. Ginny confirmed that yes, that it is almost always the case. He suggested a letter be written to the Endocrinology Department of the University Hospital making them aware of this situation and how it leaves the patient ‘hanging in mid-air’. Some suggestions of our members present at the meeting to include in letter:

    - Medication – possible side affects
    - Medic Alert Bracelet – how to obtain one
    - Use a system similar to the Arthritis patients
    - Make patient aware of the Canadian Addison Society, and how to reach them
    - Tell patient how to take care of ourselves, and what to watch for with regard to an Addisonian crisis
    - Press the need to be open minded about our questions

Submitted by Ginny Snaychuk

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.

Southern Ontario Support Group

17 people attended the May 17 meeting. Members introduce themselves and shared some of their personal history with Addison’s. The diversity of how Addison’s impacted each member’s lives was quite amazing.

Dr. Stan Van Uum, our speaker at the last AGM, and/or Dr. Chris Cameron may speak to us at future meetings. Chris has a G.P. friend who actually suffers with Addison’s whom he is going to approach to see about getting a perspective of the disease from a Doctor's point of view, and possibly her participation at a future meeting.

There was general acceptance of the Emergency Medical Card and a copy will be put onto the website. It was suggested that we put a copy of it into the next newsletter as well (a copy of this form is appended).

John gave a financial report on the Southern Ontario Group. John informed us that $5.00 from membership dues can be designated to a support group, and are to be used to cover expenses for photocopying, supplies, equipment, guest speaker gift and/or travel expenses, when organizing their local support group meetings. Money for the national organization covers advertising, website, creating educational materials and distribution. It was also noted that the organization is a registered charity and provides income tax receipts to anyone making a donation. Just as a clarification however: membership dues are not considered tax deductible.

One member mentioned that individuals wishing to make donations to the United Way may be able to ask that their donation be directed to the Addison's Society.

John discussed the possibility of approaching the Canadian Medical Journal or the Endocrinologists Journal about a onetime ad, to make them aware of the national support group for Addisonians, and that doctors can refer their Addisonian patients there for additional help and education on the disease. The cost for the CMA is approximately $2250 for a ½ page ad or $1535 for a ¼ page ad. The consensus was that we should take this idea back to the next AGM as a motion for further action.

The society's memorial plaque was shown to members and a new picture of it will be placed on the website showing updated information.

If you are interested in attending the next AGM, please advise Irene Gordon, Liaison Secretary. Billeting may be a possibility for those who wish to travel out for the meeting.

Small groups discussions:

a) How many meetings should the Southern Ontario Support Group hold over the course of the year, based on membership demographics?

Decision - there will be two meetings per year. The Brantford meeting will remain in place and we will try to hold a second meeting somewhere in Mississauga. Harold will follow up. It was suggested that we approach local police associations to see if we could make use of their community rooms for meetings. We also developed a list of members who would be willing to carpool to meetings if a member was interested in attending but did not have the transportation to get there. Members requested that we not schedule local support group meetings over long weekends.

b) Is there a hospital protocol in place for Addisonians across southern Ontario and, if so, what does that protocol look like?

Decision – that each member approach their own Endocrinologist to determine if such a procedure is in place in the hospital they currently work in, and report back to Harold with their results. A copy of a protocol as it appears on our website was distributed to all of those in attendance.

Copies of the Society's brochure were distributed to members to take to their doctor's offices and see if the Doctor's would be interested keeping a supply that could be provided to their Addisonian patients.

c) Develop a list of questions that our members would like to see given to Dr. Chris Cameron to respond to when he comes in as a speaker at a future meeting.

Decision – each workgroup developed four or five questions that Harold will present to Chris to develop a theme for a future meeting.

Future meeting schedule:

- Fall 2008: Tentatively November 1, Mississauga. Members will be advised once date and location are finalized. This meeting is being held in Mississauga to encourage those members, who have found it difficult to attend the Brantford meetings, to come out and meet your fellow Addisonian's. If you have any questions, please contact Harold Smith at 519-742-9995, email hsmith9995@rogers.com.
- May 9, 2009, in the Community Room at the Brantford Police Station, 344 Elgin Street, Brantford (details to follow).

Submitted by Harold Smith

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

Eastern Ontario Support Group

The group met May 10, 2008 in Ottawa; discussions around the table were informal.

The Eastern Ontario group is looking for someone to act as contact, and to organize future meetings. If you can volunteer, so that our meetings may continue, please contact Teresa Seasons at tseasons@magma.ca or 613-761-1195, or the Liaison Secretary at liaisonsecretary@addisonsociety.ca or at the national address shown on the front of this Newsletter.

The next meeting would normally be scheduled for October 18, 2008.

In the meantime, for information on Eastern Ontario Support Group activities or meetings, please contact Teresa Seasons at tseasons@magma.ca or 613-761-1195.

Québec Support Group

If you wish to start a local group in the area, please contact the Liaison Secretary at liaisonsecretary@addisonsociety.ca or at the national address shown on the front of this Newsletter.

Atlantic Support Group

Kelley Gamblewest has moved back to the west coast. 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/faq.html), or see previous issues of the newsletter.

Q: I was diagnosed with Lupus about 8 years ago. Now the doctor says I have Addison's. He changed my prednisone to cortef. I want to know how prednisone is equal to how much cortef.

> **A:** It is interesting that you were switched from cortisol to prednisone when you were diagnosed with Lupus. Usually, it is the other way around since the dose of steroid needed to treat Lupus is usually higher than the dose to treat Addison's disease. Prednisone has less tendency to cause salt retention than cortisol, so it is used when higher doses of steroid are needed. The usual dose comparison is 5mg of prednisone is roughly equivalent to 20mg of cortisol or 25mg of cortisone.

Q: I have had Addisons for 3 years now. I take 37mg of cortisone acetate and 0.1mg of Florinef. For quite awhile now, I have been getting these feelings of total drain. They can hit any time of day, and in minutes, I feel like a total zombie. There have been times that I have had to leave work to go home to bed. I have had all kinds of tests - B12, thyroid, iron, even for MS. I still have not gained back my muscle strength, although I do exercise every day. I have tried to increase my dosage, add salt to my water, drink more. I'm so frustrated, sometimes I just want to give up. I'm always tired, my personal life is terrible because I just can't think and I have no energy. I will not give up but keep hoping each day it will get better. I have asked the doctor to check into DHEA which may help? Do you have any suggestions?

> **A:** I am sorry you are having so much trouble getting your treatment sorted out. I am assuming that this has been going on right from the time of your diagnosis of Addison's disease and, if this is correct, I would want to go back to review the test results that led

to the diagnosis. You should review these with your endocrinologist to be sure that there are no other factors that could be causing your symptoms. If the diagnosis is definite, the dose of cortisone of 37.5mg per day, along with the 0.1 mg of florinef, should make you feel better. These are average doses and adjustments of slightly more or slightly less of each of these medications is usually required. Some individuals feel better if their cortisone is given in 3 doses, and some people find that taking their medication earlier in the day gives them more energy at work. The requirements for cortisone are quite variable and if you are not doing well, measurements of ACTH and renin can be helpful in assessing this. These tests would best be done by your endocrinologist because the interpretation is important. It is also important to remember that a proper diet is important with adequate vegetables and protein and only moderate amounts of carbohydrate to avoid a tendency for reactive low blood sugars 2 to 4 hrs after eating.

Q: I was just put on metformin for high glucose but don't know why. it is high all of a sudden. The metformin seems to be working but before that, I was gaining 5-6 pounds a week. I also did a 24-hour urine test and the cortisol was in the limits but on the low side. I am exhausted and everything directs me to Addison's. Is it possible to gain weight with Addison's?

A: It is possible to have both diabetes and Addison's disease but it seems unlikely in your case. A gain of 5 to 6 pounds per week suggests fluid retention, since it would require a very large number of calories to add that much weight in fat tissue. If the sugar is not getting from the blood into the cells, one of the symptoms would be fatigue and this may take awhile to improve after the metformin has started to work. Addison's disease is a possibility but unless there are other features to suggest this diagnosis, I would tend to focus on the treatment of the diabetes.

Q: A couple of weeks ago, I was informed I have Addison disease. The treatment is hydrocortisone (20mg in the morning and 10 mg at night). I am to travel to Ghana and Nigeria (Africa), and I don't know if it is possible to do this or not, having in mind the medication.

A: It is certainly possible to travel, even to places such as Ghana, when you have Addison's disease, but you should go over all of the potential problems with your endocrinologist as soon as possible. It depends on how long you will be away, and whether you will have people travelling with you. You should also be familiar with the emergency kit, and your travelling companions should know how to use it. You should discuss your trip in detail with your endocrinologist. You can also get some travel information and information about the emergency kit from the website http://www.addisonsociety.ca/.

Q: I was diagnosed with Addison's in 2007 and have been experiencing palpitations. I take about 20mg Cortef/daily and take a low dose of Florinef every other day. I believe my palpitations are related to the low sodium/high potassium problem and low blood volume. How can I distinguish exactly which is causing it, the low sodium, high potassium or blood volume? (I've read that they all can cause palpitations). What about hypotremia -is that when I drink too much water?

I appreciate the Canadian Addison's Society; I don't know of any support groups north of the border here. By the way, I have gratefully found 2other Addisonians here at work. Thanks for your time!

> **A:** Palpitations are not a symptom that is particularly common with Addison's disease unless your blood pressure is low and, even then, you are more likely to be light-headed that have palpitations. Your medication dose seems appropriate, and I assume that you have had your blood pressure checked and have had blood tests to measure your sodium and potassium. You should check with your family doctor or endocrinologist to be sure that there are no other factors, such as thyroid problems or anxiety, which could cause palpitations.

Q: I am 32 years old and was diagnosed with Addison 's 9 months ago. I am now on 25mg hydrocortisol delivered 3 times a day. My blood pressure began rising and I was taken off the florinef because of that. My electrolytes have been monitored by blood tests and are thus far fine. However, my blood pressure continues to be high (145-160 over 90-105) and I have been getting headaches. What should our next steps be? I gained a lot of weight originally, probably due to too much prednisone, although now that my drugs are stabilized, I am finding it very hard to lose the extra weight. Does being on a synthetic corticosteriod make it harder to lose weight, and could the extra weight (I'm about 30 lbs over) be contributing to my high blood pressure?

> **A:** It is often difficult to get stabilized on your replacement medication. I was uncertain about your cortisol dosage - you mentioned 25mg taken three times per day. I presume the dose is 25mg spread over the three times rather than 25mg three times per day (i.e. 75mg per day). The dose requirement for cortisol varies from individual to individual so even 25 mg may be more than you need. The fact that you are having weight problems and blood pressure problems suggests that the dose could be too high. You should discuss the problem with your endocrinologist, and have her/him check your ACTH and renin on a morning sample before you take your medication to determine whether your dose is correct. Your ACTH should be high before you take your cortisol - usually about 40 pmol/l.
>
> **Q:** I shared your comments with my family doctor (I am in a rural area and so cannot see an endocrinologist on a regular basis) and we did the ACTH test. The test came back indicating I had no measurable amounts. What could this mean? My doctor has been trying to contact my endocrinologist but has been having trouble, so I thought I'd get your opinion. In addition, there have been some other symptoms or lack thereof that have called my Addison's diagnosis into question. I never got any darkening of skin or scars, although I have read this is usually how Addison's ends up getting diagnosed. For two years prior to diagnosis, I suffered from chronic low blood sugar, low blood pressure, extreme fatigue and lack of appetite. I was mistakenly diagnosed

with depression and chronic fatigue and put on anti-depressants and Ritalin. I was sick all the time, and eventually ended up in the ICU due to a throat infection, which we now assume was an Addison's crisis. An internist tested me and determined I had Addison's. I was taken off the Ritalin and anti-depressants, and put on a corticosteriod replacement. My fatigue, blood pressure and blood sugar issues immediately improved. I was sent to an endocrinologist but he was unable to determine the cause of the disease, i.e. no history or other contributing illnesses. I am now on a total of 20mg of hydrocortisone a day (10-5-5), reduced from 25 to help combat my blood pressure and weight issues. Do you think this could be something other than Addison's or do you have any suggestions as to what tests we should do next?

> **A:** Your tests are interesting and fit with your observation that you did not have increased skin pigmentation at the time of diagnosis. The skin pigmentation in Addison's disease is due to increased levels of ACTH. If your cortisol levels were low at the time of diagnosis and your ACTH levels are low, it is possible that you have secondary adrenal insufficiency due to a pituitary problem. It would be worthwhile asking your family doctor to see if an MRI of your pituitary could be arranged and also check some of your other pituitary hormones - TSH, LH. FSH, and prolactin.

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.

Capital Health
EDMONTON AREA

Executive Office

February 13, 2008

Ms. Ginny Snaychuk
12307 – 137 Avenue
Edmonton, AB
T5L 4C1

Dear Ms. Snaychuk:

Re: Protocol for treatment of individuals with Addison's disease

The eCPG protocol related to management of patients with Addison's disease has been circulated to all Capital Health Emergency Department Chiefs for distribution to all department members.

An educational session to the Capital Health Regional Triage Committee will be facilitated by Dr. M. Bullard as a mechanism to get this information to the nurses involved in triage. Capital Health has also funded triage liaison physicians (TLP) in the University, Royal Alexandra, Grey Nuns, Misericordia and Sturgeon Hospitals, who assist the triage nurse in identifying the appropriate triage of patients. They are also able to initiate appropriate investigation and treatment for select conditions at the time of triage.

Thank you for your continued interest and advocacy on behalf of your society.

Sincerely,

K. Gardener, MD
Vice President, Medical Affairs
Telephone: (780) 407-7162
Fax: (780) 407-6710

KG/ds

Capital Health   CARITAS HEALTH GROUP

Possible Addison Disease Crisis
Patient Care Orders
Emergency Department

Patient ID Number:
Last Name:
First Name:
Visit Number:
Gender:
Age :
Weight Kg:
Height cm:
AH:
IPS:

1. All orders must be completed and signed by the physician. All co-signatures must be timed and dated within **24 hours.**
2. Orders may be deleted by stroking the order out, and initialing the entry or by leaving prompt blank (boxes and / or lines).

Allergies:

Date / Time	Orders Expiration Date: ☑ Old Charts
	Criteria
	Addison's patients presenting with (acute MI, acute abdomen, sepsis, severe trauma) and/or
	(Please check off box for any of the following findings):
	☐ Vomiting and/or diarrhea
	☐ Decreased urine output
	☐ Clinical signs of dehydration
	☐ Hypotension (<110/70) +/- HR > 100/min
	☐ Other relevant symptoms:
	Diet and Activity
	☐ 1. Diet: NPO
	☐ 2. Activity: Bed rest with BRP if BP and symptoms allow
	Assessment / Investigations / Monitoring
	☐ 3. T,P,R, BP, 0_2 saturation q4h (maintain 0_2 sat >92% delivering 0_2 by nasal cannula)
	☐ 4. #18 or #20 gauge IV with 0.9% saline (use D5N if chemstrip < 4 mmol/L)
	☐ 5. Blood glucose level (if not already done)
	☐ 6. CBC and differential, BUN, Cr, Sodium, Potassium, chloride, $C0_2$, calcium, magnesium, glucose
	☐ 7. Other:
	Investigation for Precipitant
	☐ 8. Serum lactate **now** AND in 6 hours
	☐ 9. Blood cultures (if temperature ≥ 38.0 degrees C) - 1 set (3 vials) using two sites; 1st site aerobic vial and anaerobic vial, 2nd site (peripheral vein) aerobic vial only. Blood cultures must be collected before the initiation of antibiotics. Do not delay antibiotics if unable to collect cultures early.
	☐ 10. Urine random and microscopic
	☐ 11. Urine culture and susceptibility
	☐ 12. Portable chest x-ray
	☐ 13. Arterial blood gas
	☐ 14. ECG if age > 50 years OR cardiac history

Possible Addison Disease Crisis
Patient Care Orders
Emergency Department

Patient ID Number:
Last Name:
First Name:
Visit Number:
Gender:
Age :
Weight Kg:
Height cm:
AH:
IPS:

1. All orders must be completed and signed by the physician. All co-signatures must be timed and dated within **24 hours.**
2. Orders may be deleted by stroking the order out, and initialing the entry or by leaving prompt blank (boxes and / or lines).

Allergies:

Date / Time	Orders Expiration Date:
	Medications
	Addisonian Specific Therapy:
	☐ 15. Hydrocortisone 100 mg IV bolus and 100 mg IV q8h
	☐ 16. In mild cases double or triple patient's (current) steroid dose x 3 days
	☐ 17. Other:
	Antibiotic Therapy:
	Consultations
	☐ 18. Consult #1:
	☐ 19. Consult #2:
	Physician Signature: MD.

EMERGENCY MEDICAL INFORMATION CARD

Provided by The Canadian Addison Society

I suffer from **ADDISON'S DISEASE** and am dependent on **Replacement Glucocorticoids** to sustain my life:

Name:	**DOB:**
In case of emergency, please contact:	**Phone:**
Endocrinologist:	**Phone:**
Family Doctor: .	**Phone:**

Addison's Medication: (Types/Dosage)

Other Medical Conditions:

Other Medications: (Types)

Allergies:

Blood Group:

Other Medical Information:

My Address: