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

ISSUE NO.42 **MARCH 2006**

In this issue:

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.

Membership Renewals:

Membership renewals for 2006 were due January 1st. If you have not yet renewed, please complete the attached membership form and forward it to the Treasurer, at the address indicated above. Or you can download the membership form from our website at www.addisonsociety.ca/membership.html.

Members with dues outstanding as of April will be dropped from the membership list, and will no longer receive the Newsletter. If members wish to check whether or not dues have been paid for 2006, they should contact the Society by e-mail at liaisonsecretary@addisonsociety.ca or toll-free at 1-888-550-5582.

Announcements:

- The Canadian Addison Society now has a new information pamphlet, available through your local group representatives. As well, a copy is attached to this Newsletter. We encourage all members to make this available through their doctors' offices, in local hospitals, or other appropriate venues.

- Marilyn Thauberger's mother passed away February 24. Our condolences to her and her family.

- Judy Stanley has a few hints and reminders for members:
  - For those of you concerned about the costs of your medications, Judy suggests that you check out various pharmacies including pharmacies at places like Costco to find a cost-effective alternative.
  - If you are concerned about possible discontinued production of your specific brand of medication, you may want to consult with your pharmacist or doctor about supplies or alternatives.

- The Canadian Addison Society received a thank-you letter from the Surrey Memorial Hospital Foundation in New Westminster B.C for the funds donated at the 2005 AGM.

- Just a reminder to check out the **revamped** website for the Canadian Addison Society at www.addisonsociety.ca. Items are being added regularly to the site, including information on local group meetings, the Newsletters, membership renewal form, frequently asked questions, and information on how to handle an emergency with full directions on how to give an emergency injection.

Annual General Meeting 2006

The 2006 Annual General Meeting will be held in Western Canada, hosted by the Lower Mainland, Vancouver, B.C. Local Support Group. The meeting will be held on October 14, 2006, 1-4 pm in the Lecture Room, Sherbrooke Centre, New Westminster BC.

We hope that knowing the date and location so far in advance will allow you to book holiday and travel arrangements in good time to attend. This offers an unparalleled occasion to meet and exchange information with fellow Society members from across Canada. We hope you can attend.

Members of the local support group have also generously offered to billet people who wish to attend the meeting. A registration form, which can be used to request billeting, is attached to this newsletter.

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Duties of the Regional Representative:

We have been asked occasionally what the regional representative's role entails. Here is a summary. Of course, each regional representative will tailor this to their area's needs and to their own capacity. Please note that we are currently looking for new regional representatives in Southern Ontario and in Quebec.

The Regional Representative usually:

- organizes and chairs two or three local meetings;
- acts as the first line of contact and support to members, new members or potential members (often newly diagnosed people who need support);
- distributes materials to membership if available;
- acts as the filter for information between members and the Board;
- informs the Liaison Secretary of updates to the membership lists.

Organizing local meetings typically involves:

- contacting members to inform them of the date, time and location of a meeting, and encouraging members to bring others;
- arranging for a speaker on a topic of interest, such as a paramedic, emergency care worker, nutritionist, endocrinologist, pharmacist, naturopath, diabetes specialist, etc.;
- arranging a location (your local police department, community centre or hospital may have space available at little or no cost to the group);
- arranging for a snack and drinks, where possible (having people take turns on bringing small snacks keeps costs down);
- ensuring minutes are taken and forwarded to the Newsletter Editor;
- reminding members to keep their dues current, and handing out copies of the membership form.

The Liaison Secretary can provide an up-to-date membership list. Where the local group has a separate fund balance, reasonable expenses incurred for the meeting, food/drink, gift for speaker, photocopying, postage, etc. can be reimbursed by the treasurer if receipts are provided.

Charitable Donations:

The Canadian Addison Society is a registered charity, (Registration # 87248 5511 RR0001) and issues tax deductible receipts for all donations of $10.00 or more. Here are some of the more common strategies available to donors.

Cash Donations - The donor receives an income tax credit for that year of approximately 22% on the first $200. of total donations for the year, and

approximately 40% for the balance. All donations should be claimed by only one family member, in order to avoid having to meet the $200. threshold more than once. Donations may be claimed if made in the year or the five previous years, so it may be advantageous for you to accumulate donations for more than one year.

Gifts of Securities - If you are thinking of selling publicly traded securities or mutual funds with an accrued gain, and then donating the proceeds to The Canadian Addison Society, consider donating the securities directly to the Society. Only one quarter, rather than one half of the capital gain realized on the resulting deemed sale will be taxable, reducing the tax owing by 50%.

Bequests - Leaving funds or property through a charitable bequest in a will allows the donor to retain use of the property while living, and the donor's estate receives the tax credit in the year of death.

There are many other options available. Professional advice regarding an individual's tax and legal status should be obtained.

Highlights from Local Meetings:

Vancouver Island Support Group

Support group meetings for Addisonians on Vancouver Island will be held in Victoria until further notice. These meetings will include members from Victoria, Nanaimo and elsewhere on the Island.

Nine people attended the meeting on February 4th, 2006.

Could taking calcium supplements be a cause of calcium deposits? Doctors advise we take calcium because cortisol replacement medication can contribute to loss of bone density. Comments voiced were: 1) we should count dietary calcium intake to ensure that we don't take more supplements than required; 2) taking adequate vitamin D assists calcium uptake; some members are taking 1000 IUs daily; 3) magnesium also aids calcium in building bone; 4) boron and strontium supplements were suggested for improved bone density. No one had heard evidence that calcium supplements caused calcium deposits but several understood that a calcium deficiency might. One Cornell University internet site cautions against taking too much vitamin D, saying that more than 2000 IU per day may actually cause calcium deposits: http://www.gannett.cornell.edu/healthAtoZ/healthAdvice/calcium.html, while a JAMA site declares vitamin D sufficiency is more important than high calcium intake: http://jama.ama-assn.org/cgi/content/abstract/294/18/2336?maxtoshow=&HITS=10&hits=10&RESULTFORMAT=&fulltext=Vitamin+D&searchid=1139186581663_6645&FIRSTINDEX=0&journalcode=jama

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Fungal problems can develop as a side effect of taking glucocorticoids. Several people admitted to having to deal with toenail fungus. Treatment medications for fungus can cause nausea, even applied topically, as one member found. Epsom salts in a footbath, or a drop of tea tree oil directly on the nail, were suggested as safe alternatives to fight fungus. Also mentioned were grapefruit seed oil and Mycoplex.

One member recently tested positive for Cryptococcus. Members were reminded that taking glucocorticoids may leave them slightly more vulnerable. Although it is extremely rare for people to become ill with Cryptococcus, you should be aware of the symptoms by checking the B.C. Health Guide website: http://www.bchealthguide.org/healthfiles/hfile98.stm#E46E435.

Replacement medications were again discussed. Several people attending had recently adjusted their dosages, working with physicians to reduce or increase meds as needed to feel better. One suggestion was made regarding the timing of taking cortisol replacement. It was ventured that taking this medication in the middle of a meal, along with some carbohydrates, may 'combine' the digestion of sugars and cortisone, giving the body a more balanced supply of nourishment, rather than taking cortisol replacement and carbs at separate times. Glucocorticoids evidently oppose the actions of insulin so the suggestion was that combining intake, rather than taking carbs and meds separately, would avoid the extremes of high cortisol or high insulin blood levels. Possible benefits might be more energy and less brain fog!

During the October 15, 2005 meeting, there was much interest in contacting the University of Victoria to arrange patient interviews for medical students. The B.C. Mainland support group now works closely with the UBC Medical Program conducting student interviews during support group meetings each fall. The patient coordinator at the Island Medical Program was reached and presented with our offer to act as chronic illness patients for student interviews. Their current program includes first and second year medical courses only, which do not encompass the study of chronic diseases. However, we are now registered with the coordinator as a source for patients when future courses focusing on chronic disorders are scheduled.

The NADF recently issued a notice of a possible cortisone acetate supply shortage from Westward Pharmaceuticals. In Canada, Westward supplies the company (Mckessen) that supplies Costco, and may be the cortisone acetate source for other pharmacies in Canada. If you use cortisone acetate, you may wish to check with your pharmacy and/or doctor to ensure your future supply.

One member raised the possibility that tests for type 2 diabetes may be affected if the patient is Addisonian. This matter is being looked into further.

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A pharmacist recommended Pepto-Bismol as one treatment for food poisoning, stating that it helps eliminate E.coli.

Colleen again quickly demonstrated how to administer Solu-Cortef to members who missed the last meeting. Instructions can be downloaded from the Society website: www.addisonsociety.ca.

Colleen recommended a nutritional book "Prescription for Healthy Healing", available at health food stores.

The Canadian Addison Society 2006 AGM will be held on October 14 in New Westminster. The Vancouver Island group will organize a carpool.

The next support group meeting in Victoria will be June 3, 2006.

Submitted by Jim Sadlish with contributions by Florence Weekes

For further information or to contact the Vancouver Island Support Group, please contact Jim Sadlish at jsadlish@horizon.bc.ca or (250) 656-6270.

BC Lower Mainland Support Group

The group met on February 26, 2006 with 13 people attending

- 2006 AGM will be held October 14th, 2006; guest speaker will be Dr. Laugh (Chris Johnson); schedule: 12:30 to 1:00 registration mixer with snacks, 1:00 to 2:30 business meeting, 2:30 to 3:00 coffee and snacks, 3:00 to 4:30 guest speaker Dr. Laugh. Those present expressed interest in more time to meet fellow members.
- We received a letter commending our group for our donation to Surrey Memorial Hospital Foundation and from Dr. Ip thanking us.
- Dr. Ip has forwarded a copy of the Ottawa Hospital protocol sheet to the Fraser Health Authority as there is nothing similar here. We are following up by requesting a list of hospitals in BC to see if they have a protocol in place.
- The package containing information from the Canadian Addison Society to Dr. Sun for inclusion of Addison's in Paramedic Training that Marilyn and Judy sent off will be adapted for their training program.
- Our third advocacy letter for linking of BC Emergency Departments has been sent to the new Minister of Health.
- 39 letters to endocrinologists in BC were mailed outlining our progress in the past year, a Society pamphlet and projects for 2006. One doctor in N. Vancouver and the clinic at Children's Hospital have requested more pamphlets for their offices. Anyone wanting handouts for their doctor's office should let Judy know.

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- There were no requests for follow-up to our interviews with medical students. This year if requested we shall be doing in-home interviews only as the AGM will take place when we normally do them.
- The new website for The Canadian Addison Society is now "live" at www.addisonsociety.ca. You can complete your membership renewal form and print it from the web site (forms also available at the meeting). Current information on upcoming meetings and what is happening across Canada is posted.
- The UK site www.addisons.org.uk has a page on surgery, dental procedures etc. and increase of cortisone that you may want to discuss with your doctor/endocrinologist if you are having any of the procedures listed.
- Arrangements have been made for Mavis Pickett of CBC, Comedy Club, coffeehouses and Osteofit to give us a short routine along with her attitude to life at our June meeting. Mavis has been featured on local radio, Arthur Black Show, and Vicki Gabereau.
- NADF reported that West-Ward pharmaceuticals have had a supply problem with raw material for manufacturing cortisone acetate. They supply Costco in Canada.
- Merck & Co., Inc. is no longer making Decadron® (Dexamethasone).
- A member on Vancouver Island tested positive for Cryptococcus gattii but is asymptomatic. The doctors weren't sure if it was a false reading or even a contaminated sample. It is not contagious but she wanted others to be aware as it is in three forest districts on the mainland and island. The BC Health Guide website has more information http://www.bchealthguide.org/healthfiles/hfile98.stm.
- A member has requested the Diabetes Assoc. look into testing procedures for those with Addison's.

Our guest speaker was Linda Zumm from the Canadian Diabetes Association who spoke on how to look for the signs of Diabetes Type II. As Linda was diagnosed with diabetes Type I, she was also able to tell us of her experiences with maintaining an active and healthful lifestyle. She had numerous handouts as well.

The ***live smart*** **Diabetes Expo** will be held in Surrey April 1, 2006. Over 250,000 British Columbians have diabetes, and many more have it and don't know it. Join the Canadian Diabetes Association on Saturday April 1 for the Live Smart Diabetes Expo in Surrey, BC. Experts from the diabetes health community will speak on subjects ranging from how to get a better night's sleep, to physical fitness and how to incorporate laughter into your life. The hands-on event will feature an Ask the Expert booth with family doctors, nurses, dieticians, podiatrists and many more health professionals. To register, call 604-732-INFO (4636), toll free 1800 268 4656, or register online at www.diabetes.ca.

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Here are some websites which you may find useful for general information relating to diabetes and Addisons:
http://bmj.bmjjournals.com/cgi/content/full/312/7046/1601
http://addisons-diabetes.gkznet.com/Control.htm
http://www.medhelp.org/www/nadf3.htm
http://www.stayinginshape.com/3osfcorp/libv/i68.shtml
http://thyroid.about.com/library/endocrine/bladdisons-disease2.htm#insul

Diabetes **Type I** symptoms include sudden weight loss, extreme fatigue or lack of energy, frequent urination, cuts and bruises slow to heal, tingling or numbness in hands or feet, and thirst. Type I diabetes requires a glucose tolerance test as opposed to a glucose fasting test. 10% of those with Type I have autoimmune disease. The glucose tolerance test shows how your body handles sugar. The hemoglobin A1C test shows the amount of sugar in your red blood cells. Normal blood sugar levels are between 4 and 6.

Type II diabetes is becoming epidemic with our diet and sedentary lifestyle. Those with high cholesterol, high blood pressure, overweight, under stress, over 40, or a member of a high risk group (Aboriginal, Hispanic, Asian, South Asian or African descent) are more prone to developing Type II diabetes. It can be managed through diet; exercise and sometimes oral medication; 20% of Type II require insulin. Those with a sibling, family member or gestational diabetes are also likely to develop Type II. Gestational diabetes is usually found with a birth weight of over 9 lbs. and your doctor should make you aware of risk factors.

You are also at risk if you have been diagnosed with any of the following:

- Polycystic ovary syndrome
- Acanthosis nigrican (darkened patches of skin)
- Schizophrenia

For our bodies to process glucose we need insulin to convert it for energy. Canada's food guidelines provide food serving sizes for body styles and the glycemic index, which make managing diabetes easier. Your diet will depend on your age and lifestyle. Alter the part of your life that you can control – eat a healthy diet and exercise (150 minutes of moderate activity over 3 non-consecutive days a week). Avoid hidden fats in food – the occasional Caesar salad will not harm you but it does contain a large amount of fat. The daily dose for fat should be about the size of the end of your thumb! Guidelines for food sizes were also available.

With her Type I, Linda tests at least five times a day. More frequent testing is required when traveling, doing heavy exercise, under stress, ill or fighting infection. The new medication Lantis, a 24-hour insulin, is for Type I diabetics only, with Type II controlled by pill or diet. Type II diabetics may also use insulin, if blood sugar

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levels are not adequately controlled by diet and other medication. Always consult your doctor if you think you may be at risk or have diabetes.

Future Meeting Dates:

- **June 3, 2006** Sherbrooke Lounge, Sherbrooke Centre, 260 Sherbrooke St. New Westminster BC 1:00 to 3:00 p.m.

- **AGM -** Lecture Theatre on Saturday, **October 14, 2006**. We have registration forms for out-of-town members who want billeting for Friday and/or Saturday. Two such requests have been received to date. For those on holiday, we'll have maps and tour information available.

Submitted by Judy Stanley

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

Alberta Support Group

Capital Health Patient Relations reports that our protocol was removed from the December meeting agenda, due to other priorities. However, the Medical Affairs Office has sent correspondence to all the Capital Health Emergency Room Site Leads with respect to the protocol. At this point, it needs to be discussed at a meeting and a decision made as to how to deal with it.

In order to move this protocol forward, and to facilitate the potential of this protocol being implemented, we have been asked to submit any personal emergency room horror stories related to treatment of an Addisonian crisis. Please take the time to share any unpleasant **Addison's-related** experiences you may have had at either a Capital Health or Caritas Health Hospital Emergency Room to:

Capital Health Patient Relations
8440 - 112 Street
Edmonton, AB T6G 2B7
Attention: Pat

Submitted by Francisca Swist

For information on this support group or any upcoming meetings, contact Francisca Swist at francisca@shaw.ca or Ginny Snaychuk at glav@telus.net or (780) 454-3866 – both are from Edmonton.

Saskatchewan Support Group

If you wish information about this support group or upcoming meetings, contact Elizabeth Hill at (306) 236-5483 kesahill@sasktel.net or elizabeth.h@pnrha.ca.

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Southern Ontario Support Group

The Southern Ontario Support Group is looking for someone to act as local contact and representative. If you are willing to take on this important role, please contact the liaison secretary at liaisonsecretary@addisonsociety.ca or toll-free at 1-888-550-5582.

The next meeting of the Southern Ontario Local Group will be on Saturday, May 13th from 1-4 pm in the Community Room at the Brantford Memorial Police Station. We are not planning to have a guest speaker at this time, but rather an information sharing session to scope out future meetings.

For the moment, for further information on Southern Ontario Support Group activities or meetings, contact Irene Gordon at liaisonsecretary@addisonsociety.ca or toll-free at 1-888-550-5582.

Eastern Ontario Support Group

The next meeting will be Saturday, May 13, 2006 – a week before the Victoria Day Holiday, location to be determined. Doug Harpur will take minutes. For information, please contact Teresa Seasons at tseasons@magma.ca (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.

Medical Q & A

Since the inception of the new website, our medical advisor, Dr. Killinger, has been kept very busy with the influx of questions. This aspect of our site has already proven very valuable. A special thank-you to Dr. Killinger for all his work in this area.

Q: There is a new form of birth control pill - YASMIN - which is contra-indicated for people with adrenal problems. Why?

> **A**: Yasmin is a birth control pill that contains an estrogen and a progestational agent as in other birth control pills. The difference is that the progestational component in Yasmin is different from other birth control pills since it also blocks the action of aldosterone, the adrenal hormone that stimulates the kidney to retain salt. This may be a desirable effect in some women because it decreases fluid retention, but in individuals with Addison's

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disease who are taking Florinef, it will block the salt-retaining effects of the Florinef and could cause a fall in blood pressure. It is therefore not a good choice for women with Addison's disease.

Q: I have been told that changing brands of drug might affect the effectiveness of my replacement medications. Could you please comment?

A: Substitution of drug preparations: Pharmacists will generally give you the least expensive preparation of a drug unless there is a specific request for no substitution. Different brands or generic versions of drugs may have slightly different binders, fillers, coatings, and densities. This might affect your absorption rate. I am not aware of any studies looking at the bioavailability of different preparations of hydrocortisone (cortisol), cortisone, or prednisone from different manufacturers, but it is generally good practice to stay with the same preparation to avoid possible differences in pill content. If you have switched brands and have symptoms of glucocorticoid excess or deficiency, discuss this with your doctor so proper adjustments in dosage are made.

Q: I have had Addison's for about 20 years. I will be going to Quito, Ecuador next month. The elevation is quite high - around 9200 feet. Do I need to be concerned about altitude illness? I do have a tendency to be light-headed.

A: High altitude should not be any more of a problem for someone with Addison's disease than for the general population. With the altitude you will get short of breath more easily with exertion due to the fact that the oxygen pressure is less. This is true for everyone. The weather will be warmer so you will have to be sure you get enough salt in your diet (you may need to add extra). If you are having episodes of light-headedness now, you should get your family doctor to check your plasma renin. This is a test to see if you are getting the right amount of Florinef and enough salt. If this is not correct, your may be more susceptible to increased light-headedness (due to a fall in blood pressure) in hot weather. Addison's disease should not interfere with your trip.

Q: My 8-year-old daughter has Addison's disease. She takes Cortef three times a day by chewing the pills. Her teeth always look like she does not brush them, even though she does, and they have white spots on them. Could this be because of the Cortef?

A: Before making any comments about the white spots on your daughter's teeth, I would like to hear what her dentist has to say. Since I don't have that option, I will suggest some possibilities, but emphasize that your dentist should see these spots to determine what part of the tooth is involved. My first thought is that in this age group, there is a high incidence of systemic

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candidiasis associated with adrenal insufficiency (Addison's disease). This candidiasis is a monilial (fungal) infection that shows up as white spots usually on the tongue and inside of the mouth. It is possible some of this material could appear on the teeth. The fact that she is chewing the cortisone could make her more susceptible to this infection if it is not being washed down well with water after chewing. Children with Addison's disease frequently also have a deficiency of parathyroid hormone (hypoparathyroidism). This can result in defects in the calcification of the teeth as they develop. This can be detected with blood tests for calcium, phosphorous and parathyroid hormone. A third possibility could be too much fluoride. All of these suggestions require the expert advice from your dentist and your endocrinologist.

Q: I have Addison's disease, celiac disease, vitiligo, Hashimoto's thyroiditis, early menopause, Type II diabetes, hypertension and LDL of 120. For years I was on 50 mg. hydrocortisone. More recently (10 years) I have been on 15 mg Cortef daily. I take 0.1 mg fludrocortisone, 16 mg Atacand, 0.125 mg Levoxyl and 81 mg Aspirin every other day. My doctor also wants me to take 1/2 tablet 10/40 Vytorin. Would less fludrocortisone help lower hypertension without the use of antihypertensives? My blood pressure still runs in the 140/80's even on Atacand.

A: You have almost the complete spectrum of autoimmune endocrine problems, but it sounds as if you are doing well and are being well looked after. Your doctor wants you to start the Vytorin because your LDL cholesterol is higher than it should be in someone with Diabetes. Blood Pressure of 140/80 is a little high and the suggestion to lower the dosage of Fludrocortisone is a reasonable one. The dose of Fludrocortisone varies from 0.05 to 2.0mg per day so you should discuss this with your doctor. Whether this is a good idea or not depends on your past treatment experience.

Q: Because I have Addison's, I have been doing research regarding Addison's and the adrenal glands, and have read of taking raw adrenal gland pills to rebuild the adrenal glands and taking Tyrosine pills. Is this actually possible? Also, I'm on a new treatment with Andriol (testosterone pill), which is supposed to raise my DHEA level. I started with three 40 mg pills a day, but cut down to two because my mind was racing at night. Can I expect some long-term side effect from this medicine, or would I be better off taking DHEA pills instead. The Andriol does seem to help me heal more quickly.

A: If you have Addison's disease, it means that your adrenals have been damaged by some process, most commonly an autoimmune process in which antibodies destroy the gland. Other possibilities include infections or hemorrhage. In all of these situations, the gland cannot be "rebuilt". Taking pills containing adrenal tissue obtained from animals will not do anything to

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improve your own adrenal tissue. Tyrosine is an amino acid which is important, but is readily available in our usual diet. Taking extra will not affect adrenal function. The question regarding testosterone is less clear. Whether or not testosterone will help depends on what your basal testosterone level is. However, it is clear that testosterone will not increase DHEA levels. In studies in which DHEA has been given to women, it will increase testosterone levels but DHEA in the usual doses does not have a significant effect on testosterone in men. Testosterone given to men who are truly testosterone-deficient will improve protein and muscle development. Since it is so important to know what your hormone levels are before taking additional hormones, you should have some testing done by your endocrinologist.

Q: Is Prednisone any different than Medrol on the ACTH suppression on the pituitary, given equivalent doses, i.e. 6 mg of medrol and 7.5 mg of prednisone or 30 mg hydrocortisone?

A: Medrol is the trade name for methyl prednisolone. It is a little more potent than prednisolone, but at appropriate doses, all three steroids have about the same pituitary suppression. Cortisol is a little shorter acting, so depending how frequently it is given, it may have slightly less suppression of the pituitary. Prednisone and methyl prednisolone are frequently used to treat inflammatory problems such as colitis or some kidney problems because they cause less salt retention and are more potent as anti-inflammatory activity than cortisol. They tend to be used in larger doses in these situations and therefore can cause greater pituitary suppression.

Q: Does Addison's disease hit all at once, or does it come on slowly? I've had off and on "symptoms" for 4 years, unexplained weight loss, diarrhea, sometimes uncontrollable body tremors/shakes and chills with body temp drops almost to 96° F, often some degree of weakness and lethargy, no libido, and little energy. Doctors have said I'm "depressed" or that it's just IBS, but, after also starting to occasionally get severe stabbing pains in my upper back that last long enough to make me lose my breath and scream, I'm starting to wonder. I have no odd skin discolouration, but does that necessarily come with the disease? I know it's rare, and I did know someone who unfortunately died from complications very shortly after her diagnosis. I've been very worried lately - should I be?

A: Addison's disease usually comes on gradually over several years. Once the adrenal damage reaches a critical stage, individuals can become ill quite quickly. Weight loss is a common symptom, but diarrhea, chills and back pain are not usually associated with Addison's disease. Skin pigmentation is a common feature but may not be obvious in some situations. If there is a family history of Addison's disease or other autoimmune diseases such as thyroid disease or diabetes, or if you are worried about this problem, you

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should talk to your family doctor. The best test to rule out the diagnosis is a serum ACTH. The ACTH goes up as the adrenal is starting to fail because of damage by antibodies and is elevated when serum cortisol and other tests are normal.

Q: I am a 48-year-old female, with minimal ACTH, low TSH, low IGF 1 reading, and low cortisol. I am taking 5 mg prednisone and .1 mg synthroid. I have nasty hot flashes and no libido, and have been on Andriol for one month, with no change. I use progesterone cream for 20 days/month. My last period was 60 days ago. An MRI discovered two small 2 mm growths on my pituitary; my doctor said these were not significant. I feel awful, fatigued, dizzy, painful moving around and body aches (fibromyalgia). My night and day are completely reversed. I also have celiac disease; antibody test ANA was negative. What else can I be doing to fix my health? I really need to get back to work.

A: Because you are on prednisone and thyroxine, you must have been diagnosed sometime in the past with underactivity of your adrenal and thyroid glands. You are also having hot flashes suggesting that your ovarian function is underactive either due to a normal menopause (age 48) or less likely, an early menopause as part of an autoimmune process involving the ovaries, thyroid and adrenals. The celiac disease could also be part of this autoimmune process. The ACTH and TSH levels depend on when they were taken. If they were taken before starting prednisone and thyroxine, it would suggest a pituitary problem. If they were taken while on medication, it may be the normal response to the medication. Small nonfunctioning adenomas can be seen on MRI of the pituitary and may be of no significance, but it is important to know the clinical situation in which they are found to rule out a functioning adenoma. The situation that is presented is a complex one that requires a detailed discussion with an endocrinologist to explain what is known in this case and what additional investigation may be needed to resolve any unexplained findings. It would be important to talk to your family doctor to arrange such an appointment if you do not already have an endocrinologist.

- **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) or submit the question. Questions and answers that may be of interest to everyone will be published in the newsletter and on the website.

The Canadian Addison Society is a registered charity, ## 87248 5511 RR0001.
193 Elgin Avenue West, Goderich, Ontario N7A 2E7
Toll free number: 1-888-550-5582
www.addisonsociety.ca

Financial Statements:

THE CANADIAN ADDISON SOCIETY
Analysis of cash on hand & in banks as at December 31, 2005

Equitable Trust -	
The Canadian Addison Society	
- $6,151.60 @2.95% due February 13, 2006	
- $9,012.68@3.25% due March 28, 2006	15,164.28
TD Canada Trust -	
The Canadian Addison Society	-222.78
Montreal Support Group - Quebec	100.00
Ottawa Valley Support Group - Eastern Ontario	548.90
Brantford and District Support Group - Southern Ontario	1,335.00
Saskatchewan Support Group	5.00
Edmonton Support Group - Alberta	251.75
Lower Mainland (Vancouver) Support Group – B. C.	363.22
Vancouver Island Support Group - Victoria	380.00
Vancouver Island Support Group - Nanaimo	15.00
Total	**$17,940.37**

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THE CANADIAN ADDISON SOCIETY
STATEMENT OF INCOME & EXPENSES
FOR THE PERIODS ENDING DECEMBER 31, 2005 AND 2004

	January 1, 2005	January 1, 2004
Cash on hand and in banks	$19,420.76	$18,332.30
Income		
Dues Received - National	$2,999.34	$3,735.00
- Support Groups	525.17	550.00
Donations	615.17	1,147.94
Interest	363.19	189.70
	4,502.87	5,622.64
Expenses		
Newsletter	1,129.10	1,398.11
Web Site	1,116.86	
Secretarial	500.00	
Annual Meeting	239.22	277.79
Donation	200.00	
Outside meetings, seminars & membership		74.54
Postage, stationery & supplies	96.10	482.40
Telephone	2,031.42	2,068.24
Travel	474.38	
Support Group Expenses	136.18	173.10
Bank Charges	60.00	60.00
	$5,983.26	$4,534.18
	December 31, 2005	December 31, 2004
Cash on hand and in banks after adjusting for O/S cheques	$17,940.37	$19,420.76

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Addison's disease is a rare disorder of the adrenal glands that affects about 2-4 in 100,000 people. It can occur in all age groups and can affect men, women and children, but is more common in women. Without proper treatment, it is fatal.

The Canadian Addison Society is a non-profit organization for persons with Addison's disease and their families. There are several local support groups across Canada including Ottawa and Brantford, Ontario; Meadow Lake, Saskatchewan; Edmonton, Alberta; Vancouver, Victoria and Nanaimo, British Columbia.

An annual membership fee of $25.00 includes information regarding this rare disease, a quarterly newsletter, contact with other Canadian Addisonians and information about upcoming meetings.

If you want more information about our organization, our support groups, or just a complimentary information package about Addison's disease, please feel free to contact us at the address below.

THE CANADIAN ADDISON SOCIETY
193 Elgin Avenue West
Goderich ON N7A 2E7

Telephone; 1-888-550-5582
Email; liaisonsecretary@addisonsociety.ca
Web Site; www.addisonsociety.ca

THE CANADIAN ADDISON SOCIETY

HAVE YOU BEEN DIAGNOSED WITH ADDISON'S DISEASE?

WE CAN HELP!! WE OFFER SUPPORT AND INFORMATION

CALL WRITE OR EMAIL

Telephone; 1-888-550-5582
Email; liaisonsecretary@addisonsociety.ca
Web Site; www.addisonsociety.ca

Symptoms of Addison's Disease

- Chronic fatigue and muscle weakness, bronze discoloration of the skin, craving for salt or salty foods
- Loss of appetite, nausea and vomiting, abdominal discomfort, weight loss
- Low blood pressure, dizziness on standing, fainting
- Mental confusion and irritability

Causes

The most common cause of Addison's disease is an autoimmune process that results in the body's production of antibodies that destroy the adrenal cells. These adrenal cells are responsible for the production of adrenal hormones. This destruction can also be caused by tuberculosis, fungal infections or hemorrhage.

Treatment

Addison's disease is treated by replacing the missing adrenal hormones with hydrocortisone (cortisol) and in most cases, Fludrocortisone acetate (Florinef). These are oral medications which must be taken daily and in cases of illness or injury, larger doses are required. Stressful situations, such as surgery or more severe medical illness, require emergency management.

Autoimmune Addison's disease can frequently be associated with other autoimmune diseases. Thyroid disease is the most common, occurring in 50% of cases. Less commonly associated diseases include diabetes mellitus, gonadal failure (ovaries), colitis, underactive parathyroid glands and pernicious anaemia.

There is no cure for Addison's disease, but with proper daily replacement medications and regular monitoring by a specialist, Addisonians can live a relatively normal lifestyle.

A person with Addison's disease should always carry his/her medical identification card and wear a Medic Alert bracelet in case of injury or an Addisonian crisis.

The Canadian Addison Society
La Société canadienne d'Addison

193 Elgin Avenue West
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http://www.addisonsociety.ca

2006 Annual General Meeting

Date of Meeting: Saturday, October 14, 2006

Time: 12:30 – 4:30 pm

Location of Meeting: Sherbrooke Lecture Theatre
260 Sherbrooke Street
New Westminster BC

Name: _____

Address: _____

City: _____ Province: _____

Postal Code: _____ Phone #: _____

E-mail Address: _____
(if applicable)

Number of people attending: _____

Billeting required for:

Friday: Yes _____ No _____
Saturday: Yes _____ No _____

Please note: We have limited billeting available.
Billeting will be assigned on a "first registered, first accommodated" basis.

Please mail completed forms to: Judy Stanley
5 Tuxedo Place
Port Moody, BC V3H 3W5

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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 Eastern Ontario Support Group – ON + $20.00 to Society*
❑ *$5.00 to Southern 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

Revised: March, 2006