The Canadian Addison Society
La Société canadienne d'Addison

193 Elgin Avenue West
Goderich, Ontario N7A 2E7
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http://www.addisonsociety.ca

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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.

Editor's Note:

You may have noticed that it's been awhile since the last Newsletter. My sincere apologies. I was preoccupied with family matters, and later with an irreparable computer crash.

This Newsletter will focus on local group reports and the great many medical questions and answers generated in the last few months. Remember that all Q & A's, both past and current, can be found on the website at http://www.addisonsociety.ca/faq.html#.

I expect the next Newsletter to contain the minutes of the 2006 AGM held in October. It should to come out in the next couple of months. In the meantime, you can consult the minutes on our website.

Announcements and Reminders:

- Our new website at http://www.addisonsociety.ca has been a success. The site administrator can count how many people hit each page - unique visitors as opposed to the same visitor hitting the page multiple times. You may find the following information interesting.

  - unique visitors (excludes repeated hits from same address): 4034 between January 2006 and October 2006.

  - # of pages viewed: 2054 (4.42 pages/per visit)

  - # of hits: 25114 (54.12 hits/per visit)

  If you haven't had a look at the wealth of information and helpful hints available there, we recommend you do so soon.

- We are sorry to note the death of Therese Sullivan from Kingston (member of Eastern Ontario group) in August 2006. We offer condolences to her family.

- Anyone travelling by air will find the report on travelling with prescriptions and emergency kits, in the Highlights from the Eastern Ontario meeting, extremely useful. We recommend that you also review the information on the official website at http://www.catsa.gc.ca/english/travel_voyage/special.shtml#a2.

- Remember to renew your membership for 2007, due in January 2007. Renewal forms can be found on our website http://www.addisonsociety.ca/benefits.html or attached to this newsletter.

- The Canadian Addison Society is a registered charity (registration # 87248 5511 RR0001). Recent changes to the *Income Tax Act* make the gifting of securities (stocks or bonds) even more attractive to donors, reducing the taxable capital gains on the donated securities to 0% (this isn't a typo!), and at the same time providing the donor with a tax deductible receipt for the full value of the securities. If you want to consider this approach, either now or within your estate plan, please consult your accountant or other professional advisor.

Back to School With Addison's Disease:

The kids are back in school, and if you're the parent of a child with adrenal insufficiency, it's time to take action to safeguard his or her health. The safest environment for your child is one in which all caretakers know about your child's

condition, so if you have not yet met with your child's teacher(s), principal, and school nurse, you'll want to schedule a meeting as soon as possible.

To prepare for this meeting, gather:
- your child's medical treatment plan, including a list of all daily medications;
- a copy of the emergency procedures (see our website under Healthy Living http://www.addisonsociety.ca/ohp.html);
- all phone numbers where parents can be reached, and for relatives who can give authorization for treatment if you are unavailable;
- phone numbers of your child's pediatric endocrinologist and pediatrician;
- instructions for giving an emergency injection (see our website under Healthy Living http://www.addisonsociety.ca/injection.html).

You'll want to make sure the principal is included in the meeting. The principal is in charge of everything that happens at the school, and if the school nurse (or, increasingly, the secretary) is unavailable, you could waste valuable time in an emergency trying to explain Addison's Disease.

Find out about your school district's policy on daily medications. Most require a doctor's order detailing the time, dose, and reason for the medication, as well as the parent's authorization. A separate order may be required for medication administration outside the daily dose. This PRN (Latin for "as needed") order should include wording such as "to be administered in times of injury, fever, and/or illness, and/or at the parent's discretion" and should include a maximum dosage ("up to X mgs").

School districts may have policies prohibiting school employees from administering injected medications, or require that only RNs can give medications. Make sure you know in advance whether a qualified person would accompany the child on field trips.

Your wishes should be put in writing, signed, and placed in the child's official file. For example, do you want to be notified immediately of any playground mishap, or just the more serious ones? Tummy-aches, or vomiting/ fever?

Make sure your child's teacher knows what Addison's is, and why your child might have special needs. Explain the seriousness of the condition in a straightforward, unemotional way. You may wish to direct him/her to the Canadian Addison Society website at http://www.addisonsociety.ca, or print out the information from the website in advance. You may find the information on the Emergency Procedures page (http://www.addisonsociety.ca/emergencyproc.html) helpful.

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Work with the teacher to schedule regular meds at a time that would be the least disruptive to the class: either at lunch, between classes, or before or after recess or gym when everyone's already moving from room to room.

All of the information shared with the school district should also be given to any after-school caretakers.

With proper planning, your child should have a great year!

Adapted with permission from COAST News, Fall 2006

Highlights from Local Meetings:

Vancouver Island Support Group

The Vancouver Island group met Saturday, October 21st, at the Victoria General Hospital in Victoria. Eleven people including one member from Ladysmith attended.

The Canadian Addison Society 2006 AGM held October 14 was discussed. The by-law revisions were passed and a new director, Ginny Snaychuck from Alberta, was voted in. We reviewed various points made by attendees at the AGM and questions answered by endocrinologist Dr. Wallace.

Other topics covered at the Victoria meeting were:

- Several members noted instances where children of mothers taking hydrocortisone (or other corticosteroids) were not permitted to be vaccinated or immunized. The rationale for this precaution is that people taking hydrocortisone may be at risk of infection. Below is an excerpt from one Merck hydrocortisone product website:

  > Administration of live virus vaccines, including smallpox, is contraindicated in individuals receiving immunosuppressive doses of corticosteroids. If inactivated viral or bacterial vaccines are administered to individuals receiving immunosuppressive doses of corticosteroids, the expected serum antibody response may not be obtained. However, immunization procedures may be undertaken in patients who are receiving corticosteroids as replacement therapy, e.g., for Addison's disease.
  >
  > Patients who are on drugs which suppress the immune system are more susceptible to infections than healthy individuals. Chickenpox and measles, for example, can have a more serious or even fatal course in non-immune patients on corticosteroids. In such patients who have not had these diseases, particular care should be taken to avoid exposure. The risk of

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developing a disseminated infection varies among individuals and can be related to the dose, route and duration of corticosteroid administration as well as to the underlying disease.

(Ed. note: Please also see a Q&A on our website on this very question. Dr Killinger's response should be useful to anyone addressing this issue.)

- A question was asked, "Should we take extra replacement for emotional stress?" The consensus was that an emotional stress such as grieving for a deceased loved one is an extreme stress and warrants additional replacement medication. As we become aware of our limitations having Addison's disease, over time we recognize when our bodies need the help of increased medication during stress. Ask your endocrinologist for advice on this subject.

  Vitamin B complex was suggested as a good supplement for stress.

  (Ed. note: Comments made by Dr Killinger in his presentation to the 2004 AGM help address this question. Please see the complete report in AGM Minutes of 2004 (on our website), replicated in the November 2004 Newsletter (also on website)).

- One member, physically active with a large family and a demanding career, asked how other Addisonians dealt with pre-menopausal symptoms including mood swings and high blood pressure and whether adjusting dosages of replacement medication was recommended. This question prompted much discussion and various suggestions although no one present had experienced quite the same symptoms. A number of supplements were proposed, including Evening Primrose Oil and using tofu in meals. It was suggested that she talk with her endocrinologist about tailoring her medication regime to alleviate her symptoms.

- Two members take dexamethasone. One wakes up before dawn to take her medication because it works best for her at that time. Another, who recently started taking 0.5mg dexamethasone at bedtime, changed from her previous medication because she was experiencing morning nausea. Another attendee noted morning 'fog' and asked if others experience this on getting up in the morning. This could be caused by low blood sugar levels in the morning.

  (Ed. note: Would the following from the UK Self-Help group site http://adshg.org.uk/quest/1997/08/01.html help?

  I advise my patients that they should take their morning dose of hydrocortisone before they get out of bed in the morning on waking. They do not need to take these tablets which are for simple replacement therapy with

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food simply with a little water whatever the bottle containing the tablets says. The reason for taking the dose of hydrocortisone on an empty stomach before getting out of bed is that normally the circulating hydrocortisone (cortisol) levels rise to their maximum value about twenty minutes after waking. They then fall through the day. By taking the morning dose of tablets fasting on an empty stomach with just a little water the normal pattern of secretion is reflected most accurately. If the tablets are taken later in the day after breakfast the absorption is very slow, circulating levels of the hormone remain low for many hours and many patients feel tired and unwell early in the morning and take a long time to "get going".

Ref: Q1- NO.33 August 1997)

- One woman was recently diagnosed with diabetes and wanted to ask how many others were dealing with both disorders. One other member with diabetes was present.

  (Ed. note: There are several Addisonians in other support groups – Southern Ontario, Eastern Ontario, BC Lower Mainland - who have diabetes. Perhaps this member could get help by getting in touch with one of them, through the local group representative.)

- A number of studies were discussed:

  - A Mayo Clinic study just presented in the New England Journal of Medicine and referenced in a Globe and Mail article October 19, 2006, dismisses the benefits of DHEA supplements for most people. This article did not mention Addison's disease. However, there is a 2006 Mayo Clinic website, *http://www.mayoclinic.com/health/dhea/NS_patient-dhea*, devoted to DHEA which rates its benefits for people with adrenal insufficiency as 'B' (having good scientific evidence for this use). Depression, obesity and systemic lupus erythematosis shared the same high rating for patients benefiting from taking DHEA supplements.

  - A Swedish study in the Journal of Clinical Endocrinology & Metabolism published on-line September 12, 2006 is titled "Premature mortality in patients with Addison's disease: a population-based study", by researcher Ragnhildur Bergthorsdottir, available at *http://jcem.endojournals.org/cgi/content/abstract/jc.2006-0076v1*.

    Granted this is not uplifting news, however, there are some very interesting points made in the Discussion section of the easy-to-read Author Manuscript in the above website. One reason this study is significant is the size, identifying 1675 patients diagnosed with primary adrenal insufficiency. Note

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that they evaluated all patients hospitalized in Swedish hospitals for primary adrenal insufficiency between 1987 and 2001.

- Another very detailed technical analysis, "Autoimmune Adrenal Insufficiency and Autoimmune Polyendocrine Syndromes: Autoantibodies, Autoantigens, and Their Applicability in Diagnosis and Disease Prediction" by Corrado Betterle, *http://edrv.endojournals.org/cgi/reprint/23/3/327*, published by The Endocrine Society in 2002 studied 317 Italian patients with primary Addison's. This study will tell you everything you want to know about why we have an adrenal disorder (if you can understand it).

Submitted by Jim Sadlish

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.

Future meetings of the Vancouver Island group will be held in Room 1814 near the cafeteria at the Victoria General Hospital in Victoria between 1:00 and 3:00 PM on each of the following dates: February 3, June 2, September 29.

For further information or to contact the Vancouver Island Support Group, please contact Jim Sadlish at jsadlish@horizon.bc.ca or (250) 656-6270. For information on mid-Island activities, please contact: Christy Lapi at clapi@shaw.ca or 250-245-7554; Barbara Hunn at bhunn@shaw.ca or 250-756-4385; or Sharon Erickson at ericksons@shaw.ca.

BC Lower Mainland Support Group

The October 16, 2006 meeting was replaced by the AGM. Minutes of the AGM can be found on our website and will be published in the next Newsletter.

Thanks to everyone for their hard work to make the AGM a success. Everyone enjoyed the time spent meeting, talking to others and putting faces to names.

Marilyn and Judy had a short meeting to start on a reply to the letter from the Health Ministry for Protocol for ER's and ambulance drivers. We will try to make arrangements to meet in Victoria with the proper authorities and have a member to represent Vancouver Island as well.

The medical students from UBC have all been assigned their interviews and are contacting those who expressed interest. Thanks to everyone who participated in the program again this year. It is so important for new doctors to be aware of our condition for early diagnosis and treatment.

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The next meeting will be Sat. Feb. 17, 2007, 1:00 to 3 pm in the Sherbrooke Lounge, Sherbrooke Centre, 260 Sherbrooke St., New Westminster, Vancouver B.C. If you have a preference for a guest speaker, please let Judy know.

Other meetings for 2007 will be May 26 (our annual appetizer get-together) and October 27.

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

The group has an opportunity to put an article about Addison's Disease in the November/December issue of the publication, *Edmonton 's Child*. Information from the Canadian Addison Society website will be used.

For information on this support group, contact Ginny Snaychuk (our new Director) at glav@telus.net 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

The next meeting is Sat. May 5, 2007, 1:00 to 4:00 pm, Brantford Police Station 344 Elgin Street in Brantford. 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 Eastern Ontario group met on Sept. 30, 2006. Unfortunately, due to a mix-up with respect to location, turnout was unusually low.

- National Society business:
  - AGM will be held Oct. 14 in Vancouver. Unfortunately nobody from our chapter is able to attend.
  - Don't forget to renew your memberships.

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- Local business
  - Pamphlets for distribution to doctors' offices will be available at the next meeting.
  - Next local meeting is expected to be May 12 in Kingston (to be confirmed). A local endocrinologist in Kingston has offered to speak. Teresa needs help finding a meeting site (restaurant, community facility, OPP?). Meeting time could be after lunch if we do not meet at a restaurant. Teresa will contact Kingston area members separately to encourage them to reserve the date.
  - The proposal of a spring picnic meeting will not be pursued at the moment.
  - Food was ordered in for this meeting, at a higher cost than anticipated. For future meetings not held in restaurants, we discussed alternate options such as altering the meeting time, snack food only, and potluck.

- Guest Speaker was Erika Mayhew, Canadian Air Transport Security Authority (CATSA).

  Screening of all passengers and their belongings must be conducted at the pre-board screening checkpoints. All regulations discussed here apply only to Canadian airports. Other countries have slightly different regulations, so be prepared to deal with them individually, for example, the US requires people to take off their shoes (which could contain metal shanks) in order to save time (it's more labor intensive to conduct a physical search if the alarm goes off than to run everything through the x-ray machine).

  Seized items can go into your checked luggage (retrieved or a separate box), or may be mailed to your residence or destination. You would need enough time to do any of these. Members suggested the use of a 'secure box' for each flight - for people who have something in their carry-on which is not permitted.

  New Security Measures:
  - Passengers will be permitted to bring liquids, gels and aerosols through security screening at Canadian airports provided that the items are packaged in containers with a capacity of 90 ml / 90 grams (3 oz.) or less, and that the containers fit comfortably in one clear, closed and resealable plastic bag with a capacity of no more than 1 litre (1 quart). One bag per passenger will be permitted.Prescriptions and non-essential medication are exempt, as are baby food and formula (if you are travelling with an infant under 2 yrs).
  - It's OK to bring things in non-original containers but better if you can bring the original container.
  - Nail files, knitting and other needles, tweezers are permitted in carry-on luggage again.
  - You still can't board a plane with an open beverage bottle; but you can purchase beverages inside the security area once again (you just have to

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drink up before you board!). Flight attendants are being very diligent about offering water to passengers.

Persons Travelling with Prescription Drugs:

- Ensure your medication is properly labelled (professionally printed label identifying the medication or a manufacturer's name or pharmaceutical label).
- Place it in your carry-on baggage in case it is required.
- Medication requiring syringes and hypodermic needles must be for personal medical use, with the needle guards in place and accompanied by labelled medication.
- Pre-board screening officers have on-going training to accommodate passengers with special needs, including Addisonians.
- Suggestions:
    - carry a current note from your physician/endocrinologist
    - photocopy of medication history from your pharmacist
    - get extra labels printed by your pharmacist
    - don't forget to wear your medic-alert bracelet
    - spouses/other persons travelling with Addisonians may carry the Addisonian's medication in the event that the Addisonian has a crisis and becomes incoherent. You can notify screening staff of this as a heads up.
    - alcohol swabs etc. are not a problem.
    - make sure to carry enough meds for the duration of your trip (unless you will be able to obtain meds when you arrive) in the event that your luggage is lost.

Other Helpful Tips:

- Avoid the rush, arrive early!
- Pack all camera film in your carry-on baggage. Screening equipment used for carry-on luggage is different from that which is used for checked-luggage. Camera film under 800 ASA/ISO will not be damaged by equipment at the security checkpoint if it is only exposed infrequently. If your trip includes multiple airports, you can ask that the film be searched manually (place it in a clear plastic bag to help speed things up).
- Dress appropriately for travel and avoid wearing metal objects that could trigger the alarm.
- It is recommended that you pack all food products in your carry-on baggage.
- Electronic devices may be screened using special equipment. This procedure will not harm your electronic devices.
- Behavioral pattern recognition is being used as a screening tool.
- Most frequently seized items: scissors, toy guns (15,000 in 2005!)

For further information, consult the web www.catsa.gc.ca or call 1-888-294-2202.

Teresa and Erika will write an article on Addisons which will appear in CATSA's monthly newsletter. As well, Erika will work with us to prepare an information page

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for our website, specifically addressing the needs of Addisonians travelling with medications

- New business
  - IM gravol (by prescription) may be a very useful option for some Addisonians.
  - DHEA update: there may be changes coming.
  - One member recounted a story of her experiences during a crisis while traveling in Italy. She was unable to communicate with the local medical staff and almost ended up having an appendectomy and a week's stay in hospital. Lesson learned: it might be a good idea to have a few key points translated into the language of the country where you are planning to travel. Our website has links to sample emergency information letters in English, French, Italian and Spanish http://www.addisonsociety.ca/emergencylett.html.

Submitted by Catherine Semple

The next Eastern Ontario meeting is currently set for May 12, 2007, in Kingston. 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

Q: I was diagnosed with Addison's in 1995. At that time, my weight was 158 lbs., now I'm at 236 lbs. I have also been diagnosed with osteoarthritis and find it very difficult to walk. I have joined an aquasize class, but it makes me so tired. Should I be taking extra medication before class and is it normal for my skin to be really dry?

A: Individuals with Addison's disease do not necessarily gain excess weight when they are on an appropriate dose of cortisol. You did not say what dose of glucocorticoid you are on, but it should be reviewed with your endocrinologist. If you are gaining weight, it could be a combination of a) too much glucocorticoid (cortisol, prednisone), b) too many calories and c) not enough activity. I would not suggest that you take extra medication before a normal exercise workout; your normal dose should be enough. Dry skin is not generally a symptom of Addison's disease, and may be a non-specific problem. It can be a symptom of an underactive thyroid which occurs in

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about half of the patients with Addison's disease, so this would be worth checking.

Q: My friend's biggest issue is an unquenchable, unrelenting thirst throughout the day and night. She awakes several times each night to drink water and urinate. It's difficult to sleep leading to extreme fatigue. Muscle spasms and high/unstable blood pressure are also issues. She also has Hashimoto's Thyroiditis and pernicious anaemia. Amaloride and Vasotec were discontinued after diagnosis of Addison's disease. Something just is not right in her medications mix and may be contributing to thirst.

A: Your friend has recently been started on cortisol for Addison's disease and is now thirsty. When someone presents with increased thirst and increase in urination, the first question would be "what is her blood sugar?" This is particularly relevant because she has recently been started on cortisol in a fairly large dose and this could bring out a latent tenancy for diabetes. Hashimoto's thyroiditis and pernicious anaemia are autoimmune diseases as is Addison's disease, so they frequently are present in the same individual.

Q: Can low aldosterone present with high blood pressure? A friend was started on 30 mg in hospital and increased by the endocrinologist to 40 mg. She is extremely thirsty and has gained 20 lbs over several weeks. Her blood pressure is high and unstable. The doctor says Florinef is not indicated because her blood pressure is already high.

A: Low aldosterone will not cause high blood pressure. The decision not to start on Florinef was a reasonable one in someone who has high blood pressure. I suspect the reason your friend gained 20 lbs is likely because he/she is on too much cortisol. A dose of 20 mg a day of cortisol is usually enough if it is spread throughout the day. While some people feel better on 30 mg, I think that 40 mg is too much cortisol.

Q: Can hydrocortisone cause body tremors (eye tremor, calf tremor and neck tremor)?

A: None of the biological effects of cortisol cause shaking, so I do not think that this would be a cause for this symptom.

Q: My 16-yr old daughter was diagnosed with Addison's disease in January after having an Addisonian crisis. She lost a lot of weight at that time but has since gained it back, plus more. Is her body falsely telling her to eat, or is it a side affect of the Cortef, Florinef and Synthroid (for her hypothyroidism)?

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A: When treatment was started, your daughter would have felt better and regained the weight she lost as she was getting ill. Her weight should level out if the dose of cortisol is appropriate. The commonest cause of excessive weight is being on too much glucocorticoid replacement (cortisone, cortisol, prednisone). The lowest dose that makes her feel well is the right dose. This can be as low as 15 mg of cortisol a day. The florinef and thyroid are unlikely to be a significant factor in excessive weight gain.

Q: Is surgery out of the question for a person with Addison's?

A: There is no contraindication to surgery in individuals with Addison's disease. They do however require coverage with intravenous glucocorticoids prior to the anaesthetic and during the surgery. The important thing is to be sure that both the anaesthetist and the surgeon are aware that the individual has Addison's disease.

Q: The doctor who treated me for Addison's has left and my new doctor says I'm taking too much of one of my pills, what should I do?

A: If you have not seen an endocrinologist about your Addison's disease, it is important that you ask for a referral. If there is any question about the dose of any of your medications, it should be discussed with your endocrinologist. If you have seen an endocrinologist in the past, just give him/her a call.

Q: Can I substitute my medications with natural products such as herbs?

A: There are no herb or naturopathic medications that will replace the medications required for treating Addison's disease. Getting the right dose is the important thing.

Q: I just went from cortef to 75 ug dexamethasone. So far, I feel really good, with no highs or lows and good energy all day. Is 75 ug a reasonable replacement?

A: The 75 ug dose of dexamethasone is higher than a normal physiological replacement of cortisol. Dexamethasone is long acting (24 hrs) versus cortisol (90 min). It is difficult to precisely compare doses as I don't know what dose of cortisol you were on before the change. Between 25 and 50 ug of dexamethasone is roughly equivalent to 20 mg of cortisol, so 75 ug of dexamethasone would be equivalent to about 50 mg of cortisol. This is a large dose and, because of its long duration of action, it tends to be more likely to result in side effects of too much glucocorticoid. You may be feeling so well because you are getting a higher dose of glucocorticoid than normal. This seems good in the short run, but may not be good in the long run. I prefer not to use dexamethasone for replacement in Addison's disease.

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Q: Can I expect weight gain with this disease? I was diagnosed 3 months ago and I am on 15 mg of cortef a day and feel pretty good. It has not happened yet, but can I expect it down the road?

> **A:** Addison's disease is due to a deficiency of adrenal steroid hormones. The treatment is replacement of these missing hormones with hydrocortisone (Cortef) and a mineralocorticoid (Fludrocortisone). If the dose of cortef is appropriate, there should not be a significant weight gain. Some people gain weight after being treated because they have lost weight prior to being diagnosed, or because their appetite has improved after being treated. If there is any excessive gain in weight, it is most likely due to being on too much hormone. The dose of cortef mentioned is 15 mg daily and this is a dose unlikely to cause weight gain.

Q: Can lowering your Prednisone and/or Fludrocortisone affect your thyroid levels?

> **A:** There should not be any effect of changing the dose of these steroids on thyroid levels as long as the doses are in or close to the normal range.

Q: I have recently been diagnosed with Addison's disease, and experienced severe abdominal pain (and inflammation), in the same spot, every day. Is this normal?

> **A:** It is difficult to be specific about your question regarding abdominal pain. It is not usually a symptom of Addison's disease itself, but some individuals may also have gastrointestinal problems which are autoimmune, so they are seen with increased frequency in individuals with Addison's disease. It is important to find the cause of the abdominal pain since analgesics may mask the true cause of the problem. It is best to review this with your family doctor or endocrinologist. The location of the pain, the presence or absence of diarrhea and things that aggravate it or make it better will all help them in determining what could be the cause.

Q: Can a young woman of 17 or 18 take birth control if she has Addison's disease?

> **A:** Yes. There is no contraindication for individuals with Addison's disease to using the pill. There are however, contraindications to using the birth control pill in the general population that should be respected.

Q: Is it possible to raise your cortisol levels in Addison's by using a certain birth control pill instead of hydrocortisone? I'm a 33-year old female and do not look forward to the side effect profiles presented by the medicines like prednisone, hydrocortisone, etc. Is there a birth control pill that would raise my cortisol levels adequately and present an alternative to hydrocortisone treatment?

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A: You have asked if there is an alternative to taking hydrocortisone for the treatment of Addison's disease. Since the problem in Addison's disease is a deficiency of hydrocortisone, there is no alterative but to replace the hydrocortisone by using hydrocortisone itself or another glucocorticoid. I prefer hydrocortisone. The good news is that you do not have to have bad side effects from the hydrocortisone if the dose is properly adjusted. By keeping the dose to the lowest dose that makes you feel well, you should be replacing what you need without an excessive dose. This dose would be a total of 15 to 30 mg per day in divided doses, generally around 20 mg. The birth control pill does not provide any glucocorticoid. In individuals on the birth control pill, the plasma cortisol levels rise to almost twice the normal levels, but this is because there is an increase in the levels of the protein that transports hydrocortisone in the blood. This increased hydrocortisone is not available to get into the tissues so the effective level of hydrocortisone is unchanged.

Q: I have a pregnant patient who has been very symptomatic with low blood pressure (weak, tired feeling, dizzy, unable to work, etc). Cortisol studies have been normal. Would she benefit from treatment with Florinef? Is there harm in using this?

A: There are several changes in adrenal function occurring during normal pregnancy that make tests difficult to interpret. Measurement of urinary free cortisol during pregnancy usually results in levels which are about twice the normal values. This suggests that cortisol secretion increases during normal pregnancy. Progesterone levels rise dramatically during pregnancy and progesterone has interesting effects on both cortisol and aldosterone. First of all, it binds to corticosteriod binding globulin (CBG), and displaces cortisol at the same time that estrogen is increasing CBG, so measurement of cortisol in pregnancy is difficult to interpret. Secondly, progesterone blocks some of the mineralocorticoid effects of aldosterone, so during pregnancy, aldosterone production increases dramatically. The usual recommendation is to carry on with the usual doses of glucocorticoid and mineralocorticoid during pregnancy, but with the physiological changes going on, it is often necessary to make some adjustments. This is particularly relevant if nausea and gastrointestinal problems complicate the situation. The dose of cortisol can be increased stepwise by 5 or 10 mg to see if it relieves some of the symptoms. The placenta converts cortisol to inactive cortisone so the fetus is protected and will not be affected by these changes. It sounds as if your patient has not required mineralocorticoid replacement prior to the pregnancy. If she is experiencing hypotension, she would probably benefit from Florinef. Measuring electrolytes in the plasma is usually not helpful because these levels only change when things are more advanced. Most individuals with

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Addison's disease do well during pregnancy on cortisol and fludrocortisone (Florinef) and I am not aware of any concerns with Florinef during pregnancy.

Q: I read, with interest, the letter to the Doctor in the June 2006 Newsletter. It included various questions, but the one of interest to me was not answered. This lady had problems with leg muscle twitching after she went to bed. I also experience this and would very much like to know if other Addisonians do as well, and I also would like to know what causes this, and/or what can be done about it?

A: Leg cramps and muscle twitching at night are relatively common complaints in the general population and I am not aware that individuals with Addison's disease are more likely to have these problems. You could discuss this with your family doctor to be sure your sodium, potassium and calcium are normal. Sometimes increased or unusual activity will cause these symptoms temporarily. If this is a problem which is interfering with your sleep, your family doctor may want to do some further studies or try you on some medication to relieve the symptoms.

Q: I was diagnosed with Addison's disease in 1992. I have always been told that I shouldn't take anti-inflammatory medication; can you tell me why? I am currently suffering from muscle spasms. I have been prescribed Baclofen vs an anti-inflammatory.

A: Anti-inflammatory medications can cause stomach irritation and ulcers. These are the major side effects of non-steroidal anti-inflammatory drugs. People who are taking steroids such as prednisone for the treatment of diseases such as arthritis are more susceptible to these side effects. In Addison's disease, the dose of glucocorticoid is physiological (within the normal range) rather than pharmacological (exceeds the normal range for treatment purposes) so the increased probability of stomach problems is quite low. In a situation where anti-inflammatory medications are indicated, it is important to be aware of possible side effects, but I would not hesitate to use non-steroidals. It is important to be sure that the drug is being used for the proper indications. This family of drugs is very helpful to treat inflammation, but is not likely to do much for cramping or spasms.

Q: I want to cut back on my pills if I can to take more natural things such as herbs and along that line. What should I do? Also my doctor who is looking after my Addisons has left to have a baby and now another doctor is saying I'm taking too much of my one pill. What should I do?

A: There are no herbs or naturopathic medications that will replace the medications required for treating Addison's disease. Getting the right dose is the important point. If you have not seen an endocrinologist about your

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Addison's disease, it is important that you ask for a referral. If there is any question about the dose of any of your medications, it should be discussed with your endocrinologist. If you have seen an endocrinologist in the past, just give him/her a call.

Q: I've had Addison's for 6 years now and feel very fatigued most of the time. I'm on a diuretic to lower my blood pressure, and am consuming huge amounts of salt. I've just switched to Himalayan Salt, which is supposed to be natural and not as harmful as normal table salt. I often feel better after consuming the salt. Is something out of whack with my electrolytes? What tests would answer this question?

A: The management of high blood pressure can be a problem in people with Addison's disease. Since part of Addison's disease is a problem with salt retention, the use of a diuretic which causes salt loss can be tricky. The use of other types of anti-hypertensives is preferable such as calcium channel blockers. The tests to check your salt balance include electrolytes and plasma renin; your family doctor or endocrinologist will know about this.

- **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.

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La Société canadienne d'Addison

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_____

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