# *The Canadian Addison Society*
# *La Société canadienne d'Addison*

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**PLEASE NOTE: The content of this newsletter is intended for basic information only and not as personal medical advice. Readers are advised to consult their own doctors before making changes to their Addison management program.**

## Announcements and Tidbits:

- There are several positions in the Society looking for volunteers – we need a new President effective October 2008, and several local groups need someone as contact person and to organize meetings. We strongly encourage members, perhaps especially newer members, who have benefited from the existence of the Addison Society forum, to consider "paying it forward" so that those diagnosed in future can get some of the same help the Society has given you.

- If you are interested in volunteering to act as our next Society President, or have someone to suggest, we would like to hear from you. This position serves to focus the Society and to act as a spokesperson, but is not labour-intensive. Please contact the Liaison Secretary at liaisonsecretary@addisonsociety.ca or 1-888-550-5582 as soon as possible.

- 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.

- Annual membership renewals were due in January. If you have not yet renewed for 2008, please do so immediately, using the attached membership form. If you do not renew your membership, this is the last newsletter you will receive.

- You may remember the announcement in the January 2008 Newsletter of a Facebook site for Addisonians. Here is an update from A. Northey:

  I am pleased to say that the Facebook group is flourishing. We are growing and now have over one hundred members from all over the world. The group is very active and new questions are always being posted on the message board. I think people enjoy having the group as an outlet. Most members say that they don't know of anyone else with the disease so you can feel the camaraderie. We cover everything from new articles to diet to medications and mood changes. Everyone wants to know if they are the only one who has noticed this or that. While Facebook has the tendency to dig its claws into your life, I would encourage people who are using the website to join our group.

- Those in SW Ontario may find the following site interesting: www.thehealthline.ca is an online directory of over 2,000 health and health-related services for South West Ontario; it is a source of current information about local health care news and events.

- You probably know that U.S. President J. F. Kennedy suffered from Addisons Disease, but did you know that Jane Austen, the writer, developed Addisons in 1817 and died in July 1817? The Jane Austen Centre in Bath, England, recognizes Austen's medical condition with a plaque.

## Personal Stories

I was diagnosed at the very last minute in 1973 and have lived for 35 years now a relatively normal life.

But what is normal anymore? People who know I have Addison's forget and sometimes I forget too. I rarely tell friends and new acquaintances but when I do, they almost fall over when they realize how active I am in life and that I am healthier than the average person.

It wasn't easy at the beginning, and after being ill with this insidious disease for two years; the deterioration of my body wasn't an indication of my condition until I was bedridden for 2 months. On a Friday evening, I was diagnosed in Calgary Foothills hospital by a doctor working overtime. If he hadn't been there, I would have had a heart attack on the weekend and not survived. After a day of medication, there was no tying me down and I haven't looked back since.

It took about 10 years for me to adjust to medication doses and the severe trauma of the disease brought on extreme migraine headaches and hair loss. So what? My specialist at the time worked from the Children's Hospital in Calgary and I saw first hand the suffering and how debilitating cancer was for young patients, but they always had a smile on their hopeful little faces.

I used to have relapses every few years and have to be hospitalized, but the last one was 25 years ago. During that time, I had the opportunity to meet the doctor who attended the Kennedy family, who also has a history of this condition.

At the time of diagnosis, I was informed what a rare condition I had. I was told that I would probably die having children but I could live a normal lifespan otherwise. I didn't have children, and in my experience since, have been attended by several specialists (I have outlived one) who have apologized for the now different outlook on this disease.

In my first stages of diagnosis, I was photographed and entered into the medical journals and was invited to speak at the University of Calgary to medical students.

I had a sister two years younger than myself who mysteriously passed away at age 6, and after I was diagnosed, was determined to probably have had adrenal insufficiency as well. I have an older brother who seems to suffer from too much adrenaline and even had to be sent to the Mayo clinic for diagnosis several years ago. I have a younger brother and sister who show no symptoms of this condition.

I have lived with the outlook that, whatever happens, happens, and have not once wondered why this has happened to me. In the end, it makes me a stronger person.

I would love to chat longer but adventure awaits.

Submitted by S. Thomas

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In the fall of 1968, I became very ill. I had 3 young children to look after – aged 7, 4, and 18 months. I had to have my Mom come and look after them when my husband was at work. Every morning, I was very sick to my stomach and very weak; I had trouble getting up and down stairs in our home; I also had a great weight loss. Our doctor finally admitted me to hospital - they thought I might have had a breakdown. When in hospital, my electrolytes were very low. They finally figured out why, at home, I would eat a whole lemon and jars of homemade dill pickles - my body needed salt. My doctor (also a friend) came into my room when I had been in hospital about 1 week, and said he thought he had found the trouble. After consulting with my internist, he said I had Addisons Disease. He started up the IV with the proper medication and within a few days I was feeling a lot better. I got home Dec.l3 so my family was very happy. We had it all confirmed in Toronto with Dr. Volpe, a great endocrinologist. He agreed with everything, and also found I had Hashimoto's thyroiditis. I take 25mg of cortisone in the am & 121/2 mg at night, also1/2 of 0.1mg of florinef & 0.05 mg of synthroid.  I also take 40mg.of lovastin, as I had a mild heart attack in July 1996, also 50mg acebutolol.

I decided to write this because so many people seem to be having such problems ( I realize everyone is different).  I remember Dr. Volpe saying to me if you were going to have any disease, it is better to have Addisons than to be a diabetic, as Addisons does not get worse with age.  I know nothing about the kits people talk about.

I feel very fortunate, as I feel quite well.  I do watch that I do not get overtired.  I have developed macular degeneration in the last few years, and I have had 5 laser surgeries on one eye, but I am able to see, thank God.  I also have osteoarthritis.

My husband and I have travelled extensively for many years, our last trip being to China and Hong Kong to celebrate our 50th anniversary last September.  I have never had any trouble while travelling.

My meds have stayed the same since the beginning.

I live a very busy, productive life.  I feel very fortunate to have a good family doctor and a good endocrinologist - I think these things are very important.

REMEMBER - ADDISONS IS NOT A DEATH SENTENCE.

Submitted by H. Christie

## How aldosterone keeps sodium in the body:

In a study appearing in the March issue of the *Journal of Clinical Investigation*, Bruce Kone and colleagues from the University of Texas Medical School at Houston, demonstrate how aldosterone keeps sodium in the body.  While the study doesn’t have immediate implications for those with adrenal insufficiency (and thus, a lack of the hormone aldosterone), it could, down the road, lead to better treatment of Primary Addison’s Disease.

The *JCI* article explains that the hormone aldosterone regulates the amount of sodium (Na+) that we retain in our body and how much we excrete in our urine by activating epithelial Na+ channels (ENaCs).  In this way it has a major influence on blood pressure and extracellular fluid volume, thereby influencing the course of cardiovascular and renal diseases.  Although it is known that aldosterone induces the expression of a protein known as SGK1 and that SGK1 can increase the expression of the alpha-subunit of ENaC (ENaC-alpha), the precise molecular details of this pathway have not yet been clearly determined.

The research team demonstrated that in the mouse, SGK1 increases the expression of ENaC-alpha by phosphorylating a protein known as AF9.  Unphosphorylated AF9 can bind a protein known as Dot1a and this complex sits on the promoter of the gene that encodes ENaC-alpha, by preventing histone methylation and thereby preventing the gene from being expressed.

Upon phosphorylation by SGK1, the AF9- Dot1A complex breaks apart, enabling high levels of the gene encoding ENaC-alpha to be expressed. This study therefore identifies the molecular pathway by which aldosterone activates ENaCs in the mouse and is likely to apply to other genes encoding proteins activated by aldosterone.

The complete article can be obtained at www.jci.org. Click on “In this issue”, then search on “Salt, sodium channels, SGK1.”

This study offers a new understanding of aldosterone’s functions while raising still more questions to be answered in the future. Someday, this many be translated into the development of new treatments for high blood pressure or Addison’s Disease.

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## Highlights from Local Meetings:

### Vancouver Island Support Group

The Vancouver Island group met February 9th, at the Victoria General Hospital in Victoria. Fifteen people attended including 5 spouses.

We have asked a medical expert to address the October 11,2008, AGM, being held in the Lecture Hall at the Victoria General Hospital, but have not received word from him if he is available to speak. Two couples from Ontario will be attending the AGM. Although their plans for visiting are as yet unknown, we will need to consider the possibility of accommodating some guests, should there be requests. Also, we must arrange refreshments for after the meeting and before the medical expert's talk.

Aspects of the recent Ontario meeting which focussed on "Living with Addison's and Living with an Addisonian", as reported in the Canadian Addison Society Newsletter, were discussed. Opinions expressed by Addisonians present at our meeting were that the candid descriptions given in the report by non-Addisonians were essentially accurate. Nonetheless, it was unsettling for those of us with Addison's to realize that the people closest to us are so overly concerned with our safety and well-being.

Discussing cortisol replacement, it was interesting to find 3 members taking dexamethasone as their primary medication. All 3 had used cortisone acetate, hydrocortisone (cortef) or prednisone previously with unsatisfactory results, so their doctors switched them to dexamethasone and they are now managing fine (note - one member takes some prednisone during the day and dexamethasone very early in the morning). One takes her dexamethasone all at bedtime. As for members taking the other medication, most divide their dosages throughout the day except one who takes it all at once in the morning.

Low blood pressure is a complaint of two members. Raising the dose of florinef to .15 mg and a high salt intake for one member has not adequately increased her BP.

On the topic of florinef, one person has had her dose gradually reduced to where she no longer requires any. Another woman misplaced her florinef while travelling and was prescribed more. The only tablets available at the pharmacy were twice the size (.2mg). She took them anyway, as it was a short holiday. With the larger dose, she proved to be "the life of the party"! Returning home she found it quite difficult changing back to her regular dose, but managed after a few days. This might indicate that our bodies are so dependent on our specific, regular input of replacements that any reduction creates a stress, taking time to overcome, before a rebalancing occurs. A reason why doctors ask us to reduce very gradually, if they feel a reduction in meds is beneficial.

Three members described what it felt like to have an Addisonian crisis:

- For one, the onset of a crisis is gradual, with a feeling of lethargy accompanied by nausea. Car sickness is a sure sign for her. These symptoms happen even after taking regular replacement medications. Her spouse is fully aware of the signs of crisis, which seem to occur once a year during the springtime.

- Another member was playing bridge when she saw the room around her swaying. She collapsed and was helped by friends who were nurses. Although she experienced both vomiting and diarrhea, a glass of ginger ale and extra cortisol meds were enough to stabilize her, without going to Emergency.

- A terrifying situation resulted when a member at the wheel of her car experienced severe stomach cramps. Fortunately, her husband took control of the vehicle prior to her passing out and got them safely home to call an ambulance. She woke to find herself in hospital! Her blood sugar was tested. Soon after this incident she was diagnosed with type 2 diabetes.

Regarding thyroid replacement, after experiencing hyperthyroid symptoms, one member had her dose reduced several times over the past year to find an optimum level. She attributed this to starting menopause and managing her Addison's better.

Depression is often cited as a chronic problem by our members, some taking anti-depressants. Being depressed for a few days may be helped by striving to be positive, being physically active, enjoying reading or music and spending time with friends who make you feel good. It was suggested that vitamin D is reputed to improve mood. Members pointed out that a clinical depression is much more serious, possibly indicating a chemical imbalance requiring medical assistance and stronger medications to bring about improvement.

Awakening during the night and not sleeping have always been problems for many Addisonians. Many doctors offer prescriptions for sleep aids. Some members take an evening dose with milk. One suggestion for a pleasant treat which often helps provide a long night's sleep was to take just a couple of squares of dark chocolate an hour or 2 before bedtime.

Studies found searching Google for papers referring to adrenal insufficiency and related topics:

1) *A randomised, controlled trial of long-term DHEA replacement in Primary Adrenal Insufficiency***.** November 13, 2007, Authors: Eleanor M Gurnell MRCP, Penelope J Hunt FRACP, et al., Journal of Clinical Endocrinology & Metabolism, doi:10.1210/jc.2007-1134
http://jcem.endojournals.org/cgi/content/abstract/jc.2007-1134v1

2) Variability in hydrocortisone plasma and saliva pharmacokinetics following intravenous and oral administration to patients with adrenal insufficiency**,** Authors: Thomson, A. H.; Devers, M. C.1; et al., Source: Clinical Endocrinology, Volume 66, Number 6, June 2007, pp. 789-796(8)
http://www.ingentaconnect.com/content/bsc/cend/2007/00000066/00000006/art00006

3) *Comparison of 24 hour urine free cortisol measurement and hydrocortisone day curve in the assessment of hydrocortisone replacement in hypoadrenal patients,* Author: Ajith George, Gina Twine & Daniel Flanagan - March 2007, Derriford Hospital, Plymouth, Devon, United Kingdom.
http://www.endocrine-abstracts.org/ea/0013/ea0013p279.htm

4) *Lack of DHEA Effect on a Combined Endurance and Resistance Exercise Program in Postmenopausal Women* (non-Addisonians) November 9, 2007, Ada Igwebuike MD, Brian A. Irving PhD, et al., Mayo Clinic General Clinical Research Center, Rochester, MN.
http://jcem.endojournals.org/cgi/content/abstract/93/2/534

5) *Effect of Dehydroepiandrosterone Replacement on Insulin Sensitivity and Lipids in Hypoadrenal Women,* Ketan Dhatariya, Maureen L. Bigelow, and K. Sreekumaran Nair**,** From the Endocrine Research Unit, Mayo Clinic and Foundation, Rochester,Minnesota, March 2005
http://diabetes.diabetesjournals.org/cgi/content/abstract/54/3/765

6) *Two Years of Treatment With Dehydroepiandrosterone Does Not Improve Insulin Secretion, Insulin Action, or Postprandial Glucose Turnover in Elderly Men or Women* (non-Addisonians)**,** Rita Basu 1, Chiara Dalla Man 2 Division of Endocrinology, Diabetes, Metabolism, and Nutrition, Mayo Clinic College of Medicine, Rochester, Minnesota
http://diabetes.diabetesjournals.org/cgi/content/abstract/56/3/753?ck=nck

The Vancouver Island support group will next meet Saturday, **May 31, 2008**, in Victoria at the **Victoria General Hospital, Room 1814**, from 1:00 to 3:00. For more information, please contact Jim Sadlish at 250-656-6270 or e-mail: wx699@hotmail.com.

Submitted by Jim Sadlish

For further information or to contact the Vancouver Island Support Group, please contact Jim Sadlish at wx699@hotmail.com or (250) 656-6270.

## BC Lower Mainland Support Group

On February 23, 2008, 8 people attended for our yearly interviews with UBC 1st year medical students, and another 10 requested at-home interviews. Next year, we will only do in-home interviews, leaving arrangements for interviews to UBC. Thanks to Marilyn for the herculean effort she put into arrangements to accommodate members.

Judy Stanley attended the UBC Diabetes Research Forum & Webcast *Diabetes – Genes or Lifestyle?* on March 8, 2008. She asked the speaker if there was any research into Addison's and diabetes, and mentioned the higher incidence of those with Cushing's and diabetes in our group. He replied that this is created by the excess of cortisol in the body. A person with Addison's taking large amounts of cortisone over time and above a replacement dose is also placing him/herself at risk of developing type 1 diabetes. One of the signs of over-medication would be osteoporosis. It is best to keep your Addison's Disease stable but if ill and you need to increase medication for extended periods of time, it would require careful monitoring of your blood sugar levels. For more information on this forum, please contact Judy Stanley.

Submitted by Judy Stanley

Marilyn has done some personal research into the use of DHEA - (Dehydroepiandrosterone) and we thank her for sharing her information. Please note that this is Marilyn's personal point of view and does not necessarily reflect the full range of questions, findings or experience of a variety of those who have tried DHEA. The general medical community may or may not agree or support her findings. The following is her summary of what she found.

> During this research I had hoped to find that taking DHEA would greatly improve energy levels, reduce fatigue, improve memory and sleep patterns. I am disappointed to tell you that I did not find what I was looking for. I was also concerned about possible risk of breast cancer, but did not find anything conclusive.
>
> **General**:
> - Produced in adrenal glands with aldosterone and cortisol
> - Precursor to estrogen and androgen
> - Declines dramatically as we age; only 20 percent by age 70
> - Lack of DHEA does not shorten one's lifespan
> - No long-term studies on patients with Addison's
> - Generally improves sense of well-being, muscle tone, look and feel younger
> - No information on effect on internal organs
>
> **Cautions**:
> - Caution is advised in patients with diabetes or hyperglycemia, high cholesterol, thyroid disorders or other endocrine abnormalities.
> - Not recommended during pregnancy or breast-feeding.

**Side Effects**:
- Insomnia, agitation, delusions, mania, nervousness, irritability or psychosis

**Mayo Clinic General**:
- May be depleted by a number of drugs including corticosteroids
- Can cause higher than normal levels of androgens and estrogens in the body, and theoretically may increase the risk of prostate, breast, ovarian and other hormone-sensitive cancers.

**Effect on Adrenal Insufficiency**:
- May improve well-being, quality of life, exercise capacity, sex drive, and hormone levels in people with Addison's

**Mayo Clinic Study**:
- Increase in insulin sensitivity in women while on oral DHEA, could be preventive for type 2 diabetes
- Reduction in both good and bad cholesterol
- Unwanted male hormone side effects like acne and facial hair
- Mild benefit in sense of well-being

**Interview with one Addisonian who has used DHEA**: (Related article: www.addisonsociety.ca April 2004 Newsletter)
- Participant in Mayo Clinic Study of 2003 of Women with Addison's
- 45 years old at the time
- Had been diagnosed 10 years before
- Two 12-week sessions, with a 2 week "cleansing" period in between
- Blind test – but knew in the second part that she was on DHEA

Benefits:
- Increased strength: she could lift a large water bottle for the cooler, which she could not lift before
- Increased muscle tone: looked better, facial muscles eliminated the fine lines
- Generally felt better

No benefits:
- No increase of energy
- No reduction of fatigue
- No increase in memory function
- Deep acne, increased body and facial hair

- Came off abruptly and felt absolutely rotten, horrible
- Tough time with mood and emotional well-being
- Took about two months for the body hair to disappear
- No longer on it for fear of it being pulled

**OTHER**:

**Women to Women** http://www.womentowomen.com/adrenalfatigue/dhea.aspx**:**

- Average adult makes 25 mg of DHEA per day with dwindling production as we get older.
- Men at all ages have more DHEA than women.
- “Mother Hormone” – the source that fuels the body’s metabolic pathway
- Healthy levels of DHEA may help stave off Alzheimer’s disease, cancer, osteoporosis, depression, heart disease and obesity, but still no clear-cut consensus.
- You can improve your DHEA levels naturally by maintaining a body mass index of 19 – 25, getting adequate rest and exposure to sunlight, exercising regularly (including sexual activity) and fostering more “downtime” in your life.
- The best way to make more DHEA is to
    - cultivate JOY in your life – positive outlook
    - connect socially: we like companionship, join a class of your interest
    - exercise: moving your body reduces stress, oxygenates your cells and boosts endorphins
    - spirituality: rituals of worship and contemplation
    - play: Kick up your heels, it’s good for your health
- Taking DHEA alone won’t do any good if your adrenals are exhausted; there are too many other factors at work.

**Paper by James Michael Howard**:

- He suggests that low DHEA triggers oncogenes in people who have them, and that is why cancer is more common in old age. His hypothesis is that if proper DHEA levels prevent cancer, then DHEA should prevent cancers induced by known carcinogens.

“**Cancer and Aging**”: by Coelho and Nordenskjold

- Low derivatives from DHEA were found in women with primary operable cancer. In a study using hamsters, treatment of cultured cells with DHEA also inhibited the rate of metabolism of {3H} DMBA to water-soluble products.

**Canadian Cancer Society**:

- Basically, DHEA acts as an inhibitor for some kinds of cancer and as a trigger for others. She couldn’t tell me which. No definitive answer, long-term follow-up is needed.

Submitted by Marilyn Thauberger

Our next meeting on **May 24**, 2008 – 1:00 – 3:00 p.m., Sherbrooke Lounge, Sherbrooke Building, 260 Sherbrooke St., New Westminster, is our Finger Food meeting - juices, plates etc. will be provided. This is always a popular meeting as we get to meet other members, so bring your spouse and family if they can attend. We reminder you that parking is cheaper on the side streets than in the lots.

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

## Alberta Support Group

We finally have our Hospital Emergency Room Protocol for Addisonians in place in the Edmonton region hospitals. A long time in the making, but it is a very thorough one! Francisca, Richard and I will review the protocol in April, and try to have a meeting for our members in May.

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

The next meeting will be Sat. **May 17, 2008**, 12:30 to 4:30 pm, Community Room, **Brantford Police Centre**, 344 Elgin Street, Brantford, Ontario. Guest Speaker arrangements are not finalized at this time but we hope to have a speaker of interest to the group.

In addition, we will be discussing the idea of an additional meeting(s) each year, possibly in a rotating fashion as to location, in an effort to accommodate those members who are far from Brantford and find it impossible to attend the meetings. Your opinion matters and we encourage all of you in the Southern Ontario Group to attend if at all possible or forward your comments to Harold Smith at hsmith9995@rogers.com or 519-742-9995 or by snail mail to 32 Meadowlane Drive, Kitchener, Ontario, N2N 1E9.

In the meantime, everyone please mark May 17 on your calendar.

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

After nearly 3 years as Eastern Ontario group representative, the time has come for me to pass the mantle on to someone else effective October 31, 2008. However, I do hope that one of you will step forward to replace me sooner than that in order to make the transition easier on all of us. This will allow me to organize two more meetings and, hopefully, to train my replacement.

I have really enjoyed my tenure and I thank you for the opportunity to inject some of my ideas into the meetings. I will be interested in seeing what the new "flavour" will be. I have enjoyed my time as chair, have learned a lot, and hopefully brought something to the group as well. I will, of course, continue as a member of the Society and look forward to attending meetings.

Anyone interested in acting as contact person and organizer for our region should contact Irene Gordon at liaisonsecretary@addisonsociety.ca or 1-888-550-5582.

Submitted by Teresa Seasons

The next meeting will be **May 10, 2008** at 12:00 at **Robbie's Restaurant** in Ottawa.

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

For information on Atlantic Canada Support Group activities or meetings, please contact Kelley Gamblewest at (902) 452-1581 or kdgwest@eastlink.ca.

## 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 am 32 years old and was diagnosed with Addison’s 9 months ago. I am now on 25mgs of 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 and although now that my drugs are stabilized I am finding it very hard to lose the extra weight. Does being on a synthetic cortical steroid 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:** My 18 year old daughter was diagnosed with Addison's Disease two years ago. Since that time her periods have become very painful. Could this be a coincidence, or is it possible the lack of hormonal stability has contributed to the increased pain? Any suggestions for pain control for her?

> **A:** Regarding menstrual pain, the pain associated with menstrual periods is due to cramping involved in expelling uterine contents and usually varies from cycle to cycle. This can occur in otherwise healthy individuals.
>
> At the time of diagnosis of Addison's disease the adrenal gland is generally more than 90% destroyed, usually by antibodies directed at one of the proteins in the pathway for cortisol formation. This means that there had been progressive destruction of the adrenal over months to years prior to diagnosis. With treatment, there is a return to more normal cortisol levels.
>
> It is uncertain why your daughter's menstrual periods are more painful now that she is on her medication. It may be a reflection of slightly greater estrogen and progesterone production in a healthier individual resulting in a larger buildup of the uterine lining and heavier menstrual flow. The usual treatment for menstrual cramping is an anti-inflammatory such as Advil, which you can get over the counter, or naproxyn or Motrin which are slightly more potent and require prescriptions. These medications are usually very helpful in relieving the cramping.

**Q:** I was diagnosed with an eating disorder July 2006. I was running 11 miles a day, eating less than 500 cal of non-carbohydrates and got down to 80 lbs. They wanted to hospitalize me but I wouldn't let them because how could I start eating if I didn't run. I started to become more restrictive during the day to save up for one thing I really wanted to eat and to make this okay in my mind I ran 15-20 miles a day. In Oct 2006, I ran a marathon, and after I did that, my face blew up. It was so swollen. They thought it was refeeding edema but the tests didn't confirm that. I slowly started to eat more of healthy foods but the weight kept on creeping up even though I was still running 10 miles a day. They were baffled. I went to a naturopath in Aug 2007, and she diagnosed me adrenal insufficiency and hypothyroidism. I have been on 1 gram of thyroid armour and an adrenal herbal tincture. I am running 6-8 miles a day and lift 2-3 times per week but I can't seem to get the weight to come off. I don't understand why my body can't work like they say it should. Do you have some sort of answer as to why I still have this intermittent facial edema and weight I can't get off unless I take extreme actions?

> **A:** There are many aspects to your problem(s) and I don't think I have enough information to make specific comments. You did not mention your current weight after being down to 80 lbs. nor did you mention the type of food intake at present. The facial swelling has me stumped for the moment. I am concerned about the diagnosis of adrenal and thyroid insufficiency. To accurately make these diagnoses requires specific testing because there are different causes of both these problems and the treatment is influenced by the cause. I think you should have your family doctor send you to an endocrinologist to check this out. Both of these diagnoses require lifelong treatment so you do not want to make them without being certain of accurate investigation.
>
> With diets that are restrictive in calories, there is always a concern about adequate vitamin intake. I am sure you have been taking care of this, but I thought it is worth mentioning. The other concern is adequate protein intake, particularly proteins containing the essential amino acids. Some vegetable proteins do not contain all of the essential amino acids.

**Q:** How will I feel if I have had too much potassium in a day?

> **A:** In general the body regulates potassium levels in the body and if you take in more than you need, this is excreted in the kidney. Without adequate aldosterone or fludrocortisone, in an individual with Addison's disease potassium levels can go higher than normal and sodium levels go lower than normal. but there are usually no symptoms specific to the elevated potassium. If you took in more potassium than you required in one day, I would not expect you to have any symptoms.

**Q:** I was newly diagnosed with severe hypoadrenia/Addison's last month. My main Addison's symptoms are still chronic fatigue and bodily weakness. I've been on 20mgs/day of Cortef for about a month now. I received about a 40% improvement for my above symptoms, so far. But, I am still very fatigued and unproductive as a result. So I was wondering if I should increase my current 20mgs/day dosage of Cortef or try another drug and dosage instead?

So far my family doctor is the only one treating my Addison's. There are no endocrinologists in the Kamloops, BC region. I need your help as soon as possible, please. Thanks for listening.

> **A:** Chronic fatigue and body weakness are non-specific symptoms. It would be helpful to know what investigation was done to make the diagnosis of adrenal insufficiency. If

the diagnosis is not correct then cortisol will not solve the problem. If the diagnosis is correct, the treatment usually includes both cortisol and Florinef a hormone that helps with salt retention. The tests to determine if you need Florinef are electrolytes (sodium, potassium and chloride), a test that is readily available, and plasma renin, a test that is available through most commercial laboratories. Twenty mg of cortisol should be sufficient. Remember that Addison's disease comes on over a period of months to years so it may take a while to reverse the changes that have taken place. Before going any further, it is important that you discuss this with your family doctor to review the original diagnosis. If there is no endocrinologist in your area, your family could get a phone consultation from one in Vancouver.

**Q:** I was recently diagnosed with Addison's Disease and find no support. What should I do if I get a cold or stomach flu? When is it necessary to receive intravenous? Any advice you could give me in general would be helpful.

**A:** It is difficult to be in a position where you feel you do not know where to turn for support. The first thing you should do is talk to your family doctor about how you feel. There must have been a doctor who made the diagnosis of Addison's disease and prescribed your medication. It would be reasonable to make an appointment with her/him and go over the everyday management of individuals with adrenal insufficiency. If there is an endocrinologist in your area, it would be important to meet with her/him so they will be familiar with your case and can respond more readily if you need help.

A second option, which should NOT replace the first, is to look at the Canadian Addison Society website (http://www.addisonsociety.ca/faq.html). There are a lot of questions from other Addisonians and some of them may be similar to yours. You can see if they are of any help.

Finally, if you are on a glucocorticoid (cortisol, cortisone or prednisone), the dose would be sufficient for everyday activities. If you get a cold, the flu, or a significant stress, you should increase the dose by 1/2 or a full tablet of what you are taking or double your daily dose depending on the severity of the situation. If you have gastrointestinal problems for 24 hrs and cannot keep your medication down, then you should go to the hospital emergency dept for intravenous solu-cortef and saline plus some investigation about the current problem. If you do not live near a hospital, you should consider having a kit at home for an intramuscular injection for use in an emergency. The details of this kit can be found on the website and you will have to get your family doctor or endocrinologist to write a prescription for you (http://www.addisonsociety.ca/emergencyproc.html, http://www.addisonsociety.ca/injection.html)

**Q:** My wife has been taking Florinef for 3 months and has suddenly begun to experience serious side effects (dizziness, intense trembling, breathlessness, high BP, confusion, nausea). We know Florinef is the cause as all the symptoms disappeared when she discontinued it.  Other than reducing the dose, are there any ways to reduce serious side effects from Florinef?  What do Addisonians do who cannot tolerate or are allergic to Florinef?

> **A:**  I doubt if your wife is actually allergic to Florinef or even sensitive to it.  The symptoms you described suggest that she was getting too much Florinef, causing excessive salt retention which in turn caused the symptoms.  The dose of Florinef must be regulated and varies from individual to individual.  Occasionally, individuals can get along without Florinef because they have high blood pressure from other causes.  Others need higher doses to regulate their blood pressure.  The most sensitive tests to determine the requirement for Florinef are a plasma renin and electrolytes.  Your family doctor or endocrinologist will know about these tests and how to use them in adjusting the dose of Florinef.

**Q:**  I was diagnosed with Addison's about 2 years ago.  I am 53 years of age, on about 20mg of hydrocortisone, 0.10 mg of florinef, and 0.088 mg of synthroid.  This question is a follow up to a recent Q&A to explain when adrenal glands do not work:

As the nerve endings produce enough adrenalin and noradrenalin to look after the blood pressure needs and the flight and fright response, is it still necessary for me to stay on florinef and if so, why?  Many thanks.

> **A:**  This is a good question.  There are many factors that are involved in the very complex mechanisms that control blood pressure.  Adrenaline and noradrenaline are one of those mechanisms and they have a specific role for specific situations.  The adrenal normally produces aldosterone which is involved in the control of sodium (salt) in the body, and sodium in the muscle cells in blood vessels is important in the ability of these cells to contract to maintain our blood pressure.  Without adequate sodium in these cells, other factors such as noradrenaline do not have the appropriate effects.  The Florinef that you are taking replaces aldosterone.  It is a very important part of your adrenal replacement.

**Medical Questions and Answers - Dr. Donald Killinger, MD, PhD, FRCPC**, Medical Advisor for The Canadian Addison Society, will answer your questions about Addison's disease.  Send your question to Dr. Killinger directly from the webpage http://www.addisonsociety.ca/faq.html#, by emailing liaisonsecretary@addisonsociety.ca or c/o The Addison Society (see address on front of this newsletter).  Questions and answers that may be of interest to everyone will be published in the newsletter and on the website.

# The Canadian Addison Society
# La Société canadienne d'Addison

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______________________________________________

*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*

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

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