



# ***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](mailto:liaisonsecretary@addisonsociety.ca)

<http://www.addisonsociety.ca>

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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.**

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## **2011 Annual General Meeting:**

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The 2011 Annual General meeting of the Canadian Addison Society will be held Saturday, October 1, 2011, 12:30 to 4:30 at the Brantford Police Station, 344 Elgin Street, Brantford, ON. All members are welcome and encouraged to attend. The agenda is:

- 1) Registration
- 2) President's Report
- 3) Minutes of the 2010 AGM
- 4) Election of Board Members
- 5) Financial Report
- 6) Membership Update
- 7) Director's Reports
- 8) Old Business
- 9) New Business
- 10) Speaker

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## **Hair Cortisol Study:**

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Please find below our published abstract for the study entitled "Hair Cortisol in Patients with Adrenal Insufficiency on Hydrocortisone Replacement Therapy". Our full article has now been published in the *Journal of Clinical Endocrinology*.

Due to copyright and ownership rights of the journal, we are unable to send you the full article ourselves. Please click on the following link to see the full paper online (a subscription to the journal is required): <http://www.ncbi.nlm.nih.gov/pubmed/21521272>.

We have thoroughly enjoyed working with you all and are happy to share our final results at this time. We wish to thank the Canadian Addison Society and the NADF for their help and support with our research. This study would not have been possible without your involvement. We have also enjoyed meeting and sharing our progress with the Canadian Addison Society's South Ontario group over the past 3 years.

Of course, our study has raised more questions and further research will be needed in the future. Our research lab hopes to continue studying the use of hair cortisol as a biomarker of chronic stress to add to our understanding of endocrinology-related health conditions, like Addison's Disease.

If you have more questions, please do not hesitate to contact us. Many thanks!

Rachel Gow & Dr. Stan Van Uum

***Hair cortisol content in patients with adrenal insufficiency on hydrocortisone replacement therapy.***

[Gow R](#), [Koren G](#), [Rieder M](#), [Van Uum S](#).  
Clinical Endocrinology (2011) 74, 687-693  
doi: 10.1111/j.1365-2265.2011.04001.x

Department of Physiology and Pharmacology, Schulich School of Medicine and Dentistry, University of Western Ontario, London, Ontario, Canada.

### **OBJECTIVE:**

Patients with adrenal insufficiency (AI) require life-long replacement therapy with exogenous glucocorticoids. Several studies have shown impaired subjective health status in these patients as well as increased morbidity and mortality risk, which may be caused by glucocorticoid over-replacement. As a measure of long-term cortisol exposure, the usefulness of hair cortisol analysis in patients receiving glucocorticoid replacement therapy was investigated.

## PATIENTS AND DESIGN:

Hair samples, demographics, medical history and perceived stress scale questionnaires were collected from 93 patients across North America diagnosed with primary or secondary AI. Sixty-two household partners served as a control group. Cortisol was measured in the proximal 2 cm of hair, representing the most recent 2 months of exposure. A modified enzyme immunoassay was used for the measurement of cortisol.

## RESULTS:

The male patients had significantly higher hair cortisol levels than the male controls ( $P < 0.05$ ), while there was no significant difference among females. Hair cortisol content correlated significantly with glucocorticoid dose ( $r = 0.3$ ,  $P < 0.01$ ). Patients with AI had significantly higher subjective stress scores than control subjects.

## CONCLUSIONS:

Hair cortisol content correlates with hydrocortisone (HC) dose in patients with AI. Our results suggest that some AI patients may be over-treated and hence may be at risk for the adverse effects of cortisol. Measurement of HC in hair may become a useful monitoring tool for long-term cortisol exposure in patients treated with glucocorticoids.

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PMID:21521272  
[PubMed - in process]

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## Emergency Kits:

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All Addisonians should have an emergency kit. Pharmacies do not carry emergency kits. The Addisonian must put it together themselves. It should contain:

- a vial of hydrocortisone (usually Solu-cortef, either 100 mg or 250 mg, although some patients prefer dexamethasone) - prescription required
- intramuscular syringes, usually 3 ml, about 20G and 3 inches long, to get into the muscle (purchased over the counter)
- alcohol swabs

A variety of containers, from a pencil case to a toothbrush holder can be used to carry these components around. The Addisonian should renew the medication based on the expiry date. Some people prefer the 250 mg vials as the syringe can be hard to fill when in crisis, and the 250 mg makes it easier to get the required amount (100 mg). For an emergency, the exact amount of medication is not too important, as long as there is **enough**. Many patients have 2 or 3 emergency kits (at home, at work).

Useful information is found on our website at <http://www.addisonsociety.ca/injection.html> and <http://www.addisonsociety.ca/emergencyproc.html>.

Most patients also carry a doctor's letter with them, which enables them to travel (e.g. board planes) with the syringes and meds. Members are encouraged to carry the emergency protocols with them - there are several from hospitals in Canada including the Ottawa Hospital's (<http://www.addisonsociety.ca/ohp.html>). As well, there is emergency information in a variety of languages on our website, for when Addisonians travel (<http://www.addisonsociety.ca/emergencylett.html>).

Lastly, we also suggest having a short note with health info on the Addisonian, for example, other meds, medical conditions, short med history, in case of accident if s/he can't respond to the paramedics. You should also carry this sheet in the emergency kit.

As an adjunct to your medical kit, we also suggest that you always wear a Medic-Alert bracelet or necklace.

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## **Announcements:**

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- A Nanaimo girl, Nakeeta, aged 14, wishes to correspond with another younger Addisonian. She has several endocrine disorders and would like to discuss what to expect with Addison's. Please contact Jim Sadlish at [wx6999@gmail.com](mailto:wx6999@gmail.com) and he will send contact details.
- One member would like to be in contact with other Addisonians who have also had shingles. If this is you, please contact Judy at [whittbj@shaw.ca](mailto:whittbj@shaw.ca).

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## **Re-Hydration Drink:**

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In hot weather or if you exercise a lot, you may find re-hydration drinks useful. Here are a couple of recipes.

- 1 litre water
- 2 Tbsp. sugar
- 1/3 to 1/2 tsp. salt
- Lemon juice (optional)

Another recipe is:

- 2 tsp sugar
- 1/4 tsp salt
- Juice of 1/2 lemon
- 1 litre of water

Feel free to experiment, and adjust the recipe to your own taste. As well, during very hot weather, or if sweating a lot while working outdoors, you may want to discuss with your medical advisor whether increasing your dosage of florinef either on hot days or every other day would be appropriate for you.

<http://www.addisonsociety.ca/tips.html>

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## Highlights from Local Meetings:

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### Vancouver Island Support Group

The Group met May 28th at Victoria General Hospital. Twelve attended including 3 spouses and 2 new members.

With new people at the table, each member introduced themselves and explained their medical history. It was evident that most were not diagnosed quickly, having to cope with pre-diagnosis symptoms, for years in most cases. Each story is different, as is the eventual treatment and changes to improve treatment. Generally, all are doing well although the new members are still progressing in this process.

The Addison's hereditary factor was touched on. One member has an adult son, also with Addison's. Most of us have family members with other endocrine disorders.  
[http://addisons.org.au/core.htm?page=/content/otherarts/oa\\_inthefamily.htm](http://addisons.org.au/core.htm?page=/content/otherarts/oa_inthefamily.htm)

Testing for celiac disease was discussed. Having Addison's may give us a slightly higher probability for celiac disease. New methods of testing for celiac may avoid the dreaded biopsy. <http://www.celiac.ca/pdfs/blood%20test-rev.pdf>

One of the new member's tests showed low levels of Vitamin D<sub>2</sub> and she now takes large oral dose replacements once each week. <http://www.ncbi.nlm.nih.gov/pubmed/12444895>

A new member is feeling fine, replacing with a low dose of hydrocortisone, but is still gaining weight. Her Florinef dose is low as well. She will see her endocrinologist soon to fine-tune her treatment.

A member with type 2 diabetes has been successful regulating her insulin. She has gained back 20 lbs and feels great.

While travelling for work in Montreal, a member developed a fever. He explained his condition to hotel staff who called an ambulance. At the hospital, the emergency doctor was not familiar with Addison's. Our member was given various tests including chest x-rays and put on 8 hours of IV treatment as a precaution. Excellent service, he said.

The group was asked if anyone experienced various symptoms such as bloating, queasiness, thinning hair, dry and itchy skin, and bruising. A number of suggestions were offered. Itchy legs need a moisturizing cream after a shower while legs are wet. Dove soap helps. Bruising may be caused by over-replacing.

Secondary Addison's was discussed at the meeting. According to the UK Self Help Group publication, *'Living With Addison's Disease'*: "Secondary adrenal insufficiency mostly occurs when a pituitary tumour (such as an adenoma) forms, although autoimmune destruction of the

pituitary gland is also known. Secondary adrenal insufficiency is even rarer than primary Addison's disease. Long-term use of high doses of steroid drugs to treat other illnesses (such as the high doses of prednisone which may be used to treat bowel disease or asthma) can also cause temporary or permanent loss of adrenal function. This is often referred to as secondary adrenal suppression."

Our next meeting will be held October 1, 2011.

Submitted by Jim Sadlish

For further information on the Vancouver Island Support Group, please contact Jim Sadlish at [wx6999@gmail.com](mailto:wx6999@gmail.com) or (250) 656-6270. For information on Central Island activities, please contact Barbara Hunn at [bhunn@shaw.ca](mailto:bhunn@shaw.ca) or (250) 714-0036 or Sharon Erickson at [ericksons@shaw.ca](mailto:ericksons@shaw.ca).

### **BC Lower Mainland Support Group**

Seven members attended the May 28 meeting. Discussion touched a number of topics:

- o Autoimmune and Addison's Disease was briefly discussed. One member raised the need for a means of delivery in a crisis of Solu-Cortef similar to an Epi-pen or pre-measured dose similar to diabetic needle dispensers. This has been looked at previously and was not an option for a number of reasons. However, we are looking forward to his ideas and solutions at a future meeting.
- o One member relieved stress by doing yoga with daily meditation, and keeping to a daily routine. Members encouraged her to return to her complete routine and to learn to say 'no' to interruptions of her special time.
- o A member mentioned she read numerous articles to find out what helps for inflammatory arthritis, then looked up on the computer to verify some of the claims. She started to use "Boswellia" from Aryurvedic medicine, "Curcumin" and "GLA" (gamma linoleic acid). The biggest concentration of this is in black current oil. She has controlled her pain with these supplements for many months. It may not be perfect, but it beats the side effects of drugs. She checked with her Naturopath before taking them.

Reminder – when taking any additional supplements or starting an exercise regime, always check with your own doctor or specialist to make sure it does not interfere with the medications you are on. Some organic herbs etc. may increase, counteract or react with prescription drugs.

- o Also discussed was keeping ourselves hydrated particularly in the summer or when under exertion. The packages of Gastrolyte for electrolyte replacement contain Aspartame which most members said they try to avoid but would take if only used infrequently and there is no other option for rehydrating. Past issues of the newsletter have a summer replacement (also on the website <http://www.addisonsociety.ca/tips.html>). One member perspires a lot when the weather is hot, and he takes the hydration mix when he has been active with exercise whether hiking, biking or cross country skiing. In the colder months, he does not need as much hydration. He finds that the biggest indicator for needing hydration is feeling fatigued at

the end of the day, even when taking his regular daily cortisone. He tries to gauge the need for hydration during activities, but if he does not get it right during the day, the evening fatigue is often an indicator of the need to hydrate. He uses Oral Rehydration salts, which have no expiry date, are approved by the UN for third world use, are corn based and contain sugar. Once mixed with water, the mix has a short shelf life but only a tiny amount is used in 1 litre of water. Jianas Brothers' Oral Rehydration salts are sold as a carton of 125 packets or a case of 625 packets. If anyone is interested in a group purchase, let Judy know.

- o People wondered why one prescription of Cortef was in glass bottles. This is the original bottle sent to the pharmacies and is used to distribute Cortef (or Florinef) if the number of pills is the number ordered by the client. If you keep a number of months of Cortef or Florinef on hand, you may want to ask for the original bottle **unopened**, to keep them airtight.
- o The AGM will be held October 1, 2011 in Ontario this year. If you would like to stand for Director, please let Judy know. All Executive and Director discussions are done by email. I will try to get our next BC Lower Mainland Group meeting in October after the AGM.
- o The absence of the Secretary and Treasurer from 2010 AGM was discussed. When questions were asked regarding finances and aspects handled by the secretary, they were missed for their expertise on numerous topics. Gerry Ott presented a motion for consideration at the next AGM: that the Executive: President, Vice President, Secretary and Treasurer have their airfares paid by the Society to attend the AGM meetings.
- o If you are not receiving your reminder for newsletters from the Canadian Addison Society, there is still time to renew your membership. Membership renewal forms are on the website [www.addisonsociety.ca](http://www.addisonsociety.ca) along with many articles and other items pertaining to Addison's.

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](mailto:bugbee@shaw.ca).

### **Alberta Support Group**

For information on this support group, contact Ginny Snaychuk at [ginray@shaw.ca](mailto:ginray@shaw.ca) or (780) 454-3866 in Edmonton, or Peter Little at [bettypeter66@gmail.com](mailto:bettypeter66@gmail.com) or (780) 918-2342 in Edmonton.

### **Saskatchewan Support Group**

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

## South/Central Ontario Support Group

The group met in Mississauga, on May 14, 2011. Our main discussion topic was:

- MedicAlert – Why don't Emergency Personnel ever look at my MedicAlert Bracelet?
- MedicAlert's potential role in raising awareness about the health problems of people with Addison's

and our speakers were Abeer Hegazi and Cindy Fritz from MedicAlert. Abeer Hegazi is an International Medical Graduate, working to obtain her license to practice medicine in Canada. Currently she is working as a Medical Profile Specialist with MedicAlert. She recently encountered a situation that gave her first-hand experience of the seriousness of adrenal insufficiency. She advised us that Paramedics are not allowed to inject Solu-Cortef. The patient in question needed to take triple the dose of steroids. This gave her a better understanding of what Addisonians are dealing with.

- Medic-Alert is a 24-hour emergency response centre (hotline telephone number on the back of MedicAlert bracelet) which can be contacted from anywhere in the world to have access to the client's complete medical history.
- Medic-Alert is trying to create a partnership with Paramedics, by showing how a partnership would benefit the paramedics, making their jobs easier and helping them treat patients if they are unconscious. Access to MedicAlert info will enable them to treat patients for better patient outcomes.
- Note that paramedic is a general term; not all paramedics have the same training.
- What the paramedic may do and what drugs (for ex, Solu-Cortef) they have available will depend on the jurisdiction, on the Medical Director in area, and on their level of training.
- A letter instructing paramedics to inject will normally not be widely accepted or acted upon by paramedics in the field, since such a letter would require all the authentication of any personal directive. Only 'advanced paramedics' can make injections, and can only use certain drugs. Their hands are tied, if they are not allowed to inject, or if Solu-Cortef isn't one of the drugs pre-approved for use by paramedics.
- If you are *alone or unconscious*, medical personnel should look at your bracelet. This doesn't always happen and this needs to change, to make both patients and paramedics happy. A 'Look, Read, Call' procedure can mean the difference between life and death.
- Medic-Alert is looking at putting a toll-free number (1-800) on the back of bracelets, and want its availability stressed during paramedic training.
- Various jurisdictions have their own data systems in place. Nova Scotia has a centralized system, which enables paramedics to get information on a patient while still en route to the emergency, thus arriving more prepared.
- Recommendations from Medic-Alert to Addisonians:
  - Keep your Medic-Alert file up-to-date. You can also include specific instructions for paramedics and what information to relay in case of emergency on your file.
  - Write a letter to the EMS medical director in your area. One voice carries only so much weight; we have greater impact as a group. The Ontario-based hospital website may list Medical Directors.
  - Urge them to include Solu-Cortef in paramedics scope of practice

- Prepare a personal directive
- Be proactive not reactive
- Wear your Medical identification at all times
- Have your emergency injection kit at all times

Other items from the meeting:

- Responses to a survey of our group indicated that:
  - 43% consider Addison's as their main health problem. Some have additional health problems;
  - 36% having good control of Addison's;
  - 50% feel the need to have the Solu-Cortef Kit.
- Injection training Clinic: Although our original volunteer to help us practice emergency injections was not available, another person stepped forward and, in teams, we all practiced injecting the Solu-Cortef. As most of the supplies were donated by medical supply companies, we have a good supply for our group to repeat this clinic many times.
- Discussions about what brings on an Addisonian Crisis and information on tablet splitting concerns filled out the afternoon.
- Reference was made to the Facebook page "Yes I have Addison's disease No it is not contagious".

Our next meeting will be hosting the AGM on Sat. Oct. 1, 2011 in Brantford, with registration at 12:30, 1 pm meeting, 4:30 adjournment.

Submitted by Harold Smith

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

### **Eastern Ontario Support Group**

The Group met May 14th and had a lively discussion. There were nine people in attendance.

- Each person introduced themselves and talked a little bit about their situation.
- Membership forms were made available and 2 new members signed up.
- There was discussion about emergency kits and documentation Addisonians should have with them at all times, such as emergency letters. Members were reminded that the Canadian Addison Society site has letters in various languages - just follow links from <http://www.addisonsociety.ca/emergencylett.html>. Also, note that the UK site has additional languages than those currently listed on our site.
- The Q&A's on the Canadian Addison Society site are very extensive now, and the full set can be found at <http://www.addisonsociety.ca/related/FAQApril2011.pdf>.
- The next Annual General Meeting of the Canadian Addison Society will be Saturday, October 1, 2011, 12:30 to 4:30 in Brantford ON.
- Newsletters are being mailed to endocrinologists across Canada on a rotating basis, one edition a year, as part of our outreach effort.

- We briefly discussed having another meeting of our group in Kingston and perhaps having Dr. Houlden attend as the guest speaker.
- Members asked for a listing of local members email addresses so those who are near each other can communicate and possibly car pool. Steve will check with local members to determine if anyone would not be willing to share their email address within our group.
- There was a question about whether a Facebook page for our local group would be useful. How many local members use Facebook? What Facebook sites already exist? [*Note from regional rep: There are numerous Facebook pages already in existence on this subject so I have concluded there is no need for a page unique to the Eastern Ontario Support Group. But if you'd like to start one, please feel free and let us know.*]
- The topic of Addisonians and sex drive was raised as a possible discussion topic. There are already some questions on this subject in the *Frequently Asked Questions* on the website and further questions can be asked of the doctor.
- One member suggested her endo, Dr. Keely, Head of Endo at the Ottawa Hospital, as the speaker at the next meeting. Dr Keely has shown an interest in the Society and asked for information about us.
- In regard to more information, here is a link to the Canadian Addison Society brochure: <http://www.addisonsociety.ca/emergencylett.html>. Feel free to print and distribute at will.
- We had fun with an active demonstration and actual practice (on oranges) on how to give an emergency injection using solu-cortef. Items to note:
  - It is much easier to fill the syringe with 100 mg from a 250 mg vial than to get the last drops out of a 100 mg vial.
  - One member found an easy way to push down the plastic rim to mix the vial contents, something many of us have struggled with. Simply hold the vial in your hand with the glass bottom in the fleshy palm, and slam the vial (plastic rim) head first flat on the table. It works beautifully.

Submitted by Steve McKenna

The next meeting will be the weekend AFTER Thanksgiving, on Saturday, October 15, 2011, at Robbie's restaurant on St. Laurent in Ottawa, starting at noon.

For information on Eastern Ontario Support Group activities or meetings, please contact Steve McKenna at [steveandpat@rogers.com](mailto:steveandpat@rogers.com) or 613-523-7648.

### **Québec Support Group**

Our representative in Québec is Marie-Josée Normand, in Montréal. If you wish to contact her, she can be reached at (514) 376-2712, by email at [marijornormand@videotron.ca](mailto:marijornormand@videotron.ca) or through the 'Local Groups' page of our website.

Notre représentante au Québec est Marie-Josée Normand, à Montréal. Si vous désirez la rejoindre, vous pouvez communiquer avec elle au (514) 376-2712, par courriel au [marijornormand@videotron.ca](mailto:marijornormand@videotron.ca), ou bien par l'entremise de notre site-web.

## **Atlantic Support Group**

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

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## **Medical Q & A**

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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.

***Before submitting a question to our medical advisor, please consult the wealth of Q&As on our website. Many questions have already been answered.***

**Q:** Do Cortef and Florinef stay stored in the body, or is there a timeframe in which they 'dissolve'? If I were to have another crisis, would I still have some medication stored to help?

**A:** Cortisol and Florinef are metabolized quite quickly. The time for the blood level of cortisol to decrease by 1/2 is about 90 min. It is bound to receptors inside the cell so its duration of action is longer, but it is used up continuously. This is why cortisol should be taken twice daily or preferably three times daily. You should never go without your cortisol for more than 24 hours. This is also why we advocate that all patients with Addison's disease have an emergency kit containing cortisol that can be given intramuscularly by a family member or friend. The details of the kit are on the website: <http://www.addisonsociety.ca/injection.html> and <http://www.addisonsociety.ca/emergencyproc.html>.

Florinef lasts a little longer in the body so it is given once a day. In an emergency, it can be replaced by added salt.

**Q:** I have had Addisons for about 16 years and just had an Addisonian crisis 2 days ago (3 years since the last one). The doctor at the hospital found my heart was rapid and irregular so she diagnosed me with 'atrial fibrillation'. When she finally gave the usual IV solution and dose of cortisone, she also gave me a beta-blocker. My husband noticed that the beta-blocker really lowered my blood pressure, which was already low. When they let me go home, my heart rate was back to normal but I was prescribed aspirin and teva-metoprolol (rose) 50 mg 2x a day. I was not seen by a cardiologist or an endocrinologist at that time, (I am waiting for appointments and calls back).

My questions are:

- 2 days later, I still have concerns about taking a beta-blocker that will lower my blood pressure, which is always on the low side anyway. I still haven't taken it. Is it safe to take this medication (teva-metoprolol) or should I ask if it's dangerous not to take it?

- Can Addisons cause a temporary condition or a permanent condition of atrial fibrillation or is it a new disease for me that has nothing to do with Addison?

**A:** It is hard to know whether you had an Addisonian crisis or whether you had an onset of spontaneous atrial fibrillation. You did not mention any factors which might have led up to a crisis so this may not be related to your Addison's disease. You had reverted back to a normal rhythm when you left hospital but it is uncertain whether this was due to the cortisol in the IV, the metoprolol or just normal progression of the underlying problem.

The metoprolol is an appropriate medication for atrial fibrillation so I think it is worth taking. It may lower your BP a little but as long as it does not go too low, it may prevent new episodes of fibrillation. If you are concerned, you could try one half tablet twice daily to start and, if you felt well, you could either stay with that or go up to 50 mg twice daily to see if you felt OK. This medication should be looked after by your cardiologist.

You did not mention any other investigation, but it is important to be sure that your potassium and sodium were normal when all this happened. As I mentioned, you should try to discuss this with your endocrinologist or your cardiologist to review the situation.

**Q:** I was diagnosed just over 3 weeks ago with Addison's (I am female and 35). Since starting my medications, I have felt pretty good - actually better than I had been pre-diagnosis - other than some slow and sluggish days. I didn't go into crisis to be diagnosed, so it was pretty much life as usual. I have returned a little to my exercise routine with 15 minutes of cardio and 20 minutes of weight training. This week, I started jogging in small amounts but tried to be smart by working out 2 days and resting on the third. On the fourth day, I could barely get out of bed, it was an effort to stand (although I won't say I was light headed), racing heart rate, freezing cold, no energy and felt better if I sat.

I went to my local ER, where I had a very slight fever and my blood sodium was just below normal. They gave me IV fluids and when they discovered my BP from the left arm was 73 over (?) and my right arm was 109 over (?), they gave me 25 mg of IV steroids. They had no idea why the readings were so different. Within an hour, I wasn't freezing cold and was feeling that I was on my way to being better.

The ER doctor told me to follow up with my family doctor and endocrinologist. He thought maybe I didn't have enough meds but really had no idea what was wrong. I called my endocrinologist's office and they won't see me. I don't think this is right. I was also told they have no appointment to just see my family doctor. I do not have my follow up appointment to my original diagnosis until September.

Do I need to slightly increase my meds for resistance training? What could have been my issues? Today (the day after), I feel 100% back to normal. I take 10 mg of Cortef at 8 am and 10 mg at 5pm.

This week, the only difference in my routine was the jogging and the night before I had to go to the ER, I didn't have a high salt snack which I usually have.

**A:** Your story is a classic, but I have to guess at some of the facts. You are taking 10 mg of cortisol in the morning and 10 mg at 5 pm. This is a good dose (it could be a little low) but since you do most of your activity during the day, you might benefit from taking 10mg in the AM, 5mg at lunch and 5mg at supper. You should probably be on Florinef if you have primary adrenal insufficiency, to maintain your salt balance. The usual dose is 0.1mg per day. Some people need less and some need more. Your doctor can determine if you are on the right dose by measuring your serum renin. You can also measure serum sodium and potassium but when these are abnormal, things have moved to a more severe level.

I can't explain the difference in bp between the two arms. It could have been the person who took the pressure or the blood flow might be slightly different in the two arms. I don't think it is a worry unless you have some specific symptoms. The bottom line is that it was low and you needed salt and fluid.

**Q:** I have had Addison's disease since 2004. I lost my job, and haven't worked since. Daily life is a severe struggle. It's the fatigue. Yes, I have heard how some people can lead a "normal" life, and more power to them. The fatigue I have is so crushing that now I spend my days alone in a room, doing nothing. I have family – and a good husband. I have always been a motivated person – construction worker, commercial diver, pipeline blaster, ex-Canadian Navy, so never, ever envisioned an isolated couch-potato life. This is not how I want to go on. I have been monitored by an internist to have my cortisol levels maintained by Prednisone, but despite that, sometimes the tests show it drops way down to 35 or so without apparent cause, but I think stress and depression are cause enough.

I also have clinical depression, for which I take medication, and I take a nerve blocker med for chronic spinal pain (I have had two spinal operations). I live in Thunder Bay, where it is hard to find a family physician, let alone a specialist. I am lucky I have a very supportive family doctor – she says I am her only Addison's patient - and I have a useless psychiatrist. I am 55, and I feel my life slipping away. I am just too tired to go out and do anything. No one who has not had this crushing fatigue can envision anything like it. And yes, I take vitamins B and D as I live in a snowy winter climate.

**A:** I am sorry to hear that you are having such a difficult time with no improvement in view. Your problem is a little complicated but I don't think all of your symptoms can be attributed to the Addison's disease.

You mentioned that your cortisol levels were being monitored while you are on prednisone. This is not a reliable method since you are measuring cortisol in the blood but taking prednisone, which is not measured in the cortisol assay. You might be better on Cortef 20 to 30 mg daily in 2 or 3 divided doses, e.g. 15-5-5, or 10-5-5 or possibly

15-10-5. The best test to see if the dose is right, is how you are feeling and you can also measure ACTH in the AM. It should be somewhere between 29 and 100 pmol/l (your family MD can check this).

You did not mention Florinef, the other medication used to treat Addison's disease. This is used to control salt metabolism and patients with adrenal insufficiency are missing both cortisol and aldosterone. The florinef is used to replace the missing aldosterone. It helps to maintain blood pressure and is important in the maintenance of blood volume. The tests to see if you are on the right dose are your serum sodium, potassium and renin. Your family doctor can look into this for you.

I think some of your symptoms are related to depression. Sometimes these can be difficult to separate, but in general, when individuals are on the proper dose of cortisol and Florinef they feel much better and function well. The medication used for depression can also make you feel tired.

There is also the problem of your back pain. This continuous strain can drain off much of your energy.

The Addison's disease is the one problem that can be appropriately treated so once you are on the right medication, you should look to the other possible factors which might be adding to your symptoms.

**Q:** I am curious if a person with Addison's would have a low white cell count due to taking steroids? I also wonder what count is so low that I should not be working in a hospital setting as I would be prone to infection. The normal range for neutrophils is 2.50 - 7.5 and the other day mine was 1.57. Six months ago it was 2.5. My leukocytes are down as well.

**A:** There are usually no problems with white blood cells in individuals with Addison's disease. The steroids can increase the number of neutrophils and decrease the number of lymphocytes depending on the dose. Your doctor can check your complete blood work including red blood cells and platelets to see if there is any abnormality and if there is any question, you should see a hematologist for her/his opinion.

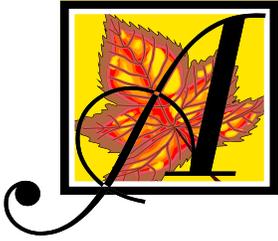
**Q:** I have had Addison's Disease for 6 years. I was diagnosed when I was 22. I have had no problems with my menstrual cycle until now. I have had blood work done that shows I am not post menopausal. There is no answer to why I am not getting my period (I am not pregnant). Has anyone ever had this issue? I am just so concerned because I would love to have a family of my own in the future.

Also, in the last 3 years my skin has started losing its pigment. Is this called vitiligo? Is this a common thing for Addisonians? Is there anything I can do to hinder this from spreading drastically?

**A:** Ovarian problems can occur in individuals with Addison's disease but there could be other causes. This can occur in women who are very thin, who exercise regularly and have low body fat. It can occur with stress and in other hormonal problems. You should relax and review this with your endocrinologist or your gynecologist. They can go through the possibilities and I am sure will be able to reassure you.

Vitiligo is an autoimmune process like Addison's disease. It frequently occurs in individuals with other autoimmune diseases and is quite common in Addison's disease. I don't know of any specific treatment for this but dermatologists can often prescribe creams that will improve the appearance.

**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](mailto:liaisonsecretary@addisonsociety.ca) or c/o The Addison Society (see address on front of this newsletter). Questions and answers that may be of interest to everyone will be published in the newsletter and on the website.



# The Canadian Addison Society La Société canadienne d'Addison

193 Elgin Avenue West  
Goderich, Ontario N7A 2E7  
Toll free number: 1-888-550-5582  
Email: [liaisonsecretary@addisonsociety.ca](mailto:liaisonsecretary@addisonsociety.ca)  
<http://www.addisonsociety.ca>

**Membership in The Canadian Addison Society is \$25.00 due January 1<sup>st</sup> of each year.**

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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.

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+ Contributions are also gratefully accepted. A tax receipt will be issued for contributions over \$10.00.

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