



# ***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.

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## **Annual General Meeting:**

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The next Annual General Meeting will be held Saturday, October 16, 2010, 1:00 to 4:30, in Vancouver, in the Sherbrooke Building, Sherbrooke Lounge, 260 Sherbrooke Street, New Westminster, BC.

- Agenda:
- 1) Registration
  - 2) President's Report
  - 3) Minutes of the 2009 AGM
  - 4) Election of Board Members
  - 5) Financial Report
  - 6) Membership Update
  - 7) Director's Reports
  - 8) New Business
  - 9) Speaker - Dr. Robert Sharpe, Anaesthesiologist & Critical Care Medicine
  - 10) Socializing

The guest speaker, Dr. Sharpe, has a background in anaesthesiology and critical care medicine. He is an O.R. anaesthetist, and also works with the ICU, so he is very qualified to speak on the topic of Addisons and the intra-operative management of Addisons. If you have questions for Dr. Sharpe (whether or not you will be able to attend the AGM), please send them to Marilyn Thauberger at [thaubergers@shaw.ca](mailto:thaubergers@shaw.ca).

If you expect to attend the meeting, please advise the organizers using the form attached to this newsletter. You can email to [bugbee@shaw.ca](mailto:bugbee@shaw.ca) or send by Canada Post to Judy Stanley, 5 Tuxedo Place, Port Moody, BC V3H 3W5.

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## President's Message:

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Our website is definitely working! We are contacted by newly diagnosed people, spouses or family members, by family doctors, and have received phone calls from members experiencing difficulty. Sometimes just being able to discuss what you are going through makes seeking the correct solution easier.

Emails also flow between our Society and contacts in the NADF (USA), the Addison's Disease Self Help Group (UK), and the Australian Addisons Disease Association, making communication so much easier.

The BC Lower Mainland Group will be hosting the Canadian Addison Society's AGM this year October 16, 2010. Information and Registration form are in this newsletter, and on the web. Dr. Sharpe is an O.R. Anaesthetist and also works in ICU at Royal Columbia Hospital.

We look forward to seeing as many of you as can make it to the meeting. Come out and enjoy British Columbia and see what the world experienced with our Winter Olympics this year.

Submitted by Judy Stanley

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## Announcements and Tidbits:

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- Recommended by members, a couple of dynamic books which give an understanding of an Addisonian:

*Living Well With Autoimmune Disease*, Mary J. Shomon, 2002 - pg 105-109: a wonderful description of Addison's Disease, tells about all testing and treatment, also about crisis. Very down to earth and laymen descriptions. Highly recommended.

*The Autoimmune Connection*, Rita Baron-Faust & Jill P. Buyon, MD, 2002 - pg 183-188; Another good description.

- On our website, we now have versions of emergency and travel letters from BC and Alberta, as well as the generic letter (Ontario) and versions in various languages through related Addison associations (<http://www.addisonsociety.ca/emergencylett.html>). The Hospital Protocol (from the Ottawa Hospital <http://www.addisonsociety.ca/ohp.html>) has been supplemented with a protocol from Alberta (<http://www.addisonsociety.ca/related/AlbertaHospitalEmergencyLetter.pdf>). We recommend that Addisonians carry a copy of one of these protocols with their emergency kit and provide it to paramedics or emergency staff when medical attention is needed.
- We have received memorial donations in excess of \$2,500 in the name of Jerid Hickey. According to Jerid's family, he had Addison's, but did not belong to our organization. His family's wish was that charitable donations be made to The Canadian Addison Society in Jerid's name.
- The family of Cheryl Ann (Villeneuve) Dufresne, who died April 19, 2010, age 48, in Cornwall, Ont., has kindly requested donations to The Canadian Addison Society in her name.

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## **MedicAlert:**

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MedicAlert and the NADF in the US have been discussing the most appropriate wording to go on Addisonians' MedicAlert bracelets. The wording currently suggested is "ADRENAL INSUFFICIENCY NEEDS STRESS DOSE CORTICOSTEROIDS".

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## **Research Project - Request for Participation:**

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Request for Adrenal Insufficient (AI) Patient's Participation in Research on Adrenal Insufficiency (AI)

The NADF affiliated Greater Houston Area NADF Support Group Facilitator Dr. Tomas Rodriguez, PhD, RN, ANP-C, PMHCNS-BC, is working on a research study that seeks to understand how adrenal insufficiency affects people's lives.

About Tom: Tom is an adult primary care nurse practitioner and a psychiatric clinical nurse specialist. He has a private counselling and psychiatry practice called Houston Mind-Body Counselling, LLC in Houston, Texas. Prior to opening up his psychiatric practice, he taught nursing at Texas Woman's University

Eligibility: Participants must have adrenal insufficiency and not have any other major medical or psychiatric condition (for example, diabetes or major depression), i.e. if you have Addison's and diabetes, you are not eligible for the research interview.

Privacy: Any personal information gathered will be kept confidential to every extent allowed by U.S. law. A typical interview "question" is "Tell me how you found out you had adrenal

insufficiency."

Goal: Tom hopes is to submit an article regarding this research for publication to a nursing or medical journal (if he can get enough people to participate).

Contact: If you have questions and/or are willing to be interviewed, please e-mail Tom Rodriguez at [tominthecity@hotmail.com](mailto:tominthecity@hotmail.com) or call him at (713) 534-1739 and leave a message with your phone number so he can call you back.

Submitted by the National Adrenal Diseases Foundation (NADF)

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## Highlights from Local Meetings:

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### Vancouver Island Support Group

The group met on Saturday, May 15th, at Victoria General Hospital. Thirteen attended, 9 with Addison's. Three people traveled from up-island to the meeting.

Most members present are prescribed yearly blood tests by their doctors to aid in their treatment. Often, a family doctor will include a cholesterol test requiring fasting for 12 hours. The test is usually taken first thing in the morning. One man, who did not take his adrenal replacement medication while fasting, was informed by his family doctor that his TSH result was so high that he should begin taking thyroid replacement. However, the results of a second TSH blood test (to confirm the first result) indicated that his reading was in the normal range. Fasting was not required for this test, which he took after having his morning adrenal replacement meds. In this instance, it appeared that taking his adrenal replacement meds may have helped to bring his thyroid reading into the normal range.

Several people have been taken off Fosamax by their doctors, calling it a "Fosamax holiday". Evidently, if a person has taken the drug, for example for 5 years, then discontinues it, they continue to have the same benefits for possibly another 5 years.

<http://www.mayoclinic.org/medical-edge-newspaper-2008/jan-20.html>

<http://jcem.endojournals.org/cgi/content/abstract/jc.2009-1947v1>

One member attending for the first time had many experiences to share about her health care. Among the information she brought to the meeting was a caution about bisphosphonates (Fosamax or alendronate sodium). Evidently, there have been cases of osteonecrosis of the jaw in some patients using bisphosphonates.

<http://mayoclinproc.highwire.org/content/84/7/632.full>

*(Ed note: see an article on this in the April 2007 newsletter*

<http://www.addisonsociety.ca/newsletters/Newsletter2007April.pdf>).  

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One woman will soon be taking a once-a-year infusion of Aclasta (Zoledronic Acid) to increase bone density. The cost is about \$700 per year, but a monthly payment plan is available. <http://content.nejm.org/cgi/content/abstract/356/18/1809>

Strontium was also mentioned and there are many studies about the effectiveness of strontium ranelate prescribed for the prevention of fractures in people with osteoporosis. One site, from which you can download a pdf of the full study, is: <http://www.springerlink.com/content/wv70642176278346/>  
(Ed note: this was also discussed at the eastern Ont meeting reported in this newsletter).

Another woman researched which calcium supplement is best. She found that it is important to check what amount of elemental calcium is available in the supplement. Talking with two naturopathic doctors, both biochemists, she discovered that taking too much calcium carbonate could cause kidney stones. The best supplemental calcium is calcium citrate, taken throughout the day with vitamin D and magnesium, at the ratio of 2:1, calcium to magnesium. The naturopaths she talked to were not selling particular products. They investigated various brands on the market and found the best was Prairie Naturals 2:1 ratio calcium with magnesium and their multivitamins. Also, Webber Naturals products were rated highly.

Digestive disorders for one woman made it difficult for her to absorb whole calcium replacement pills. She has resorted to grinding her pills using a coffee grinder to better absorb the medication. She takes liquid calcium supplements.

One long-term member of the group was recently diagnosed with gluten sensitivity after experiencing profound cramping. The resulting pain was so severe it brought on Addison's crisis symptoms. Her husband administered a Solucortef injection and called an ambulance. In crisis, she was barely able to explain her condition and treatment to the paramedics. The paramedics advised that anyone with a chronic condition should have, attached to their fridge, a note with the description of their disorder, normal blood pressure and pulse rate, plus a list of daily medications taken for treatment. We should all take heed of this good advice.

An Australian Addison's Disease Association (AADA) newsletter noted that the manufacturer of Florinef has asked patients to refrigerate their Florinef to extend its shelf life from 18 months to 2 years. Under Travel Tips, in the same newsletter, one of their members related her experiences of travelling to higher altitudes in the Andes of South America. She said that Addisonians cannot take the drug Diamox, designed to alleviate altitude sickness, because "it interferes with our maintenance medication." To stop headaches, she "halved my Florinef dose which had the effect of reducing my altitude-raised blood pressure". She also tried the local cure of coca leaves in boiling water which worked (possibly narcotic!). After 3 or 4 days, she was acclimatized and didn't need the coca leaf tea. Her Florinef dose was reduced for the rest of the trip except for days of excessive heat and exercise. The AADA now has a link on their website for doctors to request information about Addison's support.

## **EurAdrenal Project**

Based on a European network of patient registry and biobanks, a translational approach using genetics, immunology, clinical management, and epidemiology, the EurAdrenal project aims to unravel the pathogenesis and natural course of Autoimmune Addison's disease, ultimately to improve diagnosis and treatment as well as to offer strategies for disease prevention. Clinical studies are underway for early identification of patients at risk of developing Addison's disease in order to intervene, and to study continuous subcutaneous infusion of hydrocortisone as an alternative treatment modality. As an autoimmune model disease, the results of the project could not only lead to the development of novel diagnostic and therapeutic interventions for Addison patients, but also increase our understanding of the pathogenesis of autoimmune diseases in general. (<http://www.endocrine-abstracts.org/ea/0022/ea0022S1.5.htm>)

Our next meeting will be Saturday, October 2, in Room 1814 at the Victoria General Hospital, 1:00 to 3:00PM. Please note that the Vancouver Lower Mainland support group will be hosting the Canadian Addison Society AGM in October.

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.

If anyone in the Mid Island area would be interested in an information get-together, please contact Barbara Hunn.

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**

The Lower Mainland Group met May 29, 2010.

- Addison's newly diagnosed – some members indicated they felt isolated; others found our group immediately, reading about a meeting in the local paper. They found talking to others in the same situation helpful. One member mentioned her doctor advised against group meetings as they could be too negative or depressing but she found the opposite.
- In case of an emergency - have an advocate who is familiar with Addison's (suggest they go to [www.addisonsociety.ca](http://www.addisonsociety.ca) and read section 'Healthy Living' and 'Education'; there is a wealth of information there). Let people know you have Addison's and what to do in an emergency. Have a copy of your medication and personal information on the fridge.
- What positive things are you doing? Exercise at home or in a group, self-help such as Restorative Yoga and meditation, and running were mentioned. Members asked about DHEA and its benefits but it is almost impossible to get a prescription for it in Canada.

- Several were on antidepressants before diagnosis and continued antidepressants after diagnosis. Several take Celexa for depression; it helps them feel calmer. It is a Selected Serotonin Reuptake Inhibitor (SSRI), which increases the extra-cellular level of the neurotransmitter serotonin by inhibiting its reuptake into the presynaptic cell, increasing the level of serotonin available to bind to the postsynaptic receptor.
- Rick, a past member, updated us and has been doing well the past few years. He started running Sept 2007, ran the Victoria Marathon in Oct 2008 where he qualified for the Boston Marathon April 2009. He has now completed 5 marathons and is training for the Victoria Marathon this October. He is considering training for the Iron Man Canada, a one-day event in August 2011. He is also training for a bike ride from Seattle to Portland, 204 miles. Deb also mentioned that she had recently run a marathon
- A UBC 1<sup>st</sup> year medical student who did an interview with our members wrote us the following card that I would like to share with you:
 

Sincere thanks for giving me the opportunity to interview you in your home. Your story is very inspirational to me as it helps me realize just how much of a difference physicians can make when they are equipped with the right knowledge and experience. You have motivated me to take my studies more seriously and learn as much as I can while in medical school, especially about those illnesses that are not so common and often missed. I hope I will be able to provide my patients with the best care possible – the care they deserve.
- We discussed the change of BC Lower Mainland ‘Support Group’ to BCLM ‘Chapter’. It was unanimously felt that ‘Support Group’ better described what we do.

The next meeting will be the AGM Saturday, October 16, 2010, 1:00 to 4:30, in the Sherbrooke Building, Sherbrooke Lounge, 260 Sherbrooke Street, New Westminster, BC.

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**

Ginny continues to receive calls from newly diagnosed Addisonians. They are getting the information about contact people through the Canadian Addison Society web site, so that's good.

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 [litt019@telus.net](mailto:litt019@telus.net) 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).

## **Southern Ontario Support Group**

The group met May 15, 2010 in Mississauga, and were very pleased to have 28 people, including a large number of new attendees.

The meeting opened with self-introductions by the Addisonians present. This, as usual, highlighted a wide variety of Addison experiences and other conditions that members are dealing with on a daily basis. Some examples include: sleep disorders, leg cramps, hypothyroidism, finding a good endocrinologist, cortisol levels, diabetes, recovering from illness and/or surgery. Members also discussed their various vitamin and electrolyte supplement regimens as they continue to search for an improved quality of life.

### **Surviving the Health Care System—It's a Jungle Out There**

Guest speaker: Kathy Layte RN, MScN, CS, HTCP/I, Professor of Nursing, McMaster/Mohawk/Conestoga Collaborative BScN Program

Professor Layte explained to the group that she is not an expert in Addison's disease and is not a physician and therefore would not offer medical advice. Following is a summary of the points made in Kathy's presentation:

It is important for you:

- to know your rights as a healthcare consumer
- to know how to protect them
- to know what to do if you feel they are being violated.

Kathy reviewed Addison's Disease: the signs and symptoms as well as the experience of being in the hospital which is sometimes chaotic and frightening. Can you ask questions? What do you do if there are no answers? How do you talk to healthcare personnel to help them understand?

She shared that:

- Addison's Disease is covered briefly in most general nursing and medical programs.
- Lack of exposure to persons with the illness creates the ignorance — but that does not make it excusable.
- Some of the reasons that the "jungle" has become more difficult to negotiate are:
  - increased patient acuity and decreased length of stay (patients are sicker and in hospital for a shorter time);
  - more part time staff so decreased continuity of care;
  - limited exposure to knowledge about Addison's;

- squeaky wheel gets the attention;
  - rapidly expanding knowledge base about all areas of patient care.
- One interesting point that she made was that the major hormonal factor precipitating Adrenal Crisis is mineral corticoid deficiency, not glucocorticoid, and that the major clinical problem is hypotension. Therefore, patients in adrenal crisis who present with hypotension need mineral corticoid supplementation, not just glucocorticoid.
  - Each individual may experience symptoms differently.
  - If not treated, Addison's disease may lead to severe abdominal pain, extreme weakness, low blood pressure, high potassium levels, kidney failure, and shock, especially when the patient is experiencing physical stress.

In order to know what your rights are, you need to know that all healthcare professionals operate from:

- Standards of Practice from their respective Colleges (Nursing, Physicians, etc)
- Codes of Conduct, usually in their standards of practice but also at their place of employment
- Mission Statements that clearly state what the hospital believes they are there for
- Humanity/compassion — have to believe that this is why most people go into a healthcare profession

Suggestions she made to the group:

- Create a summary sheet about how Addison's affects your life and a brief summary about Addison's Disease.
- Tell healthcare providers that you understand it is not a common illness, so you have a brief summary sheet if it will help — advocate without being judgemental about their lack of knowledge.
- Know your disease, your meds — read as much as you can.
- Don't make assumptions that healthcare personnel don't care or don't know, but also don't assume that they DO know.
- Wear a Medic Alert Bracelet or necklace so that your information is available should you not be able to speak.
- Know what to do in an emergency — do you have emergency meds? Do your family or friends know where they are and how to use them?
- Know your rights — be clear about your expectations without being judgemental.

If you feel your rights have been violated, know the order of who to speak to:

- Charge Nurse
- Nurse Manager
- Social Worker
- Hospital Patient Representative
- Legal Advice

Good websites (other than The Canadian Addison Society):

<http://www.pathguy.com/lectures/addison> and

<http://www.medicalnewstoday.com/articles/186235.php>

Kathy ended the talk by suggesting we all go out there and be gentle warriors carrying imaginary machetes to cut through the jungle of healthcare. She answered a number of questions from the group and thanked them all for their hospitality and warm welcome.

### **Hair Cortisol Study**

Dr. Van Uum has confirmed that he will attend the October meeting of the South/Central Ontario Group for the purpose of presenting the final research study findings of the Hair Cortisol Study. Many members across Canada participated in this study and the final results will be made available via the Newsletter following that October meeting.

In the interim, Dr. Van Uum reports that they have recruited over 100 patients with both primary and secondary adrenal insufficiency from across Canada and the United States and he sends thanks to both NADF and the Canadian Addison Society for their help in this excellent recruitment. After screening participants, the current study includes 93 patients and 62 controls.

Dr. Van Uum reports that there is a trend toward increased hair cortisol values in the patient group as compared to the control group. He goes on to say that this may suggest that some patients are over-treated with their glucocorticoid and may benefit from a decrease in dose. When looking at the males only, the patients have **significantly higher** hair cortisol levels than the controls. However, further research will be needed to confirm this, and patients should **not** modify their current dose without consulting their endocrinologist. Lastly, the patients' perceived stress was significantly greater than that of the controls.

The results of the study will be presented at several conferences including local scientific meetings in London, Ontario, The Canadian Society of Pharmacology and Therapeutics in Toronto as well as The Endocrine Society in San Diego, California.

### **Local Research**

A member shared examples of up-to-date personal research. He qualified that he is not a physician and was sharing research articles available in the public domain, from, for instance, the following websites:

<http://addisonsdisease.researchtoday.net/>

<http://www.ncbi.nlm.nih.gov/pubmed/>

He also shared some personal experiences and displayed his 'Hospital Bag' that contains all medications, syringes, and documents to fully inform Healthcare staff in the event of an ER visit. He spoke of Canadian hospitals not carrying 5mg CORTEF tablets. He obtained these tablets through his GP and Health Canada. We will provide links to forms and more detailed information related to this in a future Newsletter.

### **Afraid to Fly with Addison's?**

Francine shared with us her experience of adrenal crisis on an air journey from Toronto to Victoria. While the end result was recovery from the crisis in a Victoria hospital (after an emergency stop), she has been reluctant to travel by air since that experience. However she now has a West Jet flight booked for this summer using West Jet's "One person, One fare" program. This program offers a free ticket to a travelling companion who will be available to help if the Addisonian suffers a crisis. (This time, Francine will be carrying her Cortef emergency kit, plus a travel canister of oxygen, supplied by Medigas). Call West Jet's Medical Desk to see if you can qualify. Details about the 'One person, one fare' program can be found on West Jet's website, under travel information. Francine advised that Via Rail has a similar program and Air Canada is expected to offer the same in the near future.

Francine also reviewed her very positive experiences with the Canadian Abilities Foundation, a non-profit, cross-disability organization, whose mandate is to inspire, encourage, and motivate. They have provided Francine with most valuable, direct, hands-on assistance and caring, regarding some issues she needs to deal with at this time. She brought copies of their magazine for members to take home with them. For more information on this organization please visit [www.abilities.ca](http://www.abilities.ca).

The next meeting of the Southern Ontario group is scheduled for Saturday, May 15, 2010, 12:30 pm, at the Erin Mills United Church, Lower Hall, 3010 The Collegeway, Mississauga, ON L5L 4X9. The church is located on the southwest corner of Winston Churchill Blvd. and The Collegeway. There is an elevator available. The agenda has not yet been finalized. In the meantime, please, mark your calendars.

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 on May 15, 2010, at Robbie's Restaurant. There were 16 people in attendance.

- Memberships were due in January. Forms were available for anyone who wished to pay.
- We are sorry to inform members of the death of Al McConnell, a long-time member from Montreal who attended our Ottawa meetings with his wife, Doris, for many years. A condolence card was sent in the name of the local group.
- The Canadian Addison Society annual general meeting will be held in Vancouver this year in October 2010. Watch the website or newsletter for further information.

The guest speaker was Scott Watson of Watson's Pharmacy and Wellness Centre on Main St. in Ottawa. Scott has his Masters in drug design, and answered a range of questions from those present:

- Milk can decrease the absorption of thyroid medication by 50-60%. However, if you are on thyroid medication, your dosage has been adjusted to reflect the conditions in which you normally take it.
- Florinef vs. blood pressure: If you have high blood pressure, it may not be related to your florinef dosage. High blood pressure can be caused by factors unrelated to those aspects connected to florinef, and if so, modifying your florinef dosage would not have the required impact.
- Having Cortef with calcium should not create a problem. However, calcium should not be taken at the same time as an antibiotic as it will affect the absorption of the antibiotic.
- Some members are taking over-the-counter strontium to reduce the risk of osteoporosis. Strontium ranelate on prescription is under consideration by Health Canada, but there is no decision as yet.
- High doses of prednisone for cancer treatment can cause depression in some patients. Can Addisonian moods be affected by their medication, or is it more likely the moods are simply from the Addisons itself?
- DHEA can legally be included with other medications in compounded preparations.
- In Ontario, prescriptions of certain targeted drug substances are only valid for one year. There is no time limit on the validity of prescriptions for the vast majority of prescribed substances, including Cortef, prednisone, cortisone acetate, dexamethasone and Florinef. However, the pharmacist has the discretion to request an updated prescription, and major chains may have across-the-board policies in place limiting their lifespan.
- There is a database in drug and herbal interactions available to pharmacists, but it is incomplete. Further, some supplements may not be standardized or may be adulterated, affecting potential interactions.
- The idea of transdermal or patch preparations of cortisol was discussed. Some patients can have problems with the glues used in patches.

Submitted by Steve McKenna

The next meeting will be at Robbie's Italian Restaurant, 1531 St Laurent Boulevard, Ottawa, at noon on Saturday October 16, 2010.

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**

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

Nous avons maintenant une représentante, Marie-Josée Normand, à Montréal. Si vous désirez la rejoindre, vous pouvez communiquer avec elle au (514) 376-2712, par courriel au [marijornormand@sympatico.ca](mailto:marijornormand@sympatico.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:** I was recently diagnosed with Addison's disease and was told I needed to get a medic Alert bracelet, however I am unsure of what I need to get engraved on it

**A:** I am glad to hear that you are getting a medic alert bracelet. It should say: Addison's Disease on cortisol 20 mg & Florinef 0.1 mg (this is just an example, you can fill in the proper medications and doses).

The important thing is to make sure who ever sees this will know you are on medication and that you need attention, and that the doctors in the emergency room know you are on cortisol or other glucocorticoid and may need solucortef. In addition, you can carry in your wallet a note from your doctor stating your diagnosis and any other particulars and medications, and that in an emergency you require intravenous saline and solucortef.

*(Ed note: See item on wording in this Newsletter; examples of such letters can be found on the Society website at <http://www.addisonsociety.ca/emergencylett.html>)*

**Q:** How can my doctor diagnose Addisons, and is it often misdiagnosed? Also, are there other diseases with similar symptoms? I have had these symptoms for a long time and they are now becoming very overwhelming; I am having a difficult time managing them

**A:** In the early phases, the symptoms of Addisons can be non-specific. Weakness and fatigue are common to many illnesses. Some of the specific signs such as skin pigmentation may only come on as the disease progresses, and in secondary adrenal insufficiency there is no skin pigmentation. It is a situation where your doctor has to think about the possibility of the problem and then do some testing. If you bring your concerns to your doctor, she/he can discuss with you whether testing would be appropriate. The screening tests for Addisons are a serum cortisol and ACTH. The results of these tests will help to determine whether other testing is indicated.

**Q:** I have Addison's disease! I was diagnosed in March 2010, so I am not familiar with all the things I should and shouldn't do. I work as a nurses' aid in a large hospital. My job is direct contact with all patients from the emergency room to the Cancer wards. Is it fact that I will easily catch disease because of my low immune system, which is jeopardized because of Addison's? As of this date, I am not working - I still can't function for more than 2 hours at a time. I can't increase my medication because my Endocrinologist tells me I am at a very high dose. I take 50mg of Cortef per day (higher when my children stress me out). My main concern is getting sick with some disease because of my Addison's. Does it matter that I also take synthroid and prozac? Do these other two drugs hinder the effectiveness of Cortef?

**A:** If you were just diagnosed in March, you are just getting adjusted to your medication but you should be feeling a lot better. Addison's disease is most often an autoimmune disease with antibodies damaging the adrenal gland. The remainder of the immune system which is involved in fighting infection is working normally. You should not be at increased risk of getting infections.

In general, individuals with Addison's disease are on Cortef and Florinef (which is involved in salt retention). You should discuss this with your endocrinologist to be sure your medication is optimized.

**Q:** I was told by the Tropical Disease Doctor that anyone taking over 10mg of cortisone should not have a live vaccine as they are apt to present symptoms. This causes problems whenever I want to take cruises or certain trips.

**A:** The problem with individuals taking cortisone is difficult to get sorted out. Since individuals with normal adrenal glands secrete between 15 and 30 mg of cortisol daily, there should be no problem with individuals with no adrenal function taking up to 30 mg of cortisol daily. It is my impression that the Tropical Disease doctor meant 10 mg of **prednisone**. This is the preparation used to treat patients who need extra steroids to treat a variety of disorders. Large doses can suppress the immune system, which is why the Tropical Disease doctor was concerned. You should get a note from your endocrinologist or family doctor indicating that the cortisol or cortisone that you are

taking is a replacement for non-functioning adrenal glands and is a physiological dose, so there should be no problem.

**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.

Registration Form  
2010 Annual General Meeting  
Canadian Addison Society

**Date:** October 16, 2010  
**Time:** 12:30 – 4:00 pm  
**Location:** Sherbrooke Lounge  
260 Sherbrooke Street  
New Westminster BC

Name: \_\_\_\_\_

Address: \_\_\_\_\_

City: \_\_\_\_\_ Province: \_\_\_\_\_

Postal Code: \_\_\_\_\_ Phone #: \_\_\_\_\_

E-mail Address: \_\_\_\_\_

Number of people attending: \_\_\_\_\_

If you have any questions for the guest speaker, please forward by our website to Judy Stanley or Marilyn (Moh) Thauberger.

If you need accommodation, please let us know and I will forward information on sites close to the meeting.

**Please send completed forms to:**

Judy Stanley  
5 Tuxedo Place  
Port Moody, BC V3H 3W5

[bugbee@shaw.ca](mailto:bugbee@shaw.ca)