



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

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**ISSUE NO.41**

**DECEMBER 2005**

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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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## **New Website:**

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Finally – the announcement so many of you have been waiting for!!! **The completely revamped and updated website for the Canadian Addison Society is fully functioning! You can find it at [www.addisonsociety.ca](http://www.addisonsociety.ca).**

The new website contains medical information, including frequently asked questions, information on how to handle an emergency and full directions on how to give an emergency injection. You'll also find information on local group meetings, and minutes from the Annual General Meeting. As well, the website offers easy email contact with local support group representatives, the liaison secretary, and the Newsletter editor.

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You can now read the Newsletters on the website as soon as they are written! And can consult previous Newsletters for helpful information. Indeed, you will notice that your membership renewal (due in January) provides an option for you to get your copy of the Newsletter from the website, offering the Society a possibility of saving more than a thousand dollars a year in printing and postage.

Please be sure to visit the website – take a look, browse around and let us know what you think. Use the links to the many categories in this user-friendly format.

There is a lot to see, learn and share for all those affected by Addison's Disease. This website is also a great reference tool for family members and friends. If they don't fully appreciate what you suffer from, or if they need to know how to deal with an Addisonian, send them the link to the website and they can learn for themselves what it means to have Addison's Disease.

A great big thank you to Lisa Harpur, Patricia Hehner, Irene Gordon and all the others who helped bring this new website into existence for the Society.

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## **Announcements:**

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- The 2006 Annual General Meeting will be held in Western Canada, hosted by the Lower Mainland, Vancouver, B.C. Local Support Group. Members of the local support group have also generously offered to billet people who wish to attend the meeting.

The meeting will be held on October 14, 2006, 1-4 pm in the Lecture Room, Sherbrooke Centre, New Westminster BC.

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

- Recently, the spouse of a member posed the seemingly simple question, "What does an Addisonian Crisis look like?" We realized that there is quite a range of answers. As a result, we would like to include an article in the Newsletter on this subject. Members are asked to describe what your crisis looked like and how it was dealt with, and send this to the Newsletter (email: [newsletter@addisonsociety.ca](mailto:newsletter@addisonsociety.ca)). It does not have to be long and it can be anonymous. The information provided could be a great help to others suffering from Addison's and to their families, and bring relevant content to the Newsletter.

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## **Membership Renewals:**

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Annual membership renewals are due in January 2006.

Memberships can be renewed by sending in the form attached to this newsletter, or by downloading the membership form from our updated website at [www.addisonsociety.ca/membership.html](http://www.addisonsociety.ca/membership.html).

When renewing, please be sure to indicate if you need to receive the Newsletters by regular mail, or if you will read them (and print them, if desired) from our new website, potentially saving the Society a thousand dollars a year.

Please take a moment to renew your membership in the Canadian Addison Society, so that it may remain vital and provide a useful resource to Addisonians and their families. Remember how lost and alone you felt when first diagnosed? Let's make sure the Society is able to help newly diagnosed Addisonians, as it helped you.

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## **Minutes: 2005 Annual General Meeting**

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1. Meeting was chaired by Athena Elton, President. There were 9 members and 5 guests in attendance (including Sandra Rock – Chairperson of the Michigan Support Group of NADF and spouse) and guest speaker Dr. Don Killinger
2. President's Address
  - Sincere thanks and appreciation is offered to Joan Southam (Past President), Greta Fraser (Interim President) and Elaine Hall (Past Secretary) for the many years of dedicated service and hard work they all provided to the Society. A letter, to be written by the President and a gift of roses will be sent to Elaine Hall who retired as Secretary to the Society this past year. Both Joan Southam and Greta Fraser continue to be actively involved at this time.
  - The following are deceased members who will have their names added to the Society's memorial plaque: Maxine Carpenter, Margaret David, Myra Marnoch and Margaret Shouldice.
  - Members were also informed of the recent death of member Don Archi's mother-in-law, and we extend our sincere condolences.
  - Irene Gordon was welcomed as the new Secretary.
3. Adoption of Minutes, from 2004 Annual General Meeting  
THAT the minutes of the 2004 Annual General Meeting be adopted as distributed: Moved by Athena Elton, Seconded by Steve McKenna, CARRIED

*Business Arising from the 2004 Minutes*

- Motion to invest \$6,000 in short-term instruments – action completed.
- Motion to approach Dr. Killinger for a letter that could be used in emergency situations: this appeared in the June Newsletter and is available on our new website.
- 1-888 number answering service was activated with the transfer of the telephone from Ottawa to Goderich in August 2005. As well, all previous telephone lines except for the 1-888 number have been disconnected and are no longer to be published on our materials.
- Website update will be discussed under agenda item #8.

4. Financial Report

The financial report to October 31, 2005 was presented and discussed by John Gordon, Treasurer, after noting income levels and explaining larger expense items (see Appendix A attached).

THAT the financial statements to October 31, 2005 be accepted as presented: Moved by John Gordon, Seconded by Joan Southam and CARRIED

5. Elections (3 Year Term)

President	Athena Elton (AB)
Liaison Secretary	Irene Gordon (ON)
Director	Joan Southam (ON)
Director	Elizabeth Hill (SK)

THAT we accept the nominations of the above-noted individuals as officers and Directors to the Society for the next 3 years: Moved by John Gordon, Seconded by Steve McKenna, CARRIED

It is with regret that we accept the resignation of Al McConnell (PQ) from the Board of Directors after many years of dedicated service.

The Society thanks Patricia Hehner for her work in putting together and distributing the newsletter for the Society. As Newsletter Editor is a voluntary position, she has been encouraged to accept recognition for her work by including her name in our materials and on the website as the Newsletter Editor.

6. Directors' Reports

- Athena Elton reinforced the Society's constitutional objectives and expressed appreciation for the dedication of our Regional Representatives. She stressed the need to educate the community-at-large, to continue to expand our member base and local chapters across

the country, and the need for fundraising for research into the causes and control of the disease.

- Joan Southam expressed the importance and need for open communication and continual contact.
- John Gordon reminded everyone of the need to keep membership dues coming in.
- Greta McKague thanked Athena Elton for taking on the role of President; Greta continues to be active in reaching out to the community.
- Steve McKenna encouraged people to submit articles to the newsletter for publication.
- John Gordon was asked to provide an article for the newsletter on how one can leave money from their estate to the Society.
- Irene Gordon will approach the CMA [www.cma.ca](http://www.cma.ca) to find out the cost to insert an ad in their medical journal. We are also going to investigate the possibility of obtaining a mailing list of Toronto endocrinologists.

***Follow up –CMA Journal is published bi-weekly, and the cost of an eighth of a page advertisement is \$1,035/per issue.***

- We need to develop a brochure that can be given to directors and members for distribution in their doctors' offices. If we can locate one, we may be able to revamp a brochure that was used in the past.
- Suggested that we approach Medic Alert [www.medicalert.ca](http://www.medicalert.ca) to see if they would consider donating fanny packs they no longer distribute, to the CAS for our members to use.

***Follow-up –Medic Alert fanny packs are not available.***

- Patricia Hehner will investigate the possibility of reproducing a small plasticized brightly coloured card (\$2-\$3), that could be carried by members identifying their Addison condition and the type of emergency treatment needed.
- Steve McKenna proposed that the Society offer thanks to Lisa Harpur our web site designer and Patricia Hehner for the numerous hours spent in the redevelopment of the Canadian Addison Society website.

## 7. Membership Update

- Irene Gordon informed members that membership usually fluctuates between 150 and 200 members from year to year. We currently have 153 members.
- A question was raised as to how many people in Canada have Addison's disease. Dr. Killinger noted that there are 20-40 Addisonians per million or 2-4 persons per 100,000. It was mentioned that our society has less than  $\frac{1}{3}$  of Addisonians registered as members.

## 8. Web Site Development Update

- Patricia Hehner took the members through a short demonstration of what the new website looks like and how to move around in it.
- It is our web site developer Lisa Harpur's intention to have the site go "live" by November 31, 2005.

***Follow-up – The new website is now operating.***

- Athena agreed to write up a list of "Benefits for Membership in the Society" and will submit the information for publication on the website.

***Follow-up – Article has been written and appears on the website.***

## 9. New Business

- A request was made that the Canadian Addison Society give a charitable donation, in the amount of \$100, to the Surrey Memorial Hospital Foundation in New Westminster B.C. This would be in addition to \$100 from members of the Lower Mainland BC Chapter and \$100 requested to be used from their local funds. Members noted that making this contribution was not to be viewed as setting a precedent for future contribution requests.
- Donations made to the Society in the amount of \$10 or more are provided with tax receipts.

THAT the Canadian Addison Society donate \$100 to the Surrey Memorial Hospital Foundation. We will ask Judythe Stanley to forward the \$100 donation received from members (including the names and breakdown of individual donations) to the Treasurer. Members who donated \$10 or more will receive a tax receipt from the Society. The Treasurer will provide a cheque in the amount of \$300, together with a letter from the Society and send it back to Judythe Stanley for presentation to the Hospital. Moved by Joan Southam, Seconded by Steve McKenna and CARRIED

- A request was made by the Treasurer, that the Canadian Addison Society renew its membership in the Canadian Organization for Rare Diseases (CORD). There is an annual membership fee of \$50.

THAT the Canadian Addison Society renew its membership in CORD and that this membership continue on an annual basis: Moved by Athena Elton, Seconded by Steve McKenna and CARRIED

- A Society member presented a personal health testimony.

## 10. 2006 Annual General Meeting

- The Lower Mainland, Vancouver, B.C. Local Support Group will host the next AGM.

- Members of the local support group have also generously offered to billet people who wish to attend that meeting.
- Being able to publish the date will allow interested parties to book holiday and travel arrangements in good time to attend.

***Follow-up – The 2006 Annual General Meeting will be hosted by the Lower Mainland, Vancouver, B.C. Local Support Group on October 14, 2006 in the Lecture Room, Sherbrooke Centre, New Westminster (Vancouver), B.C.***

11. Guest Speaker – Dr. D.W. Killinger – Endocrinologist

Dr. Killinger’s presentation was based on a series of questions provided to him for response.

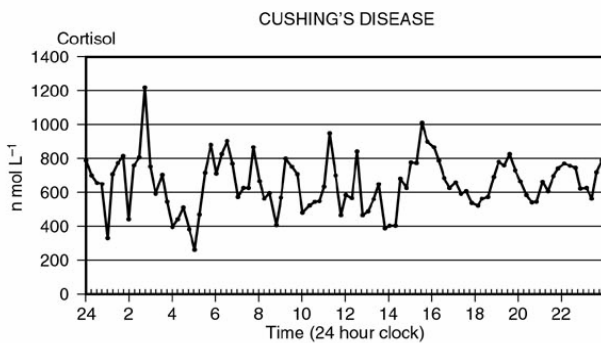
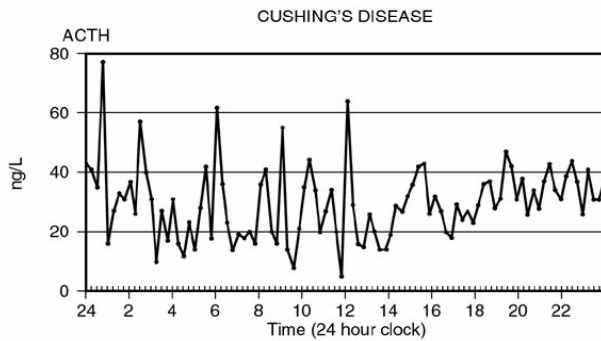
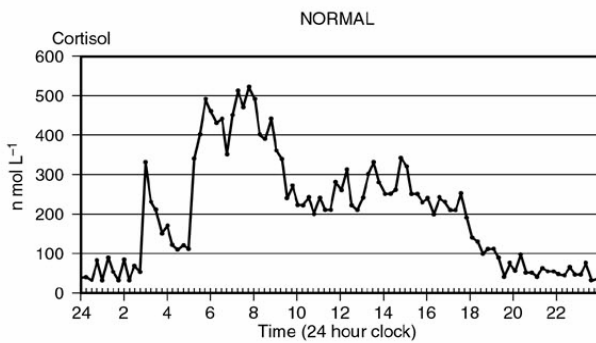
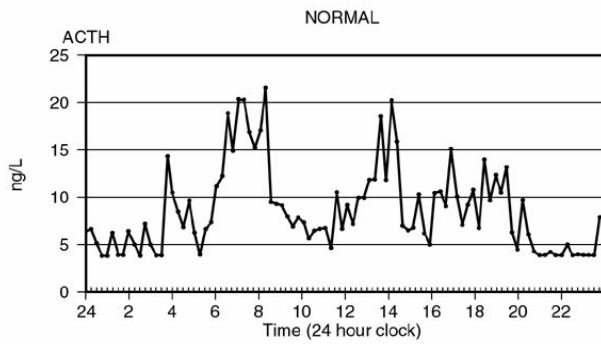
**Medications available to treat Addison’s disease - glucocorticoids and mineralocorticoids**

	Anti-inflammatory activity (relative strength)	Salt retaining activity (relative strength)
Cortisol (hydrocortisone, cortef)	1	1
Cortisone	0.8	0.8
prednisone	4	-
dexamethasone	25	0
Fludrocortisone (Florinef)	12	125

**Treatment routines -- examples**

	AM	noon	PM	bedtime
cortisol	20 mg		10 mg	
	20 mg	10 mg		
	10 mg	10 mg	10 mg	
	10 mg	10 mg	5 mg	
	10 mg	5 mg	5 mg	
prednisone	5 mg		2.5 mg	
	5 mg			
florinef	0.1 mg			
	0.2 mg			

## Cortisol levels throughout the day



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### **Protection in the event of a flu pandemic**

- Individuals with Addison's disease are no more likely to catch the flu than the general population.
- They may have more problems if they catch the flu because their response may not be as good as individuals with normal adrenal function.
- They should therefore:
  - get a flu shot to provide the best chance to avoid the flu;
  - if they feel flu symptoms (muscle aches, nausea, severe fatigue), they should
    - take extra cortisol or prednisone tablet(s);
    - take extra salt in the form of soups or other foods;
    - drink extra fluids—water, juices, gaterade etc.;
    - go to the emergency department, if they can't keep their pills and fluids down;
    - use their emergency kit only if they can't get to a hospital. A hospital is required as they need fluids.

### **Possible causes of Addison's disease**

Could it be a bacterial infection like peptic ulcer (*H. pylori*) that can be cured by antibiotics?

- The most common cause of Addison's disease is destruction of adrenal cells by antibodies that target one of the proteins involved in making cortisol (autoimmune). The tendency for this is thought to be inherited, although often there is no obvious family history.
- The next most common cause is tuberculosis, which is a bacterial infection that is treated with antibiotics. Before modern antibiotic treatment, more people developed adrenal insufficiency because the infection went on to destroy the adrenals. TB used to be the most common cause of Addison's disease.
- Fungus infections such as histoplasmosis can invade the adrenal and cause Addison's disease, but viral infections have not been shown to cause adrenal destruction.
- The adrenal can also be destroyed by hemorrhage or by invasion by cancer cells.
- Stress or "adrenal fatigue" is not a cause of Addison's disease.

Greater than 90% of the adrenal has to be destroyed before symptoms of adrenal failure are noted. Therefore, treating the underlying cause does not restore normal function.

### **Muscle cramps**

- Muscle cramps are not specifically related to Addison's disease and frequently occur in individuals who have no underlying disease.
- They can occur after exercise that is more strenuous than usual.

- They are more common in older people.
- Muscle cramps can be associated with abnormalities in blood levels of some salts including low sodium, potassium, calcium and magnesium. They can also be associated with high levels of calcium.
- In Addisonians, sodium and potassium levels are influenced by the amount of Florinef taken. If muscle cramps are more frequent than usual, these levels should be checked.

## Recent research

### **Laboratory**

- Laboratory research has determined many of the genes involved in the normal development of the adrenal gland.
- Other research has shown which proteins (enzymes) the antibodies attack to cause the adrenal destruction in Addison's disease.
- This research has helped us to better understand the process underlying adrenal problems, but has not resulted in new treatment options.

### **Clinical**

- Treatment consists of replacement of the missing adrenal hormones – glucocorticoids (cortisol, prednisone) and mineralocorticoids (Florinef).
- The use of DHEA is still controversial but there has been very little recent research.

### **Comments on an article entitled *Stress and Cortisol* by Dr. Perricone**

This article was submitted by a member and appeared in the September 2005 Addison's Society newsletter. It was covered on *Oprah*. It describes cortisol as the "death hormone" and suggests that cortisol levels increase with age and are "toxic to our brain cells, cause a decrease in our muscle mass and shrinkage of our vital organs".

This article is misleading and does not reflect current medical information. It is extremely important to screen all information obtained through websites to evaluate the credibility of the sources.

To set the record straight:

- Cortisol levels do not increase with age. The normal cortisol response to specific stimuli is maintained with normal aging.
- There is no evidence that cortisol is a factor in the aging process.
- It is well known that large doses of glucocorticoids (prednisone) used in the treatment of some diseases can have serious side effects and can cause protein wasting but this is not relevant to the normal aging process. For Addisonians, **cortisol is a "life saving hormone"**.

**APPENDIX A**

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

	<b>January 1, 2005</b>	<b>January 1, 2004</b>
Cash on hand and in banks	\$19,420.76	\$18,332.30
<b>Income</b>		
Dues Received - National	\$2,334.34	\$3,735.00
- Support Groups	415.17	550.00
Donations	300.17	1,147.94
Interest	267.67	189.70
	<b>3,317.35</b>	<b>5,622.64</b>
<b>Expenses</b>		
Newsletter	831.52	1,398.11
Web Site	416.86	-
Annual Meeting	-	277.79
Outside Meetings, Seminars and Membership	-	74.54
Postage, stationery & supplies	96.10	482.40
Telephone	2,047.97	2,068.24
Travel	474.38	
Support Group Expenses	20.86	173.10
Bank Charges	50.00	60.00
	<b>\$3,937.69</b>	<b>\$4,534.18</b>
Cash on hand and in banks after adjusting for O/S cheques	<b>October 31, 2005</b>	<b>December 31, 2004</b>
	\$18,800.42	\$19,420.76

## THE CANADIAN ADDISON SOCIETY

### Analysis of cash on hand & in banks as at October 31, 2005

#### Equitable Trust -

The Canadian Addison Society	\$15,068.76
- \$6,116.53 @2.3% due November 14, 2005	
- \$8,952.23@2.65% due December 28, 2005	

#### TD Canada Trust -

The Canadian Addison Society	727.47
Montreal Support Group - Quebec	100.00
Ottawa Valley Support Group - Eastern Ontario	508.90
Brantford and District Support Group - Southern Ontario	1,310.00
Saskatchewan Support Group	5.00
Edmonton Support Group - Alberta	241.75
Lower Mainland (Vancouver) Support Group - British Columbia	453.54
Vancouver Island Support Group - Victoria	370.00
Vancouver Island Support Group - Nanaimo	15.00

**Total** **\$18,800.42**

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## **Highlights from Local Meetings:**

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### **Vancouver Island Support Group (Nanaimo)**

Nanaimo meetings: Christy Lapi at [clapi@shaw.ca](mailto:clapi@shaw.ca), or 250-245-7554 or Barbara Hunn at [bhunn@shaw.ca](mailto:bhunn@shaw.ca) or 250-756-4385. Nanaimo meetings are held at Nanaimo Regional General Hospital, Room G245.

### **Vancouver Island Support Group (Victoria)**

Sixteen people attended the meeting Saturday, October 15 at the Victoria General Hospital, including Judy Stanley, the Vice President, from Vancouver, and several members from Nanaimo.

One of our members, Colleen, a practical nurse at VGH, demonstrated how to prepare and administer a Solu-Cortef emergency injection. Members brought outdated vials of Solu-Cortef for this demonstration and everyone was given the opportunity to experiment with their vials and the syringes supplied by Colleen. This practical exercise brought out the various pitfalls we will encounter attempting our first emergency injection. When in need of crisis medication, our ability to mentally cope with learning how to prepare and administer an injection is impaired. This chance to experiment demonstrated the prudence of regularly practising to prepare an injection as vials become outdated.

Complete instructions for giving an injection of hydrocortisone, Solu-Cortef, were attached to meeting report, and version was handed out at the meeting. Thanks to Dale for researching and photocopying this information. Injection instructions are also found on the Canadian Addison Society website: [www.addisonsociety.ca/injection.html](http://www.addisonsociety.ca/injection.html).

Observations and difficulties noted during this hands-on exercise at the meeting:

- Pushing down on the yellow vial cap to dislodge the rubber stopper separating the powder and saline solution may require standing and bearing down with the heel of your hand on the vial, while pressing it against a table top or counter.
- We rolled the vials gently between our hands to mix the powder and liquid then removed the small circular tab from the top of the yellow plastic cap to expose the spot where the needle will be inserted into the vial.
- We took the plastic protective cover straight off from the syringe to reveal the needle, which is about 1 1/2 inches long. Before inserting the needle into the vial, we were instructed to pull the plunger of the syringe back to the 2 ml mark drawing in air. Then the needle was inserted into the vial and the plunger depressed.

- In drawing medication from the vial to the syringe, the needle must be inserted so that only the tip of the needle enters the vial. The vial is then inverted and medication is drawn into the syringe to the 2ml mark, by pulling back the plunger. We found, if the needle was inserted fully, the tip bypassed the liquid level when the vial was inverted and only air from within the vial was drawn into the needle.
- Once the syringe is withdrawn from the vial, it is important to depress the plunger until a small 'fountain' of medication leaves the tip to tell you there is no air in the syringe before injecting.
- The preferred site to self-inject is the outer thigh. The syringe is held like a dart. Use your other hand, thumb and two fingers, to spread the skin by pushing down lightly. The needle is darted into the thigh at a 90-degree angle.
- Colleen suggested we exhale as we inject to relax the thigh muscles.

*(Editor's note: Please also read the information from the Alberta and Eastern Ontario meetings on this subject.)*

Dexamethasone, another injectable medication which can be used in a crisis situation, can be prescribed by your doctor. As the ingredients do not need to be mixed, it may be easier to prepare and therefore quicker to administer. A vial of dexamethasone may contain enough medication for multiple injections. Although dexamethasone is more powerful than hydrocortisone and is longer lasting, hydrocortisone is faster acting once injected.

One member required 2 visits to Emergency recently and found the Victoria Jubilee ER staff knowledgeable about Addison's and willing to follow the Ottawa ER Protocol. If you wish to attach a copy of the Ottawa Protocol to your emergency letter, you can find it on the website at [www.addisonsociety.ca/ohp.html](http://www.addisonsociety.ca/ohp.html).

Evidently, in British Columbia, some paramedics are trained to administer saline IV in an emergency. Ask for "Advanced Life Support" if you are in crisis and need to call paramedics.

In discussions on medications, one new member takes a daily dose of one .75mg tablet of Dexamethasone at bedtime and wakes full of energy, as this drug is slow release and has a long half-life. Another takes 4 drops of liquid DHEA before sleeping and wakes with lots of energy.

Flu shots should be available November 1 and we all need them, along with our families.

A number of members stated that they get hot feet just after getting into bed.

A big thank you to Colleen for demonstrating the emergency injection and for the photocopied information on diet for adrenal disorders that she provided attendees.

Judy presented the suggestion of hosting the Canadian Addison Society 2006 Annual General Meeting in Vancouver, and encouraged Vancouver Island members to attend. This is an opportunity for B.C. members to attend an AGM without flying to Ontario. A West Coast meeting would likely be held in October 2006. Instead of a speaker, Judy's idea is to hold UBC medical student interviews following the business portion of the meeting. Members planning to attend the AGM would confirm beforehand if they wish to take part in the one-on-one interview process. If you are interested in attending the AGM in Vancouver, please contact Judy Stanley, 604-936-6694 or [bugbee@shaw.ca](mailto:bugbee@shaw.ca).

2006 membership renewals are due in January. Membership forms were made available.

Meetings for 2006, of the Vancouver Island support group, will be booked when the date for the AGM in Vancouver has been determined. You will receive notice of these dates when they are known.

Submitted by Jim Sadlish

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

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

Twenty people attended the meeting on Saturday, October 29, 2005.

- 2006 AGM: Members were enthusiastic to host the 2006 National Addison's Society Meeting, and showed a willingness to be involved with the preparation. Some members are willing to billet out-of-town attendees.

Because we have decided to host the AGM, we will not have an October meeting next year. Therefore we will arrange for home interviews with the UBC medical students.

- Donation to Surrey Memorial Hospital Foundation: Members voted to ask the national group to approve our request for a donation of \$100 from our national account, to be given to Surrey Memorial Hospital Foundation for their new Emergency Department. This supports Dr. Ip, Head of the Surrey Memorial Hospital, who has spoken with us and has acted as counsel to us. He is working with us on Emergency Department computer access to Addison's,

and has signed a letter for members to present to the triage nurse if they have to go to an Emergency Department. As well, members made personal donations of \$100.00 to increase the total Addison Society contribution.

- Speakers for future meetings: Someone who deals with children/teenagers who have Addison's Disease (possible contact is Sheila, a nurse at the Endocrinology Clinic at Children's Hospital); a veterinary who treats dogs with Addison's Disease (this will not be pursued); someone to speak about Addison's and diabetes, as a number of our members also have diabetes, and it is something about which a number of us are concerned (February meeting)
- Announcements
  - It is the start of flu season, and members are encouraged to get their flu shots.
  - Membership forms for 2006 dues are available.
  - Future Meetings: Sherbrooke Lounge, Sherbrooke Centre, 260 Sherbrooke St. New Westminster BC 1:00 to 3:00 p.m. Please mark your calendars.
    - February 25, a speaker from the Canadian Diabetes Soc. to speak on Managing Diabetes and Addison's at our February meeting.
    - June 3, 2006 Mavis Pickett - Senior Comic - A savory Sage with "thyme" giving a short comedy sketch combined with her tales of her teaching Osteofit. Mavis has been on the CBC Arthur Black show, local television, radio and does comedy sketches at Comedy Club and in coffee houses.
- Interviews: 17 UBC medical students attended the meeting and conducted one-on-one interviews with the members.
- 2005 Recap by Judy Stanley

It has been an exciting year for the BC Lower Mainland Group. We have completed another successful interview session with first year medical students from the UBC Doctor, Patient and Society Course. Thanks to Marilyn and all those who participated; your advocacy may save a life one day.

In addition to our donation to support Dr. Urbain Ip, we will pursue his suggestion of flagging specific disease treatment protocols at the time of patient arrival at triage in any Emergency department.

Our February guest speaker, Darlene Redman, Paramedic Chief for New Westminster, started a process of contact with the BC Ministry of Health for



inclusion of Addison's Disease in paramedic training in BC. We are now in the process of putting together a package for presentation to Dr. Sun. MD FRCPC who will rework it to suit their program along with posting information on Addison's disease from the Society on their website with a link to our website.

We shall be following up on both these projects and continue our lobby for a common database for all Emergency departments in BC.

Submitted by Judy Stanley and Marilyn Thauberger

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**

- The Alberta Addisons group met on October 15, 2005 at the Royal Glenora Club. We had seven in attendance, including Athena Elton, President of the Canadian Addison Society from Calgary, Maxine Cochran from Condor, Ginny Snaychuk, Colleen Lane, Elaine Mattson and her husband Norm, and Francisca Swist who are all from Edmonton.
- It was great to meet Athena Elton. We all shared some of our experiences, which is always enlightening. Colleen Lane demonstrated how to open, mix and use the cortisone injectable. *(Editor's note: Injection instructions are also found on the Canadian Addison Society website: [www.addisonsociety.ca/injection.html](http://www.addisonsociety.ca/injection.html). Please also read the information from the Vancouver Island and Eastern Ontario meetings on this subject.)*
- The focus of the meeting was working toward establishing a protocol for hospitals with respect to treatment of patients with Addison disease. Ginny Snaychuk has been in contact with Capital Health. Endocrinologist, Dr. Jody Ginsberg, is helping us in the process. The Patient Relations representative from Capital Health has informed us that they did not have time to discuss the emergency room protocol at their meeting in October, so it is back on the agenda for November 17.
- Colleen Lane made a suggestion for obtaining grant money from a local Edmonton society. If realized, the funding would be used to establish an education program geared toward physicians, dentists, and nurses.

We'd like to wish everybody a Merry Christmas and a healthy holiday season.

Submitted by Francisca Swist

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

### **Saskatchewan Support Group**

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

### **Southern Ontario Support Group**

For further information, contact Janet Stewart at (416) 265-3027 or [janetstewart@rogers.com](mailto:janetstewart@rogers.com).

### **Eastern Ontario Support Group**

The Eastern Ontario group met on October 15, 2005, at Robbie's Restaurant, in Ottawa.

Teresa Seasons has recently taken over as representative for the local support group. Thanks to Susan Steedman for her service and to Teresa for stepping in. Teresa hopes to facilitate more structured meetings, with agenda, guest speakers and meeting reminders by email or mail. If possible, please provide Teresa with your email address to save postage. Members are encouraged to suggest agenda items and guest speakers.

Members were encouraged to attend the November Annual General in Toronto.

The new website for the Society, designed by Lisa Harpur (web designer and daughter of local member, Betty Harpur) is up and running. The address is [www.addisonsociety.ca](http://www.addisonsociety.ca). Please go browse through it.

Several members demonstrated how to give an emergency injection of solu-cortef, and shared their experiences doing this.

- It can be tricky to push down on the plastic vial cover in order to mix the solu-cortef.
- It is easier to draw the solu-cortef into the syringe if you draw air into the syringe before inserting the needle into the vial, then push in the plunger to expel the air into the vial before drawing up the solu-cortef.
- Ensure the tip of the needle is inserted into the medication portion of the vial and not beyond and into air.
- Avoid the very middle of the buttock being injected, as there is a major nerve in that area.

- An intra-muscular injection of 100mg of solu-cortef may result in only about ½ that dosage being absorbed. Intramuscular injection of solu-cortef absorbs faster and more completely than oral cortef, but is less effective than IV solu-cortef. Members were also reminded of Dr. Weinberg's comments two years ago that the consequences of injecting more than 100 ml are insignificant. In an emergency, don't worry too much about exact amounts.

*(Editor's note: Injection instructions are also found on the Canadian Addison Society website: [www.addisonsociety.ca/injection.html](http://www.addisonsociety.ca/injection.html). Please also read the information from the Vancouver Island and Alberta meetings on this subject.)*

The spouse of a member posed the seemingly simple question, "What does an Addisonian Crisis look like?" which produced quite a range of answers from the members. This could form a useful newsletter article. Members are asked to describe what your crisis looked like and how it was dealt with, and send this to the Newsletter editor (email: [newsletter@addisonsociety.ca](mailto:newsletter@addisonsociety.ca)). It does not have to be long and it can be anonymous. The information provided could be a great help to others suffering from Addison's and bring relevant content to the Newsletter.

The possibility of holding our next meeting in the Kingston/Belleville area was discussed, to encourage members from that area to attend. Teresa will canvass those members to see if they would attend a local meeting. Betty Harpur suggested her endocrinologist, Dr. Robin Holding, of Kingston, as a speaker.

Guest speakers were Michel Philion, *Advanced Care Paramedic Program* co-ordinator at Algonquin College and experienced Paramedic, and Andy Fenton, Ottawa Paramedic and recent Advanced Care Paramedic Program graduate.

#### Highlights

- Both thought attending this meeting provided a great way for those in their profession to learn first-hand what Addison's means.
- Paramedics are currently working to establish a College for Paramedics, which will bring a consistency and validation to their profession.
- Only qualified paramedics may attend the intensive one-year Advanced Care Paramedic program, which accepts 50 of the 1,000 applicants a year. Advanced paramedics may undertake many more procedures including insertion of IV and administration of many drugs.
- 80% of Ottawa ambulances have advanced care.
- With 105,000 calls per year, Ottawa paramedics are usually in and out of a call within 10 minutes.
- After hearing our stories, they appreciate the urgency of starting Addisonian in crisis on solu-cortef and IV, and recognize that the patient (or family member) may be the best-informed person on what is needed.

- Ottawa will pilot a project through which Advanced Paramedics will diagnose and treat some patients on-site, eliminating unnecessary hospital visits. (This might be excellent in cases of Addisonian crisis, delivering both IV fluids and solu-cortef in the home.)
- With an Addisonian in crisis, an advanced paramedic can start the I.V. saline immediately but is not allowed to inject Solucortef, as this medication is not in their toolkit. S/he can assist someone (ex: the spouse) to do so but, unless given direct permission by the doctor, s/he is not permitted to do it.
- The speakers learned from the members that there is no downside to taking too much medication in a crisis. The patient might become a bit fidgety but, unlike some medications, it is not dangerous for an Addisonian. When a paramedic sees the solu-cortef vial and a needle, this is an immediate signal that something serious is going on here. It is a red flag.
- It is VERY IMPORTANT to have the patient's medical history available to the paramedics and hospital staff. Write the information (heart history, current medications, conditions, allergies, etc.) on a piece of paper and have it laminated. Then put it on the fridge (this is where paramedics have been trained to look for such information) so it can be handed to the paramedic in a crisis. By doing so, you've just saved up to 10 minutes of the most valuable time.
- They were impressed by the emergency kits of several members, which included both the hospital emergency protocol (available at [www.addisonsociety.ca/ohp.html](http://www.addisonsociety.ca/ohp.html)) and a patient information sheet documenting the condition, basic patient data, medications and other conditions, typical signs of crisis, and exactly what crisis treatment was needed.
- In an accident, the paramedics look immediately for a MedicAlert bracelet (ensure it will not be overlooked by appearing to be jewellery). Also, if you have an emergency kit (don't we all?), ensure it is clearly labelled so that it will immediately be identified as relevant. If it is just in a toothbrush holder tube, they'll think it is a toothbrush. Label it clearly in big letters.

Teresa thanked the guest speakers for coming and presented them with a small gift of appreciation.

Submitted by S. McKenna

The next meeting will be Saturday, May 13, 2005 – a week before the Victoria Day Holiday, location to be determined. Doug Harpur will take minutes. For information, please contact Teresa Seasons at [tseasons@magma.ca](mailto:tseasons@magma.ca) (613) 761-1195.

## **Québec Support Group**

If you wish to start a local group in the area, please contact the Liaison Secretary at [liaisonsecretary@addisonsociety.ca](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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**Q:** I'm curious about whether I should be getting the hepatitis immunization shots that are being offered by the organization I volunteer with. These shots would take place in January or February. From what one of the nurses said, they will not provide hepatitis immunization to anybody who is immunocompromised."

**A:** This is a very interesting question that is particularly relevant right now since we are all being asked to get flu shots. The nurses giving the injections have to be sure that the recipient is not allergic to material in the immunization injection or, if they have breathing problems and are using an inhaler, that they have the inhaler with them.

Individuals with Addison's disease are not immunocompromised and should respond normally to the hepatitis immunization. The only situation where this may not be true would be if they had a problem requiring larger doses than normal of cortisol or prednisone. If this were the case, they should wait until the problem is resolved, and then proceed with the immunization once they are back on maintenance doses of their steroids.

- **Medical Questions and Answers - Dr. Donald Killinger, MD, PhD, FRCPC**, from Ontario, who is the Medical Advisor for The Canadian Addison Society, will answer your questions about Addison's disease. Questions and answers that may be of interest to everyone will be published in the newsletter. You may email a question to Dr. Killinger at [liaisonsecretary@addisonsociety.ca](mailto:liaisonsecretary@addisonsociety.ca) or c/o The Addison Society (see address on front of this newsletter).

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## **Reminders:**

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- Please send your stories and articles directly to [newsletter@addisonsociety.ca](mailto:newsletter@addisonsociety.ca) or c/o the Addison Society.
- If you are pleased with your **endocrinologist** – let us know. We have many requests not only from recently diagnosed Addisonians but other Addisonians from all parts of the country, who may be moving from one area to another

and require the services of an endocrinologist knowledgeable about Addison's disease and its treatment.

- One member highly recommends her endocrinologist, Dr. David Thompson, in Vancouver, B.C. To quote her: "He's awesome."

- And at this time of year, we all want to wish you and yours a

*Happy Holiday Season  
and  
Best Wishes for the New Year !!*



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

193 Elgin Avenue West  
Goderich ON N7A 2E7

Website: [www.addisonsociety.ca](http://www.addisonsociety.ca)

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

New Membership       Renewed Membership       + Plus a Contribution

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

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

Postal Code: \_\_\_\_\_ Telephone: \_\_\_\_\_

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

How do you wish to receive the Newsletter?

- I will read it on the website at [www.addisonsociety.ca](http://www.addisonsociety.ca)
- by mail

If you **DO NOT** want your name to be made available to other Addisonians in your area, please sign here.

\_\_\_\_\_

You may also direct \$5.00 of your annual fee to one of the local support groups below. Please check a box of your choice.

\$25.00 to go to The Canadian Addison Society

OR

- \$5.00 to Eastern Ontario Support Group – ON + \$20.00 to Society
- \$5.00 to Southern Ontario Support Group – ON + \$20.00 to Society
- \$5.00 to Saskatchewan Support Group – SK + \$20.00 to Society
- \$5.00 to Alberta Support Group – AB + \$20.00 to Society
- \$5.00 to BC Lower Mainland Support Group – BC + \$20.00 to Society
- \$5.00 to Vancouver Island Support Group (Victoria) – BC + \$20.00 to Society
- \$5.00 to Vancouver Island Support Group (Nanaimo) – BC + \$20.00 to Society

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

Please make cheque or money order payable to The Canadian Addison Society and send c/o Treasurer, 193 Elgin Avenue West, Goderich ON N7A 2E7

Revised: November, 2005