



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
<http://www.addisonsociety.ca>

ISSUE NO. 52

OCTOBER 2008

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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.

Annual General Meeting

The 2008 Annual General Meeting was held Saturday, October 11, 2008 in Victoria B.C. with about 25 people present (members and guests). Our thanks to Jim Sadlish and the Vancouver Island Support Group for hosting the meeting.

1) *President's Message:* The Secretary read the message from the outgoing president.

In my experience of living with Addison's disease for eight years, it is an easy disease to control, until it becomes miserable. I'm 38 years old and I have had two children and one event-packed life since diagnosis, including hypothyroidism and insulin-dependant gestational diabetes. Most of the time, I live my life with relative ease, controlling my medications in such a way that I do not even think about having a chronic disease. It is only when I get sick, or severely emotionally stressed, that suddenly my life is in danger. The irony is, it happens when I am weakest, yet I am expected to be strongest and know when to adjust my medications and by how much. Better yet, I need to know when to call 911 when everyone around me is wondering what the "big deal" is.

If there is one nugget of knowledge I would want to pass on to others living with the disease, it is this: prepare ahead of time and teach those around you how to treat you in times of stress. Don't wait to get prescriptions filled when you are down to your last pill, carry all appropriate information for the medical staff and expect the worst. When you are in crisis, don't anticipate that the medical staff will know what to do, go armed with letters, pamphlets and one firmly attached medical alert.

As with most people living with Addison's disease, you would never guess I had it until you REALLY got to know me. I suspect the same is true of most people living with the disease. Go out and live: run marathons, manage hostels in faraway lands, have kids, be happy – but never forget yourself and PREPARE. Oh yeah, and stay a member of the Canadian Addison Society because it's a great organization that will remind you of the importance of keeping on top of your disease.

Good luck and take care.

Athena Elton

2) *Adoption of Minutes from 2007 Annual General Meeting:* Motion to adopt Minutes: Jim Sadlish; Seconded: Stephen McKenna; Passed unanimously. Updates from the AGM 2007 will be dealt with under 'Varia'.

3) *Financial Reports:* The reports are attached to this newsletter.

Highlights:

- Donations are lower than last year due to a large one-time donation in 2007.
- Irene will study the use of the 1-800 line to determine if it is cost-effective and recommend if it should be dropped or retained.

Motion to accept the financial statements as presented: Jim Sadlish; Seconded: Judythe Stanley; Passed unanimously

4) *Slate of Officers & Directors for 2008/2009:*

President	Judythe Stanley (BC)
Vice President	Jim Sadlish (BC)
Treasurer	John Gordon (ON)
Secretary	Irene Gordon (ON)
Directors	Derek Clarke (BC) Patricia Hehner (ON) Elizabeth Hill, (SK) Greeta McKague (ON) Stephen McKenna (ON) Harold Smith (ON) Joan Southam (ON) Patricia Hehner (ON)

Newsletter Editor:

Motion to accept the Slate of Officers and Directors: Irene Gordon; Seconded: Stephen McKenna; Passed unanimously

Regional support group representatives needed: Eastern Ontario; Atlantic Provinces; Alberta; Québec

Editor's Update: Following the AGM, Marilyn Thauberger volunteered for the Board of Directors and was accepted following a Board vote. Welcome, Marilyn.

- 5) *Membership Update:* There are currently 111 active dues-paying members. Regional reps are reminded to encourage members to keep their memberships current, and encourage non-member Addisonians to join the Society.
- 6) *Web Site Update:* Our volunteer web designer has things well in hand. Thanks to Cliff Darroch for his time and help.
- 7) *New Business: Medical Information Card:* The question of incorporating additional medical information on a form available on the web or on our medical cards was again discussed. The suggestion was made that printing a large number of cards that do not have the dates pre-printed would bring cost savings that could offset a bi-fold membership card. This bi-fold card would contain the information on the current card on the outside, and the personal medical information of the member on the inside (to be completed by the member).

Moved that Irene examine the cost for a brightly coloured bi-fold card incorporating information from the current card and the medical information form, and submit her recommendation to the Board for approval as appropriate.

Moved: Judythe Stanley; Seconded: Marilyn Thauberger; Passed unanimously

- 8) *Varia:*
 - *Ad in medical journal:* The issue of using funds to put an ad in a medical journal to inform/remind doctors of Addison's disease and of the Canadian Addison Society was again discussed. It is not yet clear if our objective should be to increase awareness of the Society or of the disease, and whether our target audience should be family doctors, endocrinologists or emergency room doctors. We have received varying opinions from recent presenters at Society meetings.
- Moved that Irene discuss the options with Dr. Killinger, and, based on his advice, make a recommendation to the Board for expenditure of funds if needed. This issue does not need to return to the AGM for discussion or approval.
- Moved: Jim Sadlish; Seconded: Derek Clarke; Passed unanimously
- *Memorial Plaque:* Although the memorial plaque can be seen on the website, it is still a physical plaque and there is a financial charge for each addition. A virtual plaque, once in place, could be modified at no cost.

Moved that Irene investigate the cost of paying a web consultant to create a virtual plaque, and if feasible, to proceed:

Moved: Stephen McKenna; Seconded: Derek Clarke; Passed unanimously

- Our congratulations and admiration to Canadian Olympic gymnast, Nathan Gafuik, who has Addisons and doesn't let it hold him back.
- 9) *2009 Annual General Meeting:* The next Annual General Meeting will be at the Brantford Police Station, Community Room, Brantford ON in September/October, 2009 (exact dates to be determined).
- 10) *Guest Speaker:* Victoria endocrinologist Dr. Richard Phillips, our guest speaker, responded to questions sent in advance. These will be included shortly.

Announcements:

- We are sorry to advise you of the death of Conrad Conwell of the Southern Ontario Group on September 6th, 2008.
- Annual **membership dues of \$25.00** for 2009 are due in **January 2009**. Please use the form attached to this newsletter to renew your membership.

Bad Day for Addisonian

I've often found it hard to adequately describe what a bad day feels like when asked by those interested to know what we deal with. In an attempt to provide some insight into this matter, I have captured some of the random images and feelings that have occurred when my health is being challenged by our shared condition. Hopefully this will help a bit when they ask you, "what does it really feel like" or "what does a bad day feel like"?

Please feel free to contribute your own set to the editor of our newsletter.

- I don't want to move at all.
- I feel dizzy and want to throw up.
- There's not enough air to breathe.
- I feel nauseated and don't want to eat anything ever again.
- My body feels like it is shutting down.
- All my muscles don't seem to have the strength to move.
- I feel as worn out as if I'd just run 3 marathons in a row.
- My heart seems to be working very hard just to keep me going.
- I do not want to talk to anyone, I just want to lie here for a while and melt into the floor.
- I can't walk anywhere without having to catch my breath.
- Salt, I want anything with salt on it or even just salt by itself.

- My family doctor won't sign my leave form because of Addison's Disease and my endocrinologist says I should see my family doctor for these matters, and back and forth and Disability doesn't understand, and on and on and on...
- Intermittent muscle spasms are a regular now.
- There is no such thing as a little cold or a bit of flu.
- I can't seem to walk up the stairs some days without great effort.
- It's hard to understand what you're saying to me.
- You hear yourself saying, "I don't need any help, I just need to lie here for a minute and I'll feel better soon", and it's in the middle of the grocery store or the airport!
- Am I just tired or am I feeling the effects of the condition?
- My legs feel like they either can't carry me or, on other days, feel like lumbering weights that are hard to move.
- I can be surly or irrational to those around me and don't even realize I'm doing it.
- Having people speaking to me is sometimes too much to handle – I need it all to stop. Need quiet, need peace, need to be left alone.
- I am numb to all that surrounds me and am not able to relate to anything.
- Feeling of being torn down inside my whole body.
- I'm told that my medication should make me feel normal; well it's not always like that, is it?
- Some people wonder what all the fuss is about as I seem to look fine.
- Many people don't ask questions, are wonderful to deal with and come to help immediately.

Fortunately this is not what happens most days. May the bad days be few and far between in your world!

Submitted by Stephen McKenna (on a bad day)

Highlights from Local Meetings:

Vancouver Island Support Group

Kelley Gamblewest, now a member of the Vancouver Island group was in Victoria for the AGM, in part to rest up for a marathon the following day. She reports: "I completed the marathon - slow but sure. I received a lovely medal and technical shirt. My legs wouldn't work the next day but that is not uncommon. The pain is almost gone and I plan to take my dog for a nice walk today. I start right away on more training for running (Times-Colonist 10k in April) and the Triathlons I want to do in the spring/summer. Call me crazy! Oh well, it makes me happy."

The next meeting of the Vancouver Island support group will be in February 2009. Members will be advised of the date and location.

For further information or to contact the Vancouver Island Support Group, please contact Jim Sadlish at wx6999@gmail.com or (250) 656-6270. For information on Central Island

activities, please contact Barbara Hunn at bhunn@shaw.ca or (250) 714-0036, or Sharon Erickson at ericksons@shaw.ca.

BC Lower Mainland Support Group

16 people attended the meeting on September 20. Members were reminded to update their flu vaccine for 2008. Members discussed the feasibility of fundraising to support a research project on Addison's. Dr. Zelichowska commented that not much research of this nature is done locally but the possibility of approaching an eastern university might prove more fruitful. An update of the guest speaker's talk will be sent to members. Also discussed was re-establishing contact with the BC Health Minister for a protocol common to all emergency departments in BC, similar the one in Alberta.

Several members indicated their willingness to participate in our advocacy project of interviews with UBC 1st year medical students - part of their 'Chronic Condition' course curriculum in February/March. Students are required to interview, prepare a paper for submission, and give a talk to their class on the condition. Members will be contacted by UBC students for interview times to be conducted at members' convenience. Anyone from outside the Lower Mainland can call to participate, if they can make arrangements for the interview to coincide with an appointment or trip to the Lower Mainland. Anyone interested in participating, please contact me at 604-936-6694 or bugbee@shaw.ca so your name can be forwarded to UBC.

Submitted by Judy Stanley

Meeting date and program for February 2009 will be announced in the next newsletter.

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

Alberta Support Group

For information on this support group, contact Ginny Snaychuk at ginray@shaw.ca or (780) 454-3866 in Edmonton.

Saskatchewan Support Group

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

Southern Ontario Support Group

The next Southern Ontario Support Group meeting will be held Saturday, Nov 1, 2008, 1:00 pm to 4:30 (latest) at the Erin Mills United Church (Lower Hall), 3010 The Collegeway, Mississauga, Ontario, L5L 4X9. The guest speaker will be Dr. Stan Van Uum, MD, PhD,

Assistant Professor, Endocrinology and Metabolism, Dept. of Medicine, University of Western Ontario.

This is a special opportunity for those of you in the Toronto area to attend a meeting without having to travel far. Don't miss it!

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

Eastern Ontario Support Group

The group met October 18, 2008 in Ottawa.

- Please see the AGM minutes in this newsletter.
 - A question was raised with respect to paying for several years at a time. Logistically, this would be too complicated.
 - With respect to maintaining the 1-800 number, our group input was that we discontinue the line as people who need help will make a phone call that costs them a bit.
 - Our members questioned the value of the memorial plaque, given that we are all going to die of something someday and there is no way to determine whether a person dies of Addison's. Several people remarked that they would not want their names to go on such a plaque.
- Teresa Seasons reported on Eastern Ontario group status.
 - This was her last meeting as chair. No one has stepped forward to take on the job of regional representative. Members committed with a show of hands to meet in the spring on May 9th at Robbie's. Elaine Lowe volunteered to chair the meeting and to do email reminders. Glenda Myers will do phone call reminders.
 - The autumn meeting will be October 17, 2009. A volunteer to make the necessary arrangements/reminders is still needed.
 - Survey results on our meetings: Small number of surveys returned. Most members supported the current format, with a speaker at every meeting and meeting in a restaurant. Fewer Addisonians in Montreal and Kingston were willing to travel to a meeting, i. e. would only attend one in their area. Most others were willing to travel. Discussed how much we would be willing to accommodate members who won't travel. Tentatively decided that every third meeting, we could meet in Kingston. Pending further discussion.
- Guest speaker, Dr. Deborah Barry had us all laughing using a laughter therapy technique. She generally found our group to have lots of positive energy.

Submitted by Elaine Lowe

The next meeting will be held Saturday, May 9, 2009, at noon, at Robbie's Restaurant, St. Laurent Blvd, Ottawa, Ontario.

The Eastern Ontario group is looking for someone to act as contact, and to organize future meetings. If you can volunteer, so that our meetings may continue, please contact the Liaison

Secretary at liaisonsecretary@addisonsociety.ca or at the national address shown on the front of this Newsletter.

Québec Support Group

If you wish to start a local group in the area, please contact the Liaison Secretary at liaisonsecretary@addisonsociety.ca or at the national address shown on the front of this Newsletter.

Atlantic Support Group

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 or at the national address shown on the front of this Newsletter.

Medical Q & A

There is now a very large and wide-ranging set of questions on both daily living and very situation-specific issues that have been answered by our medical advisor. To review these questions, please go to the Canadian Addison Society website under Education (<http://www.addisonsociety.ca/faq.html>), or see previous issues of the newsletter.

Q: Is there a relationship in women between hormonal shifts and Addisonian crises? I was first diagnosed at puberty. Shortly after receiving treatment and stabilizing, I started my periods. With my first 2 pregnancies, I had crises during the first trimesters. For my 3rd, we doubled my cortef intake immediately and throughout the pregnancy, and kept out of the hospital. I'm now 44 and often have a 'down' day with Addison-type fatigue just before my period starts. Should I be concerned about how to approach menopause without major glitches?

A: You have raised some good questions. When you were first treated for Addison's disease at about the time of puberty, you were probably quite unwell. With treatment, your condition would have improved and you then began normal menstruation. Menstrual periods often stop during periods when you are unwell. During pregnancy, the requirement for cortisol increases and the increased requirement is about 1½ to 2 times the regular dose, so you did exactly the right thing. The "down" days prior to menstrual periods are not necessarily related to your Addison's disease and may be due to the changing hormonal production as you approach the menopause. It is not unusual to have some cycles in which you do not ovulate in this situation. With the menopause, I would not anticipate any change in your requirement for cortisol, so your dose for both cortisol and florigen should be about the same.

Q: I'm 44, diagnosed 30 years ago, my daily dosage is: 25mg cortisone acetate morning, 12.5mg evening, and 0.1mg florigenef. I lived in D.R.Congo for 5 years in my late 30's. I was unable to see an endocrinologist during this time. The constant level of stress coupled with my frequent discovery that I'd skipped my evening dose led me to increase my cortisone intake to 50mg daily. After returning to Canada, my endocrinologist urged me to drop back to my original dose of 1.5 pills/day, and sent me for bone scans. He warned that it would take awhile to adjust to lower cortisone intake because the body becomes accustomed or 'addicted' to the dose it receives. I didn't have any crises, but my energy levels were low for several months, and I had cold/flu symptoms all winter. With a history of crises during hormonal adjustments in my body (puberty, pregnancies and pre-periods), I'm cautious as I approach menopause years. I'm keen on preventing osteoporosis, yet I'm nervous about how my body would handle a further reduction in cortisone intake. Are Addison patients recommended to gradually reduce cortisone intake as our bodies slow down? Should I be considering this? I take calcium supplements - is there a recommended dosage for adult female Addison patients?

A: The average dose of glucocorticoid is 37.5 mg of cortisone or 30mg of cortisol (hydrocortisone). The dose is usually taken twice a day as you are doing, but it is probably better to spread it out to three times a day e.g., 12.5/12.5/12.5. The dose requirement is quite variable from individual to individual so a dose of 25mg cortisone daily is not unusual. This is related to the fact that tissue receptors for cortisol vary from person to person. We always say that the right dose of cortisol or cortisone is the lowest dose that makes you feel well. It is also important to be sure that the dose of Florigenef is also optimized. The best way to do this is to have your doctor measure your plasma renin. When you change doses of cortisone, it is not unusual to feel less energy for a while, but remember, we all feel better some days than others, so don't blame everything on the cortisone.

Q: I had a right adrenalectomy 4 years ago. After surgery, my left adrenal and pituitary glands shut down. I was placed on prednisone, and six months later, was off of it, as my glands "woke up" and were functioning fine. Last year, I noticed some symptoms similar to Cushing's syndrome but also had these with the tapering of prednisone: weak, aching muscles; a few times my legs felt like they would buckle; headaches; blurred vision; nausea; vomiting after a glass of wine and a meal. There is one little difference - I have noticed a few scars have turned a brownish colour; not all my scars but one in particular that has been there for 5 years has turned this colour. My blood pressure is normal, I have only lost a few pounds in the past week, but I have had diarrhea, similar to what I experienced when I tapered the steroids after surgery 4 years ago

Does this sound like a return of Cushing's or Addisons? I realize diagnosis is difficult without testing, but I am wondering is it possible that my other adrenal has shrunk, just tired of working, or something similar to that?

I have an appointment with my GP. I spent a miserable weekend and decided that these gradual symptoms need some investigating.

A: I am not sure that I can answer your questions because I am not sure that I have all the information. I am assuming that your adrenalectomy was for a cortisol secreting adrenal adenoma. In this situation, the pituitary and the other adrenal are suppressed and depending on how long this had been going on, it can take months to years for the pituitary and adrenal to respond so that you do not need replacement with cortisol or prednisone. This sequence seems to have proceeded in your case.

Your new symptoms are difficult to assess without some lab work. If you are off the prednisone, you should ask your doctor to measure your serum cortisol and ACTH. This will tell you if the other adrenal is working and whether the pituitary gland is functioning normally. If you have this information, it will remove the guesswork so you will know whether you are having a return of your symptoms of Cushing's syndrome or whether there are other causes for your symptoms.

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

THE CANADIAN ADDISON SOCIETY
STATEMENT OF INCOME & EXPENSES
FOR THE PERIODS ENDING DECEMBER 31, 2007 AND SEPTEMBER 30, 2008

Cash on hand and in banks	January 1, 2008 \$20,865.16	January 1, 2007 \$18,394.25
 Income		
Dues Received – National	\$2,070.00	\$2,599.85
– Support Groups	355.00	385.00
Donations	839.26	2,871.14
Interest	<u>476.65</u>	<u>659.55</u>
	3,740.91	6,515.54
 Expenses		
Memorial Plaque	-	-
Newsletter	733.31	1,163.46
Web Site	188.95	174.90
Secretarial	600.00	1,200.00
Annual Meeting	73.22	126.14
Postage, stationery and supplies	600.66	132.71
Telephone	752.55	1,024.74
Support Group Expenses	27.25	146.36
Bank Charges	<u>55.15</u>	<u>76.32</u>
	\$3,031.09	\$4,044.63
 Cash on hand and in banks after adjusting for O/S cheques	September 30, 2008 <u>\$21,574.98</u>	December 31, 2007 <u>\$20,865.16</u>

THE CANADIAN ADDISON SOCIETY

Analysis of cash on hand & in banks as at September 30, 2008

Equitable Trust -

The Canadian Addison Society - \$6,831.95 @3.15% due November 10, 2008	
- \$10,033.14 @3.95% due December 22, 2008	\$16,865.09

TD Canada Trust -

The Canadian Addison Society	891.76
Montreal Support Group - Quebec	100.00
Ottawa Valley Support Group - Eastern Ontario	590.70
Brantford and District Support Group - Southern Ontario	1,730.26
Saskatchewan Support Group	40.00
Edmonton Support Group – Alberta	309.60
Lower Mainland (Vancouver) Support Group - British Columbia	557.57
Vancouver Island Support Group – Victoria	475.00
Vancouver Island Support Group – Nanaimo	<u>15.00</u>
Total	<u><u>\$21,574.98</u></u>



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Membership in The Canadian Addison Society is \$25.00 due January 1st 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

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 (Victoria) Support Group – BC + \$20.00 to Society

\$5.00 to Vancouver Island (Nanaimo) Support Group – BC + \$20.00 to Society

\$5.00 to Atlantic Provinces Support Group (NB/NS/NF/PEI)+ \$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: September 2007