



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. We advise readers to consult their own doctor before making changes to their Addison management program.

President's Message:

Dear Friends and fellow Addisonians:

Summer has finally come in with a bang with record breaking hot temperatures here in Ontario. It also brings with it the dangers of sun exposures and dehydration. Remember to drink lots of fluids and some physicians even suggest that we increase our salt intake (or Florinef). It may be a question that you wish to check with your own physician or endocrinologist for further information.

This past May, several of us here in Ontario got to meet Elizabeth Hill, our representative for The Canadian Addison Society in Saskatchewan. Elizabeth, her husband Kelly and two daughters were in Burlington visiting with relatives. We met for lunch and had a great time – 5 Addisonians and 4 “regulars”. It is not often that those with Addison's disease outnumber those without Addison's except in an Addison support meeting. However a couple of weeks later, we got the shocking news that Elizabeth's daughter Sarah was in a serious car accident and suffered undetermined brain injuries. She is now doing quite well in Rehab and will continue to work with physio and occupational therapy. School in the fall also seems a very good possibility. We wish Elizabeth and Sarah and the rest of the Hill family a bright and happy future. Many of us have received and completed the UK International Survey that was sent out in May. The survey is a group effort with the UK, Canada and Australia. Please, if you have not sent your survey back, it is not too late! We

have had a fairly good return response – 256 out of the 460 sent out but there are still others out there that will help with the survey results. Our deadline has been extended and there is lots of time left. If you think of anyone that did NOT get a copy of the survey and would like to receive one, just let me know and I will send two copies of the survey out – one for the Addisonian and one for a friend.

The emergency department situation in Canada is finally being addressed. Dr. Killinger, our medical advisor, has agreed to try and bring it before the Canadian Medical Association and hopefully to the division of the Emergency Physicians as well. To add to that on September 27th, we will have an Emergency physician Dr. Gene Jarrell speak to our local support group meeting here in Brantford. It is surely a date to mark on your calendar! He spoke originally to us in 1997 and many have requested his return visit.

If you have a concern or a problem that you feel may be of interest to other Addisonians, please let us know. We are all equal partners in this large group and sharing relevant information is very important to us all!

Have a safe and healthy summer and enjoy this lovely warm weather.

Sincerely,
Joan Southam

Important Announcements:

The Annual General Meeting for The Canadian Addison Society will take place on Saturday October 18th 2003 at The Ottawa Police Station (East). The building is on the north west corner of Tenth Line and St Joseph Blvd. Refer www.mapquest.com for directions.

AGENDA

Welcome
Presidents Address
Adoption of 2002 minutes
Financial Report
Charitable Funds and usage
Update on UK survey
Portable web and Email for Addison Society
Adoption of Executives for 2003/2004
New business

Slate of Officers:

President: Joan Southam
Vice President: Judy Stanley
Secretary: Elaine Hall
Treasurer: John Gordon

Director: Greeta McKague
Director: Jim Sadlish
Director: Francisca Swist
Director: Al McConnell
Director: Don Archi
Newsletter: Sharon Erickson

**** Please note that officers all will stand for re-election unless we hear otherwise! If you are interested in a position on the executive, please contact Joan Southam, President.

The Annual General meeting will be held from 10:30am to 12:00pm. We will then break for lunch until 1:00pm, when Dr. Mark Silverman will join us.

New News:

- The survey questionnaire is now online at <http://www.addisonsdisease.org.uk/> and look for the article on the UK questionnaire. It is about 12 pages long and can be printed off with Acrobat Reader. Anyone printing it, COMPLETE IT and send it off to one of the three addresses on the side panel – one in the UK, one in Canada and the other in Australia.
- Just received the sad news that Laurie Wizgird, the support leader for Michigan died. She has undergone treatment for Scleroderma and was doing well but went back into hospital when she was not feeling well. Her family said that her heart just stopped. She was a wonderful friend and she will be missed by many.

Highlights From Local Meetings:

Vancouver Island Support Group (Nanaimo)

The Vancouver Island Branch of the Canadian Addisons Society will meet in Nanaimo Saturday, Oct. 18 from 1-3 p.m. The meeting will be in Room G235 of Nanaimo Regional General Hospital. The meeting will be informal; no speaker is planned.

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

Vancouver Island Support Group (Victoria)

The Vancouver Island support group of the Canadian Addison Society met June 14, at Victoria General Hospital, for 2 hours of helpful discussion of experiences with Addison's disease. Nine attended, including a group from Nanaimo. The scheduled B.C. Ambulance Service supervisor was unable to attend.

Jim Sadlish reported on Joan Southam's recent correspondence with Dr. Donald Killinger, London, Ontario, medical adviser to the Canadian Addison Society. Following a letter Joan sent Dr. Killinger to outline the frustrations - and dangers - Addisonians often face because of others' ignorance about their condition, Dr. Killinger writes that he will contact the Canadian Medical Association and the Division of Emergency Physicians about the problem. Meanwhile, Jim is preparing an information

package to send to the District Superintendent of the B.C. Ambulance Service. One member reported that every time (4) in recent years she has called an ambulance, her warning to the paramedics that she has Addison's has been met with, "What is Addison's disease?" Some members carry detailed information about their medications and needed care, and this procedure was recommended for all with Addison's.

Discussion of treatment included:

- Florinef: With summer approaching, it was noted that heat intolerance is common and that extra salt and extra fluid is generally indicated. Some also temporarily increase Florinef dosage, though one member does not take Florinef at all.
- Cortisone: With both hydrocortisone and cortisone acetate there is continuing experimentation in both timing and amount of the doses to try to find the routine that gives the greatest and steadiest amount of energy. Daily dosage ranged from 17.5 mg/day of hydrocortisone to 50mg/day of cortisone acetate.
- Thyroid: Two reported they become shaky if they take too much thyroid replacement.
- DHEA: Concern was expressed regarding the Canadian government's latest strengthening of its objections to DHEA and its ban on this hormone. The reason given is that absence of DHEA is not considered life-threatening. Members' physicians find that their requests for Health Canada approval to permit DHEA replacement are no longer granted. However, Kripp's Pharmacy, the only Canadian source for government authorized DHEA, has found that a few patients have succeeded in getting Health Canada permission by asking their provincial government MLAs to intercede on their behalf.
- Calcium: Not a prescription drug but important for Addisonians because of their increased risk for bone loss. At least 1,500 mg/day are recommended, with calcium citrate the preferred form.

Discussing symptoms, several reported on frequent headaches, often the result of delay in either medication or meals. In the matter of familial autoimmune conditions, two remembered (years after the fact) that their late fathers had shown Addisonian symptoms (such as extreme weakness, darkening of the skin, salt craving, low blood pressure), though they had not been diagnosed back then. One member has a son who also has Addison's, another a niece with it as well as a nephew with diabetes. One's late mother had pernicious anemia and there is also a low thyroid problem in the extended family.

Recorded by Florence Weekes

The next meeting in Victoria will be Saturday, September 13, 2003, Room 1814, Victoria General Hospital, room 1814 from 1:00 to 3:00 PM.

For further information: Victoria meetings: Jim Sadlish at x699@victoria.tc.ca or 250-656-6270, or Florence Weekes at fmweekes@telus.net or 250-598-0321.

BC Lower Mainland Support Group

The May 31 meeting of the Lower Mainland group had two new people attending and three sent their regrets. The schedule for the next year will be: Sherbrooke Lounge, 330 Sherbrook Ave. New Westminster Oct. 18, 2003, Feb. 28, 2004 and June 5, 2004 Saturday from 1:00 - 3:00. There is parking on site or a cheaper rate down Sherbrooke at the day care centre. Marilyn is going to try to get someone from the Ambulance Service to speak to us. Any suggestions for guest speakers would be appreciated.

An update to using diabetic needles for injections. Judy went to demonstrate her kit and the alcohol swabs had erased the printing on the needles. Also a write up in the Illinois Newsletter mentioned the needles are not long enough for an intramuscular injection but are subcutaneous - this will be checked into.

The Hall's son in Salmon Arm when applying for his drivers license was asked if he had any medical conditions and was given an endorsement under the medical and physical disability section that reads 'addisonian on medication'. After e-mailing the Superintendent of Motor Vehicles no notation endorsement is needed. Recorded and submitted by Judy Stanley

Alberta Support Group

For information on this support group or any upcoming meetings, contact Francisca Swist at francisca@shaw.ca or Ginny LaValley at (780) 454-3866 – both are from Edmonton.

Saskatchewan Addison Support Group

If you wish information about this support group or upcoming meetings, contact Elizabeth Hill at Meadow Lake (306) 236-5483 or Rob Zaleschuk at Caronport (306) 756-2339.

Eastern Ontario Support Group

The next meeting of the Eastern Ontario branch will be held on May 24th at Robbies Italian Restaurant, St Laurent Boulevard, Ottawa. Lunch will begin at 12 noon, please call Sue Steedman at (613) 726-7414 if you are planning to attend.

Southern Ontario Support Group

The Southern Ontario Support Group met on April 26/03 at the Brantford Police Station. The meeting was opened by Lynda Daniels. We introduced ourselves and each of us reported how many years we have had Addison's Disease. Since we had a new member joining us, we answered his questions and recanted how important it was to carry a crisis kit.

Lynda then introduced our speaker, Wendy Andrews from Human Resources Development Canada. Wendy spoke to us about applying for Canada Pension Plan Disability, (CPPD) and the rules while you are receiving this benefit. CPPD paid out 2.8 billion dollars last year and receives approximately 60,000 application per year with about 34% of applications being accepted first time. At any one time they have approximately 281,000 clients. Some of her points were as follows:

- When applying for CPPD, it is very important to fill out the application forms as completely as possible.
- Pensions are not handed out by diagnosis – ONLY on an individual basis. You will need your doctors certification and support as well as any specialists that you have seen. This will probably make the biggest impact in your application if you have the full written support of your physicians.
- To qualify you must have contributed to the Canada Pension Plan in four of the last six years and be under the age of 65. Your amount of benefit will be made up of a flat rate amount plus

a second amount determined by how long and how much you have contributed while working. There is a provision made for the years spent raising children.

- Your disability may be physical or mental and must be "severe and prolonged". "Severe" means your condition prevents you from working regularly at any job and "prolonged" means your condition is long term or may result in your death.
- You must get in touch with Human Resources Development Canada if your situation changes. They may from time to time contact you or your doctor to confirm that you still meet the necessary conditions to continue benefits.
- You are allowed to work during your disability, but there is a cap on how much you can earn. In 2001 this cap was \$3,800. Volunteer work is also permitted and courses are encouraged and financially supported if you wish to try and return to the work force.
- CPPD offers training to those who are able to try and re-enter the job market.
- If your application is denied and you would like the board to reconsider your application, there is an appeal process in place for you to use. A booklet is available from Human Resources Canada, which explains this process.
- No disability is permanent since things are changing all the time with new drugs and treatments.

For further information, visit your local Human Resources Office or call 1-800-277-9914 or visit on the internet at www.hrdc-drhc.gc.ca/isp . Recorded and submitted by Helene Perry

Brantford Support Meeting – June 3, 2003

Opening remarks:

- Chairperson position for the Brantford Support Group is available. Lynda Daniels has completed her term and is going to the Phillipines to do missionary work. If interested in this chairperson position, please let us know.
- Addison Survey - please return even if not complete. Date has been extended due to heavy returns; very well-received in U.K.
- May 6/03 letter from Dr. Killinger regarding widespread problems in emergency rooms. Despite letters from doctors, Medic-Alert and caregivers, Addisonians are having difficulties getting the right help when needed. He has sent a letter to Canadian Medical Association and hopefully to the attention of Emergency Room Physicians.

Keynote Speaker:

- Margaret Brown, Peterborough Chapter Rep of the Canadian Celiac Association ... she is an addisonian as well.
- Spoke about Celiac Survey with expected results later in 2003.
- Celiac Annual Conference took place in Kamloops this year and had more information about related diseases like Addisons than any other year. They strongly recommend that Addisonians be screened for celiac disease; according to their expert, Dr. Cynthia Reuter from Atlanta Georgia with the largest patient load of celiacs in USA. Celiac disease is a life-long disorder in which the absorption surface of the small intestine (villae) is damaged by a protein called gluten. It causes malabsorption of carbohydrates, fat, protein, vitamins and minerals and can lead to anemia and colon cancer. Only cure at present is a gluten-free diet.

- Another related form of celiac is Dermatitis Herpetiformis, an itchy, burning red rash, diagnosed from skin biopsy.
- "Gold standard" test for celiac is a biopsy. Blood test is also available and useful for initial screening. This may or may not be covered under medical health plans.
- Vitamin and mineral supplements are recommended for celiacs because vitamin deficiencies can occur.
- Many celiacs are also lactose intolerant and should be aware of this.
- Untreated, can lead to vitamin/mineral deficiencies, osteoporosis (esp. relevant to Addisons), cancer, infertility, diabetes, thyroid, arthritis, Addisons.
- Higher numbers in Irish population; symptoms may "disappear" during teen years only to return later.
- Symptoms include: anemia, weakness, Vitamin A, D, E, K & B12 shortage, depression, diarrhea/constipation or both, steatorrhea (floating foaming feces), flatulence, abdominal bloating, abdominal pain, nausea, vomiting, mouth ulcers, weight loss, easy bruising of skin, bone/joint pain, edema of ankles and hands
- Screening tests in Canada available, more so at teaching hospitals. Other tests are recommended that include: Antiendomysial, IGA, EMA, Antitissue transglutaminase antibody - available in USA, not as likely in Canada. If these show disposition, a small bowel skin biopsy should be done.
- Gluten found in wheat, rye, barley, tricale, kamut, spelt. Also in oats, but mainly because it is processed with these other grains. An expert on oats is developing a chemical and gluten-free breed.
- Other sources are: medicines, herbs, cosmetics, hydrogized veg protein, malt and certain flavourings, seasonings, soups, sauces, dressings, baked goods, flavours.
- Canadian Celiac Association has a website for more information www.celiac.ca but several other chapters have excellent websites as well. Hamilton, ON www.penny.ca/hamilton.htm Edmonton, AB www.celiac.edmonton.ab/ca; Vancouver, BC www.scn.bc.ca/celiac/ There are 27 chapters of the Canadian Celiac Association and many have their own websites.
- Approx. 1 in 150 has celiac disease, which is more common than originally thought and numbers are increasing. Recorded and submitted by Angela Timms and Joan Southam

- The local support group meeting for Brantford will be on Saturday, Sept 27th from 1:30 – 5:00 p.m. at the Brantford City Police Station at the corner of the Wayne Gretzky Parkway and Elgin Street. Our guest speaker will be emergency physician Dr. Gene Jarrell head of The Brantford General Hospital Emergency Department.

Quebec Support Group

If you would like information about upcoming Quebec meetings or more information, please contact Sophie Lapointe at (514) 521-6538 or email sophiel@sympatico.ca

Dear Editor:

- Other members are hoping to connect with you -
 - If you have experienced "vitiligo" as part of your symptoms - Please respond c/o the editor.

- Emergency Room Visits:

Dear Fellow Addisonians:

I am enclosing part of the letter that I received from Dr. Killinger, our Medical Advisor for the Canadian Addison Society. As you can see from his response to our letter, he agrees that there is definitely a serious problem with care for Addisonians in an emergency situation that has to be addressed.

Hopefully bringing the situation to the Canadian Medical Association and the Division of Emergency Physicians in the Canadian Medical Association will get some type of action/recommendations that all Addisonians can have available to them in an emergency situation.

Sincerely,
Joan Southam *President,*
The Canadian Addison Society

Dear Joan:

Thank you very much for your recent email and the copies of the International Addison's Survey that you sent along. I agree that it is quite disturbing to hear that either the triage nurses or the emergency physicians are not taking into consideration the information provided when people with Addison's Disease go to the emergency department. I am sure that their response is that everyone has to be treated equally and no one can be favored and moved to the head of the line, but this argument has to be dealt with. The treatment for our patients can be sorted out in a matter of minutes rather than a matter of hours if the situation is dealt with appropriately.

I am going to try to bring this up with the Canadian Medical Association to see how we might expedite the situation. From your information it would appear that this problem is widespread and we may see if we can review this with the Division of Emergency Physicians in the Canadian Medical Association to bring this to their attention.

Sincerely,
Dr. D. K. Killinger

Reminders:

- Medical Questions and Answers - Dr. Donald Killinger, MD, PhD, FRCPC, from London, 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. Dr. Killinger has asked that we not write him directly, but to address your questions by letter/e-mail or fax through The Canadian Addison Society and they will be forwarded on to Dr. Killinger.
- Please – 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.

This is your newsletter! We need your contributions. Please send your stories, tips, ideas directly to our editor Sharon Erickson via email: ericksons@shaw.ca or c/o the Addison Society.
