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

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In this issue:

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.

Welcome to the New Liaison Secretary:

The Canadian Addison Society's search for a new Liaison Secretary has finally succeeded. We are pleased to announce that Irene Gordon has accepted this position, which is the contact point of the Society with both new and existing members and with other societies around the world, and will be responsible for our website.

Irene has several years of administrative knowledge and skill, has been actively involved in the Society for several years with her husband, John (Treasurer), helping track membership and maintaining the Society's charitable donation records.

Irene's computer and internet experience should ensure that our web site will always have the most current information available.

John and Irene are members through the Southern Ontario Chapter and regularly attend meetings held in Brantford. Because of John's involvement at the executive level, they have also attended Annual General Meetings.

Irene can be reached at the Society mailing address (indicated in the Newsletter header):

Liaison Secretary
193 Elgin Avenue West
Goderich ON N7A 2E7
Telephone #: 1-888-550-5582
Email: liaisonsecretary@addisonsociety.ca

Thank you, Irene, for accepting this pivotal position.

Important Announcements: Annual General Meeting

The 2005 **Annual General Meeting** of the Canadian Addison Society will take place on Saturday, **November 5th, 2005** at Deer Park United Church, 129 St. Clair Avenue West, in **Toronto**, Ontario (just a little east of Avenue Road), from 1:00 pm to 4 pm. Parking is available at the Church.

Agenda:

1) Reports from Directors
2) Financial Position to date
3) Election of Board Members
4) Recognition of Past Members
5) Membership Update
6) Web Site Development
7) Guest Speaker (to be determined)
8) Emergency Room Protocol

We encourage all members who are available to attend.

New News:

- Bill Horlick is trying to set up a local chapter of the Canadian Addison Society in the York / North Toronto area. If you are interested, please get in touch with Bill Horlick at bhorlick@netrover.com or 905 722 8498.

- Judy Stanley has found an interesting website from Children's Hospital in Vancouver which has good information pertaining to Children and Endocrine deficiency: www.cw.bc.ca/endodiab/handouts.asp. Check it out.

- We regret to inform you that Margaret David, a member from Fort Erie, Ontario, passed away in April of cancer. Our sympathies go out to her family.

Website Update:

As announced last November, the Canadian Addison Society has a new web address: http://www.addisonsociety.ca. Please ensure that this is the address you have bookmarked, as the old address no longer functions. (Our thanks to Joan Southam for hosting the previous site.)

The site is currently being revamped, updated and a whole lot of new information is being added. As well, it will have contact email addresses for general information (liaisonsecretary@addisonsociety.ca), membership and the newsletter, as well as email contacts for each of the regional representatives. We expect the changes to be visible on the site later this autumn.

Addisons in the 1950's:

Submitted by Evelyn Paul

I was diagnosed with Addison's Disease in December of l953, when I was 15 years old. I was very fortunate to have a mother who was a nurse and a family doctor who was very good at diagnosing illnesses. I was living on a farm at the time; I was very weak and had very dark skin (sound familiar?). I was sent to the Civic Hospital in Ottawa and was cared for there by an internal medicine specialist for three weeks. I came home a new person.

The discovery of cortisone had only happened a few years before this, so again I was very lucky because I could receive this treatment. I was prescribed cortisone pills, large red-coated salt pills and a monthly injection of another form of cortisone. Since we lived in the country, I boarded in Carleton Place during the winter and took the school bus to high school in the fall and spring. This meant that I (at age 15) was responsible for taking my own medication regularly. My sister was a nurse and so she was able to give me my injections. I used to wonder why my mother was always asking me if I had my pills with me. Now that I have had teenage children, I understand!! All of this happened before any kind of OHIP, so my hospital care and medication must have been a big financial strain on my parents since I am one of six children. However, they never made me feel upset about this aspect of my care.

One of the things I remember about those years was not being able to talk to anyone who had this condition, and wondering why I had to go through this. The first time I had the flu and was vomiting, we didn't realize that I needed to go to the hospital. I ended up unconscious, and thus became the second person to be admitted to the new Carleton Place Hospital. After the IV treatment, I was fine. And I never had that happen again.

When we had the first meeting of the Addison's Society at our house in Perth, it was like a dream come true to be sitting in a room with five other people, who, as one doctor said, "You are a very select group".

When my doctor came into that hospital room 52 years ago to tell me I had Addison's Disease, he said to me "You are not an invalid and don't ever let anyone make you one". I guess that advice has stayed with me over the years as I have been able to have three children, now five grandchildren, have lived in three provinces, been married to a minister for 43 years, have a teaching career and a good life.

Setting up a Local Support Group: Getting in Touch

Submitted by Steve McKenna

When you are first diagnosed with Addison's Disease, it's a scary and lonely feeling since Addison's is somewhat rare. It's hard to know what it will mean to you, whether certain feelings or reactions are normal, how to deal with stressful situations, and, even, what stress means for an Addisonian. Often your family doctor's knowledge is limited, and your endocrinologist is too busy to provide day-to-day advice.

This is what the Canadian Addison Society is all about. It lets you know that you are not alone, and gives you others to share knowledge and experience with.

The Society not only offers information and support to Addisonians and their families, but also education about the disease to the medical community and the public.

The purpose of joining or putting together a local support group is to have personal contact with others who have experienced the same problems as you are having. On a personal note, when I was finally diagnosed with this condition, meeting with other Addisonians was extremely helpful.

So, the first step is to become a member of the Canadian Addison Society. The next is to join a local support group. If there is none in your area, get in touch with a couple of groups elsewhere in Canada to learn how they work, where they meet, how they run their meetings, etc. Next, try to contact others who also suffer from Addison's and start creating a local support group. The Society can help identify members already in your area who might be interested in a local group. As well, an announcement can be put on the Society website to publicize your new local group.

To let others know of a new local support group, use as many ways as you can, especially freebies, such as:

- announcements in local community newspapers or in the Community section of the major newspaper
- medical flyers in grocery stores, clinics, doctors' offices etc.

- a letter to endocrinologists' offices in your catchment area (a listing should be available through the provincial Medical Association)
- contact physicians with a poster or letter for display in their waiting rooms
- community spots on radio and TV
- give a copy of the Society Newsletter with your local support group poster to anyone in the medical community.

In order for you, and your group, to become part of the Society, you must be members in good standing – this is very important.

Once a local group shows that it is viable, it may become a formal local support group under the Society umbrella, and receive certain monetary support through annual membership fees.

Please remember, support is one of the best tools in the on-going treatment of Addison's disease, and getting and staying in touch is what it is all about. Since it is such a rare disease and the medical community does not know a whole lot about it, it makes it all that more important for those affected by this condition to meet and share their experiences with each other and the medical community.

Highlights from Local Meetings:

Vancouver Island Support Group (Nanaimo)

Nanaimo meetings: Christy Lapi at clapi@shaw.ca, or 250-245-7554 or Barbara Hunn at bhunn@shaw.ca 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 met on Saturday, June 4, at the Victoria General Hospital. Thirteen people attended, eight with Addison's. The two-hour meeting was filled with exchanging news, experiences, questions and helpful discussion.

Regretfully, Maxine Carpenter of Errington passed away recently from cancer. Maxine had been a support group member attending the Nanaimo meetings and a good friend to several members.

- Promising news about a new French drug for treating osteoporosis, not yet available in Canada. **Strontium ranelate** increases bone formation and decreases bone resorption. It has been shown to reduce the risk of vertebral fractures and increase bone mineral density. Some internet sites say that strontium is the active ingredient in this drug and that health supplements with strontium may be beneficial. Sources for strontium supplements are few but one is Aor (aor.ca), an Alberta company with distributors selling 'Strontium Support'.

Ref: The New England Journal of Medicine Vol 350:459-468 Jan 29, 2004 No 5

- A report in the Archives of Internal Medicine Vol. 165 No 4. February 28/05 titled Increased Prevalence of Celiac Disease and Need for Routine Screening Among Patients With Osteoporosis, investigated the link between celiac disease and osteoporosis. Symptoms of celiac disease are often so subtle that many people don't know they have it. This study suggests that people with celiac disease should follow a non-gluten diet which promotes intestinal healing and results in better absorption of calcium and vitamin D and a reversal of bone loss.

- Questions were asked about injecting Solu-Cortef. Many of us keep at hand an injection kit consisting of a Solu-Cortef vial, syringe and alcohol swab, but most have not actually used it. Evidently, mixing the two ingredients in the vial, prior to injection, can be difficult. It was suggested that we ask for a demonstration by a health professional. For on-line instructions or downloadable pdf info, visit the UK Addison's Self-Help Group website at: http://www.adshg.org.uk/info/emergency/solucortefguide.html. A manual for injecting Solu-Cortef is available at: http://www.cc.nih.gov/ccc/patient_education/pepubs/mngadrins.pdf.

- Source information was requested for the "Living With Addison's Disease" Owner's Manual which is available in pdf from the UK Addison's Self-Help Group website: http://www.adshg.org.uk/info/manual/page1.html.

- DHEA supplements were again a topic of interest. There are few sources of supply available to us now that the federal government has withdrawn authorization for Canadian distribution. However, internet stores have served some members. Stannic (tin) oxide has been used by some to alleviate the side effect of scalp acne and itching. This is available from Kripp's Pharmacy in Vancouver for about $20 per 100 tablets, plus mailing. Members taking DHEA have found that it gives more energy and helps them deal better with stress.

- Thyroid antibody tests prescribed by your endocrinologist may show that no antibodies are present in your system at the time of testing; however, you can still develop thyroid antibodies in the future. Even without thyroid antibodies we can evidently develop thyroid disorders requiring replacement.
- Victoria endocrinologist, Dr. Richard Phillips, had been asked if "arrhythmia" should be included as a symptom of adrenal crisis in our Emergency Letter. He felt that focusing on low blood pressure was more appropriate.

- One member advised that a homeopathic reference showed low tolerance to pork could indicate an adrenal disorder. Three Addisonians present had some intolerance to pork ranging from slight discomfort to violent allergic reactions.

- There was a query about the BC PharmaCare coverage for the financial cost of replacement medication and possibility of qualifying for a disability income. The PharmaCare program will pay a portion of drug costs once a certain deductible is reached. Your family's net income is used to determine your family deductible. If your family income has decreased significantly, you may apply for a lower deductible by calling 1-800-387-4977. Addison's Disease alone is a treatable disorder so it was thought unlikely that we would be considered to have a disability or qualify for assistance. However, it was suggested that those concerned contact the B.C. Ministry of Human Resources to clarify eligibility. There is a Disability Tax Credit available for federal income tax, although it seems difficult to qualify. I have more information for those interested or call 1-800-267-1267. Also there may be a program in place for medical EI which could be worth looking into.

- Other topics discussed were:
    - getting a regular bone density check and taking calcium supplements
    - whether taking calcium supplements contributes to calcium deposits, joint pain or kidney stones
    - Vitamin E may cause blood thinning
    - viewing a doctor's letter stating conditions, medications and treatment in an emergency
    - comparing medications, dosages and side effects
    - regular check-ups for signs of glaucoma
    - lengthy period before diagnosing Addison's and the resultant harmful stress on general health

Submitted by Jim Sadlish

The next Vancouver Island support group meeting is scheduled for **October 15, 2005**, at the Victoria General Hospital in Room 1814 from 1:00 to 3:00 PM. One of our members, Colleen, a nurse at VGH, will arrange to demonstrate the injecting of Solu-Cortef, our emergency injection. We ask members to please bring their outdated vials of Solu-Cortef for this demonstration. There will be a discussion on emergency meds after the demonstration.

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

BC Lower Mainland Support Group

The Lower Mainland support Group met June 4, 2005 with 14 members family and friends present. Canadian Addison Society membership renewal forms were available.

- We have some sad news: Sheralyn, daughter of Louise and John Calder, has passed away, as has Sherri Bychyk's husband. Our condolences to the families. Cards have been sent.

- Once again we will be having UBC First Year Medical students interviewing members for our October 29th, 2005, meeting as part of their curriculum. Our initial meeting last year was well received by both the medical students and our members. We had the highest incidence of replies to the forms sent out following interviews. The government has opened up 30 more positions in the program. If members are unable to attend the meeting, arrangements can be made for interviews in their homes. Marilyn and I will be contacting members in August and September to see how many would like to be interviewed. This is of great benefit to us as it makes the students aware of our condition and may save a life in the future. For those that attended last year, thank you for coming and we hope you will commit to this year as well.

- I received an email from Catherine Semple, now living in Ottawa. She says hello to everyone. She was recently diagnosed with osteoporosis and is seeking information on appropriate fitness programs.

- Reply to our letter to the Ministry of Health BC Ambulance Service: A reply will be sent regarding the best approach to awareness of Addison's disease and their teaching program.

- We will continue with our quest to have all ER's in BC on a common database to save time when entering the system.

- Below are websites mentioned at the meeting:
    - Web site: UK Addison's booklet http://wwwsurreyweb.org.uk/adshg/ADSHGGUIDELINES.pdf
    - The Canadian Addison Society is redesigning its website and updating the links. A good site to look at is the *Ottawa Hospital Protocol (http://addisonsdisease.tripod.com/id4.html).*
    - MedicAlert www.medicalert.org. Addisonians are encouraged to wear a MedicAlert necklace or bracelet, inscribed with "*Adrenal Insufficiency - needs Cortisone*" or "*Addisons - Cortisone Dependent*". You can also list any life-threatening allergies etc. Make sure it does not look like a piece of jewelry or it risks being missed by medical personnel.

- NADF (National Adrenal Disease Foundation) in the US is working on an emergency project, also update on research and new clinical trial for adrenoleukodystrophy (ADL) and Adrenomeyeloneuropathy (AMN) - Lorenzo's oil is being tested. An update on Osteoporosis and Diabetes Gene from NORD and an article on Sleeping from the NZ Newsletter, all printed with permission. An Emergency Information sheet and letter to Emergency Personnel were also included. The use of Medicool's Insulin protector Case or insulated carrying cases to keep Solu-Merol, Solu-Cortef or Dexamethasone etc. stored at the optimum temperature (of 68' to 77'F) to ensure viability.

- Reminder to keep well hydrated for summer. An easy re-hydration mix: 1 litre water, 2 tablespoons sugar, ¼ teaspoon salt, 1 tablespoon lemon juice for flavour. Or, Gastrolyte can be purchased from your local pharmacy

- The following article on DHEA and Addison's has been brought to our attention by a member in Victoria:

DHEA May Prevent Diabetes in Hypoadrenal Women

Reuters Health Information 2005. © 2005 Reuters Ltd.
By David Douglas

NEW YORK (Reuters Health) Apr 04 - Treatment with dehydroepiandrosterone (DHEA) significantly increases insulin sensitivity in hypoadrenal women and may prevent the onset of type 2 diabetes, according to the results of a 12-week trial.

As senior investigator Dr. K. Sreekumaran Nair told Reuters Health, "in women with adrenal deficiency or who had their adrenal gland removed, DHEA replacement may prevent the occurrence of diabetes."

Dr. Nair and colleagues at the Mayo Clinic and Foundation, Rochester, Minnesota randomized 28 hypoadrenal women to a daily 50-mg dose of DHEA or placebo. After 12 weeks, the team found that fasting plasma insulin levels were significantly lower with DHEA (42 versus 53 pmol/L). This was also true of glucagon levels (178 versus 195 pmol/L), the researchers report in the March issue of Diabetes. Moreover, "the average amount of glucose needed to maintain similar blood glucose levels while infusing the same insulin dosages was higher during DHEA administration (358 versus 320 mg per minute)," Dr. Nair's group reports. Rates of endogenous glucose production did not change with DHEA treatment. DHEA also prompted a significant reduction in total cholesterol, LDL cholesterol, triglycerides and HDL cholesterol.

Thus, the researchers conclude that "DHEA replacement could have a potential impact in preventing type 2 diabetes." However, added Dr. Nair, "we need long-term studies." Also an area for investigation is whether "in older people, DHEA replacement has any effect on insulin sensitivity." Diabetes 2005;54:765-769

The next meetings of the BC Lower Mainland Group: will be held **October 29, 2005**, February 25, 2006, and June 3, 2006, in the Sherbrooke Lounge, Sherbrooke Centre, 260 Sherbrooke St., New Westminster B.C. from 1:00 to 3:00 p.m. Please mark your calendars.

Please note that the parking lot on Sherbrooke Street has been taken over by the city and is no longer available for cheap parking. However, metered street parking down Sherbrooke St. is $1.00/hour for up to 10 hours. If using the RCH and Sherbrooke lots, it is better to pay with a credit card as the machines regularly fail.

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.

Alberta Support Group

- The Alberta Support Group is gathering data to demonstrate a need for an emergency protocol in a crisis situation for an Addisonian. We are interested in any personal experiences that resulted in unsatisfactory treatment in the ER during a crisis. Please send your experiences by e-mail to francisca@shaw.ca or by fax to (780) 482-5016 (no cover sheet needed). Please ensure that your full name and contact information are included.

- The next meeting of the Alberta support group is scheduled for Saturday **October 15, 2005**, at 2:00 PM, at the Royal Glenora Club, 11160 River Valley Road, Edmonton. Check the board in the Glenora Club social entrance for the specific room.

  One of the agenda items will be to discuss how to implement an Alberta emergency room protocol for treatment of a person in an Addisonian crisis. As well, Athena Elton, new President of the Canadian Addison Society, will be attending.

  Please let either Ginny Snaychuk (780) 454-3866, e-mail glav@telus.net; or Francisca Swist (780) 488-8540, e-mail francisca@shaw.ca know if you are planning to attend. Thanks and hope to see you there!

For information on this support group or any upcoming meetings, contact Francisca Swist at francisca@shaw.ca or Ginny Snaychuk at 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 or elizabeth.h@pnrha.ca.

Southern Ontario Support Group

On Saturday April 16, 2005, the Southern Ontario Group held its meeting at the Brantford City Police Station.

The guest speaker was Dr. Holly Fennell, a naturopath practicing in Toronto. Dr. Fennell gave a brief overview of naturopathic medicine in general and how it could assist those with Addison’s disease.

If anyone would like a copy of the presentation, please contact Jordan Latter at annemarielatter@yahoo.com for an emailed copy of the PowerPoint presentation.

For further information, contact Jordan Latter at annemarielatter@yahoo.ca or (905) 905-794-7903 or Janet Stewart (416) 265-3027 janetstewart@rogers.com.

Eastern Ontario Support Group

The next meeting will be held on **Saturday, October 15, 2005**, at Robbie's Restaurant on St. Laurent Boulevard in Ottawa at noon. We have learned that Algonquin College has a fairly new Advanced Care Program for paramedics/ambulance attendants. Several of us have noticed an improvement in our emergency care, and it seems to be related to this program. We are attempting to schedule a graduate of the program to speak at our next meeting.

For information, please contact Sue Steedman at (613) 726-7414 or steedman@magma.ca (or Teresa Seasons at tseasons@magma.ca).

Québec Support Group

If you are aware of any support group activities in Québec, or have a contact name or address, please forward the information to the Newsletter editor at newsletter@addisonsociety.ca.

Help Needed:

Our special thanks to Evelyn Paul for submitting her article on *Addisons in the 1950's* for this Newsletter. We hope more members will contact us to share experiences or what you've learned or to submit articles. To get you started, here are a few ideas members have asked to hear about::

- services the regional contact person can provide to local members
- benefits and how to designate the Canadian Addison Society, a registered charity, in a Will or as a remembrance
- living with Addisons, from a spouse's perspective
- how to advocate for an Addisonian in crisis – a checklist of information
- how to educate family and friends on Addisons—do's and don'ts

Please send your stories and articles directly to newsletter@addisonsociety.ca or c/o the Addison Society.

Reminders:

- **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. Dr. Killinger has asked that we not write to him directly, but rather address our questions by letter, e-mail or fax through The

Canadian Addison Society and they will be forwarded to Dr. Killinger. This will be easier to do once we have our web site fully operational.

- **NOTE: –** 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.