



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

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President's Message:

Dear Friends,

The Montreal meeting planned for June instead will be held in September or October, as no speaker confirmed as yet. Please contact Sybil Harrison at [514] 486-9817 for information. I also wish to have a meeting in the Kingston area in the fall and also in my own area, but do not have dates as yet. If interested in either please call me at [519] 538-4012 or e-mail to gfraser@grey.net. I should have confirmed dates by the September newsletter.

In the meantime I hope you all have a happy, healthy summer. Thank you for the e-mails. If you are in the Meaford area, please give me a call.

Sincerely
Greta.

!!! NEW WEBSITE !!!

The Canadian Addison Society has a new WEBSITE! Through the continued efforts of Francisca Swist from Alberta and the technical support of Geoff Charlebois from Studioline Consulting in Ontario, the website is up and running! Please check it out, check out the website links and please let us know if there is any problem in accessing any of them or whether you can see where information could be added/changed. Please add us as a link to any other Addison site. Your comments are welcome.

Our site is at: <http://members.home.net/jsoutham>

Recognition and appreciation goes out to Francisca Swist for her hard work and dedication in helping to get the new website up and running. A cheque has been sent to Francisca for \$100.00 - the money voted on at the last annual meeting. Thank you Francisca for a fine job well done!

The following articles/information submitted by Joan Southam:

Acknowledgements:

The Canadian Addison Society wishes to acknowledge and thank Beverly Ruffo, Chair of the **Canadian Celiac Association** Conference 2000, that was held in Hamilton, Ontario on May 27, 2000. Ms. Ruffo kindly invited us to distribute information materials at their conference. Joan took down to Hamilton 200 brochures and 150 business cards for distribution.

Also, The Canadian Addison Society wishes to thank Mrs. Barbara Cobbe, President of the London Area Chapter of the **Thyroid Foundation of Canada**. We have exchanged information packets and we now have some very interesting information provided by the Canadian Thyroid Foundation on different thyroid conditions. We will endeavor to present this information in future newsletters, as space allows.

Three emergency information cards have been forwarded to Neil Atwood in Australia and he will complete the finished cards and send them to us. He has forwarded his cost - \$7.00 US (\$10.00 Canadian) - and that will be sent at the completion, since he has to pay \$10. Australian to change over one cheque or money order. There is still time to send your information in as he will do another set for us if there is a need. A sampling of this emergency card was printed in the April 2000 edition of our newsletter.

Convention News-submitted by Joan Southam (Canadian Addison Society)

Recently Greeta Fraser and I were the guests of the National Adrenal Diseases Foundation (NADF) in Toronto, Ontario as hosts of their booth at the Endo Convention 2000, held this year at the Toronto Convention Centre (June 21-24). It was an exciting time but also a very busy time. After unpacking and setting up all the information, from the NADF as well as some from the Canadian Addison Society, we were ready.

Wednesday morning was the official beginning of the convention and what a busy time -thousands of people from all over the world descended on the Convention Centre. We were in the below ground levels and all was going well until the lights went out! The very large and crowded convention hall was in total darkness until the emergency lights finally came on at the far end of the hall. It was one of two times that the lights went out!

Even though the Endo 2000 is a North America based convention, there were visitors from all over the world - physicians, researchers, endocrine nursing staff and other support staff. We handed out a lot of patient support information and material, answered many questions, discussed a lot of different and new ideas, and met some very nice people. There were many physicians from Europe and they were especially interested in Congenital Adrenal Hyperplasia (CAH) information since many of the countries (especially Germany) do screening for CAR at birth. Many physicians from South America were very interested in any and all information on Addison's disease and some in Cushings.

We also had a chance to meet Dr. Paul Margulies, the Medical Director of the NADF and author of many of the information pamphlets and a regular contributor in the NADF newsletters. We also met Dr. Phyllis W. Speiser, author of the NADF CAH pamphlet.

Many of the presenters, either in the oral presentation or the poster presentations, had Diabetes and Diabetes research as a topic. Many may remember Dr. Don Killinger and associates from London Ontario, who did the two-year DHEA research with 62 Ontario Addisonians. He and his associates had two poster presentations - both on the one-year information of the two-year research project on DHEA. They are sorting through the second year research information now and hopefully that will be in print near the end of the year.

Many of the physicians especially asked "WHAT" autoimmune disease that we suffered from. Greeta has several different autoimmune diseases, including Addison's disease, thyroid, diabetes and more and I have had for over forty years - Addison's disease. Both raised many eyebrows and brought forth a lot of questions.

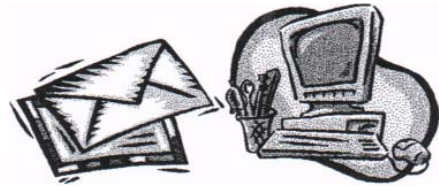
Thank you again to the NADF from Greeta and I for this wonderful experience.

Important Dates:

The National Annual Meeting will be held on Saturday, September 23rd from 10:00a.m. to 4:30p.m. at the Brantford, Ontario Police Station on Wayne Gretsky Pkwy. Business in the am. A potluck lunch at noon - everybody please bring finger food. Dr. Killinger or one of his colleagues will speak at about 1:45p.m. If anyone has any issues or thoughts that they wish presented or discussed at this meeting, please call/write or e-mail your concerns to Joan or Greeta before this date.

Mark your calendars!

The next meeting for the **Southern Ontario Support Group** will be held in Brantford Ontario on **Saturday, August 12th** starting at 1:30p.m. Meeting will take place at the Brantford Police Station, Wayne Gretsky Pkwy. Dr. Cameron Purdon, an endocrinologist and thyroid specialist from Guelph will be the speaker.



Letters to the Editor

This is a new section to the newsletter in which we hope everyone will feel free to participate. It is meant to be your vehicle for offering your opinions, ideas, tips or experiences in order to share with and help other Addisonians and yourself. It is not only a place of exchange and sharing, but also a place to voice your frustrations that come from dealing with people, professional or otherwise, while living life with Addison's.

Having a rare condition such as Addison's Disease can leave a person to feel disassociated and misunderstood, especially during those times when you're just not quite yourself. We've all learned to cope in our own way in order to save our precious energy. Share with others what bugs you and how you think things could/should improve for Addisonians. Perhaps you have a tip or two or maybe an incident happened to you while at home, traveling or at work, that you could share with others. Tell us how you have coped, or are coping daily. Maybe something amusing happened to you concerning your Addison's Disease that may give another reader a lift and a chuckle for the day.

Has anyone had some surgery or been very ill and dealing with Addison's? Did your doctor take the time to explain what to expect. Most of us have wondered what is involved if suddenly I needed surgery. What can I expect to happen to prepare myself for surgery and recovery? These are genuine concerns/fears for most of us. A little information/story about your experiences, good or bad, could be a big help to a fellow Addisonian. Remember, we are all in this together and for life, so we should share our experiences in order to help each other to cope. Maybe you would like to make some suggestions on how we could improve our newsletter.

Let us know if you wish to be anonymous. You don't have to be a great writer to share with your own words; all submissions are welcome. Very few of us are great writers.

If you have some ideas/opinions/experiences/funny or horror stories, or just something to get off your chest, mail it to the address or send by e-mail below.

Helene Perry
75 WendoverDrive#218
Hamilton, Ontario
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Or e-mail to: herry@interlynx.net

Highlights From Local Meetings

Vancouver Island Support Group (Victoria) - April 15/2000

Following is a report from Florence Weekes:

Options in naturopathy were described to the Vancouver Island support group at their meeting April 15th at Victoria General Hospital. Peter Bennert, ND,DHANP, told of the work being done with various conditions at his Helios Clinic, Saanichton, BC. Dr. Bennett's Addison's presentation, which he illustrated with slides, provoked many questions and much interested discussion from the group, who regularly share new information and ideas on the best ways to deal with their medical/life situations.

Dr. Bennett first gave a detailed picture of adrenocortical deficiency and its effects. He pointed out that, although cortisol is vital, Addison's disease should not be treated in isolation. "It is a myopic viewpoint," he said, "to think health problems can be related to only one system. The structure and function of all glands are related." He particularly stressed the relationship of cortisol to the immune system, 60% of which he said is in the gastrointestinal system.

The work of the late Dr. Hans Selye was cited in describing adaptations to stress, which run from the alarm phase of fight or flight, through the resistance phase of adaptation, to the exhaustion phase of multiple system failure. Citing the role of cortisol in gluconogenesis, Dr. Bennett pointed out that when a patient has to deal with metabolic stress or trauma, "It all comes down to cortisol because every unit requires glucose." His information-packed lecture touched on many items from the dozens of hormones secreted by normal adrenals (and depleted or missing for Addisonians) to mood changes, stomach ulcers, allergies and other immune-system responses, diet, food supplements, exercise, basal metabolic rate in relation to thyroid output, the biochemical pathways of steroid hormones, types of environmental, mental and physiological stress, and sundry other subjects of interest to persons in an Addisonian support group such as ours.

There was much interest in Dr. Bennett's statement, news to most, that, "All steroids of diagnostic significance can now be measured in the saliva." Such a simple, non-invasive, inexpensive test could make it much easier to monitor medication on an individual basis and adapt it to different or changing needs. Testing is apparently not yet available in Canada; the Helios Clinic sends specimens to U.S. laboratories for analysis. It was pointed out that Aaronson's compounding pharmacy on Fort Street, Victoria, can also order test kits. (A later check by a member found saliva testing for steroids available from several U.S. internet sites. These include tests for cortisol, DHEA, IgF 1, progesterone, testosterone, estrogen, and estradiol.)

The Vancouver Island support group will meet again **July 8, at Victoria General Hospital, room 1814 next to the cafeteria, 1 p.m. to 3 p.m.** Meanwhile, to try to help more up-island Addisonians, a new group is planned and will hold its first meeting June 3, in

Nanaimo at the Nanaimo Regional Hospital. Room G235A. Christy will send out a notice re further directions before the Nanaimo meeting.

For information about Vancouver Island Addison's support group, please call Jim Sadlish at 250-656-6770 or e-mail at wx699@victoria.tc.ca or Florence Weekes at 250-598-0321 or e-mail at fmweekes@islandnet.com.

Vancouver Island Support Group (Nanaimo) - June 3/2000 - First Meeting

Following is a report from Florence Weekes:

Vancouver Island's branch of the Canadian Addison Society met at Nanaimo Regional General Hospital, June 3rd, in order to allow more up-island people to come without having to drive to Victoria. The meeting, arranged by Christy Lapi, attracted 22, 17 with adrenal-related conditions and 5 as supporters.

It was noted there is no endocrinologist in Nanaimo. The wish was expressed by several that one would settle there, and also that there could be more endocrine training for both emergency-room staff and ambulance attendants, not only there but in all British Columbia communities.

The group enjoyed a major educational experience as everyone introduced themselves, in turn, around the table, and gave a short history of their symptoms, diagnosis, complications and treatment. More than one was initially prescribed anti-depressant treatment or worried they were becoming hypochondria! as symptoms worsened, energy flagged, discouragement set in and diagnosis remained illusive. It was common for diagnosis to come only after crisis brought on by such events as kidney problems, urinary infection, shingles or staphylococcal infection. Serendipity played a part for some: one's physician had been a doctor in the navy, where Addison's is, or was, apparently more often found, and another's physician had been taught by a professor who himself had the condition.

Hypothyroidism proved common among the group, as well as heat intolerance. "The heat just kills me," and "heat really bothers me," and "a minute of cool and I'm fine," were all heard. One young woman wondered about having children and was reassured by a member who has successfully borne two children and had major surgeries since her diagnosis.

Interest was expressed in supplementing prescription cortisone with plant hormones, but it was pointed out that manufactured drugs are more easily measured for dosage. There was considerable variety in daily drug regimens reported, some taking prednisone, some cortisone acetate, some on florinef, some not - and with much variation in time and amount of these replacements. It was stressed that every person is different and that treatment must be tailored to the individual as well as to changes in the person's life or health situation, and that dosage should always be enough but not more than required.

Replacement of another cortical hormone, dihydroepiandrosterol (DHEA), precursor to

adrenal androgens and estrogens, was of interest to several. Some are obtaining it from the United States and some are in the process of obtaining it through their own doctors, who can apply to federal health officials for permission to import and prescribe it.

The pre-filled emergency syringes of dexamethasone the Addison Society has been trying to bring into Canada were reported to be no longer being manufactured even in the United States, because of the small potential market. One member passed around the Solu-cortef vial and syringe available on prescription here and which she carries. The drug comes in an hour-glass shaped glass vial, with a crystal of the drug in one end and sterile water in the other. In emergency, the vial must be shaken to dissolve the drug, then the vial broken, then the fluid drawn into the syringe, all before it can be injected.

The woman's family is trained to administer it when needed but it was agreed that for an Addisonian alone facing crisis, rapidly losing both mental and physical energy, it would be too complicated and cumbersome to use.

Another meeting at the **Nanaimo hospital, room G235A, is tentatively set for Saturday, September 23, 1 p.m. to 3 p.m.** For details or changes, please contact Christy Lapi, Ladysmith, telephone 250-245-7554 or e-mail clapi@island.net. The next meeting in Victoria will be at Victoria General Hospital, room 1814, right beside the cafeteria entrance, on Saturday, July 8, 1 p.m. to 3 p.m. For information, please call Jim Sadlish at 250-656-6270 or e-mail at wx699@victoria.tc.ca or Florence Weekes at 250-598-0321 or fmweekes@islandnet.com.

BC Lower Mainland Support Group

Following is a report from Judy Stanley:

Please note the dates for the upcoming years meetings. These have now been confirmed with RCH. If you have any suggestions or know a guest speaker for next year, please let me know so arrangements can be made. Thanks to everyone who let me know they were unable to attend. Have a great summer and I'll look forward to seeing you in the fall.

Twelve people were at the June 17th meeting and four sent their regrets. It was nice to see so many out on one of our few nice weekends this year. Jackie had her adrenals removed two weeks ago and is looking forward to feeling better soon. We have our own marathon runner. Donna Smith participated in 2 - 10 K runs and a half marathon of 21 K in May. Congratulations!

There are several publications available from CAS. A new Dutch Study book 'Gushing Patients in the Netherlands' - \$35.00 Canadian, as it is bigger and ring bound. The study is based on 325 patients and ex-patients with Cushings.

1. The latest CAS Newsletter has a page and a half of websites, highlights from local meetings. If you haven't sent in your membership yet you are missing a lot of valuable information.

2. All the newsletters NADF, CAS, Australian, NZ have medical columns. The Australian, NADF, CAS all have great articles posted on the internet. If you don't have a computer there are always ones available in your local library for research.

Connie Waterman was our guest speaker talking about Osteofit, exercise for those with osteoporosis, limited energy and/or mobility. Connie was nominated for the BC Women of Distinction Award this year for her work founding the program.

- Corticoids cause secondary osteoporosis and osteopenia as cortisone robs bones of calcium
- ¼ of women over 50 have osteoporosis and ½ over 70
- 1 in 8 men over 50 also have osteoporosis - men are usually diagnosed later in life and it is usually a genetic disease in men
- Osteofit is a strengthening and stretching program done twice a week as opposed to a cardio workout which needs to be done every day
- objectives are to improve posture, bone density, reduce or eliminate pains associated with osteo, reduce falls (particularly in older people), increase strength, coordination and balance
- 50 % of elderly people who fall will be in care after and 50 % of those will die
- prevention is the best remedy
- the DEXA test is to measure the amount of calcium in bone and soft tissue

Exercise

- to increase bone density it has to be a weight bearing exercise i.e. walking, running, highland dance not swimming, stair master machines etc. You need impact to make stronger muscles which will increase bone density where the muscles are attached to bone.
- research is not available on how much but it's best to increase gradually what you are doing
- walking minimum of 5 days a week 30 minutes a day. It can be broken into shorter walks
- side arm raises with weight increases stabilizer muscles which increase spinal bone density
- beware of forward flexation of spine
- helps maintain or improve posture
- your spine is a lacy structure of cross bridges which can start to crush and will result in a compression fractures
- goal is to strengthen back muscles to stand erect by strengthening erector spiny muscles
- to relieve your back - sit up straight in your chair every 30 minutes
- Connie demonstrated some exercises for strengthening stabilizers, shoulder blades, abdominals, ham string stretch
- information brochures which will be available at the next meeting

Meetings for the upcoming year will be October 14th, 2000, February 17th' and May 26th, 2001. Please mark your calendar. Judy Stanley -604-936-6694 or e-mail:

bugbee@direct.ca.

Alberta Addison Support Group Meeting

Save-On-Foods - Mayfield Common (167 St & Stony Plain Road)
Edmonton Alberta
April 29, 2000

Doret Cheng a pharmacist from London Drugs spoke to the group regarding several types of medications that are typically taken by individuals with Addisons. Her discussions surrounded the potency and interactions between the medications.

One new Addisonian attended. The meeting was very informal and consisted mainly of casual discussions.

A comment made by Doret Cheng, who spoke at the meeting - (Getting back to you about the availability of Solu-Cortef... according to my wholesalers, I can order it from them anytime, so I don't see why other pharmacies can't).

Next meeting Fall 2000.

Let's Hear It For Life!

Salmon Sandwich Puffs:

Yesterday's favorite, creamed salmon on toast, is updated in this streamlined recipe. It's lower in fat and doesn't require cream sauce preparation. Instead, simply combine all ingredients, fold in beaten egg whites and use to top whole grain bread toast slices or toasted English muffin halves. You can use white bread, but do try one of your favorite grainy breads for a much better texture and nutritional benefit.

| | |
|-------------------------------|---|
| 1 can salmon (7.5oz/213g) | 2 egg whites |
| ¼ cup light mayonnaise (50ml) | 6 slices toasted bread or 3 English muffins, halved and toasted |
| ½ tsp horseradish (2ml) | Parmesan cheese |
| ½ tsp dried dill weed (2ml) | |

In bowl, combine salmon, mayonnaise, horseradish and dill. Beat egg whites until stiff; gently fold into salmon mixture; divide mixture equally onto toasted bread or toasted muffins and sprinkle with Parmesan cheese. Bake on a sheet in a 350°F (180°C) oven for 15 minutes or until bubbly and lightly browned. Makes 6 servings.

Per Puff: about 171 calories - 10.8g protein - 7.3g fat - 14.9g carbohydrate

Fascinating Fact: ½ cup (125ml) canned salmon (liquid and solids) has only 128 calories and 194mg of calcium. That's 24% more calcium than an equal quantity of 2% milk.

Do you have a favorite healthy recipe or tip that doesn't take too much of our stamina resources to create? If you would like to share your recipe or tip with other Addisonians, please send them to hperry@interlynx.net, or mail to Helene Perry, 75 Wendover Dr. #218, Hamilton, Ontario, L9C 2S7. Please let me know if you do not want your name used. Let's share with each other and we all win!

Look at a day when you are supremely satisfied at the end. It's not a day when you lounge around doing nothing. It's when you've had everything to do, and you've done it.

Margaret Thatcher

People judge you by your actions, not your intentions. You may have a heart of gold, but so has a hard-boiled egg.



Websites

A listing of websites offering information on Addison's Disease and related topics. Italicized headings indicate a 'new' site. Please let us know if you have an interesting site which could be included in our list (or if a URL is incorrect).

The Canadian Addison Society dedicated, up-to-date, information, <http://mcinbers.liome.net/isonthani>

ACIF (Addison and Gushing International Federation) of Holland. <http://www.spiii.ii/iivap0302.htin>

Addison's Discussion Board. This is a new site set up by a woman from New Brunswick with Addison's. She has been through a lot and is now able to share with others.

<http://www.fiisideTheVVeb.com/mbs.cgi/inb3l0405>

The Addison's, Schmidt's, Cushing's and other Related Autoimmune Diseases Support Forum This forum is dedicated to the freeflow of information, experiences, questions and answers related to Addisons, Schmidts and other similar autoimmune diseases, <http://www.healinglight.com/addisois/>

American Autoimmune Related Diseases Association (AARDA). A non-profit association bringing a national focus to autoimmunity, the major cause of chronic diseases. <http://www.aardn.org>

American Botanical Council. Herbal medicines. <http://www.herbalgrain.org/>

Australian Addison's Disease Association Inc. <http://addisons.org.au>

BioScientifica. Services to biomedical science which includes the European Journal of Endocrinology online. <http://www.bioscientifica.com>

Centers for Disease Control and Prevention. <http://www.cdc.gov/travel>

Combined Health Information Database, <http://chid.nih.gov>

Library of Medicine (Harvard School). <http://www.countway.harvard.edu>

Cyndi's Addisons Disease and Adrenal Insufficiency Board. A new bulletin board started and maintained by a Canadian woman, <http://www.insidetheweb.coni/nicssagcboard/mbs.cgi7acct-mb310405>

Endocrine Web - Endocrine Disorders and Endocrine Surgery. A site written by doctors for patients. Although the site on Addison's Disease is coming soon, there are other hormone related problems discussed, as well as pictures of the various glands and their locations, <http://www.cndocrineweb.com>

John Hopkins Health Information <http://www.intelihealthli.co.in>

Health Answers. A user-friendly site that provides additional information on items such as the ACTH test through hyperlinks. Go to Search area, select "Endocrine System" and then "Acute Adrenal Crises".

<http://www.healthanswers.com>

Institute of Medical Technology — a Finnish study project dealing with rare diseases, specifically Addison's Disease. The site offers a discussion forum, <http://www.iita.ri/laitokset/imt/addison/index.html>

The International Society of Travel Medicine and the Journal of Travel Medicine, www.istm.org

Joan Hoffman's site. Joan is the editor of the Addison News Newsletter from Michigan.

<http://www2.dnici.net/users/hoffmanri>

Karolinska Institutet from Sweden has "MeSH (Medical Subject Headings) Classified" Resources on the Internet for lay persons, health care professionals and researchers. Scroll down and access the "Endocrine Diseases" site. <http://www.inic.ki.se/Diseases/index.html>

Mayo Clinic Site <http://www.niayohcaltli.org>

National Adrenal Diseases Foundation (NADF) <http://medhlp.nctiisa.net/www/nadf.htm>

National Institute of Diabetes and Digestive and Kidney Disease (NIH)K. <http://nidk.nih.gov>

National Institute of Health (NIH). Includes a 9-page booklet "Managing Adrenal Insufficiency" which has 4 pages, with pictures, on how to give yourself an injection. http://www.cc.nih.gov/cccpatient_education/ai/aifinal.html

New England Journal of Medicine. For those of you with an understanding of medical terminology. Articles are available but occasionally with a cost, <http://www.nejm.org>

Rosenthal Center for Complementary and Alternative Medicine <http://cpmcnet.columbia.edu/dept/rosenthal>

RxList - The Internet Drug Index. An excellent reference site to check out the properties and side effects of medications, <http://www.rxlist.com>

Skip Howell's bulletin board. An e-mail listserv. After joining you receive e-mails from people on the list. The bulletin board is divided into two topics, Addison's and AH. To subscribe to the bulletin board, go to addisons@home.ease.isoft.com and in the text write "SUBSCRIBE ADDISONS" followed by your name.

Society for Endocrinology. Full-text online journals, <http://www.endocrinology.org>

Travel Health Information Service, www.travelhealth.com

Vitamin Buzz. See how medications can sap your body of vitamins; plus, herbal news. www.vitaminbuzz.com

WebDoctor- a comprehensive index of medical resources on the Internet produced in Canada. <http://www.gretmar.com/webdoctor>

The World Health Organization. <http://www.who.int>