



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:

After a very long and hard winter, we hope that spring has finally decided to stay! Flus and colds have plagued many of us so far this year but with the new warmer weather, may it bring renewed health and well being to all of us.

It is with sadness that we announce the death of one of our Ontario members, Isabel Rathbun who died at the age of 88 years. Isabel was instrumental in the formation of the Brantford and District support group in Ontario. We send our condolences to her family. When I was visiting at the funeral home, I spoke to one of the directors about the possibility of placing some of our own donation cards at that funeral home. The idea was well accepted by that funeral home. Would any of you place any of these donation cards in your area funeral homes? What are your thoughts about this idea?

I urge all of you as well to let us know if you are pleased with your endocrinologist. We are always asked for referrals of names from either people searching for a knowledgeable endocrinologist or just a person who has moved from one area to another and looking for good quality care.

This is a group made up of many different people from all parts of our country and all walks of life who all have much to offer each other. This is YOUR group - I encourage you to get involved!

Sincerely,
Joan Southam

Important Announcements:

- The UK Survey is in the final stages. Associated Addisonian groups in Canada and Australia will be participating in this survey along with the UK. Surveys will be sent to you in June through the Canadian Addison Society. Please complete and return ASAP – the more participants, the more Addisonians will benefit. The results certainly will produce worthwhile information, not only for us as Addisonians, but for information to share with our physicians - General Practitioner and endocrinologist.
- CAS is the acronym for Children's Aid Society in Ontario, thus the Canadian Addison's Society is unable to use it in any circumstances.

New News:

- New contact information for the Addisons Society
Telephone 613-590-1019
Fax 613-590-1021
Toll free 1-888-550-5582
E-mail lainger_1@sympatico.ca
- Francisca Swist, a member from Edmonton, has been interviewed and was quoted in an article on page 69 of the November 2002 Homemaker's Magazine. The article concerns the various types of hormones produced by the body, their function in the body, and the results when things go wrong, along with some of the available treatments. Although her name is misspelled in the article, Francisca reveals how she felt prior to her diagnosis of Addison's Disease and the quick recovery she made on her medication. Thank you Francisca, for helping to educate people about our condition. If you have trouble locating this edition, and would like to read the article, it should be available at your local library. Homemaker's Magazine can also be seen at: www.homemakers.com
- Emergency Injections – excellent step by step instructions with diagram available through Warren Grant Magnuson Clinical Center (USA), Patient Information Publications, Managing Adrenal Insufficiency – requires Acrobat Reader to download. A copy is included at end of newsletter. http://www.cc.nih.gov/cc/patient_education/pepubs/mngadrins.pdf

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@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 March 1, at Victoria General Hospital. Dr. Richard Phillips, endocrinologist, of Victoria, give an over-view of the history and current situation regarding Addison's disease - its incidence, recognized symptoms, methods of diagnoses, and variations in administration of the available drugs. He pointed out that Addison's, first described in 1855 by Thomas Addison in London, England, is still a rare condition about which many doctors still know little. Because only a relatively small percentage of the population has Addison's disease, medical researchers cannot obtain enough grants to study the condition and pharmaceutical companies cannot justify investing large sums in new drugs that would have such limited sales.

Dr. Phillips noted that autoimmunity is the most common cause of Addison's in today's society, although tuberculosis and metastasized cancer in the adrenal, and surgical removal of the gland, are among other causes. Secondary Addison's also adds to the list when cortisone has been prescribed over a long period.

For years after they were suspected, laboratories did not have facilities for finding adrenal-cortex antibodies, but today Dr. Phillips and some others are availing themselves of this useful diagnostic procedure that allows them to identify these indicators of autoimmune activity. He noted that often, when Addison's patients are first diagnosed, blood tests indicate that they may have thyroid disease also. Low cortisol levels can be the real cause. Now there are tests for antithyroid antibodies to determine if patients have autoimmune thyroid disease. During his lecture Dr. Phillips included Solu-Medrol in his discussion of emergency medications. Manufactured by Pharmacia & Upjohn, Solu-Medrol contains methylprednisolone sodium succinate and is available in injectable form for intramuscular administration. Solu-Medrol is much longer lasting than Solu-Cortef, our more familiar crisis medication injection.

Questioned on sleep problems in Addison's, Dr. Phillips referred to a study titled "Glucocorticoid Replacement is Permissive for Rapid Eye Movement Sleep and Sleep Consolidation in Patients with Adrenal Insufficiency" published in the Journal of Clinical Endocrinology & Metabolism in 2000. The full study can be viewed and a pdf copy downloaded through the journal's search website: <http://jcem.endojournals.org/search.dtl>. Essentially taking cortisol replacement at bedtime may increase and improve REM sleep.

Treatment for Addison's has changed in recent years. Lower dosages of cortisol replacement are now being prescribed initially after diagnosis. Optimum dosage can't always be determined by ACTH testing. Dosage by weight does not work. Factors that play a part in finding an optimum dosage are

the presence of other associated diseases and stomach absorption capabilities. With so many variables involved in each case, individual experimentation working in concert with our medical advisor is probably the best plan to establish a safe and comfortable medication regime.

Hydrocortisone does not require enzyme action to convert it to cortisol whereas cortisone acetate and prednisone must be converted.

It was once thought that adrenalin is not altered with Addison's disease, however recent findings indicate that adrenalin is somewhat dependent on cortisol resulting in lower stress tolerance in Addisonians.

DHEA has been shown in medical studies of women with Addison's to improve well being and libido plus a desire to continue supplementation. Oily skin is the most common side effect. DHEA is not listed as a drug in the USA but as a food supplement which is not regulated. So purity in some products is questionable. Our source in Canada is regulated and DHEA is standardized. Dr. Phillips noted that a DHEA product by Paladin may soon be available with prescription from pharmacies in Canada. DHEA is produced by the adrenals in much larger quantities than cortisol or aldosterone. It is long acting, having a long half-life, so remains steady throughout the day and therefore supplement can be taken at any time of day. There are no withdrawal effects of DHEA, slow and subtle.

Questioned about overmedicating, Dr. Phillips commented that too much fludrocortisone may bring about high blood pressure or fibroids of the heart muscle. A higher dose of cortisol replacement may shrink the memory centre or downregulate the immune system.

Dr. Phillips was very forthright and helpful in his reply to questions. He was well versed in recent developments in treating Addison's and informed us in a candid and friendly manner. The meeting was a rewarding experience for our members.

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

Meeting on February 22, 2003 featured Dr. Michael Chung, Registered Acupuncturist, Dr. TCM, Ph.D. (Contact information: 104-2419 Bellevue Ave., West Vancouver BC V7V 4T4 604-913-2988)

A Doctor of Traditional Chinese Medicine originally trained in Pharmacy. There is now a Chinese Medical College in BC training over 1000 Acupuncturists a year. He suggested before one chooses to go to an Acupuncturist or Doctor of Chinese Medicine, they should verify that the practitioner is registered. Verification is done through the College of TCM Practitioners and Acupuncturist at 604-638-3108 or the website at www.ctcma.bc.ca

Chinese medicine is over 5000 years old but today uses an assimilation of Western and Chinese methods. There are five areas of certified training: 1) Acupuncture – using needles, 2) Herbal – medicine combining micro-elements which are now recognized key to combined formula. Addison's has diverse symptoms and needs unique formula to fit each condition. 3) Massage or Tuina is a grasp and push method for manipulation of the body using hand on some acupuncture points.

Acupressure is digital pressing of acupuncture points. 4) Diet theory – avoidance of various foods and 5) Qi Gong – Qi is energy and Gong is exercise. It is a self-help method of doing your own exercise. Practitioner will help you learn the process to carry on exercise by yourself. Qualifications for four levels of training are Acupuncture only, Herbal only, Traditional Chinese Medicine Practitioner or can be upgraded to a Doctor of TCM.

Diagnosis is made through taking different readings from the pulse and tongue. Pulse – each element of strength, shape, pulse has its own vibration. Left side is for heart, liver and kidney. Right side is lung, digestive and endocrine. The tongues' coating tells you what is happening inside the body. Types of conditions are based on 12 different functions – heart, lung, spleen, liver etc. with adjustments made from there. i.e.: kidney network includes brain memory, urinary, sexual functions, bone and bone marrow. Addison's is in the kidney and spleen areas.

Yin – vibrating, moving, growing, hot and Yang – dark, minus, cold etc. includes Addison's. Originally caused by TB but now that TB is better controlled, autoimmune is the main cause.

Example for cancer treatment: TCM focus on lessening the side effects of chemotherapy and radiation i.e. a patient with poor appetite was given a gargle to heal ulcers which then increased his appetite and complimented his chemotherapy.

Herbs should not be taken off the shelf without consultation with a trained herbalist as there could be an instant or prolonged reaction between the drugs and medication. Computers now will automatically print out interactions of medication. Interaction could lead to increase or decrease of dosage. Some of the side effects of steroid use may be relieved with proper use of herbs with an individual diagnosis.

Herbs in a natural state have no acquired or secondary process applied. Natural herbs will lose ingredients depending on solubility if refined in water or alcohol. Processed herbs will be slightly more concentrated but will not have all the ingredients of the original herb. Some parts of the same plant can be used for opposite remedies i.e. the roots could be used to stop sweating whereas the stem or leaves could cause sweating. Ginseng is produced in several countries and was used to treat Addison's but a proper diagnosis is required before taking to suit your condition. Ask for the registered number of prescribed treatment as some are covered by medical plans. Herbs may be purchased from the TCMP if they carry stock or you can take the prescription in to fill and have the formula made up for you. They can come in leaf, tea bag or capsule form.

Acupuncture is used until symptoms disappear but if they reoccur more treatments may be required in the future.

When going to a TCMP make sure that you always provide as much information about symptoms as you can i.e. sleep, stress, lower back etc. this will assist with diagnosis for treatment.

Other notes of interest:

- From Addison News by Joan Hoffman (USA): Is Fludrocort by Global Pharmaceuticals available in Canada? Some have turned to that as an alternative to Florinef. It is about half the cost of Florinef and some Addisonians were forced to turn to it because their insurance companies would not pay for Florinef any longer. So far she hasn't heard any complaints from those folks using Fludrocort.

- Elizabeth Hill in Saskatchewan is participating in the DHEA Study with the Mayo Clinic.
- One member has a new emergency injection kit – Dexamethasone - requires no mixing. Some concerns regarding shelf life and requiring refrigeration thus the following information was obtained from Pharmacist and packaging: Dexamethasone container says 4 mg./ml. or 20 mg./5 ml. equivalency IVMSY (we thought this was for hospital use) kept at 15' C to 30' C. Endocrinologist also prescribed the injection needles which have a maximum capacity of 1/2 ml. The dosage to give is 1/4 ml. to 1/2 ml. The expiry date is 14 months from date of purchase. There is enough in each bottle a few doses (5+) at 1/2 ml.

The next meeting is May 31, 2003 Sherbrooke Lounge, Sherbrooke Centre, 330 East Columbia St., New Westminster, BC from 1 - 3 p.m. We shall be having an informal get together. Bring your appetizers, appetite and stories. There is on site parking for \$2/hour or a day care lot just down Sherbrooke St. for \$3.50 for the day.

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

Two meetings have been scheduled with group speakers:

- April 26th - Wendy Andrews will speak to us on applying for Disability through the Canadian Pension Plan
- June 7th - Margaret Brown, from the Peterborough area, representing the Canadian Celiac Foundation will speak to us on Celiacs' Disease. Many Addisonians have found that they have digestive problems that can be linked to Celiac.

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

We would like to hear from you re:

- What approach, over the counter product, alternative medicine works for you during an acute illness. Please share your tips to help make other Addisonian's lives easier.

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.
- If anyone would like to have a poster to put up in their doctor or specialist's office, (with their permission, of course), then The Canadian Addison Society has some available and can send one to you free of charge. Please contact the office at the address on the front of this newsletter with your request. It's an excellent way for you to help spread the word around that we are here.

Dear Editor:

- Jacqueline Erickson, of New Westminster, wishes to recommend her Endocrinologist Dr. Clarissa Wallace, also of New Westminster, BC.

Other members are hoping to connect with you -

- If you have developed Addison Disease, resulting from the surgical removal of your adrenal glands due to Cushings Disease
- If you have experienced "vitiligo" as part of your symptoms
Please respond c/o the editor.

- Response from Dr. Killinger re: members questions re: vitiligo, emergency Injections and correct medication dosages

Thank you for sending along the letter regarding the vitiligo and Addison's disease. The vitiligo is felt to be due to an autoimmune process in which the antibodies damage the melanocytes (pigment cells) in the skin. This usually occurs with other autoimmune diseases such as Addison's disease, but can occur on its own. It may get better with the treatment of Addison's disease because the prednisone or cortisone suppresses the immune process.

The comments about how to know when you are appropriately treated are important. The lab tests are important guides to treatment but the way you feel is also important. The goal is to use the lowest amount of prednisone or cortisone that will make you feel well but will not show signs of over treatment. The ACTH level in the morning is a reasonable guide – it should be a little high. The dose of Florinef can be gauged by the blood pressure and plasma renin.

The most satisfactory emergency kit is Solucortef Act-o-vial. The mixing instructions come with it and you need a 3 ml syringe plus a 22 gauge needle for injection.

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.
