The Canadian Addison Society
La Société canadienne d'Addison

8 Francis Street, Brantford,
Ontario, Canada N3R 7C4
1-519-751-4472
E-mail: jsoutham@home.com

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President's Message:

I would like to wish everybody a Happy, Healthy New Year and extend a welcome to all new members. I am hoping that 1999 brings as much growth to the support groups as 1998 brought.

I would like to thank Joan Southam for doing a wonderful job on the past newsletters. I would also like to thank Don Jacobsen for his loan of a new photocopier for the Addison's Society. And thank you to John Gordon for assuming the responsibility of treasurer.

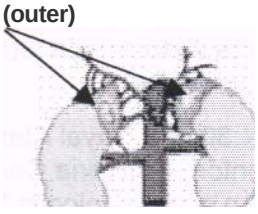
I would ask that everybody support Francisca with the Newsletter and should you come across any good articles, please send them on to her.

Please write to me any time you have something on your mind and if I can help, I will.
Sincerely,
Greeta

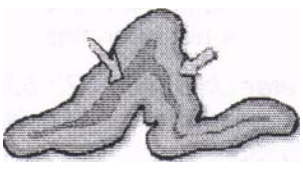
The Adrenal Glands

The adrenal glands are orange-colored endocrine glands, located on the top of both kidneys. The adrenal glands are triangular shaped and measure about one-half inch in height and 3 inches in length. Each gland consists of a medulla (the center of the gland) which is surrounded by the cortex. The medulla is responsible for producing epinephrine and norepinephrine (adrenaline). The adrenal cortex produces other hormones necessary for fluid and electrolyte (salt) balance in the body such as cortisone and aldosterone. The adrenal cortex also makes sex hormones but this only becomes important if overproduction is present.

Adrenal Glands (outer)



Adrenal Medulla (center) **Adrenal Cortex**



Source: http://www.endocrineweb.com

Did you know.....

Of the 158 Canadian members, 72% (113) of these are women. Is this indicative of Addison's being even rarer for men? Or their hesitancy to join a support group?

Upcoming Meetings and Contacts

Vancouver Canadian Addison Society - March 13

1:00-3:00 pm, Sherbrooke Lounge, Sherbrooke Centre, 330 E Columbia St., New Westminster. The building is at Royal Columbian Hospital site corner of Sherbrooke and Columbia Street.

They are hoping to have an endocrinologist speak on osteoporosis, but do not have confirmation at this time.

Contact Judy Stanley (604-936-6694) (bugbee@direct.ca) for further information.

Next meeting - July 10, same location.

Vancouver Island Support Group –February 6

1:00 pm, Victoria General Hospital, Room 1814. An endocrinologist was to be the speaker but is unavailable and an alternate speaker is being arranged.

Contact Jim Sadlish (250-656-62 70) (wx699@victoria.tc.ca) or Florence (fmweekes@mail.islandnet.com)

Alberta Addison's Support Group -March 6

1:30-4:30 pm, Royal Alexandra Hospital, Edmonton, Cafeteria Conference Room 105. An endocrinologist from the University of Alberta Hospital has promised to arrange for a speaker but the details have not been finalized.

Contact Peter Little (403-922-5307) (litt019@ibm.net) or Ginny LaValley (403-939-3730).

Please note - the area code will be changing to '780' for Northern Alberta on Jan. 25/99.

Eastern Ontario

Contact Elaine Hall (grahamhall@sprint. ca)

Southern Ontario - February 6

1:30-4:00 pm, Brantford Policy Station at the corner of Elgin Street and Wayne Gretzky Parkway.

The speaker, who is from Brantford, is Dr. Alexander Kunej, a chiropractor. He will address how chiropractic treatments can benefit Addisonians.

Unfortunately the Emergency Doctor who was scheduled to be the speaker was not available.

Contact Joan Southam (519-753-1271) (jsoutham@home.com)

Please note that Joan's e-mail address has changed!

Quebec

Sophie indicated that a small group of Addisonian's will be getting together early in February to share some of their experiences. Since it is a small group it is difficult to obtain a speaker. Sophie would welcome any ideas.

Contact Sophie (514-528-3291) (sola@colba.net)

If you wish to start a support group in your area, please contact Joan Southam at the Canadian Addison Society for information, guidelines or supplies that may be of assistance. Joan can be reached at (519) 753-1271 or e-mail: jsoutham@home.com.

Ask the Doctor

D. Killinger, MD, PhD, FRCPC

Thank you to Dr. Killinger for taking the time to respond to our questions.

Q. What is the value of taking Pregnenolone? How does it compare to DHEA? Apparently it is not a restricted drug in Canada. It this true? What is the connection with cholesterol?

> A. The adrenal cholesterol is converted to pregnenolone and the pregnenolone is converted to DHEA. The machinery required to convert pregnenolone to DHEA is primarily located in the adrenal, the ovaries and testes and possibly in the brain. Pregnenolone is popular because it is not restricted and because it is a steroid but as far as I am aware it has no biological effects.

Q. When switching a patient from one steroid to another (i.e. 0.5mg Dexamethasone to 5.0mg Prednisone), do you suggest weaning? What would you recommend as the best course of action?

> A. 0.5mg of Dexamethasone is a little more glucocorticoid than 5mg of Prednisone. I would suggest stopping the Dex and then starting with 7.5mg of Prednisone (1 tablet a.m., ½ tablet p.m.). If all is going well, consider stopping the p.m. half tablet.

Q. Do you recommend that your patients carry steroids in an injectable form in case of an emergency?

A. As you know, there is no ideal portable injectable steroid. The most satisfactory preparation is Solu-cortef which comes in a bottle with dry powder and the solvent which can be easily mixed and then drawn up in a syringe for intramuscular or intravenous injection. This combination of 100mg of Solu-cortef and a syringe (10 cc) and needle would be handy if someone were travelling to an out-of-the-way spot. Most emergency departments would have this and they would also give about 1 litre of saline with it.

Something to consider

Rosemary Brown of Caroline, Alberta raised a valid point. She commented that each of us should make it our job to check out the emergency system in our area. This would include the paramedic system, as well as the emergency departments. It may very well save our lives!
This is particularly important in the rural areas because the distance to a hospital increases our dependence not only on the emergency kits and our families, but also on the prompt services of the paramedics.

Personal Glimpses

Evelyn Scheller - Ontario
Proper Diagnosis: 3-1/2 years

I am 67 years of age and my history of Addison's started in the summer of 1992 when I suddenly became nauseated and developed a severe pain in the left side of my neck. My GP gave me Vaproxen for the pain and gravol for the nausea. When these remedies did not help and the nausea and pain became much worse, I saw an internist at Sunnybrook Hospital. He ordered a series of blood tests, CT scan, spinal tap and endoscopic exam but could find no medical cause and felt therefore that I was suffering from clinical depression. He prescribed various anti-depressants over the next year. Although the pain in my neck eventually subsided (after about six months) the nausea did not. I gradually lost weight and was unable to eat very much. I became so weak that I was unable to continue to go to work.

A year later I changed physicians and my new doctor sent me to a psychiatrist who also prescribed anti-depressants. I continued to lose weight and experience severe diarrhea. The doctor thought a change of scenery might help and so my husband and I went on a holiday to the Dominican Republic. Three months later I landed in hospital with continuous diarrhea and vomiting and nine days later it was discovered that I had a parasite. I was given antibiotics and the condition seemed to clear up so that I thought that this might have been the problem all along (as such parasites can live in the intestines for several years). However, a few months later the symptoms returned and my misery started all over again,

with a short respite in the summer of 1995, when I decided to stop taking anti-depressants, and feeling much better though this time that they had something to do with prolonging my illness. This respite lasted until September when I was rushed to the hospital with severe abdominal pain. I was treated for irritable bowel syndrome and released after five days only to be rushed back in again a few days later with severe pains in my chest. An electrocardiogram indicated possible heart problems and I was given an angiogram but nothing unusual was found and I was discharged once again. Three days later I was back in the hospital and there I stayed while was given a battery of more tests - two CT scans, nuclear medicine, endoscopic exam,, x-rays and many blood tests. Nobody seemed to know what was causing my illness.

Finally, a gastroenterologist on staff came to see me and after a couple of visits informed me that he knew what I was suffering from -Addison's disease. The ACTH test was administered by the endocrinologist and the diagnosis confirmed. I was immediately given hydrocortisone and electrolytes and in a matter of hours started to feel better and could eat normally once again. In the nearly three and one-half years of my ordeal I went from 145 Ibs. To 97 Ibs. Currently my weight is 135 Ibs.

I was originally placed on 7-1/2mg of prednisone and 0.05mg of florinef. However, as my endocrinologist felt the florinef helped to elevate my blood pressure he has reduced my medication to 5mg of prednisone daily (split in two doses) and eliminated the florinef. Prior to being diagnosed with Addison's I had high blood pressure for years but this has dropped to below normal. When treatment started the high blood pressure returned. To date I have no trouble with osteoporosis, but will have a bone density test again next month. I have taken Premarin and Provera for many years and this has helped to prevent osteoporosis.

I had no 'tanning' or other external indications of Addison's disease, nor did my adrenal glands show signs of disease - all of which contributed to the difficulty in diagnosis. My endocrinologist thinks the Addison's was autoimmune related. My own opinion is that it was caused by prolonged severe stress which I suffered at that time in connection with my workplace and the long illness of my father.

While I am now vastly improved, I still have a health problem. For three months or so I felt like a new woman but then started to get abdominal discomfort, particularly at night, so that I contacted my doctor who ordered up a Gl tract series of x-rays which showed nothing abnormal and I was then given an ultrasound with the same result. For the past nine months I have been awakened almost every night with varying degrees of abdominal discomfort. Just a few days ago I underwent another endoscopic exam to ascertain whether or not I might have developed an ulcer; however, this examination indicated no sigh of either a stomach or duodenal ulcer. Next week I shall have another ultrasound but my doctor does not seem to think anything untoward will be found.

Back to the reader: You had mentioned in your letter that you also suffer from abdominal discomfort at night and that it would appear that other Addisonians do also. I am wondering if this could be a symptom of the disease or a side-effect of the medication we must take and would be interested to hear what other sufferers have to say on the subject.

Educating the medical community
Francisca Swist – Alberta

On December 7, 1998 I had the opportunity to speak with a total of 61 medical students at the request of my endocrinologist, Dr. Ginsberg. The intention of the exercise was to see if any of the students could determine my medical condition based on only knowing my symptoms prior to being diagnosed with Addisons. The students all had an obvious clue because it was a course in endocrinology.

Dr. Ginsberg told them that as GP's they had a more difficult job because it could be anything; whereas in a specialty (such as endocrinology), the initial diagnosis had already been made.

I told them that 3 weeks prior to my hospital admission, I went to a GP complaining of exhaustion and weight loss. It was pointed out by Dr. G. that both of these are symptoms which every GP hears regularly. The GP ran the 'regular' tests and found nothing amiss. Two weeks later I went to the ER because I thought I had appendicitis due to severe abdominal pains -1 was immediately admitted. I believe the Intern who was assisting the attending physician who examined me may have suspected Addison's Disease because he asked the pertinent questions such as whether there was increased salt intake, or sun tanning (he checked my palms, etc.), but the attending physician did not treat me until a week later when I was discharged and told that I had Addison's Disease. The physician prescribed 37-1/2mg of cortisone acetate on a daily basis. The normal course of treatment would have been large doses of cortisone intravenously until there was a major improvement.

While in the hospital, I was inundated with a battery of tests and a gynecologist suggested that I undergo surgery for a cyst. Needless to say, had that surgery been performed I would not be around to help with the newsletter.

Following the presentation I received an e-mail from Dr. Ginsberg which read, "Your testimony had a profound effect on the students. Several have come to me to indicate they were affected by your story and hope that they will recognize such patients. I may very well call on you again as we have an important message to deliver."

This presentation offered a wonderful opportunity to educate some of the future doctors. Perhaps this is something that some of you can discuss with your specialists (particularly if they are working from a teaching hospital, such as the University of Alberta Hospital). Dr. Ginsberg also stressed to the students that even if they remotely suspect Addison's Disease it is best to treat with steroids (even over medicate) then not to treat at all. It could make the difference between life or death.

In a very recent communication from Dr. Ginsberg, he suggested that he may ask me to present again in February.