The Canadian Addison Society
La Société canadienne d'Addison

ISSUE NO.9 (abridged) **Addison Info** **Summer 1997**

This newsletter is a combined effort from our volunteers and will be arriving to you in July. We have included a summary of the Brant ford meeting in April, upcoming dates to remember and medical excerpts from correspondents around the world. The Internet has radically improved access to information and we are grateful to people like Joan Southam who has been diligently sourcing out contacts and medical news of interest to Addisonians. We encourage people to use these new tools, but a cautionary note to those less familiar with the information highway - Just because it is on-line or in print does not necessarily mean it is gospel truth. Like any discerning reader, one should check sources and compare notes.

Highlights from Brantford Meeting. April 26/97

Present: Joan Southam - Chairperson; Don Archi - Legal Advisor; Greeta Fraser - Resource; Isabel Rathbun, Ruth-Ann Kruger - Convenors; Angela Timms - Minutes;

- Joan opened the meeting and Don Archi gave a lecture "Looking to the Future" which asked questions about organization, name, jurisdiction and type of group we want. Food for thought.
- Question of incorporation has come up frequently and Don Archi was able to go through some of the legal steps and costs involved. At this time, there aren't the funds necessary which are quite substantial and therefore wouldn't make sense.
- Question of name clarification came up. We will use Canadian Addison Society as this translates well or unless challenged.
- A Family or Corporate membership will require annual $20.00 fee, payable on/by Jan. 31 of each year. Up to now, we have included "discretionary mailings". This was felt unfair to people who had paid. For 1st time callers an information package will be sent. To be on mailing list, receive newsletter, executive/voting privileges, wallet cards etc., $20.0O fee is reasonable. We are entirely self-supporting and have no other income.
- Main focus will continue to be support followed by information and education. This could include active solicitation of community support i.e. newspapers/media.
- Regional groups are to be encouraged, as more people hear of us. A designated link to the main group will ensure continuity and cohesion, but regional groups will determine their needs and goals. At present, there is a Quebec group, B.C., Brant ford and more to come. Provincial wings or formal groups not necessary due to high financial/legal fees. If others feel similar and would like to start a local chapter, please get in touch and we will be happy to accommodate.
- A potluck lunch followed, after which guest speaker, Dr. Jeff Mahon from London, who spoke about hormone DHEA and pros/cons for Addisonians. If approved, his research

will test 2 groups, one with placebos, to check results. More on this later.
- Dr. Mahon responded to a myriad of questions from audience and concluded with general comments regarding flu/pneumonia shots.
- Approx. 60 people attended with many travelling long distances. We thank all those who came and made the event a success.

September General Meeting

Dr.Twum-Barina will answer questions. He is an Internist and endocrinologist in Trenton. He wishes people to have their questions written down and given to him at the beginning of the meeting or given to Greeta beforehand.

The purpose of the business meeting is to form a new executive and pass resolutions for our national group. We are asking for nominations and/ or volunteers for President, Secretary, Treasurer and Board members and reps for committees etc. We also need at least one medical advisor.

International News

The Addison's Disease Self Help Group from England recently completed a survey of its members entitled "Assessing the Potential for Fine-Tuning the Management of Addison's Disease/Steroid Replacement Therapy". This 19-page document is an excellent examination of symptoms associated with Addison's disease. It is available through the national office. Its conclusion states: ”There is considerable evidence from the data collected that certain post-diagnosis symptoms exist amongst patients will Addison's Disease and in some cases are widespread. NADF wishes to thank the Addison's Disease Self Help Group from England for their hard work and for sharing this fine document with our membership.

As a result of the meeting in Oslo, Norway (10/96), at international association of groups like NADF ha: formed. This new association is called The International Federation, which now has a home page on the internet. Leading the way in the development of this important coalition have been members of the NVACP' from The Netherlands. A special thank you to Mr. Johan Beun for his dedication and hard work.

You may be interested to know that individuals from New Zealand have formed their own group.

What is DHEA?

Reprinted from Australian News

Dr Ladhani gave a light hearted approach to the topic: "What is DHEA?" He lead us into a

science lesson on how DHEA (dehydropiandrosterone) is formed from cholesterol and becomes "the mother of all the corticosteroid hormones". Not to be outdone by Albert Einstein. Dr Ladhani even had his own formula for why there was such a big interest in DHEA at present: $Z=EC^2$ where Z is Enthusiasm. E is Economic Gains and C is Cultural Trends to accept things!!! Dr Ladhani explained that DHEA was used to produce 50 other hormones in the body, including cortisol. Aldosterone, estrogen, progesterone and testosterone. This is why there are so many things DHEA is claimed to cure like: helps fight the affects of aging, bolsters libido, enhances mood, maintains ideal weight, increases energy, lowers blood pressure, reduces post menopausal bone lose, prevents complications of diabetes, acts as an anti-cancer agent, reduces mental decline like in Alzheimer's, helps build muscles and helps with chronic fatigue to name a few. DHEA is highest at birth and puberty because these are the stages in life which require tremendous energy to make the necessary changes in the body. He said, because DHEA is produced in the adrenal cortex, Addison's disease patients with adrenal atrophy would have very low levels of DHEA in their body. DHEA is available overseas in natural forms like in the Mexican Yam and certain herbal combinations, as well as in a synthetic form.

Osteoporosis

A lecture by endocrinologist Dr Robert Chen, Australis

Dr Chen defined Osteoporosis as "A systemic skeletal disease characterised by low bone mass and microarchitectural deterioration of bone tissue with a consequent increase in bone fragility and susceptibility to fracture. Put simply, it means bones are thinner and weaker and more likely to fracture." In Australia, it is estimated 50% of women over 50 years of age will suffer from Osteoporosis. In women, there is a marked rise in the risk of Osteoporosis after menopause while men are affected half as often as women of the same age. Normally the bones in the body are being formed and reabsorbed at a ratio of 1:1 but when this ratio gets out of balance, it leads to Osteoporosis. In patients on glucocorticoids, the osteoblasts (cells that form bone) appear to be less active and this results in a decrease in bone formation. Glucocorticoids also reduce the absorption of calcium. Low calcium causes an increase in the parathyroid hormone and results in an increase in bone reabsorption. We are not sure how long you can be on corticosteroids before you get osteoporosis. Patients on short courses of corticosteroids for such things as severe asthma attacks will not result in osteoporosis." Another study has shown that in patients on steroids therapy for a few months, the osteoporosis may reverse once they stop taking the steroids. This does not mean that Addison's disease patients should stop taking their medication. Estrogen is effective in both the prevention and treatment of osteoporosis in women. Rocaltrol has an uncertain action and may affect both bone formation and reabsorption. Patients on Rocaltrol need to have serum calcium levels monitored because increases in calcium in the blood stream may cause kidney stones. One of Dr Chen's slides indicated in the management of glucocorticoid induced Osteoporosis the following factors should be considered: minimize dose of glucocorticoid, calcium and vitamin D supplementation, hormone replacement in post menopausal women, drugs which inhibit bone reabsorption like bisphosphonates (e.g.Fosamax) and calcitorin, and drugs which stimulate bone formation like Fluoride. In a study done in America of 2,000 post-

menopausal women who had osteoporosis, there was a 90% reduction in multiple new vertebral fractures during 3 years of therapy on Fosamax. The main side effect of taking Fosamax is heartburn and reflux so it is important Fosamax is taken on an empty stomach with a full glass of water and that the patient does not lie down for at least half an hour after taking the tablets. Other side effects include diarrhoea and rashes. Dr Chen advised that male Addison's disease patients with osteoporosis should be on treatments like Rocaltrol or Fosamax. however in Australia men do not have access to 'free' treatment for osteoporosis

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Latest Published Report on Adrenal Insufficiency
New England Journal Of Medicine

A review article on current concepts of adrenal insufficiency by Wolfgang Oelkers, MD, was published in the New England Journal of Medicine. This article reviews the important role of the hypothalamic-pituitary-adrenal axis in the body's ability to cope with stress. It also describes primary and secondary adrenal insufficiency as hormone-deficient syndromes with many possible causes.

According to Dr. Oelkers, Addison's disease has been reported to be in 35M50 per million population. The mean age at diagnosis in adult patients is 40 years. The most common cause was formerly tuberculous adrenalitis, but now it is autoimmune adrenalitis (slow destruction of the adrenal cortex by cytotoxic lymphocytes), sometimes accompanied by other autoimmune endocrine deficiencies (autoimmune polyglandular syndrome). The most recently discovered cause of adrenal insufficiency is the acquired immunodeficiency syndrome (AIDS), in which the adrenal glands may be destroyed by a variety of opportunistic infectious agents in up to 5 percent of patients in late stages of the disease.

All causes of primary adrenal insufficiency involve the adrenal cortex as a whole, resulting in a deficiency of cortisol and aldosterone (plus adrenal androgen), although the severity of the deficiencies may vary. Dr. Oelkers lists one exception, the syndrome of isolated glucocorticoid deficiency. This is due to adrenal unresponsiveness to corticotropin (a pituitary hormone); responsiveness to angiotensin II is normal. The causes of primary and secondary adrenal insufficiency vary from autoimmune adrenalitis, tuberculosis, systemic fungal infections, to other more uncommon causes, all of which are listed in Dr. Oclkers' article.

"Current Concepts" describes the clinical manifestations of chronic adrenal insufficiency, including signs and symptoms. The most specific sign of primary adrenal insufficiency is hyperpigmentation of the skin and mucosal surfaces. Another specific symptom is a craving for salt. Many patients present themselves with symptoms of fatigue, weakness, listlessness, orthostatic dizziness, weight loss, anorexia, and gastrointestinal symptoms, including abdominal cramps, nausea, vomiting and diarrhea. Decreased libido and potency as well as amenorrhea (lack of menstrual cycle in women) may also occur.

For anyone interested in technical information such as laboratory tests for the evaluation of

adrenal function, including basal hormone measurements, adrenal autoantibody tests, corticotropin stimulation tests, tests involving insulin-induced hypoglycemia, metyrapone, and corticotropin-releasing hormone tests, this article would be a good one for your personal library.

"Current Concepts" concludes with paragraphs on treatment, listing hydrocortisone (initial dose 25 mg) and cortisone (initial dose -37.5 mg, divided into 2 doses of 25 mg and 12.5 mg as the most common. With regard to treatment "Oelkers writes, 'The goal should be to use the smallest dose that relieves the patient's symptoms, in order to prevent weight gain and osteoporosis. Patients with primary adrenal insufficiency should also receive fluorocortosine (Florinef) as a substitute for aldosterone. All patients with adrenal insufficiency should carry a card containing information on current therapy and recommendations for treatment in emergency situations, and they should also wear some type of warning bracelet or necklace such as those issued by Medic Alert. According to Dr. Oclkers, "Treatment of an adrenal crisis with full recovery of a dangerously ill patient within a few days is one of the greatest achievements of modern medicine."

Question Time

Q. What can an Addison patient do about jet lag when travelling across time zones, e.g. a five-hour difference? The person in question was really ill for five days with flu like symptoms.

> **A.** When crossing time zones, replacement therapy should be quite simply managed: I advise my patients that they should take their normal doses during the day prior to setting out for a flight. If they are taking 20 milligrams of hydrocortisone on waking as their normal replacement dose, I would then suggest that they take 10 milligrams of hydrocortisone each 6 hours until they reach their destination when they should resume their normal pattern on hydrocortisone replacement according to clock time. If they are on less than this dose in the morning, they should take their normal morning dose 6 hourly in the same way. Fluodrocortisone should simply be taken according to clock time.