The Canadian Addison Society
La Société canadienne d'Addison

ISSUE NO.8 (abridged) **Addison Info** **Spring 1997**

Brantford, ON held its second meeting of the Addison Society at the Police Station; 7:00 p.m. Jan. 27, 1997. 16 people attended, including 12 Addisons. Joan Southern chaired the meeting, noting there are 15 known Addisonians in the Brantford area. Items discussed included:

- Create a Home Page for computer users and have available items on Addison's Disease, upcoming news/meetings, and other information that would be of interest to Addisonians and the general public.
- Need for the Addison Society to become incorporated as a non-profit group in order to qualify for funding etc. This requires a charitable organization number. Greeta is following up and writing to all founding members.
- Introductions were made and people shared their experiences. Ideas for future meetings were put forth and most were interested in a research project at University Hospital, London, ON. More about this later.

Next General Meeting of Addison Society will take place in Brantford on. April 26. Agenda business to include the future of our group and its goals; Treasurer's Report; memberships; any other business. Guest Speaker, Dr. Jeff Mahon from University Hospital will discuss Addison's disease and his research project on the quality of life for Addisonians. Criteria for involvement - have Addison's disease, whether by disease or surgery and not have disease/destruction of the pituitary gland.

In Surrey B.C. a regional meeting was held Feb. 8. We wish them well.

We would like to remember Marc Charbonneau of Cornwall ON who passed away this past January, in his sleep from an Addisonian crisis.. He will be sadly missed by all who knew him. His quiet struggle is a symbol to us of the reason we exist as a group - to educate, empathize and eventually overcome this deadly disease. The Addison Society wishes to acknowledge and thank those donors who sent in bequests on Marc's behalf.

Letter from Wm Ross Rees, Alberta

In March 1996, I was an active, healthy 36 yr-old man, happily married and the father of 2 sons, with a successful business to run. By May, I was a totally different person.
I started feeling nauseated, weak and unable to sleep when I first visited my family doctor in March of 96. Initially, she thought it was gastro-intestinal and prescribed Gravol, an ultra-sound and abdominal X-rays, all of which came back negative and the medicines proved ineffective. By April, and feeling worse, I visited her again. By now I had lost 10

Ibs., had difficulty climbing stairs, and noticed how everything tasted salty. More tests and a prescription for Novo-Ranitdine didn't improve things. The doctor thought it might be depression, though I knew it was from the symptoms.

By May 13, I had lost 20 Ibs. in 8 weeks, felt even weaker from lack of appetite, sleep, nausea and muscle weakness. Feeling wasted, I again phoned and was prescribed Donperidone for nausea and Tryptophan for sleep. During this time, people in Edmonton were asking me if I had been to a tanning salon. As I am a swarthy person, I hadn't noticed my skin darkening. On a business trip to Toronto, I was still suffering the same symptoms, plus started to vomit on a daily basis. In addition, I was getting dizzy spells whenever I stood up and these got worse.

The plane trip home was one of discomfort which I will never forget. Somehow, I managed to drive from Calgary where I was greeted by relatives for my birthday. They took one look at me and drove me to Royal Alexandria Hospital on a busy holiday weekend. Fortunately, I had a list of medicines and symptoms with me and within 5 minutes was seen by a doctor. By 6 pm I was on intravenous saline. Subsequent blood tests showed dangerously low levels of sodium and high levels of potassium. My blood pressure of 80 over 50 had to be measured 3 times to be confirmed. I was now admitted. Over the next few days, I was given the ACTH stimulation test, long and short and also a glucose and cortisol drip. My Addison disease was later confirmed June 5/96 to be Primary Adrenal Insufficiency caused by my auto-immune system. I am now on 150 mg cortisone acetate a day, down from 400 mg in hospital, have regained most of the weight and my blood pressure is 115 over 65. Except for some fatigue late in the day, I am rapidly returning to the fellow I used to be.

Letter from Belle Messier, Saskatoon; Diagnosis Oct. 27/94

My story begins in 1993. I had not been feeling well for several months, attributing my symptoms of fatigue, dizziness, hyperpigmentation and nausea to pregnancy. My physician assured me the symptoms would clear after the birth. I decided to obtain a second opinion. As the pregnancy progressed, my skin darkened. When my daughter was born on April 2, the pressing question was "why are you so dark"? My doctor became concerned about the colour of a mole on my left leg, which was removed and analyzed. As months went by, my health steadily declined. I was absolutely exhausted, suffering from motion sickness, mental confusion, loss of appetite and chronic yeast infections. Once when driving to a friend's place, I became lost, even though I had driven there countless times. That was very upsetting.

By September of that year, something was definitely wrong. I had lost 20 pounds, a once healthy appetite dwindled to anorexia, was unable to walk more than 2 feet before collapsing. On Oct. 23, I was wheeled into hospital. I was so ill, I began to fear I would succumb to whatever had invaded my body. A physician ordered chest x-rays, and injected needles, all which came back negative. His diagnosis was, "I can't seem to find anything wrong with you"!

I was starting to believe there was some validity to my being a hypochondriac. A specialist was summoned who questioned me about my skin colour, race and darkly creased palms. He then took my blood pressure. It read 70/40. His opinion pointed to Addisons Disease, but more tests were needed before confirmation. The medical staff inquired if they could use me as a case study, since most doctors had never encountered Addison's Disease.

I was hospitalized four days, two of them on intravenous, then started on my meds. I began taking 15 mg cortisone (0.1 Florinef) graduated to 20 mg. cortisone, then 30 mg daily which I am presently taking. It has been a long road to recovery since. Today, I feel better than I have for a very long time. There is no limit to educating ourselves and listening to our bodies. They tell us everything we need to know.

(Reprinted from the Osteoporosis Society of Canada)

Bisphosphonates in the News
January 1996

Two bisphosphonates — alendronate (Fosamax) and etidronate (Didrocal/Didroner) — have recently been in the Canadian news, due to their recent approval by the Health Promotion Branch of Health Canada for the treatment of established postmenopausal osteoporosis. This information sheet has been developed to answer OSC's most frequently asked questions.

What are bisphosphonates?
Bisphosphonates are non-hormonal therapies, used in the treatment of osteoporosis. Specifically, they are analogues of the naturally-occurring, bone-seeking compound pyrophosphate. In the 1960's, dental researchers developed the first bisphosphonate to be used in medicine, called etidronate. This compound, and other bisphosphonates which have been subsequently developed, switch off the cells which break down bone (osteoclasts), enabling the bone-building cells (osteoblasts) to work more effectively and increase bone density.

What is etidronate (Didrocal/Didronel)?
Etidronate was first prescribed in the form of Didronel. Didronel has been used in the treatment of Paget's disease for over 15 years and has been approved in Canada for the treatment of osteoporosis. Etidronate is taken cyclically — a fourteen-day period of etidronate followed by seventy-six days of calcium supplementation. This cycle is then repeated and continues to be repeated to slow the bone resorption process.

Didrocal was developed in order to make it easier for patients to follow the sometimes confusing cycle of etidronate and calcium supplementation. It is packaged in an easy-to-use kit containing 90 days of therapy to help patients follow the treatment regimen.

What is alendronate (Fosamax)?
Alendronate is a second generation bisphosphonate. It is given as a daily medication. It is recommended for the treatment of post-menopausal osteoporosis; however, like etidronate, it is not approved for the prevention of osteoporosis.

How should I decide which treatment to use?
Both alendronate and etidronate are effective treatments for osteoporosis. Your doctor can assist you in making the decision, which depends entirely on your individual circumstances. Your doctor will be monitoring your response to treatment with periodic bone mineral density tests (possibly every 2-3 years). This feedback will help you to decide whether your current therapy is working.

Are the two bisphosphonates alternatives to ovarian hormone therapy?
No, ovarian hormone therapy remains the best available treatment for the prevention of osteoporosis. Ovarian hormone therapy is also effective in halting further bone loss in the treatment of the disease and has other benefits to the heart and in controlling menopausal symptoms. Ovarian hormone therapy is recommended because it increases bone-building activity and also improves calcium absorption. At this time, we cannot say whether or not there is any advantage in taking both ovarian hormone therapy and a bisphosphonate.

Who can prescribe these treatments?
Until recently, the only drug therapy which your family physician could prescribe for osteoporosis was ovarian hormone therapy. If your family physician is confident that osteoporosis is the correct diagnosis and is willing to treat and monitor your condition, you will not need a referral to a specialist. Some family physician may prefer that you see a specialist first.

What are the side effects?
Alendronate and etidronate appear to have very few side effects, although some patients have complained about temporary mild stomach pain, heartburn or an upset stomach. If side effects persist please discuss them with your doctor.

Are alendronate and etidronate painkillers?
No, neither contains any analgesia so you may still need to take pain relieving medication. Do not take painkillers or any other medication at the same time as the bisphosphonate or for at least 30 minutes afterwards.

How long should I take it for?
Alendronate: The license does not limit the duration of the course of treatment but beneficial effects have clearly been shown in three year studies only. Alendronate appears to have no detrimental effects in all studies to date.

Etidronate: Etidronate is safe and effective over 5 years of therapy, and the company which makes Etidronate is currently reviewing the effects of seven years of treatment. The benefits appear to persist.

What do the studies say about the benefits of these therapies?

Etidronate: In randomized, placebo-controlled trials for three years duration, nearly 500 patients with established postmenopausal osteoporosis were studied, and approximately 80 % of the patients treated with Etidronate therapy responded with increases in vertebral bone mass. Significant increases (5%) in vertebral bone mass were seen within one year of beginning etidronate therapy.

Alendronate: A recent three-year, randomized placebo controlled study of osteoporotic patients showed significant gains in bone density in both the spine and hip (gains of 8.8 or 5.9% respectively). The alendronate-treated patients had significantly fewer fractures and less progression of vertebral deformity. More than 90% of patients have a positive bone response to alendronate.

Are there any people who should not take these medications?
Rarely, allergic reactions occur. It is not clear whether an allergy.to one bisphosphonate means a patient cannot take the other. At present, it would be best to consider an allergy to one means the person is allergic to the other. Patients with osteomalacia should not be given bisphosphonates. These medications should probably not be used if a patient has impaired kidney function.