



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

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Preliminary Results of the DHEA Study

On Saturday, June 26, 1999 a group of Addisonians and guests were invited to a luncheon followed by a presentation made by the physicians in charge of the DHEA research project which started in October 1997. The group, as you may recall, was divided with half being given 50mg of DHEA daily and the other na'f receiving a placebo. With the exception of the pharmacist who made up the medication, nobody knew the key to who was receiving the DHEA or the placebo.

There were 62 Addisonians taking part in the study. Of the 41 women and 21 men, ages ranged from 18 to over 50.

We were all given the opportunity after the one-year completion, to remain on the study for another 6 months - all of us on DHEA - no placebos this time. On a quick review of the information received back from the one-year study, there were not a lot of changes. The ones that really felt well on the DHEA were balanced out by the ones that felt that DHEA did not improve their life at all. The blood tests, which included liver function and kidney function, on quick review did point out that there were no adverse lab reports. They then started to break down the participants into different categories - male, female; then age, with the women over 50 seeming to show the best results. The women over 50 on estrogen replacement showed a possible 5% increase in bone density composition while the women over 50 without estrogen replacement showed a possible 6% increase in bone density composition.

Overall, some of the findings were disappointing or non-conclusive but others were positive enough to warrant the continuation of the study for another six months and extend the study to 24 months. The participants of the first 12 months were divided between those on 50mg of DHEA and those on a placebo. For the remaining 12 months, all participants in the study have the option to remain on DHEA.

We wish Dr. Don Killinger, Dr. Jeff Mahon, Dr. B. Wolfe, Dr. Charles Rice and their associates every continued success and we would like to extend a big "thank you" from all of us, to those Addisonians who took part in this research project.

Thanks to Joan Southam for providing a summary of the meeting. It is important to indicate that all of the results, including the observations about quality of life changes and bone changes, have to be considered preliminary until they are reviewed by scientific peers.

Once that is done (possibly late fall), the final results can be obtained.

Canada Addison Society - First Five Years A National Group is Born

With the soon-to-come anniversary of the Canada Addison Society, it is a good time to reflect on the past five years.

There were a few scattered Canadian Addisonians known in the late 1980's, but things really started coming together for the formation of a national group when eight Ontario/Quebec Addisonians met at the home of Evelyn Paul in Perth, Ontario September 24, 1994. Thelma Brown, Isabelle Clift, Christine Forsyth, Greeta Fraser, Sybil Harrison, Louise Juneau, Al McConnell, and Evelyn Paul were the Addisonians present plus a few spouses.

I consider Greeta Fraser as the founder of the Canada Addison Society, as she presented the idea of forming a national organization at that September meeting. The idea met with unanimous approval and the real work began.

Since the chance meeting with Sybil Harrison in March 1990 in the Montreal Union Station while she and Sybil were waiting for trains, Greeta has worked tirelessly networking with Addisonians. She could always see a possibility for another contact or meeting, a new source to insert a notice, and freely gave of her time and effort. In June 1993 Greeta had 13 names of Addisonians. One by one the numbers grew. Now there are over 200 known Canadian Addisonians.

Greeta put together the first Canada Addison Society newsletter, now known as "Addison Info", in the spring of 1995. Succeeding editors have been Angela Timms (Ont.), Joan Southam (Ont.), and the present editor Francisca Swist (Alb.). This quarterly newsletter's heading carries the handsome logo and the Canada Addison Society name in English and French (La Société canadienne d'Addison). The newsletter along with other printed material for newcomers provides information and support.

Dr. Donald W. Killinger is the organization's Medical Advisor and handles the question and answer section of the newsletter. He is associated with the University of Western Ontario and St. Joseph's Health Center, London, Ontario.

Canada Addison Society - Local Support Groups

The eastern Ontario support group is headed by Elaine Hall.

Brantford & District is another Ontario group located in the southwestern part of the province. They have been holding meetings since October 26, 1996. Forty people attended that first meeting. What surprised me most about this area is the large number of Addisonians, more than would be expected based on the population. This likely contributed to procuring over 60 participants for the DHEA/Addison's research study at the University of Western Ontario begun in 1997 with Dr. Jeffery Mahon, Dr. Donald Killinger, and others.

Joan Southam is chairman of the Brantford group.

Sybil Harrison, Al McConnell, and earlier Sophie LaPointe, have been trying to establish a Montreal, Quebec group where Addisonians seem scarcer.

In the western provinces support groups have also been developing. The BC Lower Mainland Support Group held their first meeting February 8, 1997 with Judy Stanley as leader. The following year (May 30, 1998) a group was established and flourishes on Vancouver Island thanks to the hard work of Jim Sadlish and Florence Weeks. Members of these two British Columbia groups often go back and forth.

A newspaper article in the Edmonton Journal about the Canadian Addison's effort was read by Peter Little, who then connected with the Canada Addison Society. Along with Peter, Ginny LaValley, Richard Evans and Francisca Swist established a group May 2, 1998.

There is also a small group of Addisonians who have met in Regina, Saskatchewan. Their spokesperson is Elizabeth Hill.

Local support groups function under the guidance of the national organization; their activities are noted in Addison Info.

Canada Addison Society - International

In October 1996, Al McConnell, at his own expense, flew to Oslo, Norway for the Addison, Gushing, Acromegaly International Conference and represented Canada. Ten other countries were represented as well.

Countries, in addition to Canada, who presently have national organizations include the United Kingdom, the United States, Netherlands, Norway, Sweden, Denmark, Australia, and New Zealand.

Out of the conference arose the Addison, Gushing Int'l. Federation which furthers the awareness and information about Addison's throughout the world via a website (<http://www.spin.nl/nvap0300.htm>) maintained by the Dutch. Canada has been a financial contributor and has an entry about the Canadian Addison's Society in English and French.

I have touched on a few events and people who have brought individuals together and influenced the present Canadian Addison's Society and its early national, local, and international activities. You have a proud beginning and dedicated people. I wish you the best as you further your stated goals of spreading Addison's information, support, and education.

Best wishes,
Joan Hoffman Michigan, USA

Thank you to Joan Hoffman, who is the Editor of Addison News "Caring Through

Communication", for providing this article on the background of the Canadian Addison Society.

Oops...

Thanks to Jim Sadlish for pointing out my error in the April newsletter. The equivalent dosage for dexamethasone is 0.75mg not .5mg. Therefore the table should have read as follows:

Equivalent Dosages

Dose	Steroid	Relative Potency
20mg	Hydrocortisone	1
25mg	Cortisone acetate	0.8
5mg	Prednisone	4
4mg	Methylprednisolone	3
0.75mg	Dexamethasone	25

Jim Sadlish had also asked whether 'relative potency' corresponds to half-life. After checking with a Pharmacist, I was told that it has nothing to do with half-life and deals only with potency in relation to the dosage using Hydrocortisone as the standard.

Personal Glimpses

Chris Rombough, DVM

I read with interest a letter in the last newsletter by Evelyn Scheller and her questions on the cause of her abdominal pain.

I suffered from abdominal pain at night for many years, both before and after I was diagnosed with Addison's disease in 1994. I was scoped the length and breadth of my intestines, swallowed gallons of barium, lathered repeatedly with ultrasound gel, all to no avail. I eventually discovered through trial and error that eating a large, fatty meal for supper would trigger an "attack" about six to eight hours later. I went on a low fat diet and was much better for a few years, but then the "attacks" returned at night again and during the day I would get a low grade type of pain just underneath my ribs. This pain got worse after I ate. Often, three or four hours after eating, I would still feel full, as if I had just finished eating. I also was having increasing problems with diarrhea. After doing a bit of thinking and reading, I came to the conclusion that these nighttime "attacks" could be mild attacks of pancreatitis. Anything that causes decreased blood flow to the pancreas can trigger pancreatitis. Common causes are anything which cause a drop in blood pressure, such as major surgery or shock. I believe what was happening to me was that when I went to bed and laid in a horizontal position for a few hours, a mild drop in blood pressure would

occur due to the Addison's disease and combined with a fatty meal, this would trigger a bout of pancreatitis.

Repeated bouts of pancreatitis eventually destroy the exocrine pancreas, leading to an exocrine pancreatic insufficiency. When you get to the point where you are not producing enough enzymes to digest your food, you start to get a chronic small bowel diarrhea as well as a lot of bloating and gas.

The treatment for pancreatitis is a low fat diet and avoidance of alcohol. As I had discovered, any amount of fat in my diet would trigger an "attack" and alcohol could also cause one. I also felt that a lot of my persisting symptoms of diarrhea, bloating and low grade abdominal pain were probably because my pancreas had been so badly damaged over the years that it no longer produced enough enzymes to digest my food.

To test my theory, I went to the health food store and bought some plant enzymes. Plants actually produce digestive enzymes which help us digest them and these are basically the same enzymes that our pancreas produce. I picked the brand with the highest lipase, amylase and trypsin I could find. I started to take them with every meal and within a few days 10 years of intermittent diarrhea and abdominal pain disappeared. With the wide variation in the amount of active enzymes in the products, three different tablets with each meal would be required and since the tablets were expensive, I went to my doctor, explained my theory and he gave me a prescription for pancreatic enzymes. They worked even better! I still maintain a low fat diet, usually less than 30 grams of fat per day.

The only time I have abdominal problems now is if I go on a "fat binge" for a few days (like Christmas), or if I forget to take my enzymes for a few meals. I also no longer get those attacks at night. These enzymes do not have any side effects because they are not really a drug, they are not absorbed by the body and they do not suppress your body's own enzyme production.

There are diagnostic tests which can be run to diagnose pancreatitis and an exocrine pancreatic insufficiency (EPI). Blood tests for pancreatitis were never run on me when I was having the bouts of severe pain, which I now think were mild attacks of pancreatitis. I was tested a few times for fat in my stool but it was always negative. This test is not particularly sensitive for picking up EPI, however there are other blood tests available which are better. Because the enzymes worked so well for me, we decided not to bother with any more tests but go with that worked. I am not sure if the abdominal pain other people with Addison's disease experience is caused by a low grade pancreatitis, but it might be worth trying some enzymes and a low fat diet to see if they help.

Upcoming Meetings and Contacts

BC Lower Mainland - Oct 16

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.

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

Upcoming meetings - February 26 and June 17, 2000, same location.

Vancouver Island Support Group -September 11

1:00 pm, Victoria General Hospital, Room 1814.

For more information, contact Jim Sadlish (250-656-6270) (wx699@victoria.tc.ca) or Florence Weekes (250- 598-0321) (fmweekes@mail.islandnet.com)

Alberta Addison's Support Group - October 23

1:30pm, Save-On-Foods Community Room, 360 Mayfield Common (170 St/Mayfield Rd. & Stony Plain Rd.)

A registered dietician/nutritionist may be speaking but the details have not been finalized. We are going to try for a more informal structure to our meetings, which would allow more time for discussion. We will no longer mail-out agendas and instead contact everybody through phone calls, e-mails and community advertising.

Contact Peter Little (780-922-5307) (litt019@ibm.net) or Ginny La Valley (780-939-3730)

Eastern Ontario

Contact Elaine Hall (613) 824-0160 (grahamhall@sprint.ca)

Southern Ontario – October

Although there has not been a specific date set for the next meeting, the guest speaker will be a pharmacist.

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

Quebec

Contact Sybil Harrison (514-486-9817) for information.

Saskatchewan

Contact Elizabeth Hill (306-236-5483) for information.

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

Rehydration Drink

1 liter water
2 Tbsp sugar

1/4 to 1/2 tsp salt
Lemon juice (optional)

Meeting Notes

BC Lower Mainland - July 10

A well attended meeting with 22 present. Contact Judy if you are interested in a video tape of the meeting.

The speaker was Dr. Kendler, an endocrinologist, who presented his research on bone density.

Those at high risk are: low body mass, smoking, post menopausal, family history of osteoporosis, those on thyroid meds, high dose steroids and some anti-seizure meds. If osteoporosis were treated the same as diabetes, then every woman over 65 and those over 55 at high risk would have a bone density measurement (BDM) test. The BC government has ordered 6 new testing machines.

Ward off osteoporosis by ensuring sufficient calcium and vitamin D intake coupled with exercise (a daily walk of 20 min. is recommended). Exercise strengthens muscles and helps resist fractures. Be aware of the calcium content in the food you eat. The easiest to digest are dairy products whereas the calcium in leafy green vegetables are not as easily absorbed. Soy beverage is equivalent to milk. The average person receives 500mg of calcium a day from their diet.

Calcium Supplement Products - Look for elemental calcium on the label, do not buy if not listed. Calcium carbonate (made from oyster shells which can accumulate contaminants from the ocean) is the cheapest. It should be taken with meals to reduce acidity. Calcium citrate has no heavy metals and is easiest to absorb. Requirements are 1000mg for women and men (men 60-65), 1500mg for postmenopausal women. If on steroids take 800 I.U. of Vitamin D and 1500mg of calcium.

Four drugs to treat osteoporosis:

Premerin - stabilizes bone loss and may increase bone mass by approx. 3%

Evista (raloxifene hydrochloride) - selective estrogen with 1-2% increase in bone mass.

Didrocal & Fosomax (phosphonate) - for use by both men & women. Recommended for those on steroids and safe when taken as instructed.

Dr. Kendler suggested that many people on steroid therapy are taking too much. He suggested taking steroids at bedtime so that in the morning the body would have them, when most needed. This should be tailored to take the minimum required dosage.

Vancouver Island Support Group –May 8

Marjorie Mouttin is a Doctor of Traditional Chinese Medicine and introduced the basic concepts of this medicine and then to the specific organ systems involved in a general diagnosis for Addison's Disease.

The following is information gleaned from Dr. Moulton's handouts. Traditional Chinese Medicine dates back over 5000 years. Today, many hospitals in China practice strictly Chinese medicine while others combine both Western and Chinese methods of healing. Chinese Medicine receives global recognition by the World Health Org. Practitioners of Chinese Medicine are concerned with the whole person when making a diagnosis. Physical and psychological characteristics are key indicators of health or disease. Diagnosis includes checking the tongue and pulse coupled with detailed sign and symptom history. The practitioner is then able to deduce patterns of disharmony/imbalance. Treatment is specific to the individual and focuses on both the symptoms and their underlying cause in order to return the patient to a harmonized state of well-being. In treatment, the four disciplines applied by Dr. Moulton are Acupuncture, Herbology, Tui Na (massage) and Diet Therapy.

Dr. Moulton strongly stressed that Chinese Medicine has no alternative treatment for our cortisol replacement therapy. Chinese Medicine strives to strengthen the body, as a whole, to improve health and balance. The lecture offered dietary guidelines outlining beneficial foods and supplements plus sensible methods of food preparation, which promote long-term health and vitality. Stress, overtime, can lead to adrenal dysfunction. Emotional and spiritual care are important for good health. Dr. Moulton advised us to avoid over-committing ourselves and to take time to recharge our batteries by listening to enjoyable music, thinking pleasant thoughts, getting enough sleep and allowing ourselves to accept nurturing and affection. Apart from Chinese Medicine, Dr. Moulton discussed the possible advantages of DHEA, Pregnenolone, and Tyramine for Addisonians.

12 Addisonian's attended, including Dr. Moulton, and two family members. Those listening to Dr. Moulton's presentation were treated to a wealth of fresh ideas in ways to improve our health and well-being.

Southern Ontario - May 8

Dr. Gene Jarrell, head of Emergency Services at the Brantford General Hospital, spoke to a group of 35 attendees.

Dr. Jarrell reviewed some background on Addison's Disease and provided the clinical presentations of the disease. He then addressed questions which had been submitted at a prior date, including:

Emergency Injection Kits - Dr. Jarrell is an advocate of the kit and believes that every one of us should have one available. If we cannot take our medication, we should use the kit, then GO straight to the Emergency for assessment.

Information that would be invaluable to the emergency staff is a note, preferably written on your doctor's letterhead, containing necessary information, such as: disease name, when you were diagnosed, what medications you are presently on and any allergies. (One woman had several laminated copies made.)

If the staff does not seem sure about the treatment or does not seem too sure of Addison's

Disease, remind them that the Harrison's Textbook of Internal Medicine and several others will explain the disease. Most Emergency departments have these texts but if not, they MUST have some type of medical books available. If there is a problem, do not hesitate to contact the Administrator, with a copy to the head of Emergency Services. This will ensure the problem is addressed and will not happen again.

Medic Alert bracelets are a necessity. Several Central registries are also available now, particularly for overseas travel. These registries include a database for treatment. The Canadian foreign consulates provide emergency medical information, including translation services for treatment. When travelling, it is important that we carry extra medication separately (in case luggage is lost).

Four treatments of Addison's Disease:

Usual replacement therapy - hydrocortisone (20mg am and 20mg early afternoon) or equivalent. Mineralocorticoid therapy (florinef) .05 - 2mg orally. Liberal salt intake was added.

Acute illness coverage (includes mild to moderate acute illness). It was recommended that we increase our glucocorticoid (cortisone or equivalent) 3x for the duration of the illness. In severe illness or if vomiting is present, use dexamethasone (4mg IM) and seek prompt medical help.

Surgical procedures - for minor procedures performed under a local anesthetic and most radiological procedures, no special preparation is required. For moderately stressful procedures, e.g. endoscopy or colonoscopy, hydrocortisone (100mg IV) should be given just before the procedure. Major surgery - 100mg IV before the induction of anesthesia and 100mg every 6-8 hours for the first 24 hours and taper dose rapidly, decreasing 50% per day to maintenance levels.

Management of adrenal crisis which may involve: dehydration, low blood pressure or shock out of proportion to the severity of current illness, nausea, vomiting with a history of anorexia or weight loss, abdominal pain, unexplained fever, low sodium, high potassium, renal failure, high calcium, low sugar. Treatment included rehydration with IV fluids, hydrocortisone 100mg every 6 hours and IV glucose.

Ask the Doctor

D. Killinger, MD, PhD, FRCPC

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

Q. I have read that the hormone parathyroid has an effect on bone density. Is it true that those with evidence of osteoporosis may find that the reason for this may not lie in the fact that they are long-term steroid users as much as the fact that it may be the parathyroid

hormone? Is there any validity to this way of thinking?

A. There is validity to the possible role of parathyroid hormone in certain types of osteoporosis. Parathyroid hormone is responsible for maintaining blood calcium levels with a narrow range. In cases of calcium deficiency (low intake) or loss of calcium in the urine, parathyroid hormone draws calcium from bone to maintain blood calcium. With adenomas of the parathyroid there is excess parathyroid hormone secreted and this draws calcium from, bone and excretes it in the urine.

We encourage individuals to take in 1000mg of Calcium in their diet to deposit calcium in bone and keep the parathyroid levels low to avoid calcium removal from bone. Parathyroid adenomas are uncommon and frequently present with kidney stones. They are a possible cause of osteoporosis in rare situations

Should you have questions which you would like to have forwarded to Dr. Killinger, please send them to Joan Southam.

The following was a question from the NADF newsletter and the subsequent response provided by Dr. Paul Margulies, FACE, FACP.

Q. I have been informed by the paramedics in my town that they are not allowed to inject any medication into an unconscious patient even if the Medic Alert bracelet tells them to. Of what value is it then to carry injectable cortisol? How long can a severely injured person live without it? The paramedics can give epinephrine - will that do the job till the emergency room doctors give cortisol?

A. The paramedic limitation on giving injectable medications is not surprising -they are not physicians, and are trained to resuscitate, stabilize, and transport injured and seriously ill people. The Medic Alert badge is for emergency room personnel - nurses and physicians - so they can recognize that you have this particular medical problem, and be reminded how to treat it. Carrying injectable cortisone is for the use of the Addisonian patient or family member to use in emergencies while waiting to be transported to an ER, not for the paramedics to use.

Just for your information

The Dutch report is still available. Joan Southam has only 4 copies left and the cost is \$25.00 which includes postage and handling.

There is another Dutch report entitled, "An Improved Medication of Addison's Disease - feasibility study". Joan has one copy and would have to arrange to get more copies. These would be more expensive than \$25.00 because of the cost of printing, shipping, etc.

Tid Bits

Dial-a-Dietician

For dietary information, call 1-800-667-3438.

Osteoporosis Society of BC

For osteo information, call 1-800-363-1933.

A couple of studies

The Dutch group has done a study on Cushings and will publish in English when funding is found. Nocele Sluis of the Netherlands did a feasibility study about what is needed to improve the medication needs for Addison's and Cushings. Published report contains discussion of present Addison's medication and its shortcoming in delivering hormones that mimic the cycle of a normal body. If anyone would like a copy, please contact Judy Stanley (BC Lower Mainland) and she will look into the cost of ordering it.
