



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

8 Francis Street, Brantford,  
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**JULY 1998**

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Summer greetings! We send a warm welcome to several new members who have joined us. The support group in Alberta has had their first meeting as well as a first meeting was held for the Victoria, B.C. support group. Both meetings were very successful, thanks to the hard working people involved. There is also a new group forming in Ontario and we wish them well. If you are interested in starting a new group in your area, let us know.

Please note: Would each support group have one person responsible for sending the minutes of meetings as soon as possible after the meetings, particularly with dates for the next meetings if available. It would be a big help, as it would allow us to get the newsletter started earlier rather than have the information arrive just before the deadline. Our newsletter comes out in January, April, July, and October, as near to the first of the month as possible. Thank you! As usual your comments are welcomed and appreciated.

Sincerely  
Joan Southam

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## **President's Message by Mrs. Greeta Fraser**

Greetings! Our congratulations to the Alberta group on their meeting and to the Victoria, B.C. group for their initial meeting. Your efforts are very much appreciated by us all. I am pleased to announce that there will be another new support group forming for Eastern Ontario and the Ottawa valley. It is hoped that there will be a good turnout. All are welcome! We certainly encourage other local support groups to form. Please remember, according to our bylaws, every person holding any office in the local support groups **MUST** be a member in good standing of the Canadian Addison Society. We encourage all of you and your family to attend one of the local meetings. It is a wonderful place to gain information not only from the speakers but also from other Addisonians. I hope to see as many as possible at our National Meeting in September.

Sincerely Greeta Fraser

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## Highlights from Local Meetings

### Ontario:

The Brantford and District Addison Support group held their meeting in Brantford April 25, 1998 with 38 person attending. Our speaker was Ms. Monica Lavis, a Registered Dietician at St. Joseph's Hospital in Brantford as well as in Hamilton.

Using the Canada Food Guide, Ms. Lavis went over the requirements needed for a healthy lifestyle, with special requirements for Addisonians. In all the areas, there is a variation in the number of servings. Those interested in losing weight, should always choose the lowest number and decrease those from the "Other Foods" section.

*Grain products* should be between 5 and 12 servings a day. Complex carbohydrates, e.g. 100% whole wheat or multi grains will satisfy longer because it digests more slowly. For example: a single grain serving is equal to one slice of bread and a two grain serving is equal to ½ bagel or ½ pita, or a cup of pasta or cooked rice. Increase dietary fiber slowly and be sure to drink plenty of fluids.

*Fruit and Vegetables* should be between 5 and 10 servings a day. 1 serving is equal to one medium carrot, an apple, ½ cup fresh, frozen or canned vegetables, one potato, ½ cup of unsweetened juice, 1 cup lettuce.

Potassium is high in oranges, melons, and bananas. Addisonians who have potassium levels checked need to keep a 3.5 - 5.0 serum level. Fresh, frozen or that packed in water are better. Canned vegetables are usually much higher in sodium than fresh or frozen.

*Milk and Dairy* should be between 2 and 4 portions a day. Post menopausal women need 1500 mg. calcium while pre-menopausal need 1000 mg. Teens need 1200 mg. daily while men need 800 mg. Addisonians on cortisone replacement have a higher risk of developing osteoporosis. One cup of milk is equal to 300 mg. calcium. One serving is equal to 1 cup of milk, a 3 x 1 x 1" square of cheese, or 2 slices of processed cheese or ¾ cup of yogurt. Ms. Lavis also had a hand out "Low fat/Low Calorie ways to add Calcium to your Diet" (kindly made available by St. Joseph's Hospital to the Canadian Addison Society). Other sources of calcium include lactose-free products, tofu with calcium sulphate, canned fish with bones, vegetables such as broccoli, sprouts, spinach, bokchoy, and rhubarb.

Calcium should come from your food but if you are not getting enough, supplements are recommended. Look on the label for ELEMENTAL calcium, which is the actual amount your body absorbs.

Milk is also high in vitamin D, which help to absorb calcium. Fifteen minutes of sunlight is equal to a cup's worth of milk. Weight bearing exercises such as walking; enhance absorption of calcium and vitamins and exercise of 20 minutes duration for 3 times a week will increase the absorption rate of important minerals.

*Meat and Alternatives* are fewer in number, between 2-3 daily. This group provides protein, iron, and B vitamins. Portion size is important (between 4-6 oz. daily). Choose only

trimmed, lean cuts of meat. Try meat alternative such as dried peas, beans, and lentils for a low fat source of protein.

*Other Foods:* These include foods that are mostly fat/oils, sugar, high fat/high salt snack foods and beverage such as water, tea, coffee, alcohol and soft drinks. These foods should be used in moderation and along with food from the 4 food groups.

*Water* should be used as much as possible for quenching thirst, especially when active during the hot weather. Aim for 6-8 cups a day. Some signs of dehydration include fatigue, parched tongue, decrease urine output, and tea colored urine. Salt loss accompanies dehydration, so it is important that these minerals be replaced.

Foods high in *salt* include canned vegetables, canned soups, bouillon, processed cheese slices, processed meats, salted crackers, smoked/cured products, pickles, soya sauce, salted seasonings (such as garlic salt). Table salt contains sodium chloride. One tsp (5 grams) of table salt is equal to 2000 mg sodium (2 grams). Many salt substitutes contain potassium chloride. Too much salt may deplete calcium. A fine balance exists between getting the right amount.

A special note was also made regarding the benefits of regular *aerobic exercise* about 20 minutes 3-4 times weekly. This also helps prevent the effects of osteoporosis. Addisonians are at a higher risk of bone loss and muscle atrophy. Proper diet, moderate exercise, limited intake of "other foods" and achieving the right balance with medication were all factors listed by Monica for a healthy lifestyle. As Addisonians, we were encouraged to take more responsibility for our health, thereby reducing the amount of stress on our bodies.

Minutes by Angela Timms, Recording Secretary

Our next meeting will be September 19, 1998 at the Brantford Police Station and will be in conjunction with the Canadian Addison Society National meeting. Our speaker will be Dr. Robert Volpe, who will speak on "The clustering of other autoimmune diseases with Addison's Disease".

### **Eastern Ontario and Ottawa Valley**

The first meeting for this new support group will be Saturday, July 11th at 10:30a.m. Our guest speaker will be Dr. Silverman, an endocrinologist from Ottawa who is interested in our group. He will speak at 1:30 p.m. Our business meeting starts at 10:30 and we are asking for your full support to get this group going and please come forward if you are able to take an office within this group.

### **Alberta:**

The first meeting of the Alberta support group was held on May 2, 1998 at the Sturgeon Hospital, St Albert. There were 13 in attendance. Richard Evans welcomed everyone and introduced the core group of Ginny La Valley and Francisca Swist. Peter Little sent his regrets.

The top ten reasons to attend an Addison's support group were reviewed with the most

important being: Where else can you go where other people will understand what you are talking about?

The guidelines and rules of the meeting were reviewed stressing that "what is said at the meetings - remains at the meetings". It was suggested that the guidelines be raised at the start of every meeting. There was a voluntary introduction of the meeting attendees mentioning their current health concerns. Those with Addison's disease ranged in length from one year to 20 years. There was a review and discussion of Addison's support group, the purpose, and goals, which include:

- Help Addisonians' understand their disease and its affects on day-to-day life.
- Provide support and encouragement to other Addisonians and be there to listen when needed.
- Together with the Medical Community, work towards a better understanding and more effective treatment for Addison's disease
- Through the sharing of experiences and knowledge, provide the opportunity for the Addisonian to be better equipped to address their needs
- Create an awareness of our Alberta and Canadian Addison's support groups.

Several action items were listed to help attain these goals. These include

1. Education of the medical and dental community to allow for quicker treatment.
2. Attendance at medical conferences with a booth to offer information.
3. Preparation of a package of materials for newly diagnosed Addisonians.
4. Start a library or website to allow for access of information. Possibly approaching a public library, that might consider filing and holding relevant material.
5. Exploration of alternative interventions and their effects on Addison's disease
6. Provision of a list of endocrinologists in Alberta.

Completed evaluation forms were reviewed and the following points were listed as topics or areas of interest; nutrition, side effects and long term effects of medications, sexual function, what exactly is Addison's disease and how does it affect you, what are the impact on the family, emergency measures in a crisis, and stress management.

Several types of speakers of interest were listed as well: endocrinologist, nutritionist, naturopath or other alternative medicine specialist, speaker on stress management, and a paramedic.

Our meetings will be a minimum of 4 times a year with additional suggestions for a possible drop-in meeting on a more frequent basis, socials, and one day "Addison Awareness" conference with speakers.

It was a very successful meeting with a number of the attendees meeting another Addisonian for the first time. A very positive atmosphere prevailed throughout the meeting and will hopefully encourage attendance at future meetings.

**British Columbia:**

### **New Westminster Support Group**

The next meeting for the British Columbia, New Westminster support group, will be July 11, 1998 in Sherbrooke Lounge at the Royal Columbian Hospital, 330 E. Columbia Street, New Westminster, from 1-3 p.m. (Please note the change of meeting room). Kitchen facilities are available. The speaker will be Mrs. Jetha from C.P.P. to explain disability benefits for us. Please mark your calendar for these next meetings. The next meeting dates are November 14, 1998, March 13, 1999 and July 10, 1999 same time and location.

### **Victoria Support Group**

The first meeting of the Victoria Support Group was held May 30, 1998 under the guidance of Jim Sadlish. Nine Addisonians plus three family members attended. Judy Stanley reported on the support meetings being held by the mainland group. Discussion included: effects of different types, and dosage-regimes of glucocorticoid medication; problems encountered getting extra replacement in temporary stress situations; difficulty obtaining a pre-filled syringe that a patient could self-administer in emergency. (It is available in the United States but according to one member's experience over several years in two provinces and one state, not in sufficient demand to warrant general pharmacies' stocking it).

Those attending found the networking very helpful and informative and plan to meet again in the fall.

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**Pre-filled syringes for Emergency use:** The group in Victoria has been doing some research on the syringes that many of us have for Emergency use and have found a product called HEXADROL (1.0 mg Dexamethasone Sodium Phosphate (USP) look at <http://www.rxmed.com/index.html> for more information about this product). As this is a pre-filled syringe, it is felt to be safer and easier to use in an emergency. Unfortunately this product now is not available in Canada, as yet This may be a subject you wish to discuss with your specialist, taking this information with you. I have contacted our Medical Advisor for the Canadian Addison Society but unfortunately he is away and his input will not be in time for this newsletter. For more information or further questions, contact Jim or Florence at the above addresses. You may also wish to check with your pharmacists to see what information they have on this or any other PRE-FILLED syringes for Emergency use. We would appreciate receiving any information that you can find and will gladly share with other Addisonians in our next newsletter or at the National Meeting in September.

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### **Tidbit Section**

**DHEA Study:** DHEA is Dehydroepiandrosterone, an androgen of the adrenal cortex and the ovaries/testes. Some Addisonian women experience extreme fatigue when the ovaries stop functioning at menopause and, of course, their adrenal glands aren't functioning to compensate for the sudden drop in ovarian DHEA. This appears to be more gradual in Addisonian men. Our own Canadian DHEA study is continuing well. There are now

approximately 65 Ontario Addisonians taking part in the study. When I last inquired, there was only one participant that had withdrawn from the study. I asked Dr. Killinger, one of the doctors involved in the London, Ontario project, if this study had met their expectations. His reply was "beyond our wildest expectations". My six-month check and for several others as well, has passed and all seems well. Since the admission to the research project was staggered in time, so will our completion dates. The DHEA (U.S.A.) study (1995) of 24 Addisonians, carried out at the University of California, San Diego is now complete and is being analyzed and hopefully ready for publication this summer.

Background information and information regarding the DHEA (U.S.A.) study from the article *DHEA Update* - "Addison News" Newsletter by Joan Hoffman June 1998

**The Addisonian Book Store** Thanks to several of our members who have ordered their copy of the book "*Addison Patients in the Netherlands*". There are still some available. The books sell for \$25.00 each, which includes postage. Please send your cheque or money order payable to the Canadian Addison Society along with your order. We also have a few books *Our Addison Kids* by Joan Hoffman made available to parents of Addisonian children through the kind generosity of Joan Hoffman.

The support group in Alberta has also recommended the following books – *Endocrine Harmony, The Mind-Body-Nutrient Connection* by David W. Rowland and *Coping with prednisone\* - It may work miracles, but how do you handle the side effects? (\*and other cortisone-related medicines)* by Zukerman, Eugenia & Ingelfinger, Julie R. They also suggest the book *DHEA: A practical Guide* by Ray Sahelian.

**Old Newsletters:** We now are the proud owners of a complete set of newsletters from the Canadian Addison Society (1-13) as well as several from the English support group and several from the Australia support group. We are making these available to our members. We pay the copying and you pay the postage!

**Specialists Recommendations:** We have been asked several times by our members, particularly those who are moving, if we have received a recommendation of a specialist in their new area, from any of our members, preferably a specialist knowledgeable in the treatment of Addison's Disease. Please consider sending us information about your specialist with your recommendations, particularly if you are very pleased with your treatment with relation to your Addison's Disease and any other related autoimmune disease. Your help would be greatly appreciated.

**Osteoporosis:** For the many Addisonians that suffer from osteoporosis, there is a very informative brochure called the Osteoporosis Advisor. Your doctor, hospital, or health center may already have a copy and is well worth your reading.

There is also a **cookbook** put out by the Osteoporosis Society of Canada (about \$25.00) called "Bone Vivant" that contains many calcium-enhanced recipes and bone building exercises. Call toll-free 1-800-463-6842 for more information.

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The following is a news article by Mark Lowey of the Calgary Herald. It was sent to us by Peter Little, Edmonton.

### **Drug cuts bone loss for those on steroids\***

"A Calgarian is among international medical researchers who've found a way to prevent bone loss in hundreds of thousands of people. Dr. David Hanley is on a 12- member team that showed an osteoporosis drug reduced bone loss in both men and women taking steroid medications. Loss of bone density is a serious and often disabling side effect of corticosteroids, taken by about half-million Canadians. "This is the first study to take people as they start steroids and demonstrate that we can prevent the bone loss," said Hanley, head of endocrinology and metabolism at the University of Calgary Foothills Hospital. The one-year study involved a total of 141 men and women. Results were published in the New England Journal of Medicine, one of the world's top science journals. Hanley said the study indicates that for most patients, bone loss and broken bones can be reduced by taking the osteoporosis prescription drug. The drug Etidronate is made by Proctor and Gamble Pharmaceutical, which funded the independent peer- reviewed study. A separate osteoporosis drug, from the same chemical family, is made by Merck Frosst. Hanley noted that about half of all patients taking corticosteroids for three to four years will suffer fractures. "It is now clear that we do not have to accept bone loss and high fracture rates as inevitable consequences " of steroids therapy, wrote Australian physician Dr. Ian Ried in a commentary on the study.

The group taking the osteoporosis drug had 3½ to 4 per cent less loss of bone density in the spine and hips compared with a control group not getting the drug.

In post-menopausal women - at highest risk for broken bones - the drug helped reduce backbone fractures by 85%. Also few patients on the drug lost height during the study compared with the control group.

Hanley said the drug's side effects, such as stomach upset and mild diarrhea, are rare and minor. Sufficient calcium and Vitamin D also help prevent bone loss he said, adding the post-menopausal women should consider taking hormone replacements.

(\*Please note: This includes all Canadians on corticosteroids, not JUST Addisonians.)

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**Story Time:** We are asking all Canadian Addisonians to write down their "story" and share it with us. We are keeping a file, which may be of particularly interest to new Addisonians and many of the stories will be printed in our newsletter. It is good to know that others have gone through the same situations that you have. It is also a good idea to be able to share these stories with your families and even doctors to show that "it is not all in your mind" as many, too many of us, have been told over the years. Each of us has something to share, whether it be simple sharing of your symptoms, treatment and how you coped, an inspirational journey that we may share in, or a medical "miracle". All stories are needed

and appreciated. Please share with us!

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**Diabetes and Addison's Disease:** One of our Ontario members, Angela Timms has written an excellent article (3 pages) of her and her husband Don's findings while health caregivers to their now 14 year old son Geoff. Geoff was 2 years of age when he was diagnosed with Diabetes and age 11 years when diagnosed with Addison's Disease. This article has some invaluable insight into treatment, care, balancing and coping with these two diseases, mixed with a generous amount of common sense and lots of love, which all combines to make a very informative and interesting article. Thanks Angela! I will share with you the "summary" from the article:

1. Avoid very tight control for an Addisonian/Diabetic - it is too risky and increases chance for a crisis.
2. Do everything possible to reduce reactions - meaning more testing, extra monitoring during illness, providing guidelines for school, work and supervisory personnel.
3. Always carry extra cortisone and glucose gel in car, boat, aircraft, at school or work, or on a person.
4. Keep a medical-care guide with you for hospitalizations and for others whose care you might be under.
5. Inform as many people around you how to treat a crisis. Don't frighten them with overload - just the facts!
6. Get help fast but remain calm and others will follow your lead.
7. Find a doctor willing to listen and work with you.
8. Provide sensible routines, healthy diet, vitamins, and exercise, stress relievers and a positive outlook.

Note; The full article is available upon request from the Canadian Addison Society.

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#### **"Dear Doctor" Letter:**

We have enclosed a copy of the letter we have drafted from the Canadian Addison Society for the doctors in Canada. Please pass it along to your family doctor and especially your specialist. We are trying to make the medical community more aware of our groups, with particular interest, the local support groups. Your cooperation is appreciated.

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#### **CANADIAN ADDISON SOCIETY ANNUAL MEETING**

Our annual meeting will be Saturday, September 19, 1998 in Brantford, Ontario at the Brantford City Police Station. This annual meeting will be in junction with the local meeting of the Brantford and District Support Group. The national business meeting will start at 10:30a.m and all concerns and issues will be addressed and discussed at that time. We

will then break for a potluck lunch. Every paid up member of the Canadian Addison Society (or his/her appointed family representative) can take part as well as vote in the business meeting discussions.

The Brantford support group will start their meeting at 1:30, with a short business meeting and the speaker for the day will be Dr. Robert Volpe, a well known Toronto endocrinologist, and Professor at the University of Toronto. He will be speaking about "The clustering of other autoimmune diseases with Addison's Disease". Dr. Volpe is well known especially in the area of autoimmune diseases. We very much appreciate him volunteering his time to share with us and we are all looking forward to his presentation. It should be a very interesting and •informative day,

### **International Interest**

As many-of you are aware, there are several different Addison support groups around the world and we have had contact with several on a regular basis including the exchange of newsletters.

One such support group is the Australian Addison's Disease Association of Coffs Harbour, NSW, Australia. We contacted Secretary Yvonne Doherty and she has kindly sent us some information for us to share from their group:

Obviously all our activities revolve around Addison's disease but to give you some idea of what type of things we do, following is a list of what we have achieved over the last two years:

- Membership has grown from 3 to 125
- We have distributed fliers to medical practices and endocrinology departments at major hospitals
- Produce a newsletter very two months
- Give talks about Addison's disease on radio
- Give talks about Addison's disease to other associated support groups
- Attended the first International Conference for Addison's disease patients held in Norway.
- Had articles on Addison's disease published in regional magazines
- Listed in a publication of Australian Self Help Groups that is distributed to doctors
- Joined networks of Self Help Organizations around Australia
- We have guest speakers at our meetings
- We held the first National Conference for Addison's disease patients in May 1997 and another conference in November 1997
- A very enthusiastic local doctor has given lectures at our meetings, given a lecture to local doctors and written an article in Addison's disease for a doctors newsletter
- An endocrinologist has agreed to be our medical adviser and answer questions for our newsletter
- We have produced a video tape of a lecture by Dr. Ladhani on Addison's disease
- We have produced audio cassettes of lectures by Doctors and Endocrinologists on

the pathology tests associated with Addison's disease, Osteoporosis, DHEA, Coping with a chronic illness, and the question and answer sections of the November 1997 conference

- A list of the endocrinologists in Australia is available to our members
- We exchange newsletters and information with similar overseas organizations
- We put members in contact with other Addisonians
- Our telephone "Helpline" service is used extensively by members, their family and friends
- Keeping up with the information highway, our newsletter is on the World Wide Web and we have contributed to the information on the International Addison's Disease web site. We can now be contacted via the Internet

Our goals are as follows:

1. To educate the medical profession to have a higher awareness of Addison's disease
2. To make the general public aware of Addison's disease
3. Supply up to date information to people with Addison's disease
4. Supply a caring network to give support for people with Addison's disease.

Our membership is open to people suffering from Addison's disease and their family and friends. Members pay an annual fee (\$20.00 Australian for 1998), which entitles them to 6 newsletters a year, information on Addison's disease and able to attend our meetings and conferences.

The current committee consists of a president, a secretary, a treasurer, and a promotion officer. The people in these positions all volunteered their services and were elected to the positions unopposed.

We are a non profit organization, funded by membership fees and donations. We receive no government funding.

We have just become an association and are currently setting up branches in QLD, VIC, ACT, SA, WA and Sydney. We also have a very active group in the Newcastle area.

Ms. Doherty has also given her kind permission to reprint any of the Australian Addison's Disease Association newsletters.

## **Medical Questions and Answers**

D. Killinger, MD, PhD, FRCPC

**Q:** What is the difference between Prozac and Zoloft and which is better for Addisonians?

**A:** Prozac and Zoloft are similar but are not identical drugs. They both block the re-uptake of serotonin in the brain. I am not aware of any data proving one is better than the other in Addison's patients. Theoretically there should not be a difference.

**Q:** There has been much discussion about blood donation and organ donation of Addisonians from different parts of the world. Can we as Addisonians in Canada give blood and/or donate organs?

**A:** As far as I am aware, there is no restriction regarding these donations. Some Addisonian patients may be anaemic (low hemoglobin) and this may prevent them from donating blood but otherwise there should be no problems.

**Q:** How accurate is the salivary testing for steroids and is it available in Canada?

**A:** Measurement of salivary steroids has been used with some success, particularly by a group in Wales. It has not received much interest because it is difficult to standardize so I am not aware of any groups that are using this technique in Canada or the U.S.