



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

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President's Message:

Dear Friends,

I hope all of you are enjoying our wonderful summer weather, wherever you reside. I recently attended the Eastern Ontario group meeting in Ottawa at Robbie's Restaurant and found it very interesting and informative. It was nice to see some new members out as well. The annual meeting is coming up soon, September 29th in Brantford Ontario, and if you have anything further to add to the agenda please let either Joan Southam or myself know. We hope to see many of you out at that meeting, both for the business part, to participate in the potluck luncheon or to hear the speaker in the afternoon. The fellowship and friendship is wonderful to experience as well as the exchange of information.

We are still encouraging other support groups throughout the country and if you need any information or helpful ideas, please don't hesitate to contact us.

In friendship and continued good health,
Greta

The annual meeting for the Canadian Addison Society will take place on Saturday, September 29, 2001 from 10:00am to 4:00pm at the Brantford Ontario Police Station, Community Room, on Wayne Gretzky Pkwy in Brantford. The business meeting will take place in the morning from 10:00am to noon, which will be followed by a pot-luck lunch; finger foods only please. The speaker for the afternoon is scheduled to begin at 1:30 pm. The speaker this year will be Marion Jutzi who will talk to us about stress management. Ms. Jutzi is a professional Kinesiology Practitioner and a Registered Nutritional Consultant.

Following is a brief agenda for the annual meeting for September 29th, 2001:

1. Welcome and Introductions

2. Minutes of our last Annual Meeting held September 23,2000 (copies available).
3. Presidents Report - Mrs. Greta Fraser
4. Business arising from previous meeting
5. Correspondence - Mrs. Joan Southam
6. Financial report - Mr. John Gordon
7. New Business - Please note that each new item of business must be at the office of the Canadian Addison Society by September 01,2001, so these new items of business can be distributed to all directors and support group leaders for their comments and written input.
8. Potluck Lunch 12:00-1:30 pm (finger foods-no utensils needed)
9. Introduction of speaker - Mrs. Marion Jutzi who will speak on "Stress Management"
10. 2:45 to 3:00pm - Coffee Break
11. 3:00 to 4:00pm-Mrs. Jutzi - Questions and Answers

Medical Questions and Answers

Dr. Donald Killinger, MD, PhD, FRCPC

Dr. Donald Killinger, from London, Ontario, who is the Medical Advisor for The Canadian Addison Society, will answer your questions about Addison's disease. Questions and answers that may be of interest to everyone will be published in the newsletter. Dr. Killinger has asked that we not write him directly, but to address your questions by letter / e-mail or fax through The Canadian Addison Society and they will be forwarded on to Dr. Killinger.

P l e a s e - If you are pleased with your endocrinologist - LET US KNOW! We have many requests not only from recently diagnosed Addisonians but other Addisonians from all parts of the country, who may be moving from one area to another and require the services of an endocrinologist knowledgeable about Addison's disease and its treatment.

Dr. Killinger:

This letter came from a man in B.C. Hope you can give him some insight.

Thank you.

Sincerely,

Joan Southam

"Recent studies have related higher IGF-1 levels with increased risk of prostate cancer. Is this a concern for men taking 25 mg or 50 mg of DHEA supplementation and is it advisable that IGF-1 levels be monitored?"

Joan, I've read some studies that say there is no relationship between high readings of IGF-1 and prostate cancer, too. Hoped Dr. Killinger can clarify this concern."

The following is Dr. Killinger's reply:

The letter from the gentleman in BC raises an interesting question. There is some evidence that an increase in IGF-1 levels above normal is associated with an increase in certain types of concern - specifically, colon cancer. This is seen in acromegaly (a growth hormone secreting pituitary tumor) where IGF-1 levels are above normal. IGF-1 levels are increased by the administration of growth hormone, testosterone and DHEA. The IGF-1 rise with DHEA and testosterone is modest and the levels remain within the normal range. There is no evidence that DHEA or testosterone cause prostate cancer. In men in the post-50 age group, a prostate specific antigen (PSA) level should be measured before starting testosterone or DHEA to be certain they do not have a prostate problem before the DHEA is started.

Dr. Donald Killinger

If anyone would like to have a poster to put up in their doctor or specialist's office, (with their permission, of course), then the Canadian Addison Society has some available and can send one to you free of charge. Please contact the office at the address on the front of this newsletter with your request. It's an excellent way for you to help spread the word around that we are here.

There is also available again, copies of the North American Survey booklets, which were published by the National Adrenal Diseases Foundation, (NADF). The information packed edition can be purchased through Joan Southam at the Canadian Addison Society.

The Canadian Addison Society wishes to express its deepest sympathy to the families of Thelma Brown, Phyllis Hilton and Mary Harder. All are members who have passed away recently.

The Canadian Addison Society is now an affiliate member of C.O.R.D., (Canadian Organization for Rare Disorders). "CORD is a national organization formed in September 1995 to provide a network of mutual support for individuals and others affected by rare disorders. The goal of CORD is to provide information to individuals and health care professionals and act as a link to Canadians affected with rare disorders. Further, CORD will educate the media and the general public regarding the existence of rare disorders among Canadians", (quoted from CORD's Mission Statement). From CORD we will have:

- referrals to our organization of individuals and agencies seeking information
- links our internet web site to the CORD site
- listing us as an affiliate membership in the CORD newsletter
- notification of all CORD workshops and conferences.

The membership fee for CORD is \$50.00 a year for our organization. With the \$50.00 a year that we pay for ACIF in Holland, we pretty well have the world covered!

Submitted by Joan Southam

Subject: Next Steps Conference - April 26th-27th

On April 26th & 27th, 2001, Greeta Fraser and I attended the Bank of Montreal Institute for Learning in Toronto at the invitation of the Coalition of National Voluntary Organizations with the support of Health Charities Council of Canada. The purpose of this meeting was a follow up from the first convention held in the fall 2000 in Orangeville, Ontario, (see January 2001 newsletter). This present convention was set up to determine "common interest of small national organization working with uncommon health issues or conditions". A second purpose was to "define an appropriate structure to advance these interests, and locate the necessary resources and commitment to put it to work".

It was a busy work packed two days with a lot of discussions. We had as a guest speaker, The Honorable Alan Rock - Minister of Health. He spoke of the value of volunteer sector, and since this is the Year of the Volunteer, he commented on how our small groups have made a positive impact on the people of Canada, and stressed that he wanted to see a stronger bond between the government and the volunteer organizations sector. He spoke about more funding to the provinces, more health research papers especially about a proposal that he is putting forth that will put standards on technologies and research surrounding such studies as stem cell reproduction and cloning - the moral and the ethical standards he felt were needed in such research.

The rest of the convention was devoted to trying to come up with an accepted vehicle to carry out our short term and long term goals which included establishing a national directory, have a stronger united voice for the orphan diseases, lobbying for government changes and funding and several others. The outcome was split between wanting as this vehicle/structure - the National Volunteer Organization (NVO), Canadian Organization for Rare Disorders (CORD) and the Health Charities Council of Canada (HCCC). Both Greeta and I felt that CORD would serve as an ideal structure, since it was already well established and would best suit these goals. Unfortunately not all agreed. I am not sure that we accomplished as much as was originally planned at this conference but it was a wonderful opportunity to give and gather more information and put forth the organization of The Canadian Addison Society.

Following is the results of a study conducted by one of our members earlier this year in Alberta which was used for part of his senior thesis for his university degree. The purpose of the research was to determine whether there is any relationship between adrenal gland influences of developmental hormones and the gender of children born to people who have Addison's disease. We thank Justin for his hard work and wish him every success in the future.

Dear Participants

I am returning the information about the research questionnaire that you mailed to me in March and April of 2001. Your participation in this project was most appreciated, as it

provided me with some necessary facts, to determine whether there is any relationship between Having Addison's disease and the proportion of male and female children born to people with Addison's disease. The enclosed information is a narrow down version obtained from the research. Thank you again for participating in the questionnaire and this study.

There have been a number of studies done on the alteration of sex ratios in the human population under environmental stressed circumstances in which there has been no known specification to what causes these alterations. This study tried to determine whether the adrenal glands play an influential part in the determination of the gender of children born to people with Addison's disease. This was done by comparing the number of male and female children born to people with Addison's to the number of male and female children born to the Canadian population as a whole.

Of the 300 or more people contacted in this study, 51 returned the survey questionnaire. This represents a response rate of 17%. Thirty-eight of the respondents were female, and 13 male. The average age of the respondents was 51 years old. The average length of each respondent having Addison's disease was 18 years. Of the 51 returned questionnaires 22 respondents had had children after being diagnosed with Addison's disease. The average age of the respondents who had had children after being diagnosed with Addison's disease is 49 years of age. These 22 respondents had, on average, had Addison's disease for 25 years. Thirty-nine children were born to the 22 respondents after having been diagnosed with Addison's disease: 20 of the children were females (51.3%), and 19 were males (48.7%).

Statistic Canada's data regarding gender of the male and female children born to the general public in the years 1997 to 2000 show that 911,028 males born and 866,302 females born, or 51.26% male and 48.74% female, (www.statcan.ca) Table 1 compares the population birth data to the survey results and shows that slightly more female children were born to people with Addison's disease than was the case in the entire population. The 2.6% difference is not statistically significant as the number of respondents to the survey were far too few to generate a significant finding given the small difference between the population data and that of the survey.

Table 1

Population births and Addison Respondent birth rates By Gender

	Female Births	Male Births
Population Birth data	48.7%	51.3%
Addison Respondent Births	51.3%	48.7%

The hypothesis: that Addison's disease influences the sex ratio of the offspring of those inflicted with the disease was not found to be statistically significant. The inability to substantiate the hypothesis statistically is due to the limited number of returns from people with Addison's disease that have had children after having been diagnosed with the disease. Given the slight variation in birth data between the general population and those with Addison's disease, it is unlikely that one could obtain statistically significant data because of the relative obscurity of the disease (Addison's disease affects only 5 to 10 people in a million), and the age at which the disease is diagnosed.

Even if all individuals with Addison's disease in North America were contacted and responded to the survey it is not clear that the sample size would be adequately large enough to establish statistical significance, assuming that the results of such a survey remained constant (i.e., only a 2.6% difference was found).

Addison's disease is often associated with another disease like diabetes and is not diagnosed until later in life. Thus in 60% of all cases Addison's is diagnosed when an individual is 35 years or older. (Margulies, & Mullen, 1997) This means that a substantial percent of those diagnosed with Addison's are no longer in their childbearing years.

If a large number of people with Addison's disease could be interviewed, and it was found that they had a significantly higher number female births than that found in the survey conducted; it could provide support for this paper's hypothesis and help narrow down the biological and anatomy organs that play an important part in the sex ratio selection of stressed individuals. Such a finding would provide some biological support for the social studies that found positive correlations to stressful environment circumstances and a change in the male to female sex ratio.

Future research in this area of sex ratio differences in the population due to stress and other environmental circumstances could be explored in greater depth through a number of diseases and illness that influence specific organs. Similar studies like this could bring light to the biological and chemical structures in the human anatomy that control sex selection and help maintain the homeostasis of the body in stressful life circumstances. Hopefully future studies of this nature will have both the resources and circumstances that will permit the collection of and analysis of larger data sets that can better test the research hypothesis.

Justin Elton
Lethbridge, Alberta

Don Jacobson, a member from Ontario, would like to correspond or speak by phone to someone who has secondary Addison's Disease. If you would be interested, you can write him at R.R. #1, Ariss, Ontario NOB 1B0.

Highlights From Local Meetings

Vancouver Island Support Group (Victoria) - May 05/2001

Reported by James Sadlish:

The Vancouver Island support group of the Canadian Addison Society met May 05, 2001 at the Victoria General Hospital. The meeting was dedicated to discussion and several

interesting topics were raised. Three people attended who were new to Addison support group meetings. One man from the mainland, recently diagnosed with Addison's, has had Crohn's disease for 20 years and would like to contact anyone else with this combination.

Discussed were types of medication and dosages, calcium supplements and bone density considerations, afternoon fatigue, and difficulties experienced prior to being diagnosed with Addison's. Another new member finds he can participate successfully in vigorous sports without increasing his regular dosage. Further topics included experience with medicating during a lengthy operation under general anesthetic, allergies to common medications and certain foods, recommended endocrinologists, hypoglycemia complications, dealing with the effects of stress, plus abdominal irradiation and anti-fungal medications as possible causes of Addison's.

An excellent Addison's website: <http://www.emedicine.com/med/topic42.htm>

Of the many websites explaining Addison's disease, a few mention having a small heart as a symptom. One member, who searched various references, speculated that a small heart may result from hypovolemia (low blood volume) and hypotension which are likely symptoms of Addison's but not specific to Addison's. Dehydration and a deficiency of mineral corticoid may also be contributing factors. It was further speculated that after diagnosis, replacement medication would probably normalize the circulatory system.

A member has discovered a controversy on the internet about the hypothyroidism replacement drug, Synthroid. Evidently, Knoll Pharmaceuticals, the company that manufactures Synthroid, is reported to be reluctant to file a New Drug Application requested by the PDA before the extended deadline of August 2001. In response to patients' concerns, the company has apparently sent letters to US doctors and pharmacists stating: "We do not foresee any circumstances under which SYNTHROID will fail to be available for hypothyroid patients."

Despite limited attendance, the five participants covered numerous subjects and exchanged ideas during the two-hour meeting. Suggestions are needed from support group members who wish to have a speaker at the next Victoria meeting on September 8 at Victoria General in Room 1814. Please contact Jim Sadlish at wx699@victoria.tc.ca or 250-656-6270, or Florence Weekes at fmweekes@telus.net or 250-598-0321. The upcoming Nanaimo meeting date of the Vancouver Island support group has been moved to June 30 in room G245 at Nanaimo Regional General Hospital. For more information, please contact Christy Lapi at clapi@island.net, or at 250-245-7554 or Barbara Hunn bhunn@telus.net or 250-756-4385.

During the February Victoria support group meeting, Larry Thorne, a compounding pharmacist, suggested the possibility of a buccal alternative to our Solu-Cortef injection for crisis medication. Although this concept has generated much interest, there appears to be a lack of supporting literature. Several endocrinologists, including the CAS medical advisor Dr. Killinger, and a representative of Pharmacia, manufacturer of Cortef, could not endorse the buccal administration of glucocorticoids because of the lack of available information regarding buccal absorption and safety. As many people feel this idea has some merit, it has been suggested that we search further for existing evidence or even encourage future

studies. On our behalf, there are now two US doctors of pharmacology looking into the feasibility of sublingual delivery of glucocorticoids and checking relevant research papers. Although at present it is clearly not prudent to experiment with this alternative method, over time through joint efforts it may be possible to gather research literature that could lead to its safe use.

Vancouver Island Support Group (Nanaimo) - June 30/2001

Submitted by Christy Lapi:

Shavi Manhas, a fourth year pharmaceutical student working for Overwaitea Drug Store, answered questions on medications for six members of the Vancouver Island Addison's Support group in Nanaimo, B.C. on June 30.

Asked about the side effects of too much cortisone, Manhas said among them are the depression of the immune system, leaching of calcium leading to bone loss and possible formation of cataracts. Too much florinef can lead to water retention, anxiety and irritability.

The group was also interested in DHEA. Along with cortisol, it is normally created by the body from cholesterol. Manhas pointed out the 1999 study reported in the New England Journal of Medicine in which Addison's patients receiving DHEA found a greater sense of well being, less anxiety, and increased sex drive. DHEA may also cause acne and loss of hair.

People with Addison's who suffer pain should watch what pain killers they use. Manhas noted that both ibuprofen (Advil) and aspirin, may interact with cortisone. Tylenol may be a better choice for pain. However, although Tylenol is easier on the stomach, it can affect the liver and should not be used to counteract a hangover.

She also discussed potassium, which can fluctuate in Addisonians. While a lack of salt is often paired with too much potassium, vomiting and diarrhea can result in low salt and low potassium levels. Among the functions of potassium, it aids in muscle activity, and low potassium can lead to cardiac arrhythmia.

The next Vancouver Island meeting in Victoria is on Sept. 8 in Room 1814 at Victoria General Hospital. The next Nanaimo meeting is Oct. 20 in Room G245 at Nanaimo Regional Hospital. All meetings are from 1-3 p.m. For further information on the Nanaimo meetings, contact Christy at clapi@island.net (250-245-7554) or Barbara at bhunn@telus.net (250-756-4385). For information on Victoria, contact Jim at wx699@victoria.tc.ca (250-656-6270).

BC Lower Mainland Support Group - May 26/2001

Submitted by Judy Stanley:

The May 26 meeting of the BC Lower Mainland was a great success for the seven people who were able to make the picnic pot-luck. Ten people sent their regrets including some for Disneyland and the Bahamas which does sound a lot more exotic!

Several topics were discussed:

- Jana had just returned from Germany where she had a crisis and had to use her emergency syringe. Although she was unable to attend the meeting she wanted to stress the need to carry a syringe along with instructions on when and how to use it for your hosts or anyone traveling with you. Jana had not previously experienced any problems from her Addisons but felt that her crisis was triggered by food poisoning. After several hours of vomiting, etc. she used her vial. Anyone who has had an Addisons Crisis knows that it's not our best time for clear thinking! Even though her host is a retired RN and Jana herself is a RN it took both of them some time to figure out how to remove the top seal, insert the needle into the sterile solution, fill the syringe, inject it into the powdered cortisone, mix to dissolve and then inject intramuscularly. It pays to practice!! Members were encouraged NOT to try and deal with a crisis on their own but rather to go to the nearest medical facility for help (see info below re. Medic Alert) as recovery would likely be more swift, less discomfort and fear, and there may be less chance for complications.
- For those who have Medic Alert (and we hope you all do) you may want to have the following information added to your card:

**** IN CASE OF ADDSION CRISIS ADMINISTER _____mg. OF (i.e.:Solu-Cortef) EVERY _____HOURS, ACCOMPANIED BY SALINE SOLUTION BY INTRAVENOUS.****

I discussed this with my doctor and he felt that a common dosage of 100 mg. every 8 hours would be safe for everyone. This is the amount typically given in emergency. Have your doctor or endocrinologist recommend the dosage, medication and time span for you before you contact Medic Alert to update your file and have a new card issued (it's free). If you ever find yourself in a crisis (as both Catherine and Jana have in the past 6 months) you won't need to worry about trying to remember what doses etc. are required.

- The topic of buccal glucocorticoids was discussed. Until further data can be supplied to determine the effectiveness/validity if this possible option, we should all continue to carry the injection for emergency use.
- We also discussed what to do when you have a "foggy head". Several members felt that things improved when they took gastrolyte, (available from Costco for \$9/10 pack -has to be ordered a couple of days in advance). Judy offered the recipe her doctor gave her for preparing this at home - 2 teaspoons sugar, ¼ teaspoon salt and the juice of ½ a lemon in 1L of water.

Thanks go to Marilyn Thauburger for offering to arrange speakers for the meetings. If you have any suggestions for topics, let us know.

The Nanaimo meeting has been rescheduled to June 30 and a fourth year pharmacy student will be the guest speaker. For further information contact Christy at clapi@mail.island.net or Barbara at bhunn@telus.net. Victoria will be meeting on Sept. 8 in Room 1814 at Victoria General Hospital. Contact Jim at wx699@victoria.tc.ca or Florence at fmweekes@telus.net.

BC Lower Mainland meeting for the upcoming year will be October 13, 2001, February 16 and May 25, 2002. All dates are Saturday from 1:00 to 3:00 p.m. at 330 Columbia St. E, Sherbrooke Lounge, Sherbrooke Centre, next to Royal Columbian Hospital. Two of the dates discussed at the meeting had been previously booked so for those who attended, be sure to correct your calendars.

Saskatchewan Addison Support Group - April 28/2001

Submitted by Elizabeth Hill

As a group-10 Saskatchewan Addison's met April 28,2001 in Saskatoon for the first time. Three men and seven ladies. One of the members Rick Dixon was recently diagnosed with Addison's on Feb./01 He saw an old poster Rob Zaleschuk had put up in one of the major Saskatoon's hospital and gave him a call. Rob called me and I called Rick. It was decided it was about time we all got together to share. Rick volunteered his place of work and I volunteered the phoning of known Addisonians.

It was a very, very hot day.

Our discussion included:

- As to why we had chosen which specialist we were seeing: GP's, Endos, Internal medicine.
- It would be nice to establish the same Endocrinologist or ?????.
- It was interesting that - 6 were on thyroid medications and 4 were not. The majority had the thyroid condition first and very close to the diagnosis of Addison's. These individuals were on death door before being diagnosed. One had bilateral pheochromocytoma tumors so was a surgical induced Addisonian.
- We had twin females, now age 17 years, who were diagnosed at the age of 8 and 10 years. THEY WISH TO CORRESPOND WITH OTHERS 17 OR CLOSE TO THIS AGE GROUP.
- The group main consensus was
 1. Know your medications and how it works for you.
 2. Do not be afraid to increase or'decrease your medications..
 3. Ask questions.
 4. Go on the Internet for additional information.
 5. Get together with other Addison's for support.
 6. In time of illness or emotional or physical stress opinions varied with personal experiences.
- Spouses and fathers-in-law, children also shared what is like for them to live through the diagnosis.
- New Canadian Addison's Posters were handed out to put in hometowns, myself and Rob Zaleschuk and Joan Southam as contacts.

- The group looked over past years newsletters from the Canadian Addison's Society, NADF newsletters, Joan Hoffman's newsletters and each received a copy of the North American Survey by the NADF from Elizabeth.
- Parti Nauta is tossing around the idea to hold an Addison's meeting in Regma this fall. There are 3-4 Addison's that could meet in the southern half of this province.

We ended by eating snacks that were salty or just plain delicious and Rick showed us around his work- the area that receives old artifacts and then designs and sets up the museum displays before you see them in the main museum.

Southern Ontario Support Group - January 20/2001

Submitted by Angela Timms:

Lynda Daniels opened the meeting and introduced her guests from the Taoist T'ai Chi Of Brantford. Four members, Doreen, Harold, Donna and Fern, gave a brief summary of their purpose and a demonstration of the complete 108 Taoist T'ai Chi movements. This took about half an hour to complete, as it is one continuous sequence. It is done in silence, because participants become completely involved in what they are doing and the moves. It is a gentle form of exercise, suitable and adaptable for all ages and abilities, including wheelchair bound patients. For many of us it was the first time being introduced to the subject. As a result, an impromptu session developed, using the first 17 moves that are utilized in the Health Recovery Program. These 17 moves are advised for anyone beginning a Taoist T'ai Chi program.

Benefits are many and include help with: stress - bone density - muscle strength - balance -memory & cognitive functioning - cardio vascular system - spine & nervous system - chronic disease such as Addison's & Arthritis - problems with mobility, circulation and breathing.

Taoist T'ai Chi can be performed almost anywhere and is recommended wherever there is a lack of motion including at a desk, computer, in a chair, on a plane (especially helpful to circulation during long flights). We were told to ignore the stares and continue to restore our bodies! Despite it looking easy and being gentle, as much energy can be expended on Taoist T'ai Chi as a half hour of aerobics!

For anyone recently recovering from surgery or hospitalization, Taoist T'ai Chi can aid the process, but must be done under supervision within the Health Recovery Program. There are other forms of T'ai Chi exercise, but Taoist is the most gentle. After recovery, the beginner class can be taken before going on to the advanced forms.

Fees are kept low, and can accommodate all income levels. \$20.00 is the initiation fee, which includes a T-shirt. Under age 60 is \$30.00 and over 60 is \$20.00 per year. Staff are volunteers who must complete certification, which takes approximately 2 years and is a life-long commitment.

After thanking our guests, we finished up with coffee and snacks, organized by Ruth Ann Kruger.

There is no meeting scheduled for the summer months, but if you wish to put forth an idea for a speaker or subject matter, please contact Lynda Daniels at: 2 - 1570 King St. West, Toronto, Ontario, M6K 1J7.

Alberta Support Group - June 03/2001

Submitted by Francisca Swist:

A small group of Addisonians met on June 3rd in an informal meeting. The main conversation of the meeting was the importance for an Addison sufferer to see an endocrinologist. The importance of this fact is that the endocrinologist will be up to date on what other problems can occur in someone with Addison's Disease. Such problems are: diabetes, hypothyroidism, etc.

Eastern Ontario Support Group - May 26/2001

Submitted by Elaine Hall:

The spring meeting for Ontario East was held on May 26, at Robbie's Italian Restaurant. Fourteen people attended the meeting, apologies from Evelyn, Christine and Ruth. Welcome to Sue Hedger, and congratulations go to Theresa and Raymond on the birth of their son Parker.

Dr. Weinberg attended the meeting; he did a question and answer forum. The topics were quite general covering medication, sleep disorders, diabetic related factors, thyroid related factors and much more. Everyone seemed very pleased with his format, unfortunately hearing Dr. Weinberg was difficult due to the loud restaurant noise. Our thanks are sent to Dr. Weinberg for attending our meeting, and for the helpful input he provided.

The next meeting will be held on October 13, at the home of Susan Steadman at 46A Geneva St., Ottawa, (613) 728-3956. It will be a pot-luck lunch, please inform Elaine if you wish to attend the meeting. A speaker has yet to be organized, if anyone has suggestions please contact Elaine. (613) 824-0160

Directions:

From Queensway (Going West) - Exit Island Park Drive, take Island Park Crescent (Crescent is immediately following Highway Exit), left onto Geneva.

From Queensway (Going East) - Exit Carling Avenue, turn left into Westgate Plaza, and exit left on Merival Drive, to Island Park Drive, first right onto Island Park Crescent left to Geneva St.

Meetings are held twice annually at the following times:

MAY - The first Saturday following the Victoria Day weekend. The group meets at Robbies Italian Restaurant on St. Laurent Boulevard, Ottawa, 613-744-8585, at 12:30 for an informal lunch. Reservations are made in the name of Elaine Hall.

OCTOBER - The first Saturday following the Thanksgiving weekend. The group holds this meeting at a member's home and a "pot-luck" lunch is arranged. A speaker is invited to this meeting.

Hope to see you all there,
Elaine

A community is like a ship; everyone ought to be prepared to take the helm.

Henrik Ibsen

The only thing that ever sat its way to success was a hen.

Sara Brown

The biggest mistake you can make is to believe you are working for someone else.

Bits & Pieces

Let's¹⁴ Hear It For Life!

What is Celiac Disease?: Celiac Disease is a lifelong condition in which the surface of the small intestine is damaged by gluten and the body becomes unable to absorb the nutrients in food. It can appear at any age. Gluten is what binds bread and baked goods and prevent crumbling. It is not known exactly what causes the problems in certain people, but it is an autoimmune disease related to conditions like Addison's Disease, Thyroid Disease, Crohns and connective tissue diseases. Dermatitis Herpetiformis is another form of the disease and is a chronic skin rash with intense burning and itching, most commonly on elbows, knees, neck, scalp, back and buttocks. Diagnosis is by skin biopsy from a lesion. The best current non-invasive screening test for diagnosing Celiac Disease is a blood test for anti-endomysial antibodies. It is time consuming and expensive but fairly accurate in ruling out Celiac Disease.

The obvious gluten flours to avoid include wheat, oats, rye, barley and tricale. but many foods contain some part of these. Reading labels is time-consuming and tricky, so a handy guide, "Acceptability of Foods & Food Ingredients for the Gluten-Free Diet" by the Ottawa Chapter, Canadian Celiac Association is recommended. Other useful materials are "The Canadian Celiac Association Handbook" and "The Gluten-Free Diet" by Shelley Case (published 2001).

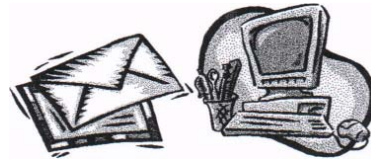
Other items containing gluten include malt, some flavorings/spices, most soups, some sauces/salad dressings, some vitamins and many fillers. Substitutes can include arrowroot, buckwheat, corn products, potato, nee, bean flours, soybean, (but not most soya sauces!) tapioca, sago. Some fine-tuning usually involves a combination of these flours. A useful recipe for flour mixture:

1 cup rice flour / $\frac{3}{4}$ cup potato flour / $\frac{3}{4}$ cup corn flour / 6 tbsp. Arrowroot flour / $\frac{1}{4}$ cup soya flour and 6 tbsp. Tapioca flour

Mix well and keep in sealed container. Use 1 cup as substitute for 1 cup wheat flour. Tip: burns more quickly, so lower temperature slightly. Xanthium gum is a good substitute for leavening. Products tend to crumble more. Experimentation is the only way!

Thank you to Angela Timms for all her hard work in getting this information and recipe out to us.

Do you have a favorite healthy recipe or tip that doesn't take too much of our stamina resources to create? If you would like to share your recipe or tip with other Addisonians, please send them to hperry@interlynx.net, or mail to Helene Perry, 75 Wendover Dr. #218, Hamilton, Ontario, L9C 2S7. Please let me know if you do not want your name used. Let's share with each other and we all win!



Letter to the Editor

On June 20th, I attended a Citizen's Panel concerning the Brant County Community Health Status Report: 2001. It was a report jointly produced by the Brant Counts Health Unit and The Grand River District Health Council. The research study from the Centre for Health Economics and Policy Analysis from McMaster University is using and studying this information. They were asking a representative from invited volunteer groups in the community to "compare and evaluate different approaches used to involve the public in local decisions in our community. In this phase of the study we are testing methods for involving the public in local health decisions".

The information about the original status report was most shocking. The complete report which is long and technical can be found at wwwvt-grdhc.on.ca was compacted into a 7 page overview for our information. Some startling facts presented were: teenage pregnancies were twice as high as the Ontario average; 8% of all Brant County babies are born prematurely, half with low birth weights. There are more smokers in Brant County (25%) compared with Ontario (21%) with 40% of all households with children less than six years of age reported having a regular smoker, compared to 30% throughout Ontario. Hospitalizations are 17% higher in Brant County than in Ontario. Among deaths attributable to diseases of the circulatory system, strokes were 60% more frequent in Brant County than throughout Ontario. The standardized mortality' rate for breast cancer was 55% higher in Brant County' than Ontario. We know that juvenile crimes are four times higher here than in Niagara Falls, a city similar to ours in numbers. Respiratory conditions were higher in Brant County than in Ontario. We already know that Scleroderma and Multiple Sclerosis and Addison's disease are more prevalent here in Brantford.

What are the causes of some of these startling facts? Some suggest lower income and levels of education, high rates of mental illness, lack of sufficient doctors and more. Some of us however suggest that there are serious physical environmental issues to be dealt with in this city. This could include the many industries that were producing goods and services in the past here in Brantford. Is it possible that many of these unchecked industries have left lasting effects on our waterways, air and even the very earth that our county is made up of? Can heavy metals for example still be affecting us now? Hopefully this study group will not run into political blockades and will answer some of these questions. I urge all of you to look at your own communities and environments - ask questions, look for patterns, not only in your own disease but other related conditions. Maybe the more questions asked, the more answers we will all receive.

Submitted by: Joan Southam - The Canadian Addison Society

Share your ideas/opinions/experiences/funny or horror stories, or just something to get off your chest, mail it to the address below or send by e-mail. You may remain anonymous if you wish. No names will be published without your consent.

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