



The Canadian Addison Society La Societe canadienne d'Addison

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President's Message:

Dear Fellow Addisonians,

It is with the sad news of Sybil Harrison's death from liver cancer that I write to you today. Sybil was the co-founder of The Canadian Addison Society. She was a great person and my friend. Having had Addison's for almost a hah⁰ century, she was a great inspiration to me, just having been diagnosed myself when I first met her. I had been told that I would die from the disease before many years, and she had had it for thirty-nine years at that time. When we first met, neither of us had known another person with the disease.

Since forming the group, [and before], she has encouraged Addisonians and tried to get an active group going in Quebec. I really hope that there is someone in Quebec who will work with Sophie La Pointe in this regard.

Sybil will be greatly missed, but her influence will live on through all of us who reach out to help our fellow Addisonians. Before her death, she asked that all memorial donations go to our organization and that in itself shows her great heart. To all who knew and her loved her, may God bless you all.

Greta Fraser.

"The best and most beautiful in the world cannot be seen, nor touched...but are felt in the heart."

Helen Keller

In Memory of a Dear Member

Sybil Harrison

1923-2002

May 27, 2002 word reached me that Sybil Harrison had passed away that morning from liver cancer diagnosed only a few weeks earlier. Sybil was a veteran Quebec Addisonian and one of the Canadian Addison Society founders.

My mind went back to July 27, 1993 when my daughter, Amy, and I met her while she was visiting her brother in Michigan. Sybil's birthday (August 1) was the day after Amy's so it became a birthday celebration.

During this lunch, I realized how much we novices could learn from Sybil's years of Addison's experience and her positive outlook. Cortisone acetate was her medication, consistent with what was in use when she began replacement April 1, 1954. She used an enormous amount of cortisone acetate - 75 mg per day for 48 years with no apparent side effects! And she used an enormous amount of salt on food. It worked for her and dispelled the notion, "one amount fits all".

Sybil had several disorders besides Addison's. One of these was alopecia, a complete lack of hair. This can be devastating but as with her other disorders, Sybil took alopecia in stride. She told about one national alopecia meeting that included an evening dance. As the dancers became warm, one by one they tossed their hairpieces on nearby chairs and tables and danced the night away.

Not only could Sybil be found regularly at the annual Canadian Addison Society meetings, she attended support group meetings in Brantford and Ottawa. She worked hard to establish a group in Montreal. It was not easy. Some of the interested Quebec Addisonians were comfortable only with English, others only with French,

Sybil enjoyed life. She seldom complained. She was loyal not only to the Addison's organizations but to her bookkeeping job, church, friends and family. May 4 she left these final thoughts with me during a phone conversation, "I've had a good life, I'm not in pain, and my kids come and wait on me."

Joan Hoffman, Michigan, U.S.A.

"The only way to have a friend is to be one. "

Ralph Waldo Emerson

Annual Meeting Announcement

The annual meeting of The Canadian Addison Society/La Societe Canadienne d'Addison has been scheduled for Saturday, September 21, 2002. The business meeting will get under way at 10:00am until 12:00 noon at which time we will break for a lunch of finger foods. All are welcome to contribute to the potluck lunch.

The afternoon portion will get under way about 1:30 until about 4:00pm and will include a short coffee break. Our guest speaker will be Dr. Don Killinger, endocrinologist and medical advisor to The Canadian Addison Society. There will be a question and answer format, therefore if any members would like to submit their questions to Joan Southam, she will send them along to Dr. Killinger or please feel free to bring your questions with you if you are able to attend the meeting.

AGENDA FOR ANNUAL/GENERAL MEETING CANADIAN ADDISON SOCIETY

September 21/02

- Call To Order: 10:00 a.m.

Items of Business:

- 1) Guidelines for Fundraising, now that we have Charitable Status. (This allows for tax receipts and official recognition as a Registered Charity with a number). Input from Members, Executive and those with expertise in these matters needed.
- 2) Discussion of Ontario Trillium Funding. Deadline for submission is Oct. 15/02 or half yearly of the following year. Report from Joan Southam and Angela Timms.
- 3) Ways to support your local or national Addison group:
 - a) Designate portion of United Way contribution to the Canadian Addison Society
 - b) Save Zehrs or other participating grocery chain tapes. Zehrs supports non-profit groups with a cash rebate based on a percentage of the total of the tapes.
 - c) Donate Canadian Tire money to the local support group for use in prizes, gifts i.e. for speakers, raffles, supplies etc.
 - d) Donate unused stamps for mail outs and help lower costs.
 - e) Ask your company if they offer a matching donation program i.e. some give their employees a matching amount to charitable organizations
 - f) Donate your community ClubZ/HBC Rewards for purchase of prizes, gifts and supplies
- 4) Investigate other forms of fund-raising. Suggestions, ideas?
- 5) Update on finances from Treasurer. Current Status and Goals. Investigate ways to pay for some secretarial help. (Information gathering, membership lists and updates, newsletter and mail outs, support to newly diagnosed or new members, public information tasks, medical advice networking, computer files maintenance, support meetings organization and much more!).
- 6) Positions of Secretary, (Joan Southam) needs filling immediately, and President (Greeta Fraser) coming shortly. Job-splitting, paid help and job descriptions need to be addressed if we are to

continue as a viable concern. This is a high priority. Also other volunteer positions including Board of Directors need to be filled as terms expire.

7) Drug Company Sponsorship. Questions and concerns regarding this issue and implications. Member participation and comments needed. E-mails and written submissions welcomed.

8) Any other Business?

LUNCH: 12:00-1:00. 1:00 OPENING REMARKS, SHORT RECAP OF MEETING AND DECISIONS MADE. 1:30 AFTERNOON GUEST SPEAKER, DR. KILLINGER.

An Announcement From Joan Southam:

HELP WANTED

We are in need of someone who will volunteer to help with correspondence and sending out information.

We need someone who will be the contact person for Canada to answer questions, supply information and education materials to all individuals, groups, medical staff etc.

To date, we have had NO responses to our cry for help! I would like to work with someone over the summer months with the long-range plan of taking over in October of this year. It is a vital and very necessary for our organization that we have person or persons to step in and fill these positions. Our organization is moving forward and we need individuals that are willing to help lay the groundwork for our future. If we did not get people to help, obviously the need is not as great as some of us think it is. The choice is up to you as a group and as individual members.

Thank you for the opportunity of helping. I thank you.

Sincerely, Joan Southam, The Canadian Addison Society, 8 Francis Street, Brantford Ontario, Canada N3R 7C4 Tel: 519-751-4472 Fax: 519-751-4473 E-mail: jsoutham@rQgers.com Website: <http://membefs.fOgefs.com/isoutham>

Have you paid your 2002 dues yet? Please send your cheque or money order for \$25.00 to John Gordon, 193 Elgin Ave. West, Goderich, Ontario, N7A 2E7. A membership form was included in the January newsletter for your convenience or call the nearest group contact for information on how to become a member.

P 1 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.

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.

Francisca Swist would like everyone to know that she has revised and updated the new web-site for The Canadian Addison Society. There were a number of links that were no longer valid and have been deleted. Please check out our site at <http://members.rogers.com/jsoutham>

Thank you Francisca for all your work in keeping our web-site current.

The sale of the UK booklet "Living With Addison's Disease" has been going well. You can still request a photo-copy through The Canadian Addison Society in Brantford at a cost of \$10.00 by cheque or money order, of which \$5.00 is our expenses and mailing costs, \$2.50 copyright royalties to the UK group and \$2.50 for the Canadian Addison Society. It should also be noted that this booklet can be downloaded on the internet through The Canadian Addison Society she. You will need an Acrobat reader to read the document and it is approximately 25 pages to print.

We would like to remind you that The Canadian Addison Society will gratefully accept donations of Canadian Tire Money. If you can spare this form of donation to help alleviate the various cost of running the organization it would be most appreciated by all.

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.

Buccal Method Query of Steroid Delivery

The buccal is the inner cheek region in the mouth. This tissue is less permeable than under the tongue, (sublingual), region of the mouth. The sublingual region has been used for many years to deliver nitroglycerin to treat angina, (pain) of the heart. There is also another form of delivery of drugs called, transdermal delivery or skin patch method. Most would be familiar with this method through advertising of nicotine patches to help smokers quit cigarettes. The transdermal method has also been used for hormone replacement therapy.

The buccal, sublingual and skin patch method all by-pass the step of processing through the liver and pass directly into the blood stream rather than being absorbed through the GI tract. With some of these methods problems including irritation of the delivery site becomes evident, depending on the sensitivity of the user. For this reason, it is recommended that the application site, on the skin especially, should be changed daily.

One of the major problems with the buccal method is that the oral cavity is a respectable barrier to drug penetration. Along with this problem to overcome is the subject of holding the medication in place. There is the possibility of using a "wet adhesive" that requires moisture to be effective. This could be supplied by saliva. Also, a penetration enhancer would be required to deliver the correct dose in a timely manner through this barrier.

Of interest to read on the subject is the book, *An Improved Medication Of Addison's Disease - A Feasibility Study*, by Nicole Sluis. This was published in 1998 by the Dutch Addison and Gushing Society. Pages 30 to 32 is titled "Possible Formulations" and discusses the feasibility of various routes possible for administration of corticosteroids. The sites discussed are oral, parenteral, topical, rectal, sublingual and nasal. The section gives a brief breakdown on the six methods studied and their findings in an easy to understand format.

Overall the buccal method, if ever developed for our needs, would have to be considered a poor alternative to the syringe when you are in danger of a crisis. A stop gap measure, at best, for when and if you are ill with a very bad sore throat or a mildly upset stomach and taking extra meds in the usual manner during this time is very uncomfortable. Pills are difficult to swallow when your throat is raw and sore and sometimes our pills make an upset stomach much worse. NEVER would you consider this an alternative to the syringe for an unconscious patient or a patient in eminent danger of a crisis. These patients need to be taken to the emergency room as soon as possible. Of course, any change to your regular medication schedule would be reported to your doctor and it's a good idea to let someone else know that you are not feeling up to par so they can check in with you often.

Following is an abbreviated copy of Dr. Killinger's reply to our group about this subject. We thank him for his continued support and invaluable advice.

If a patient who is having problems is able to swallow medication, then the appropriate approach would be to provide hydrocortisone by mouth as is usually done. This acts quickly and, if hydrocortisone deficiency is the major problem, it should work. As was mentioned in the discussion, patients will often need intravenous salt solutions, if they are unable to drink but, if they are able to take things by mouth, then salt-containing fluids such as soups will be helpful. If the patient is unconscious, then intra-muscular or intravenous injection is the appropriate route. Over the last year or two, there has been more interest in making the Sohi-Cortef injectable material available for patients to have at home, if they have been experiencing frequent crisis. If this is happening, then it seems likely that they will require a change in their underlying medication to avoid these problems. The lack of information regarding buccal absorption would be compounded in an unconscious patient, since it would be difficult to know whether the medication is appropriately situated.

At our present level of information, I think the possible use of buccal hydrocortisone should be discouraged. A clinical study to assess the absorption of this material would be of interest but because of the problems that I suggested, I am not sure how effective it would be, if it were available."

Sincerely,

Donald W. Killinger, MD, PhD, FRCPC

I would like to take this opportunity to also thank those who have given of their time to research this subject for us. Although this is not a viable alternative for us at the time, it is through the efforts of many dedicated professionals that new discoveries are made which could enhance the lives of us all, whether it be in Addison's Disease or any other affliction of mankind. Our thanks go out to:

Dr. Knutson, Associate Professor, Department of Bioengineering, University of Utah
Julia Whelan, Head of Reference, Sheppard Library, Boston: on behalf of Dr. E. Mack Donald W.
Killinger, MD, PhD, FRCPC

Mr. Thorne, Pharmacist: for encouraging us with the possibilities in medicine today. All of our members who sent in their findings on this subject.

Helene Perry

If anyone would be interested in reading the latest newsletter from the New Zealand Addison's Network, (NZAN), please refer to the website. www.addisons.org.nz. Please be advised that you will require Acrobat Reader to download this document.

Correction:

In our last issue #28 of April 2002, in the article entitled, "Update of Med Shortage", the first paragraph should have read, "possible shortage of Cortef tablets, (hydrocortisone) and not "Cortone" as stated. Jim Sadlish had contacted Pharmacia Canada to inquire about this concern.

Also, it should be noted that Cortone has not been produced in the states by Merck since October 1997.

Helene Perry

"Lots of people want to ride with you in the limo, but what you want is someone who will take the bus with you when the limo breaks down."

Oprah Winfrey

Highlights From Local Meetings

Vancouver Island Support Group (Nanaimo) - May 25, 2002

Submitted by Christy Lapi:

Seven Addisonians met May 25 in Nanaimo and discussed the new method of mixing cortisol replacement medications. Both Judy Stanley and Joan Southam of the Canadian Addison's Society have been using a combination of prednisone and cortef (hydrocortisone) to even out the peaks and valleys of an Addisonian day. (love the word Addisonian!)

Judy uses: 2-10 mg. cortef in the a.m. spaced about four hours apart, plus 1 mg. prednisone in the p.m. Joan uses: 10 mg. cortef early a.m. and 2 mg. at 2 or 3 p.m. Dave (on the internet, don't know his location) uses: 2.5 mg cortef in the early a.m., plus 5 mg cortef with breakfast, 5 mg cortef between 1 and 4 p.m., plus 1.25 prednisone at the same time. All also take florinef. Hydrocortisone works swiftly but is relatively short lived. Prednisone works more slowly, but is longer lasting.

An article on the Australian Addison's website was cautionary on the mixed medication plan, suggesting it was unproven and impractical to regulate dosages precisely. Three of the people attending in Nanaimo said they did not experience "peaks and valleys," and one experienced them rarely. One suggested that an extra half a tablet of florinef (.05) late in the day helped even out peaks and valleys.

Some reported that certain doctors are still unaware of the need for bone density tests and extra calcium.

There is some discussion on the internet about the need to keep medications at room temperature, avoiding extreme heat. Those who camp or hike might be interested in the Medport internet site (<http://www.medportinc.com/>), which sells portable packs with a compartment for ice. Designed for diabetic medication, the packs have sparked some interest in Addisonians. There certainly may be other companies selling similar products.

The Nanaimo group was also interested in the excellent Living with Addison's booklet, which can be found on the internet at <http://www.suireyweb.org.uk/adshg/ADSHGGUIDELINES.pdf>. Acrobat reader is necessary to download it but can be obtained free on the internet.

For further information:

Nanaimo meetings: Christy Lapi at ckpi@shaw.ca, or 250-245-7554 or Barbara Hunn at bhunn@telus.net or 250-756-4385.

Victoria meetings: Jim Sadlish at x699@victoria.tc.ca or 250-656-6270, or Florence Weekes at fmweekes@telus.net or 250-598-0321.

Vancouver Island Support Group (Victoria) - April 06.2002

Submitted by Jim Sadlish:

The Canadian Addison Vancouver Island support group met Saturday, April 6th, at Victoria General Hospital. Twelve attended including 9 Addisonians, three were newcomers, two recently diagnosed. All contributed to the discussion which encompassed many pertinent topics.

Demonstrating again how lethal undetected Addison's can be, those attending heard a recounting by a new member of awaking from a near-death coma after a last minute diagnosis and subsequent life-saving glucocorticoid injection.

More Victoria endocrinologists are prescribing DHEA as a replacement medication for Addison's, even for newly diagnosed patients.

For those members having an extended medical plan, Jane has found that DHEA may be covered under their plan if Kripps Pharmacy, the sole supplier, is asked to include a DIN number and compound number or drug information and prescribing physician's name on your receipt. Jane has recently been diagnosed with diabetes and will be participating in a University of Victoria study of diabetics with associated diseases. She is hopeful this may bring more attention to Addison's disease through the better funded diabetes research.

Important for both newly diagnosed and old hands at dealing with Addison's is the UK support group's Addison's owner's manual now available from website:

<http://www.surreyweb.org.uk/adshg/ADSHGGUIDELINES.pdf>

Acrobat Reader is necessary to read this pdf file. Thanks to Christy for informing us of the location of this practical guide.

The next Victoria meeting will be scheduled in the fall You will receive ample notice. For further information: Victoria meetings: Jim Sadlish at x699@victoria.tc.ca or 250-656-6270, or Florence Weekes at frnweekes@telus.net or 250-598-0321.

Nanaimo meetings: Christy Lapi at clapi@shaw.ca, or 250-245-7554 or Barbara Hunn at bhunn@telus.net or 250-756-4385.

BC Lower Mainland Support Group - May 25.2002

Submitted by Judy Stanley:

We have had some sad news since our meeting. The death of Sybil Harrison, our representative from Montreal Quebec. Sybil was diagnosed a few weeks ago with liver cancer but no one expected that she would deteriorate so very rapidly.

As most of you know, Sybil was one of the co-founders of The Canadian Addison Society along with our president Greta Fraser, who received the call from her family. Sybil has been a faithful worker and supporter of this group and she will be sorely missed.

Thanks to Marilyn for all her work in obtaining a guest speaker for us and Sandra for phoning everyone. Six people attended the May 25 meeting of CAS Lower Mainland.

Om Sairam is a senior Yoga teacher. She's been doing Yoga for most of her adult life, and has been an instructor for 25 years. She is responsible for establishing the Yoga centers in North Vancouver and Pinetree Community Center. Om gives workshops on the philosophy and the science of Yoga, as well as universal methods of meditation. She emphasized that Yoga is not a religion, but is basic to all religions.

She discussed the body / mind connection. She also said that the endocrine system is a focus of yoga.

Om also gave us guidelines to help us choose a Yoga teacher. Prospective teachers must work with her for five years before she will approve them to teach.

Homeopath in POCO: Elvira Kravenkova, phone: 604-945-4193 - Recommended by Om, for anyone interested in Homeopathic Medicine.

Hatha Yoga should be done every day allowing the body to take control. It is designed to bring body, mind, and spirit together with breath. Do only the amount of exercise for the energy that you can expend if you are pushing yourself you are not doing it properly. Practice diaphragm breathing. Do breathing exercises before rising. Om said that 1 tsp. of Tahini twice a day has all the calcium requirements for the day but she was unsure of the amount of elemental calcium in it. Tahini is an age-old wonder medicine which contains calcium balanced with magnesium. You still need to take Vitamin D separately, also Vitamin E if you take that.

Hatha Yoga was developed in ancient times for people to bring the body, mind and spirit together. They used the system to have more awareness of how the body works to promote longer life. Yoga is a system and philosophy with many inter-connecting branches or types of yoga. It is practiced for one to meditate and body awareness and what it can do.

What to expect:

Limitations of the body

Learn centering from spirit that directs body sense of seeing, hearing, touch and discernment. Centering is knowledge of the body and what is beneficial for the body

A good book is 'Hands of Light'¹ written by Barbara Anne Brenna, available at Banyan Books in Vancouver. Rid yourself of negativity and learn to love yourself mistakes and all. The five essentials of Hatha Yoga are:

Truth - who I am and what I am

Righteous living

Peace - speak and learn a different vocabulary

Love - suffuse everything with love

Non-injury - choices we make and how they effect society.

Marilyn and Om demonstrated some basic yoga stretching exercises which we then tried. Finally we did a relaxing exercise.

The next three meetings for CAS Lower Mainland have been confirmed for October 19, 2002, February 22 and May 30,2003 in the Sherbrooke Lounge, Sherbrooke Center, 330 E Columbia Street, New Westminster.

From Elizabeth in Saskatchewan:

I was wondering about using epinephrine in dental freezing?? What have you or the Alberta Addison's group used? Reactions??? I have had 2 root canals done since being diagnosed with Addison's (in 1995 and today). All 4 visits, the dentist used without epinephrine but the freezing would not hold for very long. The drilling sort of caused me great discomfort. I doubled my steroids the night before and the morning of. (I even got up at 6:00 am to take them!!!!) On all 4 visits I started to get allergic like reactions (eyes scratch-puffy, nose runny then clogged up, throat itchy) after being in the chair for 1 1/2 hours. They gave me an antihistamine and quickly finished the work. With each visit they tried something different—Latex precautions, ordered a newer vial of freezing thinking the last one was too old- exp. date 03, gave me extra...

I asked my dentist and he uses epinephrine and I have not had any problems with freezing. Other than problems with having a freezing take, no one had experienced the symptoms who attended the meeting

Cortisol test. We had an interesting series of e-mail-s after Charlotte asked if a serum cortisol test should be done every year. The messages that I got back from both Joan's have different opinions for testing for the Addison cortisol levels as does your doctor who is the one that calls the shots for lab work.

From Joan S. CAS:

In answer to your question, the only cortisol check that I have is the ACTH blood test- it may not be perfect but it is some indication of how your body is working. The other good tests of course are the electrolytes - the sodium and the potassium. With medication other than Prednisone, I understand the 24 hour urine tests are quite acceptable.

I have the ACTH blood test done every six months from my endocrinologist. My family physician does the electrolytes, and regular blood work.

You can tell when they do the ACTH blood test (it is done at the same time as the electrolytes) because they immediately put the test tube on ice! (I asked Joan about the ACTH test as I was confused and got the following reply)

The ACTH stimulation test is done in a lab setting to diagnose Addison's. The ACTH blood test that I am talking about is a simple blood test, to test the ACTH level in the blood. It is just a routine test and will tell you how your cortisol is working (for example -high ACTH – low cortisol) and this tells them whether or not you are getting the proper amount of cortisol medication. This is NOT to be confused with the ACTH stimulation test!

From Joan H. Addison's News:

I don't recall I received much response to my 1997 article about serum and urine cortisol tests. It still is my understanding that neither gives valuable information for someone diagnosed and on replacement medication. Amy does not have either done anymore. We would like to have the perfect test or gauge for Addison's medications and know for sure not too much or too little is being taken but such does not exist. It is more of an art than a science to achieve the optimal balance.

I am sorry Charlotte has glaucoma and now diabetes. She should rest assured though that she doesn't need to be concerned about those tests not being included.

Charlotte asked: Is there any other Addisonian's with 4 other major illnesses?

An e-mail was received from Don McCaig in Vernon. He was diagnosed in 1989 and has Vascular Necrosis in both hips, knees and ankles, hip replacements and numerous operation on knees. Has anyone else heard of this complication from taking Prednisone?

An article in the NORD newsletter on air travel since Sept. 11. Some people carrying needles for diabetes were not allowed on flights. Each airline seems to have a different rule and the Dept. of Transportation has issued new fact sheets to explain the rights of people with disabilities at airports and on airplanes.. These explanations can be found at: www.dot.ggv/airconsumer/Civil%20Rights%20Fact%20Sheet.htm. If you are traveling to the States this summer be sure that you have proof of Canadian citizenship i.e.: passport or birth certificate.

Christy in Nanaimo has been looking into combination of cortisone and prednisone, storage of medications, and methods to remind yourself to take your pills. Anyone wanting a copy of her findings let me know or you can read about it in the upcoming CAS newsletter.

I have 3 copies of the Living with Addison's Disease - \$10.00. I have paid for these copies from CAS and will mail it out to you if you are unable to download it from the Internet. CAS also have a pen for \$5.00 if anyone would like to order one let me know and I shall get some for the next meeting.

Don't forget to keep yourself well hydrated this summer. The easiest solution is to put 1 tsp. sugar and shake some salt into a liter of water. Adding Real Lemon will make it more palatable.

Saskatchewan Addison Support Group

If you wish information about this support group or upcoming meetings, contact Elizabeth Hill at Meadow Lake 306-236-5483 or Rob Zaleschuk at Caronport 306-756-2339

Southern Ontario Support Group - June 8, 2002

Submitted by Angela Timms:

Joan Southam welcomed everyone to the meeting and gave a moving remembrance of **Sybil Harrison** of Montreal, who along with Greta Fraser, co-founded the Canadian Addison Society in 1994. After having Addison's for over 40 years, she was an inspiration to many others with the disease. Sybil was diagnosed with inoperable cancer a short time ago and was thoughtful of others to the end. She requested that donations in her memory be made out to our group, (\$700. so far!) for which we are very grateful.

Lynda Daniels, our meeting co-coordinator, reminded people of the importance of getting a bone density test on a regular basis, with steroid use, taking vitamin supplements, and in consultation with your doctor, increasing steroids before having surgery. Lynda welcomed our guest speaker, Barbara Cobb of London, Ontario. Barbara has been President and on the Board of Directors of the Thyroid Foundation for the past 10 years.

Barbara brought two very informative videos for us to watch; one on hypothyroidism and one on hyperthyroidism. These films MAY be available for viewing through the local/national foundation for other meetings if anyone is interested.

SPEECH HIGHLIGHTS

- Thyroid Foundation was founded in Canada in 1980 by Diane Abramsky of Kingston
- Its aims are to awaken public interest, provide moral support and provide funds for research
- 1 in 20 people have a thyroid disorder.
- There are many different types of thyroid disorders, including cancer of the gland: "Hypo" such as Graves Disease or "Hyper" such as Hashimoto's Disease. In the cancer world, cancer of the thyroid is one of the easier kinds to treat by using chemo, radiation and surgery.
- Video shown with Dr. Volpe interviewed and giving basic information regarding thyroid disease:
 - 1) Described the purpose of the thyroid gland as a regulator of all body producing processes.
 - 2) A butterfly-shaped gland located at the front of the neck
 - 3) Thyroid hormones regulate digestion, heart rate, body temperature, sweat glands, nervous and reproductive systems and weight.
 - 4) Signs of an under active thyroid include: tiredness/fatigue - Dry skin, scaling - "Pins and needles" in hands & feet - Temperature changes with coldness - Constipation, bloating - Aching muscles - heart rate problems - Brittle nails - Voice changes (hoarseness, deeper) - Thinning hair, dryness - Depression - Weight gain, puffy eyes - Heavy menstrual flow - infertility - Malaise, unwell - Memory, thinking processes, - hearing may be poor - Goitre (may or may not be present)

- Can develop from other auto-immune diseases such as diabetes, arthritis, pernicious anaemia, lupus, **Addison's**. Others at risk include: Those with a strong family history, women who have recently given birth, women over 40, including menopausal women, men over 65, people taking lithium and amiodarone,
- Causes include body's own destruction of the thyroid (Hypothyroidism), surgery on thyroid gland, radio iodine treatment for overactive thyroid gland (Hyperthyroidism), rare but possible connection to pituitary gland failure.
- Simple blood test measures TSH (Thyroid Stimulating Hormone) to determine if disease is present.
- Hypothyroidism is 4-6 x more common in women than men. If left untreated, symptoms will worsen and can cause higher cholesterol levels, long-term organ damage, menstrual irregularities, infertility and worsening osteoporosis.
- Thyroxin replacement therapy when calculated to your own metabolism will provide the same amount your body produces. Regular checkups (yearly) will keep levels functioning properly and symptoms will gradually improve over weeks and months of drug use. Usually needed for lifetime.

Hyperthyroidism: Graves Disease being the most common form. Overproduction of thyroid hormones results in: - Frail, thin, wasting - Shaky, tremors, muscles pain, sleeplessness - Weight loss - Big gut, but no weight gain - Increased appetite and thirst - Mental, psychological and sensory changes - Genetic susceptibility, looks like panic disorder - In overdrive; talk fast, think fast, speeding, over-react to stress - Stress of all types (Including infections) can precipitate Graves Disease - Swollen gland

- Treatment means shutting down or removal of gland. Physical exam usually catches it as gland is larger than normal. Small radio-active treatment will destroy thyroid gland. A second treatment may be needed and then patient will go on replacement thyroxin. Non-toxic. If pregnant, may have to reduce amount and be closely monitored. For bulging eyes (Exophthalmos), surgery is the main treatment.
- Some types of antihistamines (decongestants) may interfere with thyroid medication. Always check with your doctor and /or pharmacist for any known drug interactions.

Pamphlets were available describing a large number of thyroid disorders. More information is available from the Thyroid Foundation of Canada. The London group meets the third Tuesday each month starting September at the new Library. The National Office number is (613) 544-83647 / (800) 267-8822.

Meeting closed with light refreshments and thanks to Barbara for all her information. Next Annual/ General Meeting is Sept. 21/02 at Brantford Police Station.

Alberta Support Group -May 24 2002

On the 24th of May, we had a dinner get together at the downtown Spaghetti Factory. Of the six who attended, five were Addisonian's and the sixth was Peter's wife, Betty - who, hopefully was not too bored with the conversation and will consider attending again. We had the opportunity to meet Sue, a very recently diagnosed Addisonian (Sue was diagnosed with Addison's disease, diabetes, and hypothyroidism all at the same time!), and share some of our stories; both funny and

serious. It's unfortunate that the requirement for joining our society is a disease but it's always great to meet new people!

Currently we are planning on having another dinner get together in the fall sometime. The date and location has not been determined yet.

If the rest of Canada is experiencing the same kind of weather we're currently having in Alberta --Stay Cool!

For information on this support group or for upcoming meetings, please contact Francisca Swist of Edmonton at franciscas@shaw.ca or Ginny LaValley of Morinville at 780-454-3866.

Eastern Ontario Support Group

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 at 12:30 for an informal lunch.

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

Please contact Elaine Flail at 613-824-0160 or laingeri@sympatico.ca if you require further details.

Quebec Support Group

If you would like information about upcoming meetings, please contact Sophie Lapointe at 514-521-6538 or e-mail sophiel@sympatico.ca

Don't confuse fame with success. Madonna is one; Helen Keller is the other.

Erma Bombeck

The activist is not the man who says the river is dirty. The activist is the man who cleans up the river.

Ross Perot

Use what talents you possess; the woods would be very silent if no bird sang there except those that sang the best.

Henry Van Dyke

Let's Hear It For Life!

Wake Up Fruit Blend

A delicious blend of fruit and yogurt to help you start your day!

INGREDIENTS

- 2 cups orange juice
- 2 (8-oz.) container strawberry-flavored yogurt
- 1 medium ripe banana
- 1/2 teaspoon vanilla
- 2 cups ice cubes

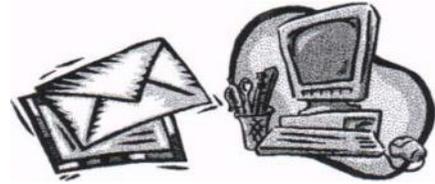
DIRECTIONS

Combine all beverage ingredients in 5-cup blender container. Cover; blend at high speed until well blended (30 to 60 seconds).

Pour into individual glasses; garnish with a dollop of yogurt and strawberries, if desired. Serve immediately.

Makes 6 servings

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 addison_editor@yahoo.com or mail to P. O. Box 1417 Bradford, Ontario L3Z 2B7. 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

I would like to share with you my experiences, this year, dealing with hospital emergency professionals, carrying a medic alert and having Addison's Disease.

The morning of the fourth of March, I woke up really feeling like a wet dish rag and called my daughters to let them know. They tend to check on me periodically throughout the days when I'm not up to par. I live alone and this arrangement gives me a sense of safety. By Tuesday, the fifth, I couldn't make any sense of anything, was sleeping a lot, and was having a problem standing up without falling back down. By this time, believe me, you are not in control of your senses and can't think straight enough to help yourself. My daughter called and because she said I was talking foolish, came over to check on me. She immediately recognized a crisis was happening, gave me my injection from my kit, and took me to the emergency room. I got the distinct impression that my daughter was having a hard time convincing the nurses that I needed some steroids NOW. The nurses have to wait for the doctor to see you and give their orders before any medication can be dispensed. No one in the emergency room looked at my medic alert although I was undressed and had it hanging outside my gown. I should also tell you that my medic alert dictates that I am allergic to bee sting as well as having Addison's, so for all anybody knew, I could have been stung. After about 30 minutes the doctor came in and ordered some x-rays of my chest and diagnosed me with infectious pneumonia in the right lung. A complete surprise considering I didn't even appear to have a cold. I spent 7 days in the hospital on major steroid doses along with antibiotics and quite a few weeks recovering at home. Getting your spunk back is the hardest. You feel ok sitting around, but your body just won't respond with the energy you need if you try to do anything.

The next time was only two months later. I awoke to a stabbing pain in the upper right side of my abdomen. I called my daughter who came and took me to hospital. The big obstacle this time was getting past the triage nurse. This is the nurse who decides who needs the doctor first. We tried to explain that I had Addison's Disease and much to our surprise her response was, "well, does your Addison's hurt you more today than it did yesterday?" This statement, coming from a professional, really put me in a panic mode. She obviously did not know what Addison's was and my daughter had to explain to her that I did not have functioning adrenals and would need a doctor a.s.a.p. I was wearing my medic alert, in full view, outside my clothes at that point.

That night at 9:30pm I was in surgery having my gallbladder out. I had never had a problem with this organ in my life! Never even suffered from heartburn! Again, I spent 7 more days in hospital recovering from surgery and on high doses of steroids. My nurse looked up Addison's Disease on the internet and put some info into my file for the other nurses who would look after me when she was off duty. The day after surgery, the surgeon who did my operation, came by my room and after his exam explained to me how vital it was that someone with Addison's Disease should always wear their medic alerts. I say, if at all possible, have someone with you who can speak for you and make someone listen! You'd be surprised how many people you are in contact with, in the hospital, who do not know what Addison's Disease is. Make no mistake, it is your very life that you are protecting if you can bring someone along to speak for you, especially when your head is a little foggy. Medic Alert is a great organization, and I support them 100%, but I have to wonder, if I did not have someone to speak for me while I was mixed up and muddled but conscious, would anyone have paid attention to mine?

Helene Perry