

# The Canadian Addison Society La Société canadienne d'Addison

193 Elgin Avenue West Goderich, Ontario N7A 2E7

Phone: 613-590-1019 Fax: 613-590-1021

Toll free number: 1-888-550-5582 Email: <u>lainger 1@sympatico.ca</u> http://www.addisonsociety.ca

**ISSUE NO.37 (Revised)** 

**NOVEMBER 2004** 

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PLEASE NOTE: The content of this newsletter is intended for basic information only and not as personal medical advice. We advise readers to consult their own doctor before making changes to their Addison management program.

# Message from the President

Dear Fellow Addisonians and Supporters,

Here I am again as President. However, I am only here on an interim basis. I want to stress how important it is that someone come forward to take this office. If any of you, or any of your family members, can find the time and energy to support our group by acting as President in the coming year, please let us know immediately. You can get in touch with me, Elaine Hall (our secretary), or any of the local support group leaders.

As well, we are urgently in need of a replacement Secretary. Elaine Hall has ably held this office for a number of years, but is no longer able to continue in this role.

Please, get involved and offer your services. We are all partners in this Society, with an interest in supporting each other. This is the reason we formed this group so many years ago, and what continues to sustain us.

Sincerely, Greeta Mc Kague

# **Annual General Meeting**

# Annual General Meeting, The Canadian Addison Society Saturday, September 25, 2004, Brantford, Ontario

#### 1. President's Address

Joan Hoffman, editor of Addison News (USA) sends her congratulations to the Canadian Addison Society on our 10-year anniversary.

Joan Southam (outgoing President) has found her association with the Canadian Addison Society extremely rewarding in the last 10 years. We have made great progress, and she foresees more changes in the coming years.

# 2. Minutes, 2003 Annual Meeting

Minutes were distributed. Jordan Latter, Chair of the meeting, highlighted the major items from the 2003 Annual meeting: UK survey, emergency care, and the presentation by Dr. Weinberg. There were no questions on the minutes.

Motion to adopt 2003 minutes: Steve McKenna

Seconded: Donald Archi

Motion carried.

# 3. Financial Report

Financial statements for the periods ending December 31, 2003 and August 31, 2004 were distributed. Given the current cash balance, there was a proposal to invest a further \$6000 in a short-term (90 day) instrument.

Motion to accept financial statements and to invest \$6000 in short-term instruments:

Joan Southam

Seconded: Steve McKenna

Motion carried.

#### 4. Emergency Care

Emergency care remains an issue for members. Discussion on possible measures to help members included:

- Having an emergency injection kit. Action: The Society will ask Dr. Killinger (medical advisor to the Society) to write an open letter, encouraging emergency injection kits, that members can use when discussing this issue with specialists or family doctors.
- Having a letter from their doctor (if possible, a doctor with privileges at the hospital most likely to be used in an emergency) on them at all times briefly stating their illness, describing their ongoing treatment and the treatment necessary in the event of an emergency. This same letter can be used when travelling, both in the event of emergency and when passing through security zones. If travelling, it is wise to also carry a translated copy of the letter.

#### 5. 1-800 number and related costs

In the past year, only 5 calls have been answered on the 1-800 line. The most likely reason for the low number is that this line has no message-taking capacity (answering machine). It is very possible that additional phone calls were made but not answered. The decision was made to add an answering machine for this line, with a very clear message that the 1-800 line is for information only; does not provide aid in the case of emergency and that, in the case of a crisis, a local emergency call (e.g. 911) should be made. We will re-examine levels of usage in a year.

**Action**: Elaine Hall will examine options (stand-alone answering machine or Bell Canada service) and have answering capacity installed. Steve McKenna will act as back-up for Elaine.

**Action**: Regional groups are encouraged to publicize this information number (1-888-550-5582) as broadly as possible. Members are encouraged to post the number in endocrinology units or other locations, as permitted, so that new Addisonians may become aware of our service.

# 6. Website update

The 2003 meeting approved the purchase of a permanent and portable freestanding Society website and email address. The 2004 meeting received an update on this matter.

The current website is hosted by Joan Southam on her personal site. Effective shortly, the Society will own its own freestanding website, using the Society name, and have its own capacity to maintain the site.

The website should be updated to coincide with issuance of the Newsletter, contain a legal disclaimer and links to other Addison information sites.

Motion to approve these measures: Janet Stewart

Seconded: Lou Bleth Motion carried.

(Late update: Elaine Hall has made arrangements for Kris Hall to do ongoing design and maintenance for \$75 a year, and will put a proposal to the Board members for approval as soon as possible.)

#### 7. New Business

- Members may wish to consider getting immunization shots against pneumonia (pneumococcus) if they are subject to illness from this strain. For more information, see <a href="http://www.lung.ca/pneumonia/bacterial.html">http://www.lung.ca/pneumonia/bacterial.html</a>
- The Newsletter will soon be made available electronically, and posted on our revised website
  once it has been created. Currently, it costs approximately \$800.00 per year to print and
  mail hard copies of the Newsletter. Members will be asked in the next Newsletter if they
  wish to receive a print or electronic copy or both, and will be asked to update their email
  contact information.
- The issue of membership dues was discussed. Currently, membership dues are \$25.00 per year. Any contribution over and above the membership cost is considered a donation under

Canada Revenue Agency rules, and can contribution.

be deducted from income as a charitable

Members at the Annual Meeting voted to retain membership dues at \$25.00 per year.

It was further recommended that the membership coordinator (Treasurer) send **one (1) reminder notice** of need to renew only. We will no longer send multiple reminder notices. If a member does not renew in a timely manner, they will be removed from the membership rolls. The onus is on the member to ensure their membership status is current and up to date.

Motion to **retain membership dues at \$25.00** per year, and restrict reminders to **one renewal notice**: Joan Southam

Seconded: Jordan Latter

Motion carried.

**Action**: The membership coordinator (Treasurer) will refine the procedure as indicated.

#### 8. Nomination and election of 2004 Board members

Amendments to the proposed slate of officers for 2004:

President: Greeta McKague (interim)

Vice-President: Judy Stanley

Secretary: Elaine Hall (interim)

Treasurer: John Gordon Directors: Al McConnell

Greeta McKague Stephen McKenna

Jim Sadlish Francisca Swist

Newsletter: Stephen McKenna (Patricia Hehner)

There are currently no nominations for President. The Society will make a new call for volunteers in the next Newsletter. In the interim, Greeta McKague has agreed to fill this role.

Duties of the President include the general management and supervision of the affairs and operations of the Society, presiding over meetings of the Board of Directors (often meetings are conducted by email), and calling any annual or general meeting of members.

One of the main responsibilities is facilitating discussion of ideas brought forward by Directors and/or members, and ensuring that there is an interchange of information within the Society and with other Addison groups around the world. Most of the networking is by e-mail/telephone. The president will have a separate phone line installed in his/her home for Addison business.

As well, we need nominations for Secretary, as Elaine Hall must resign due to health complications. The Society will make a new call for volunteers in the next Newsletter. In the interim, Elaine will continue to act as Secretary.

Motion to accept the proposed slate of officers: Jordan Latter

Seconded: Lou Bleth

Motion carried.

The Society took this occasion to thank the outgoing president, Joan Southam, for her hard work and years of dedication to the Society in a variety of roles.

# 9. Guest Speaker

The Society welcomed Dr. Don Killinger, who has been acting as medical advisor to the Society since 1994.

His presentation, "This Year Has 45 Minutes - A Year in the Life of a Person with Adrenal Insufficiency", reviewed the basic information on Addison's Disease by placing it into common situations which all Addisonians may encounter.

The main theme of his presentation could be summarized as: When your adrenal glands work, they adjust their output based on the circumstances of the moment. With Addison's, the patient must do the thinking for the glands, and adjust the medication him/herself.

# **Background**

The normal adrenal cortex secretes:

- 20 to 30 mg of cortisol daily
- 150 to 200 mg of aldosterone daily

The cortisol is usually replaced with approximately:

- 20 to 30 mg cortisol (e.g. hydrocortisone such as Cortef) or
- 25 to 37.5 mg cortisone or
- 5 to 7.5 mg prednisone

These amounts are averages; the actual amount needed will vary considerably based on the individual.

The aldosterone is replaced with:

• 0.1 to 0.2 mg Florinef

**Primary Addison's**: the adrenal glands are not functioning.

**Secondary Addison's**: the pituitary gland is not functioning, and thus is not secreting the ACTH necessary to tell the adrenal glands to secrete cortisol. However, the adrenal glands continue to produce the minerocorticoid as this is stimulated by the liver.

50% of primary Addison's patients may have hypothyroidism.

10% of primary Addison's patients may have ovarian failure.

# Responding to stress

If your adrenal glands are not working and you are taking cortisol replacement you have to do the thinking for your adrenals.

- Physical stress such as surgical procedures, a fracture or a major illness will <u>always</u> require extra cortisol.
- You will always need to administer cortisol prior to any anaesthetic, as the anaesthetic itself is a major stressor.
- Normally your doctor should look after this but since it is your body <u>never</u> hesitate to ask questions to be sure this has been looked after.

- Less severe physical stress requires judgment in deciding whether or not more cortisol is required. A headache or a mild sore throat does not normally require added cortisol.
- Emotional stress is less clear-cut since we all respond differently to stress. Regular day-today interactions do not require added cortisol, but severe or prolonged emotional stress may require additional cortisol. An extra tablet each day would normally be enough.

You are best placed to read your own body. You can adjust your cortisol level if you occasionally require it. An extra ½ or full tablet on occasion won't hurt.

However, remember that we all "don't feel good" from time to time. This is normal and may not be attributable to your Addison's.

Timing of medication can be an issue for some patients. If taken at supper, and depending on the specific medication, glucocorticoids may cause trouble sleeping. Prednisone has the shortest half-life (length of time before it wears off); Cortef has a mid length half-life; dexamethasone has the longest half-life.

In general, if taking two types of glucocorticoids, for example, Cortef and prednisone, Dr. Killinger suggests taking the Cortef, when an extra tablet is needed to respond to either physical or emotional stress.

Some of the examples of daily life used were:

A 30-year-old female saw her family doctor because she felt tired, was light-headed when she stood up, and was feeling nauseated. Her doctor said she looked very well with an excellent tan. After appropriate investigation, a diagnosis of Addison's Disease was made.

**Treatment**: Our patient was treated with 20 mg cortisol each morning and 10mg at noon and Florinef 0.1mg each morning.

After a few weeks she felt very well and she and her husband decided to take a trip to France. This involves a 6-hour time difference (later). What should she do about her medication?

**Answer**: Maintain the relationship between your medication and the <u>current</u> time of day. So, take your pills before you leave at the usual time and when you reach your destination take your pills at the same time of day as you did at home. Going eastward, this will increase your overall medication levels slightly but put you quickly onto the correct schedule.

Coming home you will gain 6 hours, so you may need some extra cortisol. Take an extra ½ tablet if you feel that you need it.

Two (2) months later, she got a bad cold which did not clear up easily and she felt very unwell. What should she do?

**Answer:** Take an extra cortisol each day for 2 or 3 days until the symptoms improve. Do not carry on longer than necessary.

In March she sees her dentist who suggests that she needs to have her wisdom teeth removed. He is going to do this in the office using general anaesthesia. What should she do about her cortisol?

**Answer**: 100mg of Solu-cortef should be administered intravenously before the anaesthetic. The patient should ensure that the dentist is fully aware of her condition and its requirements.

In June her grandmother, with whom she has been very close, becomes ill, is hospitalized and undergoes surgery. One month later she dies. The whole period has been very difficult, she felt unwell throughout. Should she have taken extra cortisol?

**Answer**: She should monitor herself, and may need to increase her cortisol, especially at the moments of highest stress, for example, during the funeral.

In October, she finds she is pregnant! Does she need to make adjustments in her cortisol or Florinef during pregnancy?

**Answer**: Generally, no. There <u>may</u> need to be adjustments as the pregnancy progresses. This will depend on any symptoms that develop during the pregnancy. However, she will very likely need extra cortisol during the delivery.

A 16-year-old male diagnosed with Addison's disease is a very good hockey player. He is on replacement with cortisol 30mg daily and Florinef 0.1mg daily. What should he do about his medication when he is playing hockey?

Answer: Playing hockey requires extreme energy and response to stress, and there is loss of salt, water and fluid during the game. Players will need extra cortisol (1/2 to 1 tablet), extra salt and water eg. Gatorade and possibly an extra ½ tablet of Florinef to help retain the salt.

He wakes one night with abdominal pain. On questioning, his mother finds that the pain is on the right side of his abdomen below the umbilicus. She looks this up on GOOGLE and diagnoses appendicitis. Her family doctor agrees and arranges for surgery. The surgeon says that he will be in and out so quickly that he does not need to give the patient extra cortisol. Should you accept the surgeon's opinion?

**Answer**: Any surgery or any general anaesthetic **will** require IV Solu-cortef regardless of the length of surgery. However, too much cortisone can decrease healing, so do not continue "extra" longer than truly needed.

#### Conclusion:

- Monitor yourself;
- Think for your adrenals;
- Don't hesitate if you feel unwell or know you are going into a stressful situation; A little
  extra won't hurt you from time to time;
- BUT DON'T CONTINUE IT LONG TERM

#### Other questions/comments

 Those on diuretics to reduce blood pressure should consider whether florinef should be decreased.

- DHEA: 50 mg DHEA will bring a person's levels to those of a normal 20-30 year old. DHEA levels naturally decrease from the age of 30; at age 60, the levels are approximately 25%.
- More women than men have Addison's.
- There is no clear indication that Addison's is hereditary. However, it is an autoimmune disease, and autoimmune diseases, in some form or another, may run in families.
- Patients taking steroids in pharmacological doses may have an increased risk of forming cataracts. Those on physiological doses (such as Addisonians) probably do not have any increased risk of cataracts.

# **Important Announcements:**

- **URGENT**: Currently, the Society does not have a permanent President, although past president, Greeta Mckague, has graciously accepted to act as Interim President while we seek a volunteer for this position. This position should be filled as soon as possible. Duties include presiding over meetings of the Board of Directors (often conducted by email); facilitating discussion of ideas brought forward by Directors and/or members; ensuring an interchange of information within the Society and with other Addison groups around the world; and calling the annual meeting of members.
- **URGENT**: The position of **Liaison Secretary** is currently vacant and we must have a volunteer to fill this important position. While the previous Secretary, Elaine Hall, cannot continue in this position, she notes that the position is very interesting and varied. It allows you to meet new people and help them understand Addison's a little better. Contacts and information are given to individuals who are unfamiliar with Addisonians and/or have recently been diagnosed. Questions are also answered via our Addison phone line (1-888-550-5582).

Anyone interested in being President or Secretary for the Society for the next year, please contact Elaine Hall by email <u>lainger 1@sympatico.ca</u> or by phone at (613) 824-0160. Please let Elaine know if either of these is a job you would be interested in, or if you have someone to suggest.

# This is your Society – GET INVOLVED!

#### **New News:**

The Newsletter will soon be available by email rather than regular mail, for those who wish to receive it electronically. This could potentially save the Society up to \$800. per year. Please make sure you let us know your email address, when you complete your Membership Renewal. As well, the Newsletter will be posted on our new website. Read it at <a href="https://www.addisonsociety.ca">www.addisonsociety.ca</a>.

We encourage those with access to a computer to choose to read the Newsletter on our website or receive it by email.

# **Highlights from Local Meetings:**

# Vancouver Island Support Group (Nanaimo)

Nanaimo meetings: Christy Lapi at <u>clapi@shaw.ca</u>, or 250-245-7554 or Barbara Hunn at <u>bhunn@telus.net</u> or 250-756-4385. Nanaimo meetings are held at Nanaimo Regional General Hospital, Room G245.

# Vancouver Island Support Group (Victoria)

The Vancouver Island support group met October 2, 2004. Eight people attended, seven with Addison's disease and one for the first time.

The main topic was emergency care letters which an Addisonian can carry. A letter drafted by Dr. David Pledger, a Victoria emergency physician, was distributed. The letter is addressed to triage nursing for use during an Emergency visit, as the triage nurse determines the priority of patients and who gets treated first. The letter explains that, although Addisonians may appear to have minor symptoms, they are at risk for "life threatening events". One person presented an emergency letter from her family MD that has served her well through numerous visits to Emergency. This letter was concise, giving dosages of all replacement medication and specific directions for treatment in the event of a crisis.

Our group's emergency form letter project has now been completed and all local members should have received a copy of a form letter developed with Dr. Pedger's help and through consultation with support group members. The form is headed by a message from Dr. David Pledger and is available in PDF format or hard copy. Members can then enter their personal health information (diagnoses, medications and dosages, doctor's contact numbers. etc.) on the lines provided. To obtain a PDF version of this form letter, please e-mail Jim Sadlish at wx699@victoria.tc.ca.

It seems a reasonable precaution for each Addisonian to keep a letter at hand for emergencies, whether a letter from their doctor, a completed version of the form letter, or a copy of both, to improve your chances of prompt emergency treatment.

Discussion of other topics during the meeting touched on:

- Eye diseases such as glaucoma and cataracts may appear more often in people taking steroids and so eye examinations are advised every year or two.
- Three people at the meeting have experienced 'frozen shoulder' which was attributed to cortisone.
- Although we are advised to take sports drinks during hot summer days, some drinks have extra
  potassium rather than extra sodium, which most Addisonians seem to need in the heat. Frequent
  aches and pains plus slowness to heat seemed common complaints among those attending. Some
  experience more symptoms than others. Age could be a factor but also discussed were the pros
  and cons of stretching, which can aggravate chronically sore muscles. Consulting with an
  endocrinologist to fine tune medications may also improve well-being.

We have confirmed 2005 bookings for Room 1814 at the Victoria General Hospital for meetings of the Vancouver Island support group on:

• February 5, 2005 between 12:30 and 3:30 PM

June 4, 2005 between 12:30 and 3:30 PM
October 15, 2005 between 12:30 and 3:30 PM

For further information or to contact the Vancouver Island Support Group (Nanaimo), please contact Jim Sadlish at <<u>wx699@victoria.tc.ca</u>>or (250) 656-6270 or Florence Weekes <<u>metay@telus.net</u>> or 250-598-0321.

Submitted by Jim Sadlish

# **BC Lower Mainland Support Group**

The BC Lower Mainland Group met October 30, 2004, for a meeting that provided great outreach and education for the medical community. The UBC Faculty of Medicine, Undergraduate Program, wanted to conduct interviews with individuals and family members with chronic conditions. At their request, 20 first year medical/dental students interviewed those at the meeting as well as conducting several home interviews with members unable to attend.

The interviews covered basic biographies, experiences with their conditions, how it has affected their family and social life, and experiences with health professionals, medical institutions and service agencies. They asked a variety of questions with regards to our acceptance, original diagnosis, problems encountered from living with a chronic condition, and its effect on home, social, and work environment.

Each of us received a consent sheet to sign, and an evaluation sheet to assess the student's interview skills. As well, interviewees identified any inappropriate questions, and explained why the question was inappropriate.

This was not a research study, but part of the medical and dental students' first year curriculum. Each student will write a brief paper based on interviews and on library research, make an oral report to their tutorial group, and write a brief report describing both the insights they have gained from their interviews and the way that this may affect their future practice. Those members interviewed were also asked to provide a general evaluation of the student's interview style.

It was a successful meeting with some students staying to talk with members well after the end.

Special thanks to Marilyn for making all the arrangements.

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Also thanks for her diligence in getting approval from Dr. Ip, Medical Director, Fraser Health Authority, to have his name on the ER letter to Triage from Jim Sadlish of the Vancouver Island Group.

For members who may have encountered problems renewing Solu-Cortef prescriptions: This product is still readily available, although pharmacies may need to obtain it directly from Pfizer rather than through a wholesale distributor.

Society membership renewals are due January 1<sup>st</sup> 2005.

Joan Hoffman from the USA will be ending Addison News after 10 years, with the January issue. Her research skills and information-packed newsletter will be missed.

Meetings for the next twelve months – Sherbrooke Lounge, Sherbrooke Centre, 260 Sherbrook St., New Westminster for February 19, 2005 and June 4, 2005. The meeting dates are Saturday from 1:00 to 3:00 p.m. Parking is available at 240 Sherbrooke St. for \$3.50 for the day.

Submitted by Judy Stanley

For further information on this support group or any upcoming meetings, contact Judy Stanley, 604-936-6694 or <a href="mailto:bugbee@shaw.ca">bugbee@shaw.ca</a>.

# Alberta Support Group

The Alberta Addison's Group met September 18, 2004 to hear special speaker Dr. Gwynne Bykowski, D.O.M., R.Ac., B.Ed. (Doctor of Oriental Medicine, Registered Acupuncturist, Chinese Herbologist).

Dr. Bykowski's presentation focused on the fundamentals of oriental medicine and acupuncture. We had seven people attend the meeting and all found it to be interesting and informative.

The essence of oriental medicine is to balance yin and yang, which is the mind, body, and spirit. The Yin and Yang symbol is familiar to most. In each of the Yin and Yang sides (represented by the circle), there is a bit of the other. The symbol represents:

Feminine (dark side) Masculine (light side)

Night Day
Cold Heat
Passive Active
Grudge, resentment Rage, fury
Receptive Projective

Chinese medicine has been practiced for over 5000 years, and works to treat the underlying problem, not just the symptoms. Acupuncture is used to get Qi (pronounced "chee") moving properly throughout the body and particularly in problem areas. Blood and Qi move together and, if there is a Qi deficiency, there is also a blood deficiency. In Canada, acupuncturists dispose of the needles once they are used. These fine-gauge needles do not hurt when they are placed. Most of the meeting attendees had a needle placed in their third eye (between and just above our eyes) and didn't feel anything when the needle was placed. This needle position helps to relax the individual as well as relieve sinus pressure. When a needle is placed on the body, the acupuncturist is looking/feeling for the arrival of Qi. There is a discernible tension if the needle is correctly placed.

With respect to disease, oriental medicine tries to achieve a balance. When there is a perceptible imbalance, it is an indication that something is wrong and there are a number of factors used to determine the depth of the illness or pain.

	Exterior	Interior		Excess	Deficiency
	(i.e. cold)	(i.e. diabetes)		(i.e. sprain)	(i.e. arthritis)
Onset	Sudden	Gradual	Onset	sudden	gradual
Location	superficial	Deep	Constitution	strong	weak
Duration	short	Long	Pain	severe	mild
			Pressure	aggravates pain	relieves pain
Tongue coat	thin	Thick	Tongue	rough	delicate
Pulse	floating	Deep	Pulse	forceful	forceless

When this is applied to Addison's Disease, it would appear that Addison's is of an interior nature as well as a deficiency.

In oriental medicine, the tongue is an important factor, and is an indicator of more serious problems. When stress is present, the tip of the tongue becomes quite red. The more severe an illness, the thicker the coating and a purplish tongue is an indicator of pain.

Heat and cold is another factor utilized by oriental medicine. Again, the ideal is somewhere in between the two.

	Heat vs.	Cold
Thirst	yes	no
Beverages	prefers cold	prefers hot
Pain	hot or burning sensation	improved by warmth
Urination	dark yellow - scanty	pale - profuse
Tongue	red	pale
Tongue coat	yellow	white
Pulse	fast	slow

If an Addisonian were to visit an acupuncturist, the goal would not be to cure the problem but to balance and strengthen the system. Oriental medicine takes a holistic view; if you feel better, you look better. Dr. Bykowski discussed the benefits of Qi Gong, a type of meditation used to build up energy. It works on the core and could be compared with "acupuncture without the needles."

According to Dr. Bykowski, any doctor, whether using western or eastern medicine, can only help 35%. The remainder is up to the individual and can be achieved through diet, lifestyle, exercise, meditation, etc.

There are a number of herbs available that have beneficial properties. A few of the herbs discussed were:

- Mint Tea (Bo He) for use if Heat is present. Draws out heat. Works well if you are sick and feel hot.
- Chrysanthemum (Ju Hua) for use if heat is present.
- Ginger Tea brings heat to the body. Works well if somebody has the chills.
- Moxabustion (also known as Moxa) brings heat and warms. This herb is burned on the body and is even beneficial in helping a baby turn (if in the 7th month the baby hasn't turned in the womb, this is used distally). From personal experience, this herb was used on my father when his stomach cancer prevented him from keeping his food down (at least at the beginning). After a Moxa treatment, he was able to eat small portions again.

- Hawthorne Fruit Tea (Shan Zha) reduces cholesterol. Helps if you feel bloated or stuffed.
- Boat Sterculis Seed (Pang Da Hai) helps for sore throats (possible side effect is bowel activation).

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At this time, there has been no date set for our next meeting.

For information on this support group or any upcoming meetings, contact Francisca Swist at <a href="mailto:francisca@shaw.ca">francisca@shaw.ca</a> or Ginny Snaychuk at <a href="mailto:glav@telus.net">glav@telus.net</a> or (780) 454-3866 – both are from Edmonton.

Submitted by Francisca Swist

# Saskatchewan Support Group

If you wish information about this support group or upcoming meetings, contact Elizabeth Hill at Meadow Lake (306) 236-5483 <a href="mailto:kesahill@sasktel.net">kesahill@sasktel.net</a> or <a href="mailto:elizabeth.h@pnrha.ca">elizabeth.h@pnrha.ca</a>.

# **Eastern Ontario Support Group**

The Eastern Ontario group met October 16, 2004, to exchange news and to talk to Dr Mark Silverman MD, FRCPC, an Ottawa endocrinologist with several Addison patients.

Dr. Silverman indicated that the Ottawa Hospital has an endocrinologist on call 24/7 and shared the Hospital's written procedures with us (attached), which indicate the patient should be seen within 15 minutes, be given 100mg solucortef immediately, up to a maximum of 300-400mg per day varying with the degree of stress. The Ottawa Hospital's protocol can also be found on the web at addisonsdisease.tripod.com.

Those present asked a wide range of questions.

- When dealing with stress at home, it is reasonable to double or even triple the normal cortisone dosage. However, high doses indicate the need for hospital attention, especially as dehydration becomes an issue.
- In cases of surgery, 100mg IV solucortef every six to eight hours is required.
- Pregnancies do not normally require additional cortisone although the delivery probably does.
- The relationship with thyroid conditions, calcium deposits, links to types 1 and 2 diabetes, B12 deficiencies, muscle cramping (under-dosing), osteoporosis (too much cortisone), and DHEA were also touched on.

A useful web site is the National Adrenal Disease Foundation (US) <a href="http://medhelp.org/www/nadf/">http://medhelp.org/www/nadf/</a>.

A book recommended for reading was "Adrenal Fatigue: The 21<sup>st</sup> Century Stress Syndrome", James L. Wilson, Smart Publications, ©2000, Petaluma CA.

The group sadly noted the death of Anne Hubbert, who had faithfully attended meetings of the Eastern Ontario Support Group for many years.

The next meeting is tentatively scheduled for noon on Saturday, May 28, 2005, at Robbie's Restaurant on St Laurent St in Ottawa. For information, please contact Sue Steedman at (613) 726-7414 or <a href="mailto:steedman@magma.ca">steedman@magma.ca</a>.

# Southern Ontario Support Group

The Southern Ontario Support Group will be co-chaired in the next year by Jordan Latter and Janet Stewart (supported by Mike Murphy).

For information contact Jordan Latter at <u>annemarielatter@yahoo.ca</u> or call (905) 893-4374

# **Quebec Support Group**

If you would like information about upcoming Quebec meetings or more information, please contact Sophie Lapointe at (514) 521-6538 or email <a href="mailto:sophiel@sympatico.ca">sophiel@sympatico.ca</a>.

## Reminders:

- Medical Questions and Answers Dr. Donald Killinger, MD, Phd, FRCPC, from 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 to Dr. Killinger. This will be easier to do once we have our web site operational.
- Please 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.

# **Annual Membership Renewal:**

Annual dues to the Addison Society of Canada are due January 2005. Please note that members who do not renew will cease to receive the Newsletter or other communications from the Society.

# **Upcoming Issues:**

Sample formats to use when discussing an emergency letter with your doctor.

Other ideas include: How to advocate for an Addisonian in crisis - A Checklist of information; How to Educate Family and Friends on Addison's: Can do – Can't Do's; an article or thoughts on dealing with an Addisonian spouse. However, we need someone to write these articles.

# Again, ANY VOLUNTEERS?

This is your newsletter! We need your contributions. Please send your stories, tips, ideas directly to our editor Steve McKenna via email at <a href="mailto:sqmckenna@cyberus.ca">sqmckenna@cyberus.ca</a> or c/o the Addison Society.



# The Canadian Addison Society La Société canadienne d'Addison 193 Elgin Avenue West Goderich ON N7A 2E7 1-888-550-5582

Website: <a href="http://www.addisonsociety.ca">http://www.addisonsociety.ca</a>

New Membership □	Renewed Membership 🛮
Name:	
Address:	
Postal Code:	Telephone:
E-mail Address:	<i>Fax:</i>
How do you wish to receive the Newsletter:  ☐ I will read it on the website at www.ac  ☐ by email(thereby saving costs for the So  ☐ by snail mail.	ddisonsociety.ca ociety). Ensure you provide us with your up-to-date email address.
If you <u>DO NOT</u> want your name to be made av	ailable to other Addisonians in your area, please sign here:
	Society is \$25.00 due January 1 of each year.
You also have the choice of directing \$5.00 of check box of your choice.	the annual fee to an <u>approved</u> local support group of your choice. <u>Please</u>
( ) \$25.00 to go to the Canadian Addison Socie	ety <u>OR</u>
( ) \$5.00 to Québec Support Group – Quebec	+\$20.00 to Society
( ) \$5.00 to Eastern Ontario Support Group – (	Ontario + \$20.00 to Society
( ) \$5.00 to Southern Ontario Support Group -	Ontario + \$20.00 to Society
() \$5.00 to Saskatchewan Support Group – Sas	skatchewan + \$20.00 to Society
( ) \$5.00 to the Alberta Support Group – Alber	ta + \$20.00 to Society
() \$5.00 to B.C. Lower Mainland Support Group	p – British Columbia +\$20.00 to Society
() \$5.00 to Vancouver Island Support Group (	/ictoria) – British Columbia + \$20.00 to Society
() \$5.00 to Vancouver Island Support Group (I	Nanaimo) – British Columbia + \$20.00 to Society

Please make cheque or money order payable to the Canadian Addison Society and send: c/o Treasurer, 193 Elgin Avenue West, Goderich ON N7A 2E7