The Canadian Addison Society
La Société canadienne d'Addison

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ISSUE NO. 61 **JANUARY 2011**

In this issue:

- Society Membership Dues for 2011
- President's New Year's Message
- Minutes of Annual General Meeting
- Announcements
- Personal Experiences
- Highlights from Local Meetings
- Medical Q & A

PLEASE NOTE: The content of this newsletter is intended for basic information only and not as personal medical advice. Readers are advised to consult their own doctors before making changes to their Addison management program.

Society Membership Dues for 2011:

Just a reminder that your annual dues of $25.00 for membership in the Canadian Addison Society are due in January 2011. Please remember that, by paying your dues, you make it possible for those recently diagnosed with Addison's to obtain the same support which has helped each of you, both through our website, local meetings and Q&As. A membership form for renewal is attached to this newsletter.

President's New Year's Message:

2010 sped by with its usual ups and downs. I wish everyone a healthy 2011!

If anyone knows of research into Addison's Disease being conducted in Canada, please let the Executive know so we can distribute the information and make sure it gets maximum participation by members.

A special thanks to Dr. Killinger for his time and for faithfully answering our letters to him. He has a wealth of information which he shares with us. Be sure to read the past newsletters to keep up to date on questions you may have but which have been answered in the past.

Be sure to support your local group meetings this year. The local representatives and assistants put a lot of effort into arrangements and appreciate your participation. As with any group, it is the input from members that make the meetings so special.

All the best

Judy Stanley
President

Minutes of Annual General Meeting:

Held Saturday, October 16, 2010, New Westminster, BC

1. **CALL TO ORDER** by Judythe Stanley, President:
Judy Stanley welcomed all in attendance including 17 members, and introduced out of town guests Paul and Cathy Jesperson from Calgary, Jim and Shirley Sadlish from Victoria. Jim is also our Vice President and Victoria representative. Our guest speaker this year is Dr. Rob Sharpe. Judy Whittaker, BC Lower Mainland, is the recording secretary for this meeting.

2. **PRESIDENT'S MESSAGE** - Judythe Stanley:
I would like to thank John and Irene Gordon, Patricia Hehner and Jim Sadlish for the extra duties they have taken on to make The Canadian Addison Society run smoothly. A big thanks to our Board of Directors for their dedication as well. Each province has their group leaders without whom information could not be passed to those seeking assistance locally.

This year, we have addressed inquiries from Ireland and Australia, and cooperated with other national organizations to further the advocacy for Addison's disease.

As in past years, a reminder to keep your flu vaccination current; this year's inoculates against H1N1 as well as seasonal flu.

Dr. Van Uum recently published a study in the journal *Stress*, September 3rd. It received a great deal of media attention all across Canada and in other countries as well. From the local Vancouver Sun – 'Just a small snippet of hair may hold the key to predicting a person's risk of heart attack months in advance, according to a new Canadian study'. They are very pleased with this positive response to hair cortisol research and look forward to publishing their adrenal insufficiency study in the future, with hopes of a similar public reaction.

I look forward to the next year as President.

3. **ADOPTION OF MINUTES FROM 2009 ANNUAL GENERAL MEETING**:

Moved by Jim Sadlish, seconded by Marilyn Thauberger to accept as distributed.

4. **FINANCIAL REPORT** – (interim statements have been replaced with year-end statements appended to Newsletter)

TREASURER'S MOTION TO BE VOTED ON: That The Canadian Addison Society invest an additional $5,000 in 90 day notes with Equitable Trust. This motion deals with the transfer of monies from the general account to our investment account with Equitable Trust. The rationale behind the motion is that there is a considerable amount sitting in the Canadian Addison operation's account that could be earning interest.

MOTION: Moved by John Gordon (Treasurer) and Seconded by Rick Larocque (Member).
All were in favour.

There was also a brief discussion on the purpose of the accumulated funds. It was suggested that it was for research such as Dr. Van Uum's study, support for ongoing research, and financial support for local groups with their expenses.

5. **SLATE OF OFFICERS and DIRECTORS FOR 2010/2011** - No Change

President:	Judythe Stanley (BC)
Vice President:	Jim Sadlish (BC)
Treasurer:	John Gordon (ON)
Secretary:	Irene Gordon (ON)
Directors:	Derek Clarke (BC)
	Patricia Hehner (ON)
	Elizabeth Hill (SK)
	Greeta McKague (ON)
	Stephen McKenna (ON)
	Harold Smith (ON)
	Joan Southam (ON)
	Marilyn Thauberger (BC)
Newsletter Editor:	Patricia Hehner (ON)

6. **REGIONAL REPRESENTANTIVE REPORTS**:

Eastern Ontario Region – Steve McKenna, read by Judy Stanley
The Eastern Ontario support group met in May of this year and had a Pharmacist as our guest speaker. The group is meeting again on October 16th and will be discussing various aspects of previous Newsletters.

We received inquiries from other Addisonians and their family members. Information on the Canadian Addison Society was provided for a local doctor as well, including information on what should be in an emergency kit.

South/Central Ontario Region – Harold Smith read by Jim Sadlish
The South/Central Ontario Support Group has experienced a positive year with a number of new members joining our ranks. Conversely, it has been a particularly difficult year economically for many in this region of the country and we believe that this has contributed to the loss of a few members. We do expect a few to return when their situation improves. Generally we are in reasonably good shape and still attracting new members.

During the year, the group underwent a subtle name change from “Southern Ontario” Support Group to South/Central Ontario Support Group. This minor revision is an improvement in describing the geography managed by the group.

Two member meetings were held over the last twelve months. We were very fortunate to attract and have the support of high calibre speakers. In May, 2010, we were fortunate to have Kathy Layte, RN, MScN, CS, HTCP/I, Professor of Nursing, McMaster/Mohawk/ Conestoga Collaborative BScN Program, present a meaningful and helpful message. Professor Layte used large doses of humour, and reality, in driving her message home. We are very grateful to Professor Layte for her interest in our cause. She is instrumental in improving the awareness of Addison’s in the classroom of our future nurses. Please refer to the July 2010 Newsletter for a brief review of her presentation.

On October 2, we were very fortunate to once again have Stan Van Uum, MD, PhD, Assistant Professor Endocrinology and Metabolism, Clinical Pharmacology, Dept. of Medicine, University of Western Ontario, as our Guest Speaker. Rachel Gow, MSc, joined Dr. Van Uum to assist in presenting a preliminary version of the results of the “Hair Cortisol Study” in which many members across Canada participated. Canadians were joined by members of NADF (North American Adrenal Disease Foundation) from across the USA. Member participation made a great difference in the success of this study and we thank you for your willingness to contribute to the study.

The detailed final results must follow protocol and due process before they can be released to the public in their final version, by Dr. Van Uum. While we may have only a sketchy picture of the final results at this time, the full details will be forthcoming in the very near future and will become yet another avenue that will increase global awareness of Addison’s disease.

A new initiative started by this group is the Brochure Holder Program. The plan is to eventually mail these directly to Endocrinologists, Family Physicians, and doctors in other medical disciplines in Canada that may have a connection to Addison’s Disease. Obviously the program will go through a rigorous test run to fine tune the details before the Society takes the plunge toward a full scale cross-Canada distribution. The Brochures would already be housed in a dedicated plastic holder, with user friendly brochure re-order instructions. The program planning is now back on track after a set back due to the writer’s health issues during 2010. A full report will be provided at the 2011 AGM, if not before.

While we may be a little bit early, we extend Season's Greetings to everyone from the members of the South/Central Ontario Support Group. We hope that 2011 will be your best year yet!

Vancouver Island Region – Jim Sadlish
The Victoria support group continues to meet three Saturdays through the year. Turn-out is excellent and this is very gratifying to the Regional Representative. Although several attempts to entice medical speakers this year have been unsuccessful, meetings were filled with friendly discussion about our common concerns and health experiences.

Meetings are a venue to inform others about how we managed a crisis, were treated at Emergency, suffered an illness or accident, accomplished difficult feats, handled new disorders or surgeries, and when doctors changed our medication or dosage. There is not one disinterested person in a support group meeting. Any of us could go through the same ordeal as you did. All information is relevant and important to our health.

Barbara Hunn, one of the contact members for Central Vancouver Island, has attempted to garner interest for a support meeting in Nanaimo through notices in the CAS Newsletter, but so far there has been no response from local members. The last meeting was held at a member's home in Qualicum, but was not too successful as only one other member came out. Evidently others felt the drive from the Nanaimo area was too far at night.

The Victoria support group is known to endocrinologists, who have referred new members to us. We periodically drop off pamphlets and notices of meeting dates to doctors' offices. We recognise that any changes to improve quality of life must be decided by the endocrinologist in consultation with the patient.

BC Lower Mainland – Marilyn Thauberger
We had a good year, with increased active participation by members.

Patti Chabot, with Judy Whittaker acting as secretary, chaired the October meeting. Guest speakers from BCAA provided up-to-date information on Travel Insurance in general, and especially with regard to underlying medical conditions.

In February, rather than have a guest speaker, Judy Whittaker conducted an excellent "practice session" for emergency medications. Members had the opportunity to learn, using syringes and out-dated Solu-Cortef, to inject oranges. This was a great practical experience.

For the seventh consecutive year, we conducted individual interviews with UBC medical students, as part of their "Chronic Conditions" course, coordinated this year by Jane Bremner. This is such an easy and important way to educate aspiring doctors to recognize and test for Addison's Disease if they are presented with a patient with symptoms similar to ours. Again, our Addison's group had the highest rate of participation of any support group for people with chronic conditions.

Topics of discussion at the Appetizer Meeting in May were Newly Diagnosed Addison's Disease — Where do I go from here?; Emergency Room visits, taking an advocate with you; Positive things we are doing to live a healthier lifestyle. This informal discussion format has proven very popular and helpful. Members volunteered to co-ordinate different aspects of the AGM. Gerry Ott - Guest Speaker and setup, Judy Whittaker - Secretary, Debbie Doggett - Setup and Kitchen, Squares - Donna Smith, Linda Stappler, Pattie Chabot and Johanna Harrison.

June 27th, Judy Stanley, assisted by Marilyn Thauberger, was invited and made a presentation at Amica at Mayfair Senior's Residence, where our member Vera Nokony resides. This was quite a learning experience for Judy and Marilyn as well as the residents.

Our group made a donation to the Surrey Memorial Hospital in memory of member Louise Calder who died last year.

Debbie Doggett presented Judy Stanley with a floral arrangement in appreciation from the BC Local Group, for all the time and effort she has given to our group.

Vacancies

We are currently seeking volunteers to act as regional representatives in the Atlantic Provinces and in Alberta.

7. MEMBERSHIP UPDATE

There are 134 current paid members. If Members wish to renew membership, they may do so today.

8. NEW BUSINESS

Discussion was held on generating ideas of contacting newly diagnosed Addisonians, to join their local groups of CAS, for support.

Those present supported the Brochure Holder Program initiated by the South/Central Ontario Region. Other initiatives such as members taking the Addison Disease Brochures to local Family Doctors and Endocrinologists for distribution were suggested. Brochures were available to members. Canadian Medical Association magazine advertisement was noted as not cost effective. Further discussion was held on local Public Health Forums, newsletters and other options.

A brief discussion was held on the outcome of the Hair Cortisol Study of Dr. Van Um. Final results to be published.

A question was presented on the likelihood of Addisonians being accepted on Long Term Disability – with a brief discussion on various members' histories.

9. 2011 ANNUAL GENERAL MEETING

The 2011 AGM will be held in Brantford, ON, in September/October, 2011 (date to be confirmed

Business meeting moved adjourned by Jim Sadlish

10. GUEST SPEAKER – Dr. Robert Sharpe RCPSC, Anaesthesiologist and Critical Care Medicine

Gerry Ott, BC Lower Mainland, introduced Dr. Sharpe:

Dr. Sharpe trained in Anaesthesiology plus a further fellowship in Critical Care Medicine. He currently works in the Operating Room at Royal Columbia Hospital (RCH), New Westminster, as well as the ICU and Cardiac ICU at RCH. Approximately half of his time is spent doing Critical Care Medicine and the other half with Anaesthesia or Cardiac Anaesthesia. He studied for an undergraduate degree in Anatomy and Cell Biology at McGill University, went to medical school at the University of Ottawa, and took anaesthesia training at Ottawa Hospital. His Critical Care Fellowship was done at Vancouver General Hospital, and St. Paul’s Hospital in Vancouver. The specialty of Anaesthesiology requires an additional 5 years of medical school after the basic Family Practice.

Dr. Sharpe presented his topic of ‘Anaesthesiology as having Multiple Components’. Basically, he described the definition of anaesthesia as “lacking feeling”, minimizing pain, a disconnection from feeling pain, minimizing pain so patients can tolerate a surgical procedure. He spoke of individualizing the type of anaesthetic to the surgery and the risks to the patient taking into consideration any co morbidities related to the individual patient.

Dr. Sharpe discussed treating an Addison’s patient having surgery with the specific needs of these patients, such as: anticipated length of surgery, stability of the patient with their steroid regime, and any other underlying factors such as blood thinner medication. All of these factors would help with the anaesthesiologist’s decision on the amount of cortisone to be given during surgery. Anaesthetists would also have a full medical history including other endocrine disorders and related medications upon which to base the anaesthetic and treatment during surgery. They should be aware of the cause of the Addison’s, if known.

Major surgery, e.g. bowel surgery, requires an anaesthetic while a minor surgery, e.g. mole removal, could be done with a regional anaesthetic which targets specific nerves which go numb for a short period of time.

Question: Do you mix your anaesthetics?
Answer: Most anaesthetics are premixed or in a powder form for reconstitution.

It is mandated which ‘monitors’ are used with each anaesthetic i.e. blood pressure, oxygen in blood, etc. A local anaesthetic causes less endocrine stress, it blocks peripheral nerves whereas a general must be monitored for several hours and requires airway management.

There are five levels of assessment:
a. Health
b. Mild systemic disease
c. Severe systemic disease
d. Severe
e. Moribund or unlikely to survive

Question: What category would Addison's patients be?
Answer: Not in a crisis would be 'mild systemic'; not diagnosed or in a crisis would be 'severe' or 'moribund or unlikely to survive'.

TB was the primary cause of Addison's Disease but now accounts for 20% of Addisonians. Number one cause is idiopathic autoimmune but some are caused by HIV, AIDS as well. A major cause is adrenal haemorrhage or infarction, bleeding into the adrenals, and can include fungal infections.

Dr. Sharpe also answered questions from the floor.

Gerry Ott thanked Dr. Sharpe for his most informative presentation and presented him with a gift from the Canadian Addison Society.

Announcements:

We were saddened to learn of the passing of Stuart Rees, a member of the South/Central Ontario Support Group. Stuart and his wife were regulars at our meetings and will be missed. Our sincere condolences to the family.

Personal Experiences:

I worked all day at my hospital as a lab technician on Nov. 11, 2010. I felt absolutely fine all day. At about 5 pm, I felt a strange feeling in my stomach, one that I had never felt before. I had to lie down as my energy level suddenly dropped. After about an hour, I began vomiting and just felt done in. This was at the same time H1N1 patients were coming to the hospital so I thought maybe I had that. Four hours after initial feeling unwell, I decided to call an ambulance, something I had never done before. It took everything I had to pick up the phone to dial.

After arriving at the hospital and being put into trauma bed, which I knew was a bad sign, I was given lots of IV fluids and had many blood tests. My blood pressure was 60/40 so they were very concerned. Seven hours after my arrival, I was air lifted to Toronto hospital because I was very ill and they were unsure if I would survive. I was put on a Leviphed drip three times to try to increase my blood pressure and save my life. It finally worked and I began to feel better. All tests for H1N1 came back negative so doctors were unsure what was wrong. The next day I was taken back to my hospital to spend 7 days there, during which time an internist, to whom I am very grateful, ordered a cortisol test. When that came back abnormal, he ordered others and determined I had Addison's.

Even now, I have a hard time writing this. The doctor told me that if I had of stayed home, and not called 911, my husband likely would have found me dead on the couch the next morning - I have three little kids, who could not lose their mommy.

This is why I urge everyone to call an ambulance if you ever become really ill, really fast. A lot of people would stay home and hope to feel better in the morning but I am urging everyone to call an ambulance if in any doubt. Even if it turns out to be the flu, that's OK; this is why health care workers are there. I am so thankful that things went the way they did and I know Remembrance Day last year is a day I will never forget!!!

Submitted by Carey Titterton

Highlights from Local Meetings:

Vancouver Island Support Group

The Vancouver Island support group met October 2nd, at Victoria General Hospital, with 13 attending, including one new member and 4 non-Addisonians.

Many of the Addisonians present had experienced some sort of dizziness. Dizziness is also called orthostatic hypotension, blood pressure suddenly falling when the person stands up or changes from a lying position to standing. The overall effect is an insufficient blood perfusion in the upper part of the body. Dizziness can also be caused by a decreased amount of blood in the body due to dehydration or anemia. Florinef can be prescribed to treat orthostatic hypotension (http://www.merck.com/mmhe/sec03/ch023/ch023c.html).

Crises are a worry for each of us. Getting to Emergency and through triage promptly is a challenge, with the outcome often dependent on the knowledge and experience of ER staff. If medics do not know what Addison's is, there could be unnecessary delays in treatment. After starting a new job and around the same time as becoming a new father, a younger man had two crises within a short time. Stress was the obvious cause. On his first visit to Emergency, telling them he had Addison's got him immediate treatment. However, on the second occasion having Addison's did not take priority and he was stuck in the waiting room, passing out of consciousness several times before he was finally looked after. Should he need to go again, he will take an Emergency letter (available at: http://www.addisonsociety.ca/emergencylett.html).

A woman with severe abdominal pain went to Emergency and was quickly triaged but then left untreated for a lengthy time. She was understandably in need of emergency medications, having to deal with the pain, but had to wait for doctors to get to her. It was a gall bladder attack for which surgery next day was necessary. Later, in hospital, she spoke to her endocrinologist, who suggested she could have taken a Solu-Cortef emergency injection before going to Emergency.

Another woman went for her regular optometry exam and was referred to an ophthalmologist who diagnosed acute angle glaucoma. This condition requires immediate surgery and an eye operation was quickly scheduled. She had no symptoms whatsoever. Another member had the exact same diagnosis and prompt treatment. In B.C., Addisonians are permitted one yearly exam by optometrists or ophthalmologists, with an initial referral from our family doctor. Taking adrenal replacement medication predisposes us to glaucoma, so have your eyes checked annually for glaucoma. Both women regretted not taken extra medication before their eye surgeries (http://emedicine.medscape.com/article/798811-overview).

Kelley, a competitive runner and member of our support group, dropped in during her lunch break to show us her medal for completing a recent Ironman competition! Evidently there are only 4 Addisonians in the world to have equalled this feat! Her husband followed her on his motorcycle during the cycling and running portions of the event to inspect her for signs of under-medicating at the check-in sites. The event took her 15 hours. Kelley had a dispenser fabricated for her bike so she could easily access her medications while cycling. Her next goal is to run another Ironman in Cancun in 2012.

Since a woman's test results indicated that she had too much calcium in her blood, she underwent exploratory parathyroid surgery. Doctors found thyroid cancer but none in the lymph. One thyroid gland was removed along with one parathyroid gland. Her calcium levels dropped immediately. She has one more surgery scheduled then radioactive iodine therapy to follow.

A founding member of the support group spent 10 days in hospital recently being treated for diverticulosis and related infections. During her ordeal with infection, when she showed signs of needing more meds, her daughter administered Solu Cortef injections. The endocrinologist, however, advised to instead increase the dose of tablet replacement, as emergency injections can play havoc with the endocrine system if administered too frequently. Double or triple your regular dose, he said. Generally, it is only when we can't retain fluids that we need the injections.

For our next meeting in February 2011, we will plan a demonstration by a nurse and member of the group who will show us how to fill a syringe and then inject into an orange. This repeat demonstration was suggested to keep us practised in loading and using the emergency syringe. We will need to bring in our out-dated vials.

Submitted by Jim Sadlish

The next meeting of the Victoria support group will be Saturday, February 19, 2011 in Room 1814 at the Victoria General Hospital, from 1:00 to 3:00PM. There will be a demonstration of loading and injecting the Solu-Cortef syringe.

For further information on the Vancouver Island Support Group, please contact Jim Sadlish at wx6999@gmail.com or (250) 656-6270. For information on Central Island activities, please contact Barbara Hunn at bhunn@shaw.ca or (250) 714-0036 or Sharon Erickson at ericksons@shaw.ca.

BC Lower Mainland Support Group

We will be contacting everyone in January 2011 for the 8th annual interviews with first year medical students. This is a great advocacy option for our members to participate in and only takes an hour or so once a year at your convenience.

The next meeting will be held in February 5, 2011,1:00 to 3:00 in the Sherbrooke Lounge, 260 Sherbrooke Street, New Westminster BC (access from Millennium Line – Sapperton Station; parking on Keary or Sherbrooke Streets, $1.10/hour or 10 hours for $4.00).

Also, Lower Mainland members are welcome at the meeting of the Victoria support group on February 19, 2011 in Room 1814 at the Victoria General Hospital, from 1:00 till 3:00. There will be a demonstration of loading and injecting the Solu-Cortef syringe. Anyone wishing to car pool for the ferry and share expenses to attend the meeting, please let Judy know.

For further information on this support group or any upcoming meetings, contact Judy Stanley, (604) 936-6694 or bugbee@shaw.ca.

Alberta Support Group

Numerous phone calls are received from newly diagnosed Addisonians who have obtained the regional contact's information from the Canadian Addison Society website, which clearly indicates how useful the website and our approach to regional representatives is.

Submitted by Ginny Snaychuk

For information on this support group, contact Ginny Snaychuk at ginray@shaw.ca or (780) 454-3866 in Edmonton, or Peter Little at bettypeter66@gmail.com or (780) 918-2342 in Edmonton.

Saskatchewan Support Group

The group met October 24, 2010 at the Saskatoon City Hospital, with 7 Addisonians, 3 spouses and 1 family friend attending.

Hand-outs included:

- Canadian Addison Society Brochures to give to their physicians.
- Canadian Addison Memberships forms
- A rare but deadly disease by Judy Adamson June 12, 2003 on Addison's disease
- Booklet - *Living with Addison's Disease - an owner's manual for individuals with the disease* from the U.K. website

- Booklet by the National Adrenal Disease Foundation (USA) - *The North American Survey*.
- Handouts from the Canadian Addison Society website: on how health care professionals can help an Addisonian in an Addison's Crisis.
- Information on an Emergency Kit when travelling abroad

We told each other how we were diagnosed with Addison's, the medications we were on, how we were living with this condition, if we worked outside the home and family. Then our spouses and family friend had a turn telling how they felt we were doing. It was so funny that most of our spouses needed to remind us almost daily to take our steroids. One member was about half an hour late to the meeting because she had to go back home and take her steroids!!

We plan to hold another meeting possibly in Regina next year-early summer.

Submitted by Elizabeth Hill

For information on this support group, contact Elizabeth Hill at (306) 236-5483 kesahill@sasktel.net or elizabeth.h@pnrha.ca.

South/Central Ontario Support Group

The Group met in Brantford, Ontario on October 2, 2010 and as usual had a very good turnout including several new members. To start, the group proceeded to their regular "self introduction" by everyone in attendance.

- A motion will be required at the AGM to adopt/accept a motion related to further investment of $5,000 in 90 day notes from the society's operation account to the investment account currently held with Equitable Trust (the timing of the transfer left to the Treasurer). The rationale is that there is a considerable amount sitting in the Canadian Addison operation's account that could be earning interest.

- The Current Membership Form has been revised to reflect the change in name of the Southern Ontario Support Group to South/Central Ontario Support Group. This is a subtle but important change to more accurately reflect the geography represented.

- Update on Brochure Holder Program: Due to health issues, the program to distribute brochure holders to local Doctor's offices was delayed this year. However, we hope to have something concrete in the near future.

Guest Speaker: Dr. Stan Van Uum, who has been kind enough to give the Society a great deal of his time at several meetings over the last three years. He has also provided a great deal of important Q & A time at these meetings, which members appreciated. Rachel Gow, MSc, who has been deeply involved in the "Hair Cortisol Study" accompanied Dr. Van Uum.

Rachel presented a review of the objective of the study and the methodology employed. The participation in the study was excellent with members of both the Canadian Addison Society and NADF across the USA providing hair samples and following the study protocol. The study results are just being finalized and must be published before we will be able to gain access to the results.

Following this, Dr. Van Uum conducted a Q&A session for the balance of the day, fielding many questions on topics of great importance to members. Members find the Q&A sessions with our guest speakers a very important feature of our meetings.

Next meeting is scheduled for May 2011 in Mississauga. Check the website www.addisonsociety.ca as the date gets closer for specific meeting details as to time, location and guest speakers.

Submitted by Harold Smith

For further information on Southern Ontario Support Group activities or meetings, contact Harold Smith in Kitchener at hsmith9995@rogers.com or (519) 742-9995.

Eastern Ontario Support Group

The Eastern Ontario group met October 16, 2010, with 16 people in attendance, including a new member. There was no guest speaker.

Update on local matters:

- the AGM was being held in Vancouver on the same date as our meeting;
- membership forms for 2011 membership dues were available (Not a member yet? Need to renew? Do it on-line with this link: http://www.addisonsociety.ca/membership.html.
- newsletters are now being sent to all endocrinologists in Canada, once a year on a rotating basis, to increase the Society's profile;
- the pamphlet on Addison's was circulated and members again requested to leave copies with their specialists and family doctors as appropriate;
- the website continues to be the source of many contacts and Q&A; as well, a doctor with an Addisonian patient contacted us to get more information on what and how to prescribe an emergency kit;
- Carol-Ann has again volunteered to update the complete set of Q&A on our website – a huge thank you to her.

Topics discussed:

- osteoporosis: the need for a bone mineral density test as baseline, and regular follow-ups every few years up to every year, depending on problems;
- the need for an endocrinologist of record, even for those who are normally managed by their family doctor;
- the use of solu-cortef and emergency hospital visits for those with severe vomiting or diarrhea;

- emergency room visits: it is very helpful to have the copy of the Ottawa Hospital protocol with you to hand the triage nurse (http://www.addisonsociety.ca/ohp.html)
- for patient information in emergencies: the first place paramedics look is on the fridge; include main elements of health (i.e. heart condition, diabetes, etc.); the sheet can be folded for privacy and clearly identified by name and ‘for use in emergency’
- the additional issues of managing Addison’s as a teenager (one member attending is 15 years old, and others were very interested in the special challenges of managing Addison’s while growing and in a school setting);
- issues related to managing Addison’s for those who also have low thyroid, as fatigue can be a symptom of under medication of either condition. One member told us that the Addison’s must be properly managed before the thyroid medication levels can be properly established: that medication for thyroid, in the absence of adequate Addison’s medication, can cause problems from rapid heartbeat and other reactions which the adrenals can’t handle;
- limitations to normal lifestyle for those with Addison’s: this is a very personal issue, some people must curtail their activities, others still run marathons, and one member spoke of going to Rwanda for 3 months (see her blog at http://elaineinkigali.blogspot.com) - in essence, each Addisonian must learn to read their own body and act on that basis;
- heat can be a real stressor: one member uses a cooling vest, which makes a world of difference for him (see July 2008 Newsletter http://www.addisonsociety.ca/newsletters/Newsletter2008July.pdf);
- several members looked at the emergency kits and letters carried by others which they found to be very informative.

Submitted by Steve McKenna

The next meeting will be Saturday May 14, 2011, at Robbie’s restaurant on St. Laurent in Ottawa, starting at noon. As requested, we will be looking at how to use the solu-cortef vials and practising giving injections (to an orange), so please save any out-dated solucortef vials to bring with you to the meeting.

For information on Eastern Ontario Support Group activities or meetings, please contact Steve McKenna at steveandpat@rogers.com or 613-523-7648.

Québec Support Group

We now have a local representative, Marie-Josée Normand, in Montréal. If you wish to contact her, she can be reached at (514) 376-2712, by email at marijonormand@videotron.ca or through the ‘Local Groups’ page of our website.

Nous avons maintenant une représentante, Marie-Josée Normand, à Montréal. Si vous désirez la rejoindre, vous pouvez communiquer avec elle au (514) 376-2712, par courriel au marijonormand@videotron.ca, ou bien par l’entremise de notre site-web.

Atlantic Support Group

The Atlantic Canada Support Group is looking for a volunteer to act as contact point. If you can do this, please contact the Liaison Secretary at liaisonsecretary@addisonsociety.ca or at the national address shown on the front of this Newsletter.

Medical Q & A

There is now a very large and wide-ranging set of questions on both daily living and very situation-specific issues that have been answered by our medical advisor. To review these questions, please go to the Canadian Addison Society website under Education (http://www.addisonsociety.ca/faq.html), or see previous issues of the newsletter.

Before submitting a question to our medical advisor, please consult the wealth of Q&As on our website. Many questions have already been answered.

Q: Do people with Addison's Disease have adrenaline rushes? Can they have them at all?

> **A:** Most people with Addison's disease have their adrenals affected by antibodies directed against specific proteins in the adrenal cortex. Adrenaline comes from the central part of the adrenal gland called the medulla. This is left intact by the antibodies so adrenaline can still be produced when required. Much of the adrenaline type of compounds are released from nerve endings, so even individuals who have had their adrenals removed surgically can have a normal response to stressful stimuli.
>
> I'm not so sure about an "adrenaline rush". This is not a medical term but I assume that you are referring to a sudden feeling of excitement that might occur in response to some sudden event. These feelings should still be possible.

Q: I am a 59-year-old woman with Addison's Disease, taking 20mg hydrocortisone. My bones were fine before; now I have significant osteopenia. Could these meds be the cause?

> **A**: I doubt if the hydrocortisone at a 20 mg dose would be responsible for significant bone loss. There is commonly a fall in bone density in the early years after the menopause. Are you taking 1000 iu of vitamin D and 1000 to 1500 mg calcium? These are important for bone health.

Q: I had an Addisonian crisis last year and almost died, so when I was referred to an endocrinologist, I asked about at home injection kits and if I needed one, as I had read about them; he said I didn't need one. Can I please have your opinion on this? It scares me to know that what I have is rare and I would like to be prepared.

> **A:** Your endocrinologist probably feels that if you are in a crisis situation, you are better off going to the hospital where you can get both intravenous saline and hydrocortisone and be investigated for the cause of the problem. The emergency kits are important if

you are travelling or if you live a distance from the hospital so that in a situation such as a snowstorm, you may be delayed for a significant length of time. I think all individuals with adrenal insufficiency should have an emergency kit at home. They are relatively inexpensive and they give you a feeling of security. If your doctor is unfamiliar with the kit, you can refer her/him the Addison's web site where there is a detailed description. These kits are relatively new but are now being used in many countries.

Q: I have been living with Addison's disease now for 2.5 years and have been successful in managing it with dexamethasone and florinef. I even completed a half marathon just eight months after being diagnosed! I want to do some trekking in the Andes though, and am wondering how the high altitude will affect me. Will it just be a case of increasing my dose of dexamethasone?

> **A:** I assume that you took extra dexamethasone when you did your half marathon and did well. The trek will be a longer stress and I think you will have to gauge the degree of difficulty to see what you will need. I am not sure how much dexamethasone you are on at the moment but as you know, dexamethasone is both potent and long acting so you can make appropriate adjustments depending on what you are doing. If you are on 0.5 mg of dexamethasone a day then 1/4 or 1/2 tablet increase would be the type of increase that would be appropriate. Be sure to take along several emergency solucortef kits. These could be important if you have any gastrointestinal problems.

Q: I am a 58 yr. old female, diagnosed with Addison's 5 yr. ago. I am on 20 mg hydrocortisone and 0.1 mg florinef daily. I also take 0.075 mg synthroid daily for thyroid. Recently the dosage of hydrocortisone was increased 5 mg, to 25 mg a day. I am now experiencing a lot of heartburn and headache. Could this be because of the hydrocortisone increase?

> **A:** I am not sure what the problem was that stimulated the increase in hydrocortisone. The best way to see if the dose increase caused your new symptoms is to go back to your old dose and see if your symptoms improve. Hydrocortisone can cause heartburn so it is best taken with food.

Q: My daughter has Addison's and is pregnant. She is having severe morning sickness. We think. Not sure if the severe vomiting, dizziness, low blood pressure is the pregnancy or Addison’s or both. She is 11 weeks and has had to go off work; she is bedridden. Is there anything that she can do? She has doubled her meds, and her family doctor is young and inexperienced. She is not feeling confident in her care. I am very worried for her. She has been referred to a specialist but that appointment is not till later.

> **A:** Your daughter did the right thing in increasing her hydrocortisone. She may not need twice as much, just a half tablet extra. With her vomiting, she should have her electrolytes (sodium, potassium, chloride) checked. The other test that would be helpful is a plasma renin. Your family doctor will know what that is. It helps to determine how much Florinef she needs.

Q: I have been on Actonel for 10 years now due to osteopenia and recently have been hearing some disturbing news about these bisphosphonate supplements. I have had gum recession for years, and now need to have 4 teeth removed due to bone loss and gum recession. The oral surgeon said I would not be a candidate for implants as I am at very high risk of infection due to being on the Actonel for so long. He wondered why I was on it for so long as your body can max out on it after 5 years. I read you should take a break from it and stop it periodically. I also read that it can increase your risk of esophageal cancer. What is a person with Addison's disease supposed to do?

> **A:** Your question is not related to Addison's disease specifically but really how long should anyone be on a bisphosphonate. I don't think you have done yourself any harm by being on the Actonel for 10 years. I think however it is time to stop it because you have received the maximum benefit and the material will remain in your bones for a further few years. I don't think your gum recession is related to being on the Actonel.
>
> You should be off the Actonel before any oral surgery; your dentist can give you advice about this but don't let comments such as "your body can max it out after 5 years" upset you because there are a lot of people who have been on these medications for 7 to 10 yrs. The ground rules are still being laid but the recent evidence suggests that now is the time to stop the Actonel. You can get a bone density done in two years to see how things are progressing. Don't be upset about the comments, everything will be fine.

Q: I am 44 years of age. I have a long and complex medical history with many problems, including a kidney transplant at age 35. By 40, I dispensed with most of my doctors and medications, except prednisone, and learned much more about natural health. Five weeks ago, I was working hard, and did not eat a lot. I eventually collapsed, almost lost consciousness, hurt everywhere, and began to throw up. The next day could barely stand, and was vomiting blood. I got to the E.R., where luckily an endocrinologist knew what was going on. He gave me 100 mg hydrocortisone. The next day, he told me I had Addison's. However, a week later, my GP told me that I do not. He was not sure what went on, but told me I had an Addisonian-type crisis, because I had over exerted myself and missed one day’s worth of 5 mg prednisone, which had been transplant protocol. I went back to the endocrinologist, who twice confirmed that I have Addison's Disease. Today, my family doctor had the letter from my endocrinologist, but he does not tell my family doctor that I have Addison's. What is going on here?

> **A:** Your encounter at the hospital was in some ways a fortunate one since it brought your adrenal situation to everyone's attention. I think both your doctors are correct; they are focused on the term ‘Addison's Disease’.
>
> If I understand correctly, you have been on prednisone since your transplant 13 years ago. The current dose is 5mg and may have been higher in the past. During the past 13 years, your adrenals have not had to work because you were getting all or nearly all

the glucocorticoid (hydrocortisone like compound) you needed from the prednisone. Your adrenal glands are probably suppressed because they have not been working as long as you have been on prednisone. When you missed your prednisone that day and probably did not have an adequate fluid intake, you had an "adrenal crisis". This just means you did not have enough hydrocortisone in your system. In your case, this was due to long term adrenal suppression; in other cases, it is due to the fact that the adrenals have been damaged by infection, antibodies or a variety of other causes. This is generally referred to as Addison's disease. When the adrenals have been suppressed, as in your case, it is not usually called Addison's disease, but since the result is the same if you miss your medication, sometimes we refer to it as an Addisonian crisis.

As you can see, your doctors were not really disagreeing about your problem, they were discussing the semantics of what to call it.

Medical Questions and Answers – Dr. Donald Killinger, MD, PhD, FRCPC, Medical Advisor for The Canadian Addison Society, will answer your questions about Addison's disease. Send your question to Dr. Killinger directly from the webpage http://www.addisonsociety.ca/faq.html#, by emailing liaisonsecretary@addisonsociety.ca or c/o The Addison Society (see address on front of this newsletter). Questions and answers that may be of interest to everyone will be published in the newsletter and on the website.

THE CANADIAN ADDISON SOCIETY
STATEMENT OF INCOME & EXPENSES
FOR THE PERIODS ENDING DECEMBER 31, 2009 AND DECEMBER 31, 2010

Cash on hand and in banks	**January 1, 2009**	**January 1, 2010**
	$22,053.27	**$24,008.82**
Income		
Dues Received - National	**$3,219.85**	**$2,516.18**
- Support Groups	**550.00**	**405.00**
Donations	**2,537.60**	**6,033.93**
Interest	**190.15**	**130.38**
	6,497.60	**9,085.49**
Expenses		
Advertising & Publicity	**-**	**389.54**
Research Support	**495.07**	**-**
Newsletter	**799.30**	**698.08**
Web Site	**186.90**	**201.14**
Secretarial	**1,200.00**	**1,200.00**
Annual Meeting	**145.99**	**100.00**
Postage, stationery and supplies	**474.11**	**309.80**
Telephone	**963.13**	**986.57**
Support Group Expenses	**215.25**	**366.28**
Bank Charges	**62.30**	**24.75**
	$4,542.05	**$4,276.16**
Cash on hand and in banks	**December 31, 2009**	**December 31, 2010**
	$24,008.82	**$28,818.15**

THE CANADIAN ADDISON SOCIETY

Analysis of cash on hand & in banks as at December 31, 2010

Equitable Trust -	
The Canadian Addison Society - $7,033.15 @1.3% due February 7, 2011 **- $15,304.94 @.9% due March 21, 2011**	**$22,338.09**
TD Canada Trust -	
The Canadian Addison Society	**2,384.18**
Montreal Support Group - Quebec	**120.00**
Ottawa Valley Support Group - Eastern Ontario	**642.01**
Brantford and District Support Group - South/Central Ontario	**1,705.03**
Saskatchewan Support Group	**130.00**
Edmonton Support Group - Alberta	**404.60**
Lower Mainland (Vancouver) Support Group - British Columbia	**499.24**
Vancouver Island Support Group – Victoria	**595.00**
Total	**$28,818.15**

The Canadian Addison Society
La Société canadienne d'Addison

193 Elgin Avenue West
Goderich, Ontario N7A 2E7
Toll free number: 1-888-550-5582
Email: liaisonsecretary@addisonsociety.ca
http://www.addisonsociety.ca

Membership in The Canadian Addison Society is $25.00 due January 1st of each year.

New Membership ☐ *Renewed Membership* ☐ **+** *Plus a Contribution* ☐

Name: ____

Address: ____

____

Postal Code: ____________________ *Telephone:* ____________________

E-mail Address: ____

How do you wish to receive the Newsletter?

☐ *I will read it on the website at www.addisonsociety.ca*

☐ *by mail*

If you DO NOT want your name to be made available to other Addisonians in your area, please sign here.

____

You may also direct $5.00 of your annual fee to one of the local support groups below. Please check a box of your choice.

☐ *$25.00 to go to The Canadian Addison Society*

OR

☐ *$5.00 to Québec Support Group – QC+ $20.00 to Society*
☐ *$5.00 to Eastern Ontario Support Group – ON + $20.00 to Society*
☐ *$5.00 to South/Central Ontario Support Group – ON + $20.00 to Society*
☐ *$5.00 to Saskatchewan Support Group – SK + $20.00 to Society*
☐ *$5.00 to Alberta Support Group – AB + $20.00 to Society*
☐ *$5.00 to BC Lower Mainland Support Group – BC + $20.00 to Society*
☐ *$5.00 to Vancouver Island Support Group – BC + $20.00 to Society*

+ *Contributions are also gratefully accepted. A tax receipt will be issued for contributions over $10.00.*

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

Revised: October 2010