

**The Canadian Addison Society
Minutes of the Annual General Meeting
Saturday, October 1, 2011
Brantford, Ontario**

The AGM meeting was called to order and thanks offered to Harold Smith, South/Central Ontario Support Group Leader whose group hosted the AGM. This segment of the day was Chaired by Irene Gordon. We began with a small tribute for Greeta (Fraser) McKague, one of the organization's founding members, who passed away quite recently. Thirty-four people were in attendance. Our thanks to Leslie James who acted as our recording secretary for this meeting.

1. Welcome – Introduction of Guests

2. Review of President's Report – Irene Gordon

Reminder - Newsletters are posted on the website.

3. Adoption of minutes from 2010 Annual General Meeting – Irene Gordon

Moved by: Rick Larocque **Seconded by:** Denise Burpee and **CARRIED** that the Minutes of the 2010 Annual General Meeting be received.

4. Financial Report – John Gordon

Financial Statements made available for periods ending Dec. 31, 2010 and Sept. 30, 2011

Sept. 30, 2011 - \$34,379.90 bank balance. \$22,535.76 invested. Balance on deposit at TD Canada Trust (\$7,454.34 for The Canadian Addison Society, \$4,389.80 for Support Groups)

Major expenses: ~\$800 Newsletter, ~\$850 Phone

Moved by: Don Archi **Seconded by:** Harold Smith and **CARRIED** that we accept the financial report as presented.

5. Slate of Directors for Nomination to be added the Board – Irene Gordon

Motion to accept and close new board nominations – Gerry Ott (BC) and Don Archi (ON)

Moved by: Nancy Bingeman **Seconded by:** Jack Mayos - and **CARRIED**

6. Membership Update – Irene Gordon

153 current paid members as of October 1, 2011.

7. Old Business – Harold Smith

- a) Update on Hair Cortisol Testing – report is on website in July edition of newsletter.
- b) Harold Smith – Update on Brochure Holder for information leaflet:

Community Awareness Initiative – Brochure Holder Program

Harold reviewed the concept – the goal is to create awareness of The Canadian Addison Society, for both patients and endocrinologists. The brochure holder would make the brochures more visible/available and the contact information in the brochures would benefit newly diagnosed or existing Addisonians seeking support.

The brochure holder is available as a tabletop or wall-mount and can hold up to 50 brochures.

Lots of discussion and suggestions.

Additional stickers/labels with contact info to be included in the test packages.

How would success be measured?

Suggested that we create feedback area on website – “How did you come across this brochure?”

Attach evaluation form with paperclip to brochure

Include Postal Code? For tracking purposes

Discussion about GP’s and ER’s – suggestion to post at Doctor’s office, but noted that with the average family doctor – the “hit” rate may be much lower.

Endocrinologist’s offices would benefit more and would be the better target.

Investigate the possibility of using TV’s infomercials in doctor’s offices to create awareness.

Change approach – ask each Member to take advantage of their situation – Endo, Doctor, Gastro, etc. Endo will remain primary contact, and perhaps 2-3 kits made available initially.

Other ways of raising awareness – Mailings – Irene. Hardly any returned. Ensuring we connect with Endo’s across country in a phased approach – i.e. By province.

Moved by: John Gordon **Seconded by:** Roger Steinmann and **CARRIED**

Motion made that we proceed with a test run of 50 kits in South/Central Ontario to determine viability of this project. Members will distribute to their own doctors to save postage costs. Endocrinologists are the primary focus.

Congratulations extended to Harold Smith for all the work and investigation that’s gone into this concept over the past couple of years.

8. New Business – Irene Gordon

For discussion: Covering travel costs and accommodation, meals, etc. for Executives to fly in for AGM.

Rationale – Treasurer and Secretary missed at meetings out West, for expertise in financial areas.

Motion to reimburse expenses for travel by Executive members was not seconded and therefore tabled.

However, recommendation was put forth to explore other less expensive communication options: Web Conferencing, SKYPE, and Teleconferencing. Begin with Teleconferencing or SKYPE and perhaps investigate video conferencing.

9. Next AGM in 2012 – Location Vancouver Island. Date TBA

10. The business of the AGM was completed and a break for 20 minutes took place.

South/Central Ontario Support Group Meeting

As the regular meeting was a little shorter in duration due to the AGM business, the focus was on the **Emergency Injection Training Clinic** run by member Denise Burpee, RN, and the Q&A session with Dr. Stan Van Uum – our Guest Speaker.

INJECTION CLINIC

Solu-Cortef Injection is simply a temporary measure just till you get to hospital. This emergency injection is going into the **muscle** as opposed to at the hospital IV; medication which will go into the **vein**.

Complete instructions were handed out as well as supplies to practice with oranges or grapefruits.

Wash hands first. Clean hands are important to reduce the spread of infection.

(For any practice session you should have a tin can or coffee jar, etc. available for needle disposal.)

Think of the injection process as two steps:

Step 1 - Getting the medication into syringe.

Step 2 – Administering the medication.

Thorough demo was given by Denise and all attendees participated.

Starts to work in a few minutes. Peaks in ½ hr to 1 hour.

Can last from 6 to 10 hours.

More important to get medication into body. Don't try to be exact or make it more complicated than it is.

Review signs/symptoms of when you may need the emergency injection –be very familiar:

Fever and flu – double or triple med for 3 days.

If vomiting or major diarrhea or if upping the dose does not work, injection may be required if emergency help is not immediately available.

Dr. Van Uum – suggestions how can we reduce barriers and to make things easier for Endocrinologists to provide what you feel you need.

There is a template on the website that can be used for travel purposes under the section “Healthy Living/Emergency Letters”. If you are going to use this letter, then it must be on a doctor's letterhead. A suggestion was made to have the letter laminated.

Triage nurse may look at letter and it may influence her/his response to your condition. **We must be advocates for our own health.**

Emergency Kit is security. Like an insurance policy.

Comment – recommended by The Canadian Addison's Society – Doctor may be more likely to write prescription for Solu-Cortef kit. You have to assemble all of the elements in the kit yourself and find a suitable carrying case. Assemble kit and include the letter

Suppositories are also available for prednisone – if nausea is a significant issue (cancer treatment).

REMINDER – Paramedics will NOT give injection, EVEN if you have documentation and a kit.

This is why it is important to have kit on hand and know how to inject.

MedicAlert is advocating on our behalf regarding the training of Paramedics to get them to consider Addison's Disease.

Important to have an advocate – someone to speak for you – partner, spouse, family member, etc.

- A quick poll was taken – Addison's Crisis CAN happen.
- For those in situations where paramedics were involved, NONE had given the injection.
- A few suggesting they had even been refused treatment.

SPEAKER – Dr. Stan Van Uum

TOPIC: What is the Endocrine Society currently studying that may be meaningful to Addisonians?

1. Must advocate for ourselves.
2. And as a group – just like The Canadian Addison's Society

General – all kinds of individual differences – presentation, impact on family, length of time for diagnosis.

Patients need to be the experts and the doctors need to learn from us.

Too many doctors think that once you are on medication, all your problems are solved.

If you look at biological treatments (i.e. diabetes, thyroid) – lots of variation due to personal differences.

Often more than one hormone to replace.

Adrenal hormones increase before you wake-up. So you may start the day when you are already behind. If a problem perhaps set-alarm a couple hours earlier – wake-up just to take morning dose – and go back to sleep.

Was surgery involved? Auto-immune? – could lead to other auto-immune – thyroid, celiac, diabetes (not familial)

Taking too much prednisone for a long time has implications

Variations with absorption (i.e. celiac), Affects metabolism.

Not every health issue you have is caused because you have Addison's. Nausea – is it from being under-dosed or something you ate.

If starting any new medications, ask pharmacists about interactions.

If you want to make a change, just do one change at a time. You will not be able to identify if there are too many changes – complicates things.

Document. Keep a journal about side-effects. Weight change. Diarrhea. Write it down to avoid falling into the same trap in the future.

What is the individual right dose?

Other things need to be considered – is it Thyroid, Vitamin D or B-12 deficiency, Diabetes. Rather than ask, “Do I have Hypothyroidism?” Say – I have not been feeling well, so other issues can be uncovered and you have a plan.

Ask for copies of any tests that are done.

Certain diseases run in families.

If Auto-Immune, Vitamin D mal-absorption could be an issue. Also screen for B12 and Celiac.

B12 – common test – if in lower half of normal range, you could ask for

Another special B12 test (more expensive).

TSH is a very good test.

No lab test is 100% perfect.

Low ACTH Readings.

DHEA – also dependent on ACTH

Discussion about Insurance premiums – starting to see questions on Travel documents re: “Do you have Adrenal Insufficiency”.

Exercise – there may be some need to increase dosage. If you make a change, keep it the same for 4wks and see if there is any difference. Keep a diary.

FINDINGS – Developments of dual release Cortef. Benefit is the release is closer to the normal physiology.

Patients feel somewhat better. Not available in Canada yet.

Suggestion – We, as patients, need something to help us feel better. Awareness in news will help.

When and how can we get it to Canada sooner?

Longer term study on side-effects. Reducing impact on quality of life. More and more are changing Cortef to 3 times a day (i.e. 20, 5, 2.5) to mimic more of the natural rhythm.

Kidney Transplant – What happens to the Addisonian? Dosing required to suppress immune system – need higher dose. Adrenal gland does not get transplanted. No studies have shown that this is possible at the moment. Need innovation.

Cortisol bind to receptors all over the body, so there is an effect everywhere. Effect on Mood Swings and Brain Fog. Higher levels of Cortisol – increased mood swings and negative effect on memory. Higher exposure to steroids has an effect. Keep track of when you take the medication and incidences.

Florinef – Affects Water and blood volume in body. Too much – blood pressure is high. Measure BP lying down and then standing up. Measuring position change.

- Cortef or Prednisone – Signs of too high dosages (like Cushing’s)
- Weight gain
- Blood Pressure increase
- Blood-sugar increase
- Lose Calcium

- Risk for Cardiovascular disease

Overall, you would like to go to the lowest dose that you can tolerate without having an Addisonian Crisis.

CLOSING COMMENTS–Harold Smith

Brochure holder – will try to roll-out test program in South/Central Ontario early and not wait for May meeting.

Thank You to volunteers. Great attendance. Thank You.

Meeting Adjourned at 4.30 pm.

DRAFT