



# **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: [lainger\\_1@sympatico.ca](mailto:lainger_1@sympatico.ca)

Http:// [members.rogers.com/jsoutham/index.htm](http://members.rogers.com/jsoutham/index.htm)

---

---

ISSUE NO.36

AUGUST 2004

---

---

---

## In this issue:

---

- President's Message
- Important Announcements
- New News
- Updates from local support groups
- Letter to Editor
- Reminders

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.

---

---

## President's Message:

---

September 2004

It is with regret that I submit my resignation as President of The Canadian Addison Society. As many of you know, I have been experiencing some increased health problems over the last year and find that I need to change the areas I can and adapt to the areas I have no control over. I have enjoyed immensely the work of The Canadian Addison Society over the past ten years and have met many wonderful people, many whom I consider friends.

If you feel this is an area you would like to become involved in (or know another person who would) send a letter of intent to The Canadian Addison Society at the above address. All executive positions will be voted on at the Annual General Meeting of The Canadian Addison Society to be held in Brantford Ontario on September 25<sup>th</sup>, 2004.

If you have any issues or concerns you want to have discussed at the Annual Meeting, please send them to the Society as well. I am sure it will be an interesting meeting and all members are invited to attend, voice opinions and vote.

Hopefully we have all weathered the lovely warm/hot weather without running afoul of the perils of dehydration or the hazards of food poisoning. The results of the latter are NOT nice as I can well attest from personal experience!

Thank you all for making my association with The Canadian Addison Society such a pleasant one.

Sincerely,  
Joan Southam

As usual any and all comments are welcomed at [jsoutham@rogers.com](mailto:jsoutham@rogers.com)

---

### Important Announcements:

---

- The position of Liaison Secretary will be available in September. Anyone interested in fulfilling this position please contact Elaine Hall by email [lainger\\_1@synpatico.ca](mailto:lainger_1@synpatico.ca) or by phone at (613) 824-0160. Elaine Hall notes that the position is very interesting and varied. The position allows you to meet new people and help them understand Addison's a little better. Contact and information is given to individuals unfamiliar with Addisonians and/or have recently been diagnosed. Questions are also answered via our Addison phone line. Please let Elaine know if this is a job you would be interested in.
- Newsletter Editor – this position is also needing to be filled with a replacement. Please contact Sharon Erickson, [ericksons@shaw.ca](mailto:ericksons@shaw.ca) or (250) 729-1446 if you are interested or have any questions. Thank you!
- Annual General Meeting

Saturday, September 25<sup>th</sup>, 2004 10:00 am  
Brantford Police Department - Community Room  
Brantford, Ontario

#### AGENDA

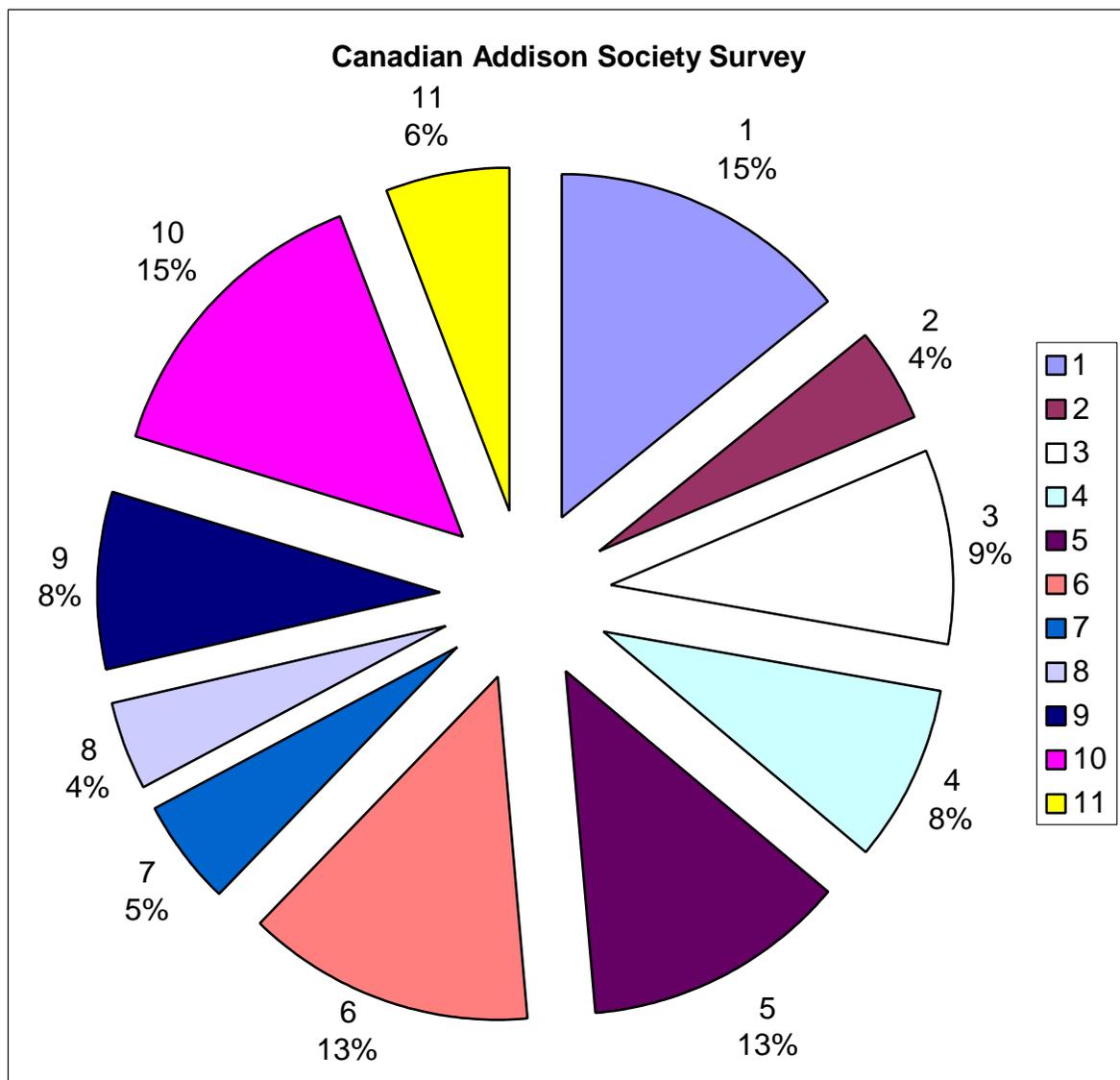
- Welcome
- Presidents Address
- Reading of Minutes 2003
- Financial Report
- Emergency Care
- 1-800 number and relative costs
- Web site update
- New business
- Nomination and Election of 2004 Board Members
- Closing Remarks
- Break for lunch
- Guest Speaker

Executives and Board Members:  
 President Joan Southam (outgoing)  
 Vice President Judy Stanley  
 Secretary Elaine Hall (outgoing)  
 Treasurer John Gordon

Directors:  
 Greeta McKague Francisca Swist  
 Jim Stadlish Al McConnell  
 Steven McKenna  
 Newsletter: Sharon Erickson (outgoing)

New News:

1. Survey Results:



- Option 1 Funding the proposed stand alone website
- Option 2 Offering additional financial assistance to the UK survey
- Option 3 Supplying copies of the newsletter to endocrinologists, internists, family doctors
- Option 4 Creating a glossy poster to increase awareness of Addison's for use in specialists offices family doctor's offices, emergency rooms, etc.
- Option 5 Funding information packages sent out to non-members, members of the medical community, insurance companies, and distributed in other for a (eg endocrinologists' annual meeting)
- Option 6 Creating an awareness campaign targeted to family doctors and insurance companies
- Option 7 Funding additional analysis of UK survey results with respect to Canadian data
- Option 8 Funding distribution of UK survey info to members and the medical community
- Option 9 Talk show appearances to raise awareness of Addison's
- Option 10 Funding information packages to go to medical researchers to encourage research on issues related to Addison's
- Option 11 Supporting the presentation of a paper based on the UK survey to the annual meeting of endocrinologists

Comments: Difficult choice since they are all worthwhile; Pick one or two and concentrate on that to ensure effectiveness, rather than spreading too thin; Initiatives that improve access to DHEA; Development of epi-pen form of cortisone; Awareness campaign for emergency room staff re: treatment of Addison's

## 2. Thank you's:

- An enormous thank you to Joan Southam who is retiring as President. Joan was elected President in 2002 but prior to that was Liaison Secretary for several years, shared the position of Treasurer and was on the Board of Directors. She has been involved since shortly after the society was formed and always has been there with a wealth of information. We wish you well and cannot thank you enough for all your hard work, dedication and perseverance to our cause over the years.
- We also want to thank Elaine Hall who has been our Liaison Secretary the last couple of years. She has been instrumental in setting up a 1-800 number for The Canadian Addison Society and along with Francisca Swist, creating a new stand alone website. Her generous time and effort in sending out information packets and answering the many calls from new Addisonians, has been great appreciated.
- We wish to thank Marion Patterson of B.C. for giving our name as a list of donors to her employer - Telus Corporation, Burnaby B.C. We received a cheque for \$443.26 from their Telus Community Connections annual fall charitable giving campaign. The employer matches the donor charitable contributor. Thank you Marion for thinking of us.

## 3. DHEA Project Correspondence with Paladin Labs Inc.

Q: Fidealin (DHEA) is listed as a neurosteroid. Since none of us knew what that was, we went searching and found some info at this website <http://www.med.miami.edu/patients/glossary/art> and there it is called a "brain steroid similar to cortisone, progesterone and gonadal hormones and is used in the treatment of anxiety and depression" Is this basically your understanding?

A: Yes. In addition to having an anabolic role as a precursor of both estrogens and androgens, DHEA was identified by Dr Emile-Etienne Baulieu as a neurosteroid. DHEA was briefly studied by Dr Wolkowitz in anxiety and depression but has never been approved for these indications in any regulatory authorities in the world.

Q: Why is Fidelin being considered for marketing when there is compounding DHEA available in Canada or is market going to be the U.S. or Europe instead of Canada?

A: EU and US has a program for so-called "Orphan Drugs" and they offer market protection of app. 7 years for drugs approved for an Orphan Disease (Paladin was able to demonstrate that Addison Disease falls into that category). Canada does not offer such protection; however we would still pursue its approval for this territory.

Q: When DHEA is so very much restricted in Canada, what is the future of such a drug in Canada? Are you expecting the restrictions of the government to be lifted because of the trials and testings that you are doing?

A: The TPD (Canadian regulatory Agency is willing to support the development of DHEA for such indication but has recently removed DHEA from their SAP program. Therefore the only way to legally get access to the drug until it is approved is for patients to participate in clinical trials. Paladin has prepared a phase III protocol in Adrenal Insufficiency but is currently trying to secure additional funding in order to start the trial in Europe and Canada.

Q: Are you testing Primary Addisonians in your test group or are you testing more people with anxiety and depression and leaning to towards more of a market in that area? What type of format are you using for your test groups? Is it similar to the research done in London Ontario a few years ago? Who are the physicians in charge of this study group and are they endocrinologists or other specialists?

A: We will run our trial with patients having Adrenal Insufficiency, both primary and secondary. They have to be naive to DHEA treatment, which is why we will run the trial in Europe and Canada where DHEA has a "Controlled Drug" status (contrary to USA) and is not easily accessible. Our Canadian investigators have not been selected yet but our key consultants should be Dr Allolio and Dr Arlt. We will select endocrinologists.

Q: Is DHEA the only active component in Fidelin and if not - what other active components are there?

A: Only DHEA

Q: What is the recommended dosage for Fidelin that you are projecting/or testing? Will it be in the form of capsule or tablets?

A: 50mg capsules for Adrenal Insufficiency in women.

Q: If Fidelin was on the market, will that mean that we will not be able to get compounded DHEA through a compounding pharmacy anymore? Will you hold a patent on DHEA in Canada then?

A: To my knowledge, compounding of DHEA is still illegal in Canada. At this moment, can not answer the patent situation.

Q: How would the cost of Fidelin compare with the compounded DHEA that many of us receive now from Kripps Compounding Pharmacy in Vancouver British Columbia.

A: I understand that Kripps can no longer sell DHEA. However, we have not yet decided on a price for DHEA.

Q: What does the Fidelin orphan drug status in Europe (noted in the bottom of your website in red) mean in practical terms? Is it already on the market in Europe? Will you market Fidelin under orphan drug status in Canada as well?

A: See my comments below. Orphan Drug designation does not mean that the product is approved but only provides for market protection.

Q: If Fidelin is marketed with government approval in Canada, will it still need the strict prescription controls from specialists that compounded DHEA has demanded or will it be readily available on script from a GP or better yet, will it too be readily available off the shelves as it is in the U.S.?

A: Regulatory Agencies, including the FDA, are aiming to restrict DHEA access in order to limit abuse. DHEA would more likely be available through Rx and subject to controlled substances regulation.

Q: Will Fidelin be registered as a "medicine"? Who will be responsibility for side effects then - doctors, patients, government or Paladin?

A: Yes, it would be approved as a drug and current regulations for reporting safety events would apply.

Q: I realize that I have asked a great many questions and I probably have just as many that I did not ask.

A: I will be happy to meet with you for further discussions.

Q: We are very concerned about DHEA for the use of Addisonians and the government has very effectively slammed the door for use of this wonderful medication for Addisonians. Many of our members have written letters to the government asking for reconsideration of it's change in status of this drug but to date, none of us have received any type of acknowledgement. Any help that you can give us will be greatly appreciated and looking forward to hearing back from you in the near future.

A: We will be delighted to work with you and suggest that we meet soon upon your return. Thank you for your interest.

Pierre Thivierge

---

Pierre A. Thivierge, M.Sc.  
Manager, Business & New Drug Development  
Paladin Labs Inc.  
Montreal, Quebec  
website: [www.paladin-labs.com](http://www.paladin-labs.com)

---

## Highlights From Local Meetings:

---

Vancouver Island Support Group (Nanaimo)

Nanaimo meetings: Christy Lapi at [clapi@shaw.ca](mailto:clapi@shaw.ca), or 250-245-7554 or Barbara Hunn at [bhunn@telus.net](mailto:bhunn@telus.net) or 250-756-4385. Nanaimo meetings are held at Nanaimo Regional General Hospital, Room G245.

### Vancouver Island Support Group (Victoria)

The Vancouver Island Addison's support group met June 5th at the Victoria General Hospital. Fourteen people attended including 4 without Addison's. For two support group members this was the first time they had attended a support group meeting.

Each Addisonian present related what replacement medications they were taking and spoke a bit about their history and medical concerns, sometimes asking questions about improving treatment. It was evident that cortisol replacement medications among those present varied considerably. Medications used ranged from cortisone acetate, hydrocortisone and prednisone to dexamethasone. Also dosages of cortisol replacement and mineralocorticoid replacement, Florinef, were quite varied among those people attending. Although most seemed satisfied with their replacement, several members have either switched medications or altered dosages, as their doctors strive to improve or fine-tune treatment.

A few people find their MDs reluctant to refer patients to endocrinologists. The group generally felt that a visit to a specialist once per year was advisable, especially if one is not comfortable with their present treatment. It is possible, with some endocrinologists, to arrange an appointment without a referral from your MD, if you have previously been a patient of that specialist within the past year. A yearly visit for blood tests and consultation to ensure that you are receiving optimum treatment is quite reasonable.

Concern was raised, that because Addison's in the majority of cases is caused by an autoimmune disorder, was there any way to prevent other autoimmune endocrine diseases and complications. This question was asked of Dr. Phillips when he spoke to the support group last year. He pretty well said there was not much we could do. The "Living With Addison's Disease" manual published in the UK states that most medical studies have found that just over one-fifth of those with autoimmune Addison's are likely to develop a thyroid problem of some kind. Of those responding (150) to the UK Addison's Survey, 17% had thyroid related problems and 5% had diabetes. Check this website for more information about the "Owner's Manual" and the UK Survey.

<http://www.addisonsdisease.org.uk/>

Submitted by Jim Sadlish

The Vancouver Island support group will meet October 2 at the Victoria General Hospital, Room 1815, at 1:00 PM. No speaker is expected at this time.

For further information: Victoria meetings: Jim Sadlish at [x699@victoria.tc.ca](mailto:x699@victoria.tc.ca) or 250-656-6270, or Florence Weekes at [fmweekes@telus.net](mailto:fmweekes@telus.net) or 250-598-0321.

### BC Lower Mainland Support Group

Everyone enjoyed the stories shared of travel, diagnosis with the euphoria and energy achieved with their first addition of cortisone and how they are mostly happy with their level of fitness but felt some improvement could be attained. Two are now on permanent disability; they felt persisting with

their claim was part of the success but both commented that complications of other conditions were the reason for the approval of their claim.

Q & A sheets to Paladin on DHEA for anyone interested were available and membership forms for CAS for anyone not already a member. The April Newsletter was 21 pages packed with information. Please contact Judy if you would like a copy of the Q & A sheet. Her email is [bugbee@shaw.ca](mailto:bugbee@shaw.ca)

The 'Nutrition Notes' from NADF Naturopathic doctor and 'Meeting Summer's Dehydration Challenge' were also available. Gerry passed on his hydration formula as well. You can also use 1 litre of water, 2 tbsp. of sugar, ¼ tsp. of salt and 1 tbsp. of lemon juice. You can adjust the amounts for taste but the main thing is to keep yourself hydrated at all times in the heat. If you are feeling thirsty and have been perspiring you are probably already dehydrated.

The 'Living With Addison's Disease (an owner's manual for individual with the disease)' was reviewed. The website is <http://www.surreyweb.org.uk/adshg/ADSHGGUIDELINES.pdf> for a copy. Another study done and printed was Addison Patients in the Netherlands translated into English.

We recently received a reply to our March 16<sup>th</sup> letter to the Ministry of Health Services for a common data source for Emergency Rooms in BC. We shall pursue the matter with the Ministry, Pharmacists and local Coastal and Fraser Health Authority. The Coastal Health Authority is having an open Board of Directors Meeting in Richmond on Wednesday, June 16<sup>th</sup>, 9am to 1pm at the Executive Inn Hotel in Richmond. There will be an open mike for Q & A from 11am – 12pm for anyone able to attend. Please visit their website at [www.vch.ca](http://www.vch.ca) for the agenda in the days leading to the open meeting. For more information about the open board meeting, please call the Board Liaison office at 604.875.4719.

I also received an e-mail from the BC Society of Laboratory Science requesting permission to include my precis as part of their professional development. I have asked for a copy of the tape they will be using for our files.

Submitted by Judy Stanley

Meetings for the next twelve months – Sherbrooke Lounge, Sherbrooke Centre, 260 Sherbrook St., New Westminster for October 30, 2004, February 19, 2005 and June 4, 2005. The meeting dates are Saturday and the time is 1:00 to 3:00 p.m. Parking is available at 240 Sherbrooke St. for \$3.50 for the day. For further information call Judy Stanley 604-936-6694

### Alberta Support Group

Next meeting: Saturday, September 18, 2004, 1:30 - 4:00 PM

Location: Christ of King Lutheran Church (basement), Address: 13111 - 79 Street, Edmonton, AB

Speaker: Dr. Gwynne Bykowski - Doctor of Oriental Medicine, Registered Acupuncturist, and Chinese Herboligist. Please contact Ginny further details on this meeting.

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

### Saskatchewan Addison Support Group

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

#### Eastern Ontario Support Group

For information about meeting dates, please call Sue Steedman at (613) 726-7414.

#### Southern Ontario Support Group

For information contact Jordan Latter at [jlatter@sympatico.ca](mailto:jlatter@sympatico.ca) 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 [sophiel@sympatico.ca](mailto:sophiel@sympatico.ca)

---

#### 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 on to Dr. Killinger.
- 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.

---

This is your newsletter! We need your contributions. Please send your stories, tips, ideas directly to our editor Sharon Erickson via email: [ericksons@shaw.ca](mailto:ericksons@shaw.ca) or c/o the Addison Society.

---