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

ISSUE NO. 62 **APRIL 2011**

In this issue:

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.

Announcements:

- A revised version of the Emergency Medical Information document has been posted on the web site and is attached to this newsletter. We suggest that you print out the form, fill it in, and keep a copy of it close at hand either on the fridge or beside the telephone, should you ever require immediate attention and are unable to give voice to it.

- If you haven't yet paid your 2011 membership dues, please do so today.

- A March 2011 press release entitled *Trademark granted in EU for DuoCort´s new Addison´s treatment*:

> DuoCort's new form of physiological treatment for the rare and life threatening disease adrenal insufficiency, also called Addison´s disease, was recently granted a registered Community Trademark within the EU. The trademark is PLENADREN. The product, which has orphan status in Europe and the USA, is currently in the European Union (EU) registration process for marketing authorisation.

Please remember that this is simply a step on the way for this drug. It is NOT currently available, so don't rush to your endos asking for it.

Grahame's Story:

So often, Addisonians worry that they will not be able to live a full, "normal' life. This article was written by an Australian Addisonian to encourage a newly diagnosed child and his family.

> I was moved to read Joshua's Story in the December 2010 (AADA) Newsletter. I just wanted to tell Joshua and his Mum, Teresa, and family, that it is really possible to have Addison's disease and live a rich, full and wonderful life. By the time you read this I will have turned 63 and know a little about living with Addison's disease.
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> I was diagnosed with Addison's in 1972 and have been fortunate to have lived pretty successfully with the disease since then. When I was diagnosed at 26, my symptoms were just like Joshua's – I lost a lot of weight, could not eat, dizziness, low blood pressure, and just feeling awful. I could just manage a day's work and spent all of my non-working time on the couch. I went from a fit strong Physical Education teacher to a wasted and very sick man. It took two years and a week in hospital for diagnosis and probably ten years or so of treatment until I felt really well again.
>
> Since that time I have had an amazing journey. I have three wonderful children and two fantastic step sons. They all have great partners and there are now five gorgeous grandchildren too. We are a close and loving family. Merri, my wife, has enriched all of our lives and is very special. To think, that I would not even have known her if I had not been diagnosed and treated so expertly. I fear I would have just wasted away by the time I was thirty.
>
> In some ways though, the testament of living positively with Addison's is provided through my work. It has taken me overseas a lot, and more recently I have even discovered that travel is for fun too. Through a combination of good luck and some good management, at times, my Addison's has travelled throughout the world with me. I have not been refused travel insurance; I have taken my medication with me; my loved ones have always known where I was; and, touch wood, I have not had a crisis while overseas. Among lots of other things, me and my Addison's have survived:
>
> - Living in France [and working in Switzerland] with a new partner and a blended family. My health was no hassle. Finding a house to rent, furniture for the house, and keeping kids happy and amused, now there's another story.
> - Men with guns, villages with the world's meanest speed bumps and roads with rock slides and lots of burros, in the middle of the night in a Volkswagen with partner and two sleeping daughters; somewhere between Mexico city and the west coast of Mexico.
> - A working honeymoon in Mauritius. I can recommend this one, great fun.

- Driving a van with 8 passengers, all family around Europe for 6 weeks, living in youth hostels.
- Talking my way into staying three nights [and not paying] in the wrong hotel in Bangkok. I was meant to be in the much cheaper version with a similar name down the road.
- Fighting with hotel staff in Ghent in Belgium regarding getting a decent room [with a TV] for my family at a Belgium Government sponsored World Health Organization workshop. I was running the workshop for them so figured I had some rights. I did in the end but it was a two day battle.
- Sleeping in numerous airports and surviving lots of long distance flights
- Bad but cheap accommodation in lots of places [and good in some].

Strangely enough, the only time I had a real hassle travelling with Addison's was on a holiday to Victoria. We drove [2 adults 4 kids] and I started throwing up in Homebush [about 15 km from home] and stopped 6 days later in hospital in Colac [in Central Victoria]. A crisis caused by my own stupidity. *"No time to get a new script, I will do it in Melbourne"*.

So what does all this mean? Well for me it means that while having Addison's is something I would rather be without, it has not stopped me from doing what I want and living my life the way I have wanted to. For that I thank God, my loved ones – especially Merri, and my own constitution which constantly says *'of course you can"*. I wake up every day feeling grateful for the life I have had and the wonderful experiences and the love it has brought me. Thankful that medical science and something more amazing, has allowed me the time I have had.

Go well with Addison's, young Joshua.

Reprinted with permission from Australian Addison's News February 2011

Highlights from Local Meetings:

Vancouver Island Support Group

The Group met on February 19th at Victoria General Hospital. Colleen, a member and nurse at Vic General, demonstrated preparing and administering the Solu-Cortef emergency injection. Sixteen people attended, including 5 spouses. Several members drove from the mid-island to see this demonstration.

Most people brought their outdated 2cc vials of Solu-Cortef and used their own syringes. The ideal size of syringe is 3cc, with a 22 gauge, 1 1/2 inch long needle. Excellent information can be found for giving an injection at the website: http://www.addisonsociety.ca/injection.html. Colleen has read that Solu-Cortef is effective immediately after injection and the 2cc of medication may last 4 and 8 hours, with a total duration of 1 to 1 1/2 days.

One woman will soon travel to Bali and voiced concerns about dealing with the heat and possible intestinal problems. She will need Hepatitis A and B immunizations beforehand. Advice from others included taking Gastrolyte for re-hydration and Pepto Bismol chewable tablets for any intestinal problems. Medical insurance is necessary while travelling. Reveal all pre-existing conditions, including the occasional use of puffers (inhalers), because insurers may quibble about seemingly insignificant omissions to avoid paying a claim.

Several members have had surgery since the last meeting. We discussed the need to ensure that the anesthesiologist is aware that you have Addison's. One woman advocated having your endocrinologist at the surgery or at least give instructions to the doctors involved.

We talked about taking extra medication before a stressful event, knowing that our adrenals cannot make more cortisol under stress as non-Addisonians can. Diabetics must take care increasing their steroids, because blood sugar levels may rise, requiring more insulin. One member suggested taking a Chronic Self-Management course to help deal with anxiety. Exercise was suggested as an important way to relax.

We all have Medic Alert bracelets or necklaces so emergency medics can see that we have a disorder. For a cost of $15, you can update your personal information at Medic Alert online: http://www.medicalert.ca/en/members/mymedicalert/why.asp.

One spouse noted that we with Addison's are seldom approved to receive disability benefits. Since Addison's can be very debilitating, he suggested that organizations such as ours should lobby to educate the medical professionals who decide who should receive benefits. Several members have applied unsuccessfully for disability benefits, even with their family doctor and endocrinologist supporting their claim.

One member who has a twin sister was involved in a research study in England. Identical twins were compared for their various medical conditions. It is quite usual for one twin to be much healthier as a child, with this difference lasting throughout their lives. Our member was the less healthy of the two, as a child and as an adult. The theory is that in the womb, the healthier child is closer to the placenta and enjoys lifelong benefits as a result.

One woman was taken to Emergency in crisis. Her mother was her advocate and explained her condition, handing the triage nurse her emergency letter. Medics were well aware that she was in an Addison's crisis. However, she was not given fluids (the saline solution) which is the usual procedure. The nurse treating her would not listen, instead insisted that our member had a "super bug". She said that she never received any Addison's medication for 4 days! It is expected that her family doctor and her endocrinologist will file a complaint. Others who have spent time in hospital advise to take your own medication with you, even hide it from nurses if necessary, just in case you are forgotten or someone does not do their job. We must look after ourselves.

In BC, blood test results can be accessed on-line if tests are done at Lifelabs or BC Biomedical Laboratories. Apply at http://www.myehealth.ca/index.htm.

The next two meetings of the Vancouver Island support group will be May 28 and October 1, 2011 in Room 1814 at Victoria General, from 1:00 to 3:00PM.

Submitted by Jim Sadlish

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

The February 2011 meeting was well attended with 10 members and one spouse. Donna hobbled in after recent foot surgery. Regrets were sent by Moh T. (back surgery), Linda S. (grandson in serious skiing accident Mt. Washington), Bev M. (broke leg before Christmas), Jackie E. (limited visibility and family emergency), also Klara had to cancel at the last minute. Best wishes are sent to everyone.

Several members had their UBC medical student interviews and, although tiring, enjoyed them. I had my interview with a mature student, which I found productive. If just one of the students who have interviewed us over the past eight years can make an early diagnosis, the interviews will have been for a good cause.

There was a recall Jan. 6, 2011 by Triad Group in the US for Alcohol Prep Pads, Alcohol Swabs, and Alcohol Swab sticks due to potential microbial contamination – Bacillus cereus – if anyone used these products.

A Survey on Drug Shortages in Canada is posted with a link on CTV – Health – Links. It does work now and there was only a problem with Prednisone in Quebec but you may want to look at the survey.

We were unable to book a guest speaker with the short notice on booking the room. Instead, we found ourselves busy getting caught up and once the question of work was posed, the discussion was quite animated.

Work - outside of home, full or part time, what we do and how we manage it? It was divided into those who found no effort going to work and those who could not manage a full or part time job. Jobs ranged from schools, medical, management and retired. A recently diagnosed member quit her management job as she still does not have the required energy or wellness to work. She is waiting to see a new endocrinologist and has lots more questions now.

http://www.addisonsociety.ca/ - under ‘Healthy Living’ are printable pages covering Injection Kits, Emergency Protocol etc.

http://www.addisons.org.uk/info/manual/page1.html - manual is listed at the bottom of the page and a copy can be printed for your files.

http://www.nadf.us/ - easily managed format for questions.

www.myehealth.ca - register after going in for blood work; results are posted within a day or two. You only have 15 days to register but it is accessible at any time once you are.

There are numerous Q & A by the Medical Advisors for national groups. I recently was looking up a question on Simmonds Disease and Sheehan Syndrome for a cousin, and the answer, when I went into the net, was found - a Q & A from Dr. Killinger of the Canadian Addison Society Medical Advisor!

From the discussion of Florinef: **QUESTION**: I recently "met" another Addisonian via an Internet chat room. This person does not take Florinef or fludrocortisone. Shouldn't all people with Addison's take Florinef?

ANSWER: Almost everyone with Addison's disease (primary adrenal insufficiency) should take some amount of Florinef (fludrocortisone) because this replaces the mineralocorticoid aldosterone, which is lacking along with cortisol in primary disease. Florinef causes sodium retention and potassium excretion in the kidneys and helps to maintain blood volume and blood pressure. There is a small amount of mineralocorticoid activity in hydrocortisone, but usually not enough. Therefore, when Addisonians try to replace with only hydrocortisone, they often are forced to take too much hydrocortisone in order to keep blood volume up, resulting in weight gain and other features of cortisone excess. The dose of Florinef can vary from as little as ½ a tablet to as much as 3 or 4 tablets daily. People who have secondary adrenal insufficiency from pituitary disease or from long steroid use usually do not need Florinef because they usually do not have an aldosterone deficiency. There are, however, some exceptions when Florinef is needed to maintain blood pressure and prevent potassium elevations.

Arrangements for the next meeting will be made shortly and everyone will be notified once they are finalized.

Submitted by Judy Stanley

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

Alberta Support Group

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

We plan to hold another meeting possibly in Regina early summer 2011. 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

Next meeting is scheduled for Saturday, May 14, 2011 from 1 pm to 4:30 pm at the Erin Mills United Church, 3010 The Collegeway, Mississauga, Ontario (registration 12:30 pm). Our guest Speaker, Ms Abeer Hegazi, will discuss MedicAlert's potential role in raising awareness about the health problems of people with Addison's. This will be a great meeting to attend. South/Central Ontario members will soon receive a questionnaire prepared by MedicAlert in preparation for the meeting. Your name is not required on the questionnaire. MedicAlert is anxious to learn of our issues and how they may help us in our quest to receive the emergency care we require as Addisonians. Be sure to bring all of your input and questions regarding MedicAlert. This is a great opportunity.

Submitted by Harold Smith

If you have questions about this meeting, or 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 next meeting will be Saturday May 14, 2011, at Robbie's restaurant on St. Laurent Blvd 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 bring any out-dated solucortef vials, syringes, and oranges 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: My husband has Addison's. Recently, a doctor was going to give my husband TYLENOL 3 with codeine. We looked up uses and side effects on this product and found, both as a senior and an Addisonian, that this could affect his medical condition. What can it do?

> **A:** It always poses a dilemma when you read that a drug should be used with caution in individuals with a specific disease. I have seen similar comments regarding Addison's disease but have been unable to find any evidence of a problem related to acetaminophen or codeine use in Addison's disease. If he needs something to control pain, what he is taking is probably one of the better choices. I would carry on cautiously.

Q: What is your opinion on an Addisonian getting the Zostavax vaccine for prevention of shingles? I found out it is a 'live vaccine'; would this be a problem for an Addisonian?

> **A**: In general, individuals with Addison's disease should have no more problems than the general population in responding to vaccines.

Q: I was diagnosed with Addison's disease in 2004 and celiac the year before. I seem to have a lot of blood sugar crashes. I take 20 mg of cortisol at 6 am and 10 mg at 2pm. I exercise as much as possible and I eat very healthily. This morning, I had my usual breakfast and went snow shoeing for a half an hour. By time I got home, I was very tired; blood sugar was 3.8. What is wrong?

> **A:** I am not sure that anything is really wrong. I am not sure what you mean by "crashes". In individuals with diabetes, a crash means a sudden fall in blood sugar. Individuals with Addison's disease can get low blood sugars because they do not have enough cortisol to stimulate the liver to release sugar when it tends to drop below normal.
>
> In your case, you took in your normal breakfast and cortisol and then went snowshoeing for half an hour. If you do not do this every day, you are using more energy and more sugar than usual, so first you are tired and second your blood sugar tends to fall because you have used a lot of it in your activity. Normally, adrenalin and cortisol would stimulate the release of sugar from your liver to replace what you have used up but if you cannot produce more cortisol, this backup mechanism cannot work and your blood sugar might drop below normal.
>
> The best way to avoid problems like this is to think about what you are going to do. If it involves more activity than you usually do, then you should eat a few more calories either before you start or during the activity. You may also need more cortisol depending on how strenuous the activity is and how long it will go on. If in doubt, take an extra half tablet of cortisol and if it goes on for a long time, you may need a full tablet.
>
> You did not mention being on Florinef. This controls the salt levels in your blood. If you do not have adequate levels of salt (sodium) it can make you tired and have low blood pressure. If there is any doubt about this, you should consult your endocrinologist. Most individuals with Addison's disease require Florinef.

Q: I am currently being investigated for Addison's Disease. I am 35 years old, female. My father had Addison’s Disease and my mother’s first cousin also has Addison’s Disease. Parts of my hands, wrist, and shin have patches of hyperpigmentation and my blood values indicated an ACTH value of 156 (my doctor said normal was under 10). Sodium, potassium and cortisol were normal. I have to wait 3-6 months to see a specialist and I am confused if this is a strong or weak indication that I may or may not have Addisons.

> **A:** An ACTH of 156 pmol/l is very suggestive of Addison's disease. You should have the test repeated to be sure there was no lab error. It should be done in the morning before 9AM, A serum cortisol should be taken at the same time. If the cortisol is low (under 100nmol/l) and the ACTH is high, that is convincing evidence that you have Addison's disease. If your family doctor phoned the endocrinologist and told her/him these results, you should be seen within the next week or so. The high ACTH suggests that you do not have any adrenal reserve. If you cannot get to see the endocrinologist, then your family doctor could start you on cortisol.

Q: My 35 year old daughter and her husband live in a small town in BC and have young children 3 and 5 years old. My daughter suffered for about seven months with severe symptoms of Addison's Disease before being finally diagnosed in Dec. 2010. I understand that her town doctor has not had previous experience with this disease. My daughter has finally been seen by a doctor in the city and is now on replacement hormones. She is now back home but is still very fatigued and not feeling well a lot of the time. I am concerned because she is so far away from major cities where she can get the best help. Can you suggest how she can best receive support? What can be done to help her recover?

> **A:** It can be difficult when you are far away from your physician, but there are usually ways around it. Your daughter's family doctor has been in contact with endocrinologists in the city. She/he can be in telephone contact with one of these specialists for advice. By reviewing the problems with the endocrinologist, her family doctor can make appropriate adjustments and carry out appropriate tests. This information can then be discussed to make any necessary adjustments. I don't think that she should feel so isolated. A good relationship between her family doctor and her endocrinologist can provide her with excellent care.

Q:. I am a 63-year-old male [200 lb] diagnosed with Cushing’s five years ago. I had both adrenal glands removed and was put on a dose of 40 mg/day hydrocortisone and .05 florinef. My physical symptoms of Cushing’s gradually disappeared and I did begin to feel much better and regained some quality of life. Today, I am much stronger physically, but suffer extreme fatigue and a lack of stamina which severely limits my quality of life. My eyes bother me often and I usually have daily bouts of generalized body pain, especially if I have been active. I still have no drive, energy, or ambition. Is this depression or Addison's? I have tried varying doses from 30 to 40 mg/day in all manner of configurations and timing with no real improvement in well-being. I see my endo every 6 mo. and have a pile of blood work done which all is basically normal. At my last visit with my endo, she suggested this may be as good as I get and I may have to live with it. I am now in the process of lowering my dose to approx. 30 -35 mg/day. Any suggestions would be greatly appreciated.

> **A:** When you go through the sequence that you have been through it is difficult. I am not sure how long you had Cushing's syndrome before you sought help but it is probable that it was several years before you were aware of your problem. The excess cortisol, over a long period of time, causes a loss of protein from your tissues including skin, and muscle. It can also cause emotional problems. When the high levels of cortisol are brought down, your body has to readjust. We usually leave individuals on slightly high doses of cortisol after surgery to avoid a dramatic change, then lower doses gradually to maintenance levels.
>
> It can take a long time to return protein levels in muscle and skin to normal and to return calcium levels in bone to normal. It can also take a while to return the emotional state to normal. From your description, it sounds as if you have gone through many of these changes successfully. I think you will continue to improve. It will help to slowly build up your muscle strength with simple exercises. As your stamina improves, your confidence will improve and you will have more enthusiasm to do things.

Your dose of cortisol to date has been reasonable. You may be able to decrease it a little. With your size, 30 mg of cortisol is about average, but requirements vary from person to person. Three times a day dosage is usually the best. The dose of Florinef can be checked by measuring your plasma renin. I am sure your endocrinologist has reviewed these things with you.

The phases you have gone through are not unusual in recovering from Cushing's syndrome. There is likely to be further improvement. You need to be patient and you should try to be as active as possible.

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.

EMERGENCY MEDICAL INFORMATION SHEET

Provided by The Canadian Addison Society

I have **ADDISON'S DISEASE** (adrenal insufficiency) and am on **replacement treatment with adrenal hormones**

Name: **DOB:**	**Address:**
In case of emergency, please contact:	**Phone: Home:** **Cell:**
Doctors: **Endocrinologist:** **Family doctor:**	**Phone:** **Phone:**

Emergency Treatment:

Intravenous Solucortef and Saline

Addison's Medication:

Other Medical Conditions:

Other Medications: (Types)

Allergies:

Other Medical Information:

HOW TO USE THIS FORM:

1. **PRINT OUT THIS DOCUMENT**
2. **FILL OUT RELEVANT INFORMATION**
3. **PLACE THE COMPLETED FORM SOMEWHERE THAT IS EASILY ACCESSIBLE TO ANYONE SHOULD YOU FIND YOURSELF IN A CRISIS SITUATION.**

   (i.e. on the refrigerator, or beside the telephone)

The Canadian Addison Society
La Société canadienne d'Addison

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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.

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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

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