The Canadian Addison Society
La Société canadienne d’Addison

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ISSUE NO.49 **JANUARY 2008**

Best wishes to everyone for a happy and healthy 2008!

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.

Facebook for Addisonians

More and more, people are joining virtual support groups using the web, whether through chat groups or social networking sites. One of our members from BC has started a Facebook group specifically for teens and young adults who have Addisons. (This is much more likely to attract younger Addisonians than this stodgy Newsletter!) Our thanks and congratulations to Aleita for this important initiative!

Facebook.com is a social networking website with approximately fifty-seven million active members worldwide. Anyone with a valid email address can join and begin to connect with their friends, family and colleagues. It was my hope that by creating an Addison's support group there, that affected persons worldwide would have a forum to discuss the management of their condition. The group, "Yes, I have Addison's Disease. No, it's not contagious," now has fifty-six members from eight different countries across North America, Europe and even Africa. Every other person to join expresses excitement saying that they have never met anyone else with the disease. To join, become a member of Facebook and then search "Addison's Disease." It's the first result on the list!

Submitted by Aleita Northey

Announcements:

- **Remember that annual membership renewals are due in January of each year. If you have not yet renewed for 2008, please do so as soon as possible, using the membership form attached to this newsletter. Any member who fails to renew will NOT receive the Newsletter in April.**

- We have a teen Addisonian from France, Mathieu, who would like to link with other teens who have Addisons. You can reach him at m-odilebd@wanadoo.fr. He would be especially interested in "talking" in French, but can also communicate in English.

- If you are interested in volunteering to act as our next Society President, or have someone to suggest, we would like to hear from you. This position serves to focus the Society and to act as a spokesperson, but is not labour-intensive. Please contact the Liaison Secretary at liaisonsecretary@addisonsociety.ca or 1-888-550-5582 as soon as possible.

Personal Stories

The Society website includes a number of personal experiences of those with Addisons: http://www.addisonsociety.ca/personalexperiences.html. If you haven't looked there lately, you might find the stories of diagnosis and living with Addisons interesting and even helpful. Here are a couple that were added recently:

> I didn't find out until I left for basic training in San Antonio, TX. I felt so weak, I couldn't stop vomiting. It got so bad that I started fainting. Being in boot camp, my instructors kept thinking I was dehydrated. So I pushed on for 5 days. I felt like a chemo patient. I hit the point where I couldn't move my legs anymore, they were so heavy. The day of my Addisonian crisis, I woke up dripping sweat and vomiting. Extremely unusual for me. I began marching and collapsed and vomited. I actually went into something that imitated diabetic shock. An ambulance began evaluating me and realized at the time my blood sugar was only 7. I should've been dead. A few days later, in the hospital of course, I was diagnosed, and was released from the military a short time after. I now receive four cortef tablets a day. Today I live normally. I haven't had an episode since.

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In 1998, after returning from a vacation, I began vomiting and having diarrhoea daily; suffered from rapid weight loss because I had no appetite; low blood pressure; fatigue; memory loss; fevers, fainting and seizures. My family physician diagnosed me with flu and put me on an antibiotic. This condition continued for several months until I had a grand mal seizure and was hospitalized. The doctor attending me told me that I was on the verge of death for several days. One of my physicians, who had been with Doctors without Borders and had seen my symptoms before, suspected Addison's, and he immediately started me on a saline solution and prescribed cortisone-acetate. He saved my life because my weight at the time was below 90 lbs and I was normally 130 lbs. I was medivaced to Vancouver; St. Paul's Hospital and began tests for several weeks. With results of blood tests, a CT scan of my pituitary gland, an ultrasound to my kidneys and a spinal tap, the endocrinologist confirmed that I had Addison's disease. A virologist informed me that I had some exotic virus that I may have picked up on my vacation that it had attacked my thyroid and diagnosed me with a viral thryoiditis. The CT scan on my pituitary revealed that I had Sheehan's Syndromes and that I have had this condition since the birth of my son in 1976. The spinal tap results showed that I had a tendency towards anorexia, and osteoarthritis was discovered on my spine, primarily lower back and neck. I received four radioactive iodine treatments for goitre, was prescribed cortisone-acetate and placed on a high protein diet with calories and sent home. About a year later, I requested a thyroid test from my family physician because I had not been placed on any thyroid medication and my weight had gone from below 90 to over 160 lbs, plus I was suffering from some uncomfortable symptoms. As a result of this test, I was placed on Synthyroid. I not only have Addison's disease but was born with Tuberous Sclerosis. Combined with osteoarthritis, when one acts up, they all do. At 62, I have learnt how to manage these conditions through diet with lots of fruits, vegetables and dairy products; through exercise with hiking, gardening and Yoga stretches, and I retired from a very stressful career as a Paralegal. Even though I take as many as seven prescribed medications a day, I live a very productive life.

My Crisis Story:

My crises nearly always come on in the middle of the night. I wake up dizzy, vomiting and with diarrhea, often all at once. Sure makes getting to the bathroom an adventure! As the crisis worsens, I get extremely anxious and will often start moaning. I am not comfortable either sitting up or completely reclined; I find that a semi-reclined position, often on my side, is the most comfortable. I get extremely fatigued and I get chills. The chills were even documented in my ACTH stimulation test, when my body temperature dropped 2° C during the one hour test.

Over time, I've learned to notice my pre-crisis symptoms. There's a particular type of tired, but at the same time it's hard to sleep and I'm slightly wired. Now, anytime that happens near bedtime, I take an extra 5-10 mg. hydrocortisone; this strategy has kept me crisis free for just over 2 years, down from an average of 1 per year. Daytime symptoms include fatigue/lethargy, irritability, lack of concentration, bad judgment (especially while driving), extreme thirst, a pinched look between my eyebrows and probably others that are too subtle to document. Depending on how bad I feel and/or what else is going on, I may take extra hydrocortisone, drink salt water or simply get a little rest.

Submitted by Teresa Seasons

Highlights from Local Meetings:

Vancouver Island Support Group

The Vancouver Island support group will meet Saturday, **February 9, 2008**, in Victoria at the **Victoria General Hospital, Room 1814**, from 1:00 to 3:00. For more information, please contact Jim Sadlish at 250-656-6270 or e-mail: jsadlish@telus.net. The May 31, 2008 meeting will be at the same location, same time.

We also have a confirmed booking for the Lecture Hall at VGH on October 11, 2008 for the national Annual General Meeting. (Note that this falls on Thanksgiving weekend, to allow more time for out-of-town members to attend.) I expect the Canadian Addison Society AGM will run from 1:00 until 4:00, but this has not yet been cleared with the executive and will be confirmed later.

Submitted by Jim Sadlish

For further information or to contact the Vancouver Island Support Group, please contact Jim Sadlish at jsadlish@telus.net or (250) 656-6270. For information on mid-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

BC Lower Mainland Group meeting October 27, with 16 members attending.

- Members signed up for interviews with UBC 1st Year Medical Students, which will take place at our next meeting or at member's homes. The interviews are part of our ongoing advocacy for Addison's.
- At the next meeting, an area will be set aside for teens to meet before the meeting.
- Aleita now has 56 young people with Addisons, from 8 countries, signed up on Addisons her Facebook site.
- You can download a copy of a letter in Spanish for emergency situations from the NAFD site (http://www.nadf.us/tools/emergency_info_span.pdf).
- One person facing surgery tried to supply the hospital with her emergency letter. When asked to remove her medic alert bracelet, it was instrumental in enabling the patient to retain the bracelet. Another member supplied the letter to an ambulance driver, but it was not passed on to ER; lesson learned – ensure you always have a copy yourself, as well, in case it is needed further down the line. Copies are available on our website www.addisonsociety.ca.

- A question on Addisons and AIDS: information can be found on out Q&A website page (http://www.addisonsociety.ca/faq.html).
- Marilyn’s family doctor, Dr. Hasham, is now a “Teaching Doctor”, meaning he has two second year medical students working with him. He asked if one of the students could interview Marilyn, to further their diagnostic skills. Marilyn had to describe her symptoms, and be interviewed as though no diagnosis or treatment had yet been given. It was somewhat disconcerting, but after an hour’s interview the student determined that the cause was adrenal, although she could not pinpoint the exact disease. Then both students were invited to continue the meeting with Marilyn, to talk about life after crisis, to ask any questions they had, and also for Marilyn to explain to them the work of the Addison Society.
- Marilyn is looking into the question of DHEA. To find if she is eligible, she has had blood tests to determine her levels of DHEA (produced by adrenals and ovaries). DHEA can increase the risk of breast cancer, high blood pressure and other side affects. Marilyn will report back at the February meeting. For more information on DHEA, see: The Canadian Addison Society Newsletters - Issue #35 - April 2004 and Issue #39 - June 2005; NADF and Addison News – Editor Joan Hoffman. An email has been sent to Paladin requesting an update on their proposed study but no reply has been received.

Guest Speaker: Gerry Kasten, Nutritionist, Fraser Health; Instructor, UBC Medical School

Gerry brought Canada’s Food Guide to life for us, with full explanations and humourous anecdotes. He also showed how we can apply the guidelines to our daily eating

In recent years, there have been many changes in nutritional thinking, and in the Guide. Babies start with breast milk and eat when they are hungry until full and then stop. Parents may be starting the process of overeating by encouraging their children to clean up their plates. Food companies often encourage larger than required portions, promoting overeating. We usually eat the amount given to us. The guide explains what a serving is. Most servings are ½ cup with the exception of leafy vegetables which are 1 cup. A large glass of juice is equivalent to 3 servings. The #1 under-consumed section is fruit and vegetables.

Children have attained half their height by age 2, to puberty they usually grow another foot, and then continue to adult height after reaching puberty. After puberty the Food Guide separates male and female, as men have larger muscle mass and require more calories.

Almost all of your nutrition can be achieved by following the recommendations of the food guide.

Fruits and Vegetables:
Fresh food, if produced and bought locally, should be our first choice. “Fresh” food from out-of-country may be a week to a month old before it reaches us. In that case, it may be more

nutritious to use frozen food, especially during the winter. Foods in the freezer are usually picked ripe, then flash frozen. Canned foods will always be the third choice; they lose vitamins but not minerals in the canning process. Don't boil vegetables; steaming is better. There is no consensus on benefits or loss of nutrients when cooking vegetables in the microwave. Apples retain their nutrients over winter as they are waxed before being put into storage. Then CO_2 is pumped into the storage unit to keep fruit from spoiling. Broccoli contains more vitamin C when eaten raw, but more available calcium when cooked, so eat some raw, some cooked. Eat lots of different coloured fruits and vegetables each day. A good rule of thumb is to eat fresh foods that are in season, here or elsewhere.

Grain Products:
Quinoa is a Peruvian grain. It has a natural soapy kind of coating, so wash it until the water runs clear before you cook it. Kamut and Spelt are ancient forms of wheat, but larger than wheat. You can use these as a substitute for pasta in a salad. There are many colours of rice, like black, red, brown, wild and white. Eat a variety of colours of rice. Try using black rice and coconut milk, or a brown sweet rice (like sticky rice) with milk, to make rice pudding.

Milk and Alternative:

- Milk provides vitamin D. Skim and 1% are recommended, although 2% is also good, it just has a higher fat content. The Canadian Cancer Society recommends 1,000 IU daily.
- Probiotics are live, 'friendly' bacteria that we need in our stomach and intestines. All yogurt contains such bacteria. Kefir, a fermented milk product, also contains live bacteria. It is naturally carbonated and looks kind of 'bubbly' like beer. Antibiotics kill the friendly bacteria in our system, so eat yogurt after taking a round of antibiotics to reintroduce 'friendly' bacteria. Tempeh, kim chee, miso, sauerkraut are other natural sources of probiotic bacteria.
- Prebiotics are food for probiotics. Prebiotics contain 'inulin', which is found in breads and some fibre supplements.
- There is a difference between soluble and insoluble fibres. Soluble fibres dissolve in water or liquid. Insoluble fibres fill up like a sponge, and work to clean out the stomach and intestines. Some inulin supplements are Benafibre and Fibresure. They contain soluble fibre like the pectin in jams and jellies. Metamucil contains both soluble and insoluble fibres.

Meats and Alternatives:

- One serving of meat or fish is about the size and thickness of your palm. Another way to think of it is as the size of a deck of cards. Meats should be low in fat. Just look at the meat and you'll be able to tell from the edges and marbling how much fat there is. Choose leg and back cuts, resist shoulder cuts or prime rib.
- Two servings of fatty fish per week are recommended. The Provincial government issues warnings about fish because of contamination of some lakes and rivers. Check with the local health unit before consuming freshwater fish you've caught. In salt water fish, the biggest controversy is over methyl mercury. It is more prevalent in large, fish-eating fish that live a long time, like yellow tuna, shark, etc. Plant-eating fish that live a short time,

like salmon, light tuna, sardines, and herring are okay. (They eat their green leafy veggies!) (http://www.hc-sc.gc.ca/fn-an/securit/chem-chim/mercur/merc_fish_qa-poisson_qr_e.html). Farmed salmon gets its flesh colouring from the coloured feed it eats. If you don't like or eat fish, you may wish to take a fish oil supplement. It's recommended to take from 1,000 – 4,000 mg of DHA and EPA (http://www.americanheart.org/presenter.jhtml?identifier=4632). Supplements should include fatty acids to replace the fish that you are not eating.

- French green lentils are excellent. There are other coloured lentils and dahls which are also very good for us, and don't need to be soaked before cooking. To cook dried beans: soak overnight, drain and rinse, use fresh water and cook, OR, bring to a boil, let sit for one hour, drain, rinse, use fresh water and bring to a boil again. Gas is a by-product of eating beans and lentils. It is a natural occurrence in our bodies. In fact, most bodies produce a litre and a half of gas a day, so we should just burp or let out the flatus to get rid of it. If you have gas pains, you may 'poke yourself in the belly' or lie on the floor on your stomach, then roll from side to side to release it. If you eat more legumes, you will produce more enzymes to break down the gas, and it should no longer be a problem for you.

Calcium, bone-building and exercise:

- Calcium carbonate does not absorb as well as others like calcium citrate, maleate, gluconate or glubinate. Because our bodies cannot absorb more than about 500 mg of calcium at a time, it is best to stagger your dose throughout the day. Try to not take calcium with a meat meal, as the calcium will inhibit the absorption of iron from the meat.
- Calcium supplements should be multi-factorial to be effective for maintaining bone density. 1,000 – 1,300 mg of calcium is generally recommended. Vitamin D is essential for calcium to be used. As well, estrogen plays a part.
- Weight bearing exercise with 'jarring', like walking, is a necessary component. In a study, 25% of adults were active enough for good health, although 75% thought they were. These are some examples of moderate activity: if you can still talk while exercising, but it requires some effort; or, you see a bus coming and you hurry to catch it. You can 'add up' your daily exercise in 10- or 15-minute instalments. Most people walk an average of 5,000 steps in daily activity. 10,000 steps are recommended. Using a pedometer will help you to track the number of footsteps you walk or run.
- In a study by Linda Bacon et al. (*J Am Diet Assoc*. 2005; 105:929-936), half the group were on a diet, working with a dietician; half were taught to eat 'intuitively', i.e.: eat when hungry until they were full. Look at the results:

Time Period	Diet	Intuitive
Immediate	Lost weight, metabolic indicators improved, i.e.: blood pressure, cholesterol and blood sugar	No weight lost, but same metabolic indicators improved, ie: blood pressure, cholesterol and blood sugar
Drop out rate	41%	8%

6 months	Some gained back some weight, lost some benefits	Maintained weight and metabolic indicators
One year	ALL had gained weight back; metabolic indicators back to original	Maintained weight and metabolic indicators
Two years	Most had gained more weight and lost on metabolic indicators	Maintained weight and metabolic indicators

The BMI (Body Mass Indicator) is only good for use with populations. It is not suitable for individuals, as it does not take fitness factors into account. No matter how much you weigh, your fitness level is very important.

Nutrition Facts charts on foods:
5 mg fat = 1 teaspoon
4 mg sugar = 1 teaspoon
2,300 mg salt = 1 teaspoon
Women require 25 grams of fibre per day
Men require 38 grams of fibre per day.

The Nutrition Chart on all foods is based on a 2,000 calorie/day diet. The gram column gives the actual number of grams in the food. The percentage column is to be used for comparison with other foods.

Miscellaneous:

- Many foods which used to be treats, like French fries, nachos, etc have now become mainstream in our diets. These should be consumed only in limited amounts, the same as baked treats and ice-creams.
- There is a movement away from fast foods to "slow foods" which emphasizes value and enjoyment of food (http://www.slowfood.com/). The 100-mile diet (consuming only foods from a radius of 100 miles) tends to be simpler, with just a few ingredients (http://100milediet.org/).
- Most farms in Canada are still family farms, not huge agri-businesses.
- Five companies in North America control most of the processed foods. A general rule when shopping at supermarkets is to shop around the perimeter where you'll find the fruits and vegetables, meat and dairy, and ignore most of the middle section.

Submitted by Judy Stanley and Marilyn Thauberger

The next meeting for the BC Lower Mainland Group will be held on **February 23, 2008** 1:00 – 3:00 pm at the **Sherbrooke Centre**, 260 Sherbrooke Street, New Westminster BC. First year students from UBC Faculty of Medicine will be attending to interview members for their course curriculum 'At Home Interview' assignment. Members can also be interviewed at a time of their choice at home. Anyone wishing to participate, please contact Judy Stanley at 604-936-6694. These interviews are part of our ongoing advocacy for Addison's Disease.

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.

Saskatchewan Support Group

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

Southern Ontario Support Group

The next meeting will be Sat. **May 17, 2008**, 12:30 to 4:30 pm, Community Room, **Brantford Police Centre**, 344 Elgin Street, Brantford, Ontario. We will advise you of the guest speaker in the April Newsletter. In addition, we will address what we believe is an important topic to some members in the Group at the May meeting - the idea of an additional meeting(s) each year, possibly in a rotating fashion as to location, in an effort to accommodate those members who find it impossible or difficult to attend the meetings in Brantford. If you would like to be attending meetings but find it impossible to get to Brantford and have an opinion on this topic, please forward that to Harold Smith who will share it with the group. Harold can be reached at hsmith9995@rogers.com or by telephone at 519-742-9995.
In the meantime, everyone please mark May 17 on your calendar.

Submitted by Harold Smith

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

Eastern Ontario Support Group

Eighteen people (10 members, 8 guests) attended the meeting on October 13, 2007 at Robbie's restaurant in Ottawa.

- The Society is looking for a new President as of October 2008. If anyone is interested in the role, please contact the Secretary.
- The next AGM will be in Victoria, BC, October 11, 2008.
- The last meeting, in Kingston, brought out a number of new members. Teresa is looking at options for a meeting schedule which will include those members who are not from Ottawa, while providing stability and continuity of meetings for group members. In this regard, she will be sending out a survey to members with a number of options, for example, 1 meeting a year in Ottawa + 1 meeting in Perth, or 1 meeting a year in Ottawa + 1 meeting rotating in the Valley; 1 meeting in a restaurant, 1 meeting in a home or

public facility. This information will determine the location of our May meeting, so stay tuned.

- We had a focussed discussion around 'Living with Addisons/Living with an Addisonian' which was very informative - and reassuring. For this discussion, we were divided into three groups, one consisting of people without Addison's and two groups of people who have Addison's. The notes included here are a compilation of everyone's comments; as a result, there are some conflicting points:

Non- Addisonian

Positive Feelings

- Diagnosis helped me to understand events and reactions which had happened in the past.
- It helps us understand their moods, put them into the context of Addisons, rather than take them personally.
- It made me get to know him much better – his moods, reactions – so that I could read him better.
- Over time, I’ve learned to recognize the impending signs of a downturn, and found I **can** do something to improve the situation. I feel less helpless.
- Having a label for everything was a relief; knowing what it is and what to do with the symptoms helped.
- I learned not to take things (reactions, outbursts, fatigue, unwillingness to participate, non-communicativeness) personally.
- We can still do a lot – if we maintain a slow steady pace.
- It has caused me to do research, to learn a lot.
- It increased my medical interest.
- It improved the crisis protocol at the Ottawa Hospital.
- I feel protective towards them.

Negative Feelings

- If I say too much, he gets mad (so I am unable to help him avoid a downturn).
- I can’t tell her that she is tired (so I am unable to help her avoid a downturn).
- I feel powerless.
- I am afraid something will happen to him.
- It’s difficult to travel.
- It’s hard for the family to deal with a chronic condition – which will never go away.
- Life changed.
- It’s hard.
- Inability to plan, or count on plans going forward
- I wonder if I will be able to count on them when I am in need.
- Protectiveness
- It’s hard to see them in pain.
- Frustration, when they don’t pace themselves, and the inevitable downturns affect my life
- Anger at the medical system

Problems resulting from having an Addisonian in your life

- It's hard to plan for activities, and expect the plans to go ahead. It's difficult having to plan for all eventualities.
- Dealing with the spontaneity of a crisis is difficult.
- Explaining what's happening (symptoms, cancellations, absences, and departures) to friends, and to others in a social setting, can be tricky.
- Balancing everything is hard.
- Having to 'mind' them all the time is wearing.
- I feel responsible to 'take care' of them.
- Trying to be aware for them of what's happening to them, and measures to take to mitigate problems, is difficult and wearing.
- Having to avoid them if I am unwell (so they won't be unwell) is awkward.
- Attributing everything to Addisons is too easy – and may avoid dealing with other underlying issues.
- Dealing with the ongoing never-ending cycle of them being balanced and feeling fine versus unbalanced days feeling unwell and unable to function is a major cause of stress for me.

Changes/adjustments to accommodate Addisonian

- It takes lots of patience.
- I find I avoid discussions which could lead to disagreements, arguments, fights.
- I've learned to leave him alone, and let him deal with it.
- Life takes being really flexible.
- being prepared
- being aware of what's happening
- We're more cautious.
- We find we need to be aware of what's involved in medical procedures, other conditions and drugs prescribed for other reasons; we need to do the research on interactions and have learned to be wary of them.
- We have to understand the real definition of 'stress', and help the Addisonian, family, friends understand what all 'stress' encompasses.
- My own problems take a backseat. I am reluctant to bring up my problems/stresses/needs.
- Learning to help the Addisonian recognise when they are stressed.
- I've had to learn and become aware of their body's reactions.
- Family comes first now.

Addisonian

Good things about having Addisons

- We all have good stories about how bad it is.
- We now completely appreciate the good health we once had.
- We wouldn't recommend it to anyone.
- The good days are appreciated much more now.

- Pay attention to our lives – especially how we feel
- Teaches one to prioritize
- Good attention from hospital staff, especially if they know you
- Meeting other Addisonians at meetings
- Grateful to be alive
- Addison's is a manageable condition
- Term "hypochondriac" doesn't apply to us
- Does not stop us from having children
- Don't have to cut back on salt

Effect of having Addisons on those around us

- Some people/family/friends have no idea what you're talking about.
- Some family members are very understanding and take care to ensure you're OK.
- Some work colleagues aren't happy or comfortable with the idea of giving shots in a crisis situation.
- Abrupt changes in plans (last minute cancellations)
- No difference
- Laissez-faire about hospital visits
- Children notice how tired I get
- Family has to watch out for signs of impending Crisis
- Family has fewer activities
- Have to help keep track of meds

Difficulties/problems resulting from living with Addisons

- Some of us are much more sensitive to heat and cold.
- The heat of the summertime is extremely hard to deal with.
- For some of us, the house is never warm enough.
- One person in particular is worried about being injured at work.
- Most of us need to get enough sleep to ensure the next day or week will be a good one.
- Some of us worry about travelling for work purposes – will there be a hospital there that can help me?
- Travel to exotic locales can be restricted.
- Worry about the lack of recognition by others (nurses, friends, co-workers, some doctors) of the condition and how serious it can be.
- Can be frustrating trying to deal with this lack of recognition.
- Many doctors differ on what medications to use.
- Most of us experience a "mental fog" when not feeling well.
- The issue of the very serious topic of the need to retain salt is not stressed enough.
- Fatigue
- Not able to plan ahead (may need to cancel)
- Must plan ahead (need to know how schedule is shaping up and make sure rest periods are included)
- Fear
- Cautious

- Avoid germs, careful not to get exposed to illness
- Careful about leftover food
- Feel bad about cancelling plans
- Increased sweet tooth
- People around us blame Addison's for all bad feelings.

Changes/adjustments to accommodate Addisons

- Work at being very careful not to get sick, to avoid exposure to flu and colds.
- Didn't know how to replace the salt effectively and various suggestions were shared (salt in food, some take it straight, some in warm water, etc.).
- One person's comment after having dealt with the condition for decades was, "Just deal with it!" and don't go on and on about it.
- Others have had to change jobs and/or retire early due to the condition.
- Some mention that their sleep patterns are interrupted.
- The concept of 'somogyi' or the "dawn effect" – where the body re-aligns at 3 a.m. or so was mentioned as a possible reason for sleep patterns being interrupted.
- Always have to pay attention to how you feel (internal awareness)

Submitted by Teresa Seasons and Patricia Hehner

Teresa was unable to send out the promised survey regarding meeting location. Therefore, the next meeting will be **May 10, 2008** at 12:00 at **Robbie's Restaurant** in Ottawa. The survey will be sent out shortly and the responses will be discussed at the meeting. Thanks to everyone for their patience in this matter.

For information on Eastern Ontario Support Group activities or meetings, please contact Teresa Seasons at tseasons@magma.ca (613) 761-1195.

Québec Support Group

If you wish to start a local group in the area, please contact the Liaison Secretary at liaisonsecretary@addisonsociety.ca or at the national address shown on the front of this Newsletter.

Atlantic Support Group

For information on Atlantic Canada Support Group activities or meetings, please contact Kelley Gamblewest at (902) 452-1581 or kdgwest@eastlink.ca.

Medical Q & A

Q: In the last month I seem to have developed an intolerance to alcohol. About 5 minutes after drinking alcohol, my face breaks out in blotches starting around my eyes, nose and mouth which then spread across most of my face. The rash is a reddish purple and lasts for about 20 to 30 minutes. My face felt very warm during these episodes, but not itchy, and I did not have trouble breathing. I reacted to gin and tonic and white wine. Lately I have been feeling tired and 'foggy' and seem a bit off balance at times. I have scheduled appointments with my GP and endocrinologist, but do you have any suggestions of what could be causing this reaction?

Do these symptoms ever appear with pernicious anemia?

I have: hypothyroid (1979), vitiligo (1983), Addisons (1998), hypogylcemia (1999). My medications are: Cortef (15-20 mg), Florinef (0.05 mg), Synthroid (0.112 mg) and Estrace (1.5 mg). My hypoglycemia is diet controlled (no meds).

I had an abdominal total hysterectomy and oopherectomy (due to severe endometriosis) in June and started the estrogen therapy right away.

I took calcium citrate for a few days before the first alcohol reaction, but have discontinued that for now.

> **A:** The symptoms that you are describing sound much like a deficiency of a liver enzyme that metabolizes alcohol resulting in the release of a metabolite that causes the flushing. This is usually a hereditary problem but possibly could develop later in response to some liver insult. I am not aware of this problem being associated with the series of autoimmune problems you have described. The fact that you have not been feeling well recently makes me wonder if you could have a mild viral infection which could be contributing to your current problem.

Q: Whenever I try to explain to my friends and family that I have a disease in which my adrenal glands don’t work (i.e. I don’t produce adrenaline, among other things), I always get the reaction of "So you don't get scared or excited?". I never know how to respond! There must be a correlation between being scared and having little adrenaline. What is it and what is a better way of explaining it?

> **A:** This is an interesting question. You are correct that the adrenal makes adrenalin in its inner portion (medulla) and cortisol is made in the outer portion (cortex). Adrenalin and a related hormone, noradrenalin involved in the "fright, flight" response to acute stress, are also produced at the ends of specific nerves. In Addison's disease, the cortex is destroyed by antibodies directed at one of the proteins used in the formation of cortisol. The medulla is left alone so can still produce adrenalin.

Even if the adrenals are removed surgically, the nerve endings produce enough adrenalin and noradrenalin to look after blood pressure needs and our fright response.

Q: My husband has Addisons and is experiencing bouts of nausea, but he is never sick to his stomach. He takes cortef: 20 mg in am, 10 mg in pm (hydrocortisone). He has also had an ileostomy.

A: I am not quite sure what the problem is. The dose of hydrocortisone is a little high at 30mg /day, but that would not cause nausea. You did not say why he had the ileostomy. He may have had inflammatory bowel disease which is more common in individuals with Addison's disease,or perhaps it was for some other reason. My first reaction would be to review the gastrointestinal problem to see what it was, and whether it may not be completely controlled. There may be other aspects to the problem that might shed more light on the situation.

Q: Should I be concerned about recent lab work I had done, with the result showing a high reading of 51 ACTH, as well as a high reading of 829 cortisol? My GP said to wait and discuss it with my endocrinologist, whom I don't see for another 4 weeks.

A: I am assuming that you have Addison's disease and that you are taking cortisol (cortef) as your glucocorticoid replacement. When ACTH is measured on a morning blood sample, the levels are almost invariably high. The upper normal level for ACTH in most labs is 10 pmol/l and levels of 30 to 75 are usually found on a morning sample before taking the cortisol. The cortisol level is usually low in the morning before taking the cortisol and peaks 1 to 2 hours after taking the medication. The normal range after taking medication is up to about 600 nmol/l depending on the lab, but this can be affected by the protein that carries cortisol in the blood. The commonest medication that affects this protein is estrogen found in the birth control pill or in hormone replacement therapy. Under these circumstances, cortisol levels can be up to 1000 to 1200 nmol/l. The cortisol that is bound to the protein is not active so if you are taking the appropriate dose of cortisol there should be no problem.

Q: I have Addison’s - my adrenals bled out internally from heparin and fragmin(?). Should a person take an herbal adrenal support? I’ve been taking 25mg cortisone acetate with breakfast and 12½ mg cortisone acetate at supper, plus Florinef 0.1mg every other day since December 2004. Should I be on 20mg of hydrocortisone divided throughout the day? I’m tired, my hands and feet bones are becoming weaker, eyes etc.

A: The dose of cortisone acetate and Florinef that you are on would be considered a reasonable replacement dose and the twice a day dosage is appropriate. In most European studies, virtually all of the individuals are on cortisol rather than cortisone, but theoretically, since cortisone is converted to cortisol, this should not make much difference. The general rule is that the lowest dose that makes you feel well is the right dose for you. It depends on several factors including size and weight. You can discuss with your doctor the possibility of lowering the dose of cortisol to 25mg daily. Taking 12.5mg in the AM, 6.25mg (1/4 tab) at lunch and 6.25mg in the afternoon. Depending on age etc., it may be worth checking your bone density. Once again, check this out with your doctor. There are no herbal preparations that can replace your adrenal hormones.

Q: I have a question about the emergency kits that people were talking about. Are they prefilled syringes like the Anakit or is it a multidose vial and a syringe? What is the name of the medication used? Is there a patent name for the Kit? I see an internist not an endocrinologist, and neither my doctor nor pharmacist knows what I am talking about. Do you know of a website or other place where I can fine out when to use it?

A: Sorry if there is some confusion about the injection kit. There is some information on our website about its use (http://www.addisonsociety.ca/injection.html, http://www.addisonsociety.ca/emergencyproc.html). The kit has to be put together from its components and is not sold as a kit. It consists of:

- Solu-cortef 100mg Act-o-vial
- 3ml syringe with a 20 or 22 gauge needle
- alcohol wipes

The instructions for mixing the solu-cortef in the vial should be included in the package. You have to ask your doctor for a prescription for these items and you can package them together so the components will not be hard to find.

The reason this does not come already prepared is that the solu-cortef is not stable in solution after mixing.

You should let your travelling companions know that you have this kit with you and they should be shown how to use it if needed. The kit is not much help if no one knows how or when to use it. If you are staying away for a prolonged period, you may want to take more than one kit with you depending on the destination.

You should also have a letter with you from your doctor that says that you have Addison's disease and that you are carrying this kit with you for emergency purposes, so that you don't have any problems at customs.

It will not be surprising if your doctor is not aware of this kit. It is only in the last few years that it has been discussed and she/he may not have any other people with Addison's disease. If you have any problems, you can copy some relevant information from the web site and take it to her/him or you can direct her/him to the web site.

Q: I was diagnosed with Addison's and Hypothyroidism at age 27, and am 52 now. I have a nephew who was diagnosed with the same thing at the same age, and all of the brunettes in our family have hypothyroidism. I was given very little explanation of what to expect with this condition, except to take extra cortef if I was sick or stressed. I didn't even know about having a solu-cortef kit until I had a crisis, about 10 years ago. This led me to realize that if I want answers about Addison's, I will have to find them outside the doctor's office. I hope you can put my mind at ease over this question. Over the last few years, I have experienced a few odd "symptoms" and I was wondering if they could be related to Addison's, if they indicate that something needs to be checked, or if they are purely coincidental. For the last 3 years, my left outer-ear has been very tender/sore, from time to time keeping me awake if I try to sleep on the left side of my head. I also seem to have some tinitus. My current doctor sent me to have my hearing checked, and I was told that my ears and hearing are normal for my age. The doctor prescribed pentasone ear-drops, and they seem to be helping, which I don't understand. How do drops for the inner ear relieve pain in the outer ear?

In May 2005, my skin erupted in huge, hot, itchy, red welts. Twice I had to go to emergency because the pain was so bad I couldn't think straight. The first time, I was put on IV cortisone, and some kind of pain medicine. The second time, I was put on hydroxzine, and the welts went away and didn't come back. I still have the rest of the bottle of hydoxzine, but haven't needed it since. A couple of years ago, my blood pressure spiked so high that my doctor almost didn't let me drive home from the clinic. He put me on blood pressure medicine, in ever increasing doses, until it finally seemed to be under control. I asked him if it wouldn't be easier to just cut back on my florinef, but he was afraid to do that, so I cut my dose in half on my own. My blood pressure went back to normal, I quit the blood pressure meds, and I feel better than I have for years. I also cut back on my cortef and dropped about 20 pounds.

I was told years ago that I had irritable bowel syndrome, but it seemed to be under control. In March, I started to experience terrible stomach pains, and had diarrhea for months. I asked my doctor if I should be tested for food allergies, but he dismissed this as very unlikely. An endoscope in August diagnosed a hiatus hernia, and I am now on Pantoloc. Things are almost normal now, with just a little tenderness and the occasional loose bowel movement.

Over the last few years my feet, especially my toes, seem incapable of staying warm. I have to have at least one hot bath a day to warm up, and it is interesting to watch my toes go from dead white to dark purple to healthy pink as they warm up in the hot water. My fingers get cold too, but I can usually warm them up by running warm water over them, and it is not as dramatic. One doctor said I have Reynaud's syndrome, but didn't suggest how I should deal with it. Finally, after complaining all summer to my doctor about burning, hot eyes, he sent me to get my eyes checked. Yup, they are dry, and now I use eye drops every few hours to deal with that. I asked the optician if the dry eyes could be related to my occasional dry mouth, and she thought that was interesting, but didn't say anything else. So, am I a nut that collects interesting but meaningless symptoms, or could there be some pattern here?

A: I am sorry that you have been going through so much stress the past 3 or 4 years. It distresses me when someone says that they cannot get the information they need from their doctors. First of all, you should have an endocrinologist who can discuss these concerns with you. Not all questions have answers but at least you should be able to go over your concerns with your endocrinologist to see if there is a relationship with the family of autoimmune diseases that include hypothyroidism and Addison's disease.

Secondly, it would be unwise of me to try to specifically answer your questions because I am not aware of the context in which these symptoms are occurring. I will try to make some general comments about some of the questions you have raised.

- The pentasone ear drops contain a cortisone-like steroid so when you put them in your ear canal, there would be local absorption which would relieve inflammation and therefore decrease your pain in the outer ear.
- The skin problem that occurred in May 2005 must have been an allergic reaction. The fact that it has not recurred since Aug 2005 is good and you may not find out what the offending allergen was. This is not likely related to your Addison's disease.
- The blood pressure problem and the dose of medication for Addison's disease are ongoing considerations. These must be discussed with your endocrinologist. The general rule is that "the lowest dose of cortisol that makes you feel well is the correct dose". With respect to Florinef, blood pressure and plasma renin are helpful in making decisions.
- A hiatus hernia is not part of the autoimmune complex.
- Dry eyes and dry mouth could be due to a condition known as Sjogren's syndrome. This problem and Raynaud's syndrome are generally treated by rheumatologists. These conditions are not generally part of the family of autoimmune endocrine problems, but since they are probably autoimmune in origin, they may occur more frequently in individuals with autoimmune endocrine problems.
- Be sure to review all of your concerns with your endocrinologist!

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 YEARS ENDING DECEMBER 31, 2007 AND 2006

Cash on hand and in banks	January 1, 2007	January 1, 2006
	$18,394.25	$17,940.37
Income		
Dues Received - National	$2,599.85	$3,212.18
- Support Groups	385.00	535.00
Donations	2,871.14	1,010.00
Interest	659.55	581.61
	6,515.54	5,338.79
Expenses		
Memorial Plaque	-	15.41
Newsletter	1,163.46	653.24
Web Site	174.90	491.15
Secretarial	1,200.00	1,200.00
Annual Meeting	126.14	202.31
Postage, stationery and supplies	132.71	1,078.01
Telephone	1,024.74	896.74
Support Group Expenses	146.36	282.13
Bank Charges	76.32	65.92
	$4,044.63	$4,884.91
Cash on hand and in banks after adjusting for O/S cheques	December 31, 2007	December 31, 2006
	$20,865.16	$18,394.25

THE CANADIAN ADDISON SOCIETY

Analysis of cash on hand & in banks as at December 31, 2007

Equitable Trust -	
The Canadian Addison Society - $6,643.54 @4.47% due February 11, 2008 - $9,744.90 @4.55% due March 24, 2008	**$16,388.44**
TD Canada Trust -	
The Canadian Addison Society	**986.34**
Montreal Support Group - Quebec	**100.00**
Ottawa Valley Support Group - Eastern Ontario	**500.70**
Brantford and District Support Group - Southern Ontario	**1,615.26**
Saskatchewan Support Group	**30.00**
Edmonton Support Group – Alberta	**274.60**
Lower Mainland (Vancouver) Support Group - British Columbia	**504.82**
Vancouver Island Support Group – Victoria	**450.00**
Vancouver Island Support Group - Nanaimo	**15.00**
Total	**$20,865.16**

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.

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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 Eastern Ontario Support Group – ON + $20.00 to Society*
☐ *$5.00 to Southern 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 (Victoria) Support Group – BC + $20.00 to Society*
☐ *$5.00 to Vancouver Island (Nanaimo) Support Group – BC + $20.00 to Society*
☐ *$5.00 to Atlantic Provinces Support Group (NB/NS/NF/PEI)+ $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: September 2007