



The Canadian Addison Society **La Société canadienne d'Addison**

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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.

Double-Edged Meds: Bisphosphonates:

Bone-building drugs may adversely affect oral health

The next time you come in for a consultation, the dentist may be asking you the following important question: are you taking any bone-building medications such as Fosamax? The reason for the question is simple: doctors suspect a link between the use of bisphosphonates such as Fosamax, Aredia, Actonel, Aometa, and Boniva and a condition known as osteonecrosis, also called bone death.

These bisphosphonates are used successfully to treat and prevent osteoporosis in post-menopausal women and to increase bone mass in men. However, it is suspected that if a patient undergoes certain dental procedures while using these drugs, it's possible that bone loss, or even osteonecrosis may occur. Initially research pointed towards patients

with cancer as being chiefly at risk, but now dentists and doctors are seeing cases in otherwise perfectly healthy patients who are being treated for bone loss.

The *American Dental Association* recommends that before starting bisphosphonates, patients have a comprehensive dental exam and treat any tooth or gum problems immediately. In addition, while on bisphosphonates, you must ensure your home care is impeccable: brush regularly, floss daily, and keep your dental recall appointments. If invasive dental care is necessary, ask the dentist to discuss the implications with you, and choose the most conservative treatment possible.

Please be sure to let the dentist know if you suffer from osteoporosis, and if you're taking, or considering taking, bisphosphonates.

Adapted from an article by Dr. John Augimen
Dental View Winter 2006/2007

Other references on this issue:

<http://www.ada.org/public/topics/osteonecrosis.asp>

<http://www.rheumatology.org/publications/hotline/0606onj.asp>

http://www.rcdso.org/dispatch/Dispatch_JulyAug06.pdf see page 24, 27 and 32

<http://www.ada.org/prof/resources/topics/osteonecrosis.asp>

<http://www.annals.org/cgi/content/full/144/10/753> or

<http://www.annals.org/cgi/reprint/144/10/742.pdf>

Our thanks to Conrad Conwell, from the Southern Ontario Support Group, who suggested this article.

What Does *Quality of Life* Mean?:

The following request for survey responses was received via NADF in the United States.

HSCNews International is conducting one of its first patient/disability surveys and wondered if you could help them in this matter. The subject of this survey is Quality of Life, as viewed from the patient/disabled person perspective.

Do you believe that doctors and the healthcare system should do more to improve the quality of life of the people that your organisation represents? If you do, one problem is that the medical profession, managers, administrators and politicians have little idea what you (and everyone else) mean when you use the phrase 'quality of life'.

To help overcome this barrier to improvements in patients' quality of life, you are invited to add your opinions to a worldwide study on what constitutes patients' quality of life. The results of this survey will help patients from across the world determine the key characteristics behind an improved quality of life.

The study is being conducted by *HSCNews International*, an independent publication for health advocates, in collaboration with the QALYity Project (a UK-based alliance of prestigious patient groups, medical professionals, academics, and journalists). The Project is trying to develop an index that can measure how effective each individual medical treatment (or form of care/support) is at improving the quality of life of people with a long-term medical condition (or a disability) — as determined by the individuals themselves, not by clinicians. The results of this international survey, and the tools that emerge from it, will be made publicly available, and will also be presented to the National Institute of Health and Clinical Excellence (NICE), a UK-government-funded body that decides which treatments and care should be paid for by the healthcare system in the UK. Many of the actions taken by NICE are relevant to other countries' healthcare systems.

In December 2006, the QALYity Project published the results of a survey, which had collected the views of over 270 patient/disability/carer organisations in one country (England and Wales)¹. These groups have kindly provided a wealth of potential definitions of the phrase 'quality of life'. But people are different, and not all of the December 2006 definitions are likely to apply to everyone. This second questionnaire which is being sent worldwide should allow individual differences to be collated.

If you wish to input your opinions to this quality-of-life survey, you may do so by completing the short questionnaire online at: [QUALITY OF LIFE SURVEY](http://www.surveymonkey.com/s.asp?u=736323418494), (<http://www.surveymonkey.com/s.asp?u=736323418494>) where further details about this survey can also be found. If you would prefer a hard copy of the questionnaire, please email your contact details to the email address below, and you will be sent a PDF version of the questionnaire, which can be emailed or faxed back.

The administrative costs of this international survey are being paid for by HSCNews International.

Please note that the QALYity Project is supported by an educational grant from NovoNordisk (a Danish company that manufactures medicines for people with diabetes).

For general enquiries about this study, please feel free to contact Dr Alexandra Wyke at:

PatientView
Woodhouse Place
Upper Woodhouse, Knighton
Powys, LD7 1NG, Wales
Tel: 0044-(0)1547-520-965
Fax: 0044-(0)1547-528-501
Email: info@patient-view.com
<http://www.patient-view.com>

¹ The results of the QALYity Project's first survey into patients' quality of life can be read at <http://www.patient-view.com/qalyity.htm>.

Addison's, Salt, and Heartburn:

Most Addisonians have been told by their doctors that adding extra salt to their foods (even when taking Florinef, which should eliminate salt craving) would not hurt them, and can be beneficial. Many Addisonians continue eating salt at nearly their pre-diagnosis rate, which can be substantial. Now, a study in Sweden indicates that dietary salt intake can significantly increase the risk of acid reflux.

Acid reflux is caused when stomach acid flows back into the esophagus, causing heartburn, indigestion, and excessive belching. In a study published in the December 2004 issue of Gut, nearly 50,000 Norwegians were surveyed about their lifestyles, including diet, exercise, alcohol intake, and tobacco use, as well as their occurrence of heartburn and other symptoms of acid reflux. Lifestyle was strongly linked to acid reflux symptoms. People who had smoked every day for 20 years were 70% more likely to have acid reflux than non-smokers. Salt intake also proved to be a major risk factor. Those who routinely added salt to meals were 70% more likely to have acid reflux. And those who ate salted meat or fish three or more times a week were 50% more likely develop acid reflux as those who never ate salted foods.

But lifestyle factors can abate as well as contribute to the symptoms. Those who ate a high-fiber diet and who exercised strenuously at least 30 minutes a week halved their risk of developing the condition. What's a salt-craving Addisonian to do? Mostly, just be aware of how much salt you're eating. If you're consuming a lot of salt and suffering heartburn, discuss this with your endocrinologist during your next appointment.

With permission from COAST News, Summer 2005

Fund Raiser:

June Tyler has asked that we insert this announcement into our Newsletter.

Since being diagnosed with Addison's Disease 8 years ago, I have found that many people have no idea of what it is. For example, two years ago, I was rushed to hospital with very low blood pressure. Unfortunately, although the paramedic was informed that I have Addison's, he didn't realize what it meant. I was unconscious for 2½ hours. Fortunately, I was all right. It had been a severe drug reaction. At that time, I said to myself that if I ever had the opportunity to make more people aware of what Addison's is, I would.

This year, as Worthy Matron of Grey Chapter #170 Order of the Eastern Star, I can help choose a special project. This year, we are fund-raising for chronic depression, alcoholism and Addison's. We have had several draws, with the big draw on June 10th, 2007 at our 80th birthday party. All you have to do is give a donation, and in turn I will put your name on a ticket for a 12" high Waterford Crystal caelyn carafe and a little patio set. All monies collected will be

divided equally between chronic depression, alcoholism and The Addison's Society. To date, we have raised over \$1800.00. If you would like any further information, please don't hesitate to get in touch with me at 519-599-6393 or email rityler@bmts.com.

Thank you very much for allowing me to share this information with you.

June Tyler,
Worthy Matron, Grey Chapter # 170 O.E.S.
R.R. # 1, Ravenna, Ontario NOH 2EO
519-599-6393
rityler@bmts.com

Announcements and Reminders:

- Don Newman, long-time member of the Vancouver Island Support Group, died of cancer in February 2007. Don always had a wry way of dealing with his many health woes. We will dearly miss him.
- Several Addisonians have contacted us, through NADF, looking for other Addisonians in their age group with who they could be in touch via email. If this would interest you, please contact them directly:
 - A 23-year old young woman, living with Addison's disease since she was 10 years old. If you would like to interact with Sandi, please e-mail her at sugarsandi2001@yahoo.com.
 - An Addisonian in her 40's, named Linda, can be e-mailed at LAMellison@aol.com.
- All former Newsletters from the Canadian Addison Society, going back to March 1995 when the Society was born, have been scanned and are now available on our website at <http://www.addisonsociety.ca/newsletters.html>. We invite you to browse through them, read interesting (and still pertinent) Questions and Answers, hear others' stories, and obtain interesting information.
- Membership renewals were due in January 2007. If you have not yet renewed, please do so immediately, using the form at the end of this Newsletter or via our website at <http://www.addisonsociety.ca/benefits.html>
- Over the years, we have had many members asking questions related to the impact of Addisons on surgical and dental procedures. The Addison's Disease Self Help Group in the U.K. has created guidelines for surgical procedures which can be seen at <http://www.adshg.org.uk/comms/publications/surgicalguidelines-colour.pdf> (a hard copy is attached to the print version of this newsletter) and dental guidelines <http://www.adshg.org.uk/quest/2004/07/01.html>.

- For those of you about to travel, we note that the U.K. Addison's Disease Self Help Group site now has emergency letters in German and Spanish, as well as the previous versions in English, French and Italian. You might find these useful if travelling <http://www.addisons.org.uk/info/emergency/page5.html>.

Highlights from Local Meetings:

Vancouver Island Support Group

The Vancouver Island support group met, February 3rd, at the Victoria General Hospital in Victoria. Ten people attended.

- The group discussed changes and improvements to the treatment of several members. Two members had worked with their endocrinologist to adjust medications.
- Thyroid replacement is evidently more effective if taken at bedtime, according to a recent article from the Netherlands. One member advised that calcium supplements should not be taken at the same time as thyroid replacement.
- One member pointed out by that iron supplements can decrease absorption of prescription drugs including bisphosphonates. One member takes Evista which is prescribed for the prevention and treatment of osteoporosis in post menopausal woman. Evista has recently been found to also reduce breast cancer with results similar to Tamoxifen. Osteoporosis medications discussed were Actonel (Risedronate) taken once per week, Calcitonin nasal spray, and Evista mentioned above. Several members take 1000 IU Vitamin D daily to help calcium absorption but also to improve mood.
- One woman mentioned having leg cramps at night.
- Another topic was glucosamine, which has proved very helpful for two attending members - one for back pain and another for aching hips. It must be taken for a long period to be effective. What helps as a sleep aid? Several suggestions included exercise, not eating or drinking late in the evening, taking both calcium and/or magnesium supplements before bedtime, and Valerian root (smells doggy).
- For thinning skin, using collagen cream was suggested.
- When travelling by plane several members had no difficulties taking syringes for emergency use in carry-on luggage as long as they have the manufacturer's label plus your prescription.
- A Medic Alert bracelet was checked by hospital Emergency staff when one member was in hospital. One person mentioned that during a trip to Emergency in an ambulance, the medic agreed to administer her emergency medication with a doctor's permission given over the phone.
- A new Danish study was discussed, about the effects of taking DHEA on the heart. The conclusion states 'Restoration of physiological androgen levels using 6 months of DHEA replacement in this pilot study did not affect cardiovascular parameters and endothelial function in female adrenal insufficiency.'

Submitted by Jim Sadlish

The next meeting of the Vancouver Island group will be held on **June 2, 2007** in Room 1814 near the cafeteria at the Victoria General Hospital in **Victoria** between 1:00 and 3:00 PM. The following meeting is scheduled for September 29, 2007.

For further information or to contact the Vancouver Island Support Group, please contact Jim Sadlish at jsadlish@horizon.bc.ca or (250) 656-6270. For information on mid-Island activities, please contact: Christy Lapi at clapi@shaw.ca or 250-245-7554; Barbara Hunn at bhunn@shaw.ca or 250-714-0036; or Sharon Erickson at ericksons@shaw.ca.

BC Lower Mainland Support Group

11 members attended the meeting February 17, 2007

- “The Heart of Diabetes” webcast from UBC, Saturday, March 10, 2007 is a free public forum to explore and discuss what’s new in the fight against diabetes and its cardiovascular complications. You can offer opinions, ask questions or just listen. If you are interested, visit: <http://www.med.ubc.ca/research/events>
- BC Paramedic Protocol request in process. We’ve sent letters to Dr. Christensen at the Health Ministry requesting an interview to look at changes to the protocol for paramedics and ambulance personnel for Addison’s patients. When we meet with Dr. Christensen, we will take your e-mails regarding your ER and ambulance experiences in the past two years.
- Discussion of the need for injection pens for our emergency kits. Marilyn will contact the makers of Dexamethasone to request same.
- 2007 meetings will be held from 1:00 – 3:00 pm in the Sherbrooke Lounge, 260 Sherbrooke Street, New West (Royal Columbian Hospital). Parking on Sherbrooke Street is cheaper than in the lot. Future meeting scheduled are:
 - May 26 Social get-together with finger foods.
 - Oct 27 UBC Interviews with first year medical students
- Our guest speaker, Ruth Ditchburn, RN, B.m.p, a nurse in private practice and a foot care clinician, spoke on *Dealing with Adrenal Fatigue*.

How Can We Be More Healthy?

Test our level of adrenal fatigue to ensure that our medications and lifestyle are adequate for our needs. If they are not, we should work with our physicians to make necessary changes, in medications or lifestyle.

There are three tests that are indicators:

- Blood Pressure: Lie down for 10 minutes, take your BP, then stand and take the BP again. If it drops 10mmHg or more then you probably have some form of Adrenal Fatigue. If your BP remains very high, over 140 / 80, consult a vascular specialist for hardening of the arteries.
- Iris Contraction Test (discovered in 1924 by Dr. Arroyo): Shine a light into your eyes. Your irises will contract — it will take longer to return to normal than in the general population but should not be sluggish.
- Saliva Hormone Test: Done once a year, it's the single best lab test, to indicate the amount of hormone inside the cells, where the hormone interactions take place. (Urine test measures the spill-over of hormones out of the blood.) NOTE: this test is done in Calgary. We must buy and pay for the test, which includes a report to your physician. The tests are available from Ruth at Pharmasave in Port Coquitlam (604-942-9813) or ask at your local pharmacy. *Note: There is a PhD., not a medical person, who is doing testing of saliva in Burnaby, but it is not an approved setting. Be wary where you get things done.*

Six Areas of Our Lives We Can Control for our Health

1. De-stressing: List the stress related activities in your life under three headings: home, work, people. The items you list are energy robbers. Categorize them into where you need to: Change or Reframe, Adapt, Leave.
2. Exercise: Take a 30-minute walk each day; take time for yourself to rebound. Walking 20 minutes outside will give your body 400 mg of Vitamin D.
3. Not Smoking:
4. Insomnia: Prepare yourself for sleep; remember to take some protein before retiring, for example, celery with peanut butter.
5. Water: Drink 64 oz. of water daily to remove toxins. Caffeine, juices, etc. all add toxins to the body.
6. Diet: Eat a healthy diet. Eat two fruits daily (mid-morning and mid-afternoon), and three vegetables — no fruit after dinner as it could interfere with sleeping. Digestive enzymes for fruits and vegetables are different. Eat every 2.5 – 3 hours daily. Restrict white flour, and yeast as they can interfere with the absorption of medications. Eat protein at each meal as it aids digestion and refuels the body. Be aware of where your food is coming from. For example, bananas are picked green, then treated with ethyleneoxide (a gas used to sterilize instruments in the operating room) to ripen them during shipping. Aspartame: when ingested into your body turns into wood alcohol (formaldehyde) which is used for embalming bodies. Do you want that in your body?

Supplements: Do you really need them all? Ensure you have sufficient calcium daily and always take supplements with your food. Calcium is a calmer and needs food for

absorption. If you're using grape seed extract, ensure it is 95% standardization. Make sure supplements are compatible with your medications — ask your pharmacist. *Be wary of supplements that say they can cure!*

Medications

Discuss new medications with your doctor before taking the prescription to the pharmacy. Will they interact with other medications you're on? Fosamax may now be taken for up to five years, rather than the previously thought two years. Lipitor is not too helpful for women or after 70 years of age.

Steroids: decrease muscle mass over time with usage, but not as pronounced for Addison's patients.

Environment

Anything plastic (plastic wrap, hard plastic containers such as Tupperware, or other cheaper brands) is an oil-based product which gives off an estrogen-like product which clogs our natural estrogen receptors and this creates a problem. Plastic drinking bottles, Styrofoam — heating them in the microwave just makes it worse. Always use glass in the microwave.

Submitted by Judy Stanley

The next meeting will be May 26 (our annual appetizer get-together).

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

Alberta Support Group

The Alberta Addison's group met on February 3, 2007, hosted by Ginny Snaychuk, with five members present.

The group reviewed the outcome of the last meeting held in October 2005. Ginny Snaychuk distributed notes from the Addison Society's Annual General Meeting of October 14, 2006, as well as the financial statements for the Alberta group.

The topic of hospital protocols for Addisonians generated a good deal of discussion. Capital Health in Edmonton is now working on an emergency room protocol and the Alberta society will be notified when this is in place. The intent is to have the protocol for the treatment of Addison's patients on-line in Capital Health emergency departments. Those present thanked Ginny for all of her work on this protocol. Ginny Snaychuk and Athena Elton will now direct their efforts to getting a similar protocol in place in Calgary.

The final item of discussion was some correspondence regarding the idea of producing an injectible cortisol pen, similar to the Epi-Pen. Ginny has been in contact with Merck, as well as the manufacturers of Epi-Pen and the National Adrenal Diseases Foundation. She would welcome any ideas or suggestions on how to move this forward.

The rest of the meeting was devoted to an open discussion, sharing our experiences and getting to know each other better.

For information on this support group, contact Ginny Snaychuk at glav@telus.net or (780) 454-3866 in Edmonton.

Submitted by Ginny Snaychuk

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

Please note that, due to construction at the Brantford Police Station, we have **re-located** our next Southern Ontario Regional Meeting to the **Brantford Visitors Centre**, – 399 Wayne Gretzky Parkway (north of the 403), **Saturday May 5th, 2007**, 1 – 4:30 pm.

Directions to the Visitors Centre are as follows:

Traveling Eastbound on Highway 403 from Woodstock/London

Exit No. 38 / Wayne Gretzky Parkway

Turn left onto Wayne Gretzky Parkway

Turn right into the Lynden Park Mall entrance off of the Parkway, Edmonson Street

Follow the Tourist Information Signs (“?”)

Traveling Westbound on Highway 403 from Hamilton/Toronto

Exit No. 38 / Wayne Gretzky Parkway

Turn right onto Wayne Gretzky Parkway

Turn right into the Lynden Park Mall entrance off of the Parkway, Edmonson Street

Follow the Tourist Information Signs (“?”).

Dr. Killinger, the Society’s medical advisor or an associate, will be available to answer questions (approx. 1 hr). The remainder of the meeting will be spent in member-to-member discussion.

If you plan to attend, and in order to know how many will be there, please call or e-mail Irene Gordon at 1-888-550-5582 or liaisonsecretary@addisonsociety.ca.

We look forward to seeing you all.

Irene Gordon (Liaison Secretary)
Joan Southam (Director)

For further information on Southern Ontario Support Group activities or meetings, contact Irene Gordon at liaisonsecretary@addisonsociety.ca or toll-free at 1-888-550-5582.

Eastern Ontario Support Group

The next Eastern Ontario meeting will be in Kingston, to enable Addisonians who are not in the Ottawa area easier access to our support group.

The next Eastern Ontario meeting is set for Saturday, **May 12, 2007, in Kingston**, 12:00-2:00 PM (but the room is reserved for 11:30 so people can wander in early), at the Aquaterra Restaurant, Fort Henry Room in the Radisson Hotel, at 1 Johnson Street in Kingston.

Speaker: Miriam Davis, R.N. will speak about diagnosing Addison's in a family member and what it's like to be the parent of an Addisonian.

Directions to the Radisson: Take EXIT 617 (Division Street Exit) off HWY 401. Follow Division Street until you reach Johnson Street - you will turn left onto Johnson (it is a one-way so it is the only way to turn on Johnson). Follow Johnson until you come all the way to the water and the Radisson Hotel is on your left at 1 Johnson Street. Go up the ramp to park. Parking is not a guarantee.

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.

Medical Q & A

- Additional useful Q&A's can be found on the U.K. Addisons site at http://www.adshg.org.uk/quest/mqdates_index.html, the Australian Addisons site at http://addisons.org.au/core.htm?page=/content/ga_med.htm, and the N.Z. Addisons site at <http://www.addisons.org.nz/newsletters.html>. If you have not already done so, we encourage you to browse through these complete sites. After all, Addison's is the same disease, wherever you live.

Q: Can you please tell me where in Canada I can go to get a cortisol day curve done on my wife who has Addisons?

A: A day curve follows cortisol levels throughout the day. For individuals who are not in hospital, this would mean going to the lab every 2 or 4 hr starting at 8 AM until the lab closes, usually at 6 PM. This is most useful in someone who is not on cortisol replacement since it would provide information about the output of cortisol by the adrenal gland. In someone who is on cortisol, it would reflect the levels of cortisol produced by the medication and would depend on when the cortisol tablets were taken. In general, this would not provide much useful information unless there is some reason to be concerned that the metabolism of cortisol is altered. This can occur in individuals on some types of medication such as anticonvulsants. Another way to get this type of information is to do a 24-hr urine collection for free cortisol. It would be lower than expected if metabolism is increased. These tests can be arranged at any of the commercial labs.

Q: I was diagnosed with Hashimotos thyroiditis 8 years ago. I was only able to get treatment in the past three with Armour thyroid. I have had a lot of trouble getting the dose right, with many periods of hypo. I increased to as much as 6 grains a day and was still hypo. My doctor thought I was probably suffering from thyroid hormone resistance. However, with hormone resistance, the TSH should not be suppressed, and mine was. I did some research on the internet and discovered that my adrenal glands could possibly be insufficient, so I ordered a 24-hour urine test (4X/day) and sure enough, my levels for all 4 were from 0-4 on a range to 20, I believe. I stopped taking thyroid and took only cortef for about 2 weeks, increasing the dose until I felt better. When I started on Armour again, I found I was much better able to tolerate it, with improvement in symptoms that nagged me for years (hair very brittle, severe hair loss, cystic acne, severe dry skin on legs and hands, insomnia...to name a few). My question is this: I felt better on a dose of 25 - 35 mg cortef a day. Then the pharmacy put 10 mg tabs in a bottle labelled 5 mg. and I took approx 60 mg cortef a day for a week before I noticed. I actually felt better, lost weight, hair improved and so forth. I lowered it immediately upon discover to 40 mg a day (by the way, I divide my dose 3x/day). I would like to get it lower and then stop eventually when my adrenals appeared to have healed sufficiently. Are these doses all together too high? I have not been diagnosed with Addisons, yet find I'm taking as much or more cortef than those who have. It scares me a little. Also, when I go to have another 24-hour urine test for adrenals, should I take my dose of cortef that day or hold off? Lastly, how can I know it's time to begin to decrease my dosage?

A. You have posed some interesting but difficult questions. Both your thyroid situation and the adrenal problem are not straightforward. You should be discussing these questions and lab results with your endocrinologist. There are several types of thyroid resistance so even with a suppressed TSH, it would still be a possibility. The Armour thyroid medication contains more T3 than T4 so the blood results can be difficult to interpret if this is not taken into consideration. I am not sure how to interpret your urine

cortisol results. If you are going to do more urine cortisol tests, you will have to be off medication for at least 48 hrs before starting collection.

This is a complex series of problems, which needs the expertise of an experienced endocrinologist.

Q: I am not sure if I have Addison's or if I am heading in that direction. I have had two cortisol saliva tests and both came back below normal limits on 6 am and 12 midnight levels. I feel like I have a bad hangover most of the time and moderate depression (I am a non drinker) but start to feel better after 6:00 pm every day (you could set your watch by it). If not early stages of Addison's, then what else could this be (going on 4 years)? I have tried many herbal remedies and glandulars, which worked for a short time, then stop working after a few days. My doctor put me on very low dose cortef but I felt worst after taking it.

A: The symptoms you have described are quite non-specific and could be associated with a variety of problems. None of the labs in this area measure salivary cortisol so I am not sure how accurate the values are that you have had. If they are done well, they are very good.

The most satisfactory way to diagnose adrenal insufficiency is to measure cortisol and ACTH levels. In Addison's disease, the problem is in the adrenal gland and ACTH levels will be high in attempting to make the adrenal work harder. If the problem is in the pituitary gland, both cortisol and ACTH will be low.

If you are taking cortisol, the tests will be difficult or impossible to interpret. You should discuss the situation with an endocrinologist who can assess both your symptoms and your physical examination and help to suggest further lab work or suggest other possible causes for your symptoms.

Q: I have had Addison's Disease since I was 16 and am now 42. I had to receive solu-cortef and saline solution in the hospital 2 or 3 times when I have had food poisoning or similar illness. I am planning to cross the Atlantic with 5 other people aboard a 65 foot sailboat. I wonder if this is too risky, or if in the event of not being able to absorb cortef (i.e.: seasickness) I can manage with injecting solu-cortef.

A: A trans-Atlantic trip on a 65-foot sailboat sounds very exciting. I assume that all of you are experienced sailors and are well prepared for the sail. The fact that you have Addison's disease adds an extra concern to the trip, but if you are well prepared you should be able to handle it without too much of a problem. As you know, you should have the Solu-Cortef emergency kits available and each of the members of the crew should be aware of your situation and should be able to do the injection for you. The Acto-vials come in boxes of 10 and I think you should have a box and at least 10 syringes and needles with you. If you should get sick and can't keep your pills down, you will need one and possibly two injections a day depending on the situation. It would

also be a good idea to have some drinks along which contain salt such as Gatoraid. It sounds like a great opportunity; I hope you have a great time.

- **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 La Société canadienne d'Addison

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Goderich, Ontario N7A 2E7

Toll free number: 1-888-550-5582

Email: liaisonsecretary@addisonsociety.ca

<http://www.addisonsociety.ca>

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

New Membership

Renewed Membership

+ Plus a Contribution

Name: _____

Address: _____

Postal Code: _____ Telephone: _____

E-mail Address: _____

How do you wish to receive the Newsletter?

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

by mail

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

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

\$25.00 to go to The Canadian Addison Society

OR

\$5.00 to 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

+ 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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