



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

193 Elgin Avenue West

Goderich, Ontario N7A 2E7

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<http://www.addisonsociety.ca>

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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.

Message from our new President:

Dear Members,

Seven years ago, a 21-year-old man was going into cardiac arrest for no apparent reason. He was transferred from hospital to hospital while doctors looked for a reason

The Canadian Addison Society is a registered charity, # 87248 5511 RR0001.

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for his illness. He was a football player and seemingly so healthy, and tanned; it was impossible to believe he was dying. Rare disease specialists could not diagnose his condition.

Luckily, a nurse had a personal interest in his case and searched her textbooks until she was able to diagnose him with Addison's disease. Unfortunately, the doctors refused to believe her, and he had to slip into crisis before they tested and treated him for Addison's disease.

The nurse in this story is my sister and the young man is my brother. Four years later, I could not walk up a flight of stairs without having to catch my breath. I was thin as a rail and dark as a bran muffin. Sound familiar? My doctor kept treating me for a kidney infection that just wouldn't go away. After suffering for several months with a recurring "kidney infection", my brother diagnosed me with Addison's disease. After confirming the diagnosis with an endocrinologist, my personal experience of living with Addison's disease began.

I think these kinds of stories are familiar to all of us reading this Newsletter. We need to have more support from the medical community, and to get this support we need to educate medical practitioners about Addison's disease. We also need support on how to live with our condition and how to control our medications. With a condition as rare as Addison's disease, it is easy to believe you have to suffer alone. There is fatigue, and then there is "Addisonian" fatigue. On-line chat groups and meetings with an endocrinologist once a year do not suffice; we need the community of others who share our experiences.

The Canadian Addison Society is an excellent organization to help fulfill our needs as people with Addison's disease. The Society's mandate is to support people with Addison's disease and other associated adrenal gland diseases, by distributing information, and providing the opportunity to meet with other people who share the same condition.

I cannot express the personal benefits I have experienced from talking with other members of the national Society, and meeting with members in my former chapter of the Society in Eastern Ontario. For this reason, I would like to give back to the Society by taking on the responsibilities of President. I look forward to working with the membership and the Board of Directors to continue the amazing and inspirational work of Greeta McKague and Joan Southam.

Greeta and Joan, thank you, thank you, thank you.

There is much to be done, and I am looking forward to the challenge. If you would like to contact me, please feel free to e-mail me at athena@pathcom.ca (and shortly, we will

add an email link to the President from our new website which is currently in development).

Yours sincerely,
Athena Elton

Important Announcements:

- We regret to inform you that Maxine Carpenter and Sheralyn Calder, both from B.C, have passed away. We send our condolences to their families.
- This is your newsletter! We need your contributions. There are a few ideas, but we need **YOU** to write a short note or article on:
 - services regional contact person can provide to you (add to website)
 - benefits and how to designate the Canadian Addison Society, a registered charity, in a Will or as a remembrance
 - how to start a regional support group
 - thoughts on dealing with an Addisonian spouse
 - how to advocate for an Addisonian in crisis – a checklist of information
 - how to educate family and friends on Addisons—do's and don'ts

Please send your stories, tips and ideas directly to our editor Steve McKenna via email at sgmckenna@cyberus.ca or c/o the Addison Society.

New News:

- The new website is slowly taking shape, with contact email addresses for general information (liaisonsecretary@addisonsociety.ca), membership and the newsletter, as well as email contacts for each of the regional representatives.
- Francisca Swist has brought an interesting website to our notice: http://www.pihealth.com/adrenal_glands_and_stress.htm. Check it out.

Liaison Secretary:

We still do not have anyone for this essential position. We recognize that everyone is quite busy and that this job will take a little time. In recognition of both its importance and the energy these tasks require, the Canadian Addison Society is willing to offer \$100.00 as a monthly stipend.

This position is responsible for liaison with members and individuals who are unfamiliar with Addisonians and/or have recently been diagnosed; with international Addison

associations (especially in the USA, UK and New Zealand); responding to queries through the website or our Addison phone line (1-888-550-5582); and helping with arrangements for the annual general meeting of the Canadian Addison Society.

Please consider coming forward to help your Society continue to function.

Share the Newsletter:

Don't just keep the Newsletter to yourself – spread it around!

To make sure that as many people as possible can learn about Addison's Disease, please consider making copies of each Newsletter as you get it, and ask to leave one with your family doctor, your specialist, the local hospital, at a medical school or with any others who may be in the medical field or just plain interested. The more we get the word out about our condition, the better it is for those of us who may need help at sometime in our lives in dealing with a crisis situation.

For example, earlier this year I was taking a course and found that some of the other participants work in the medical field. One person, who works at the Royal College of Physicians and Surgeons, was quite interested to see a copy of our last newsletter and she intended to post it on the internal bulletin board at the College. Another person works at a medical facility in Ottawa. She found the Addison Society Newsletter to be interesting and informative, and she too was going to post our Newsletter on her workplace bulletin board.

Getting the Newsletter read in places where it would not normally be seen can only benefit the Society and those that suffer from this condition. So, whether you receive the Newsletter via email, or still receive the Newsletter via Canada Post, find a copier. If everyone spreads the information in this way, perhaps we can help people become a little more familiar with this condition, making life a little safer for those of us who suffer from Addison's Disease. I always have a couple of extra copies in my briefcase just in case I run across someone who is interested in reading about the disease.

Remember, a small effort from each of us will bring this condition to a wider audience.

The Newsletter will soon be available on our website. Read it at www.addisonsociety.ca.

Mayo Clinic Study:

DHEA Effects on Insulin & Cholesterol*

Dehydroepiandrosterone (DHEA) is produced in the adrenal glands. In 2003, 28 adrenal-deficient women participated in a 12-week trial at Mayo Clinic, Rochester, Minnesota. A portion of that study was designed to assess the effects of DHEA on insulin sensitivity and lipids. The women received single daily 50 mg doses of DHEA.

The findings:

- DHEA replacement significantly increased insulin sensitivity. It may prevent the onset of type 2 diabetes.
- Total cholesterol, low density lipoprotein (LDL), triglycerides and high density lipoprotein (HDL) were significantly reduced with DHEA replacement. Reducing triglyceride and LDL levels may prevent cardiovascular death.

The researchers stress, though, that further work needs to be done before DHEA can be routinely recommended for adrenal-deficient people.

* "Effects of Dehydroepiandrosterone Replacement on Insulin Sensitivity and Lipids in Hypoadrenal Women", Ketan Dhatariya, Maureen L. Bigelow, and K. Sreekumaran Nair, *Diabetes* 54: 765-769, 2005.

Submitted by Joan Hoffman

(Ed. note: The full article can be obtained by sending a request to the Newsletter editor S. McKenna sgmckenna@cyberus.ca.)

Results of Research Project – Stress Associated with Type-A Behaviour as a Contributing Factor to Autoimmune Addison's Disease:

Francisca Swist, in Alberta, thanks everyone who replied to her survey in the last Newsletter. She completed her research project, and would be pleased to send the full version (about 6 pages) along with a copy of the survey questions used and the actual statistical analysis to anyone who would like it. Francisca can be contacted at francisca@shaw.ca

Abstract

The negative results of stress are many, particularly when the stress levels are prolonged, or even chronic as they are for those individuals with type-A behaviour. Stress has been associated with some autoimmune diseases, but the autoimmune disease of particular interest is Addison's Disease. As a means to

demonstrate a relationship between type-A behaviour and Addison's disease, a survey was developed and distributed to individuals with autoimmune Addison's Disease. The survey questions focus on a few key components of type-A behaviour, but in particular impatience and aggression, which are the two cardinal features according to Sharma (1996). The results of the survey indicate a strong tendency toward type-A behaviour among the respondents. Through the survey results and interpretation of various studies, there seems to be a possible correlation between the stress associated with type-A behaviour and autoimmune Addison's Disease.

Submitted by Francisca Swist

Emergency Letters:

A number of members have expressed an interest in the format and contents of a letter which could be used in case of emergency, at a hospital, when travelling (especially when crossing international borders with a syringe), etc.

All the letters we have seen follow a basic format, and include the following elements:

- Letterhead - Medical Centre
- Name of the patient. (and date of birth)
- Statement that the patient has Addison's disease.
- Replacement medications (giving dosages of all replacement medication)
- Statement that the patient may also be carrying an emergency kit and syringes
- "In an emergency situation the patient should receive hydrocortisone (Solu-Cortef) 100 mg IV stat. and then another 100 mg over 8 hours plus normal saline IV to maintain blood pressure and potassium as needed."
- "Patient may need more Solu-Cortef over 24 hours."
- Signed by the doctor

We have included several sample letters as annexes to this Newsletter. You may find these useful when asking your doctor for such a letter to carry with you.

Emergency Letters – A Personal Experience:

Just wanted to stress how important it is for all Addisonians to **always** have a note or letter from their doctor with them at all times, in case of emergency. The note should indicate we have Addison's Disease, how serious it can be, and the type of treatment which should be administered.

In early March, I was admitted to Nanaimo Hospital for relatively minor surgery. With me, I had a letter from a physician from the Victoria, B.C., Hospital, explaining the symptoms and treatment of Addison's. I took extra Cortisone Acetate before, during my stay, and following release. Apparently, the dosage was not high enough for me at the time. I was still stressed from Christmas (horrid flight to Southern U.S., husband ill there with Norwalk Virus, etc, etc.) I ended up going into crisis, and a dandy one it was. An ambulance was called. Luckily, in ER, I was seen quickly by the on-staff physician who called an internist. IV was started immediately, but I went into shock, was rushed to ICU where my husband was told I was losing all my vital signs. Heart problems followed, pneumonia and another infection. Finally, two weeks later, I was released after mega-doses of antibiotics and Solucortef IVs.

A couple of days later, I felt weak, nauseous and dizzy. My husband again called an ambulance, fearing I would go into crisis on the short drive to the hospital.

This time, I did not have a copy of the Doctor's letter. The triage nurse, when told her I had Addison's, asked, "What's that?". I waited over 4 hours without treatment, before being seen by a hospital physician. The IV was finally started and I began to feel a bit better.

Moral of the story: I really believe the doctor's letter was vital. It was distributed to us through the Chairperson for Vancouver Island (Victoria) Support Group. (A copy of this letter is attached to this Newsletter as *Sample Letter Provided by a BC Specialist to the Vancouver Island Addison's Disease Support Group.*)

Barbara Hunn, Co-chair, Mid Island (Nanaimo BC) Support Group

Hospital Emergency Room Protocol:

We have received several enquiries about the Ottawa Hospital Emergency Protocol for dealing with Addison patients in crisis included in the last Newsletter. Therefore, we are reproducing the information as an annex to this Newsletter, for anyone who missed the February 2005 newsletter. The Ottawa Hospital's protocol can also be found on the web at <http://addisonsdisease.tripod.com/id4.html>.

We encourage you to keep several copies of this protocol with your emergency kit(s). We also suggest that you keep a copy with you at all times, perhaps in your wallet or purse.

Although you may not live within the area served by the Ottawa Hospital, you may find that your local hospital has a similar protocol in place. If not, here's your chance to make a difference in your area – not only for yourself, but also for those who come later with the same condition. If your local hospital does not have such a protocol in place, they may be interested in using the one from the Ottawa Hospital to add to their

collection. Please encourage them to do so. If they need more information on this document, have your local hospital contact the Ottawa Hospital's Endocrinology Department or Dr. Silverman.

Re-Hydration Drink:

With the hot weather coming, we have been asked to re-print a recipe for a "re-hydration drink" first published in the July 1999 issue of the Newsletter.

1 litre water
2 Tbsp. sugar
1/3 to 1/2 tsp. salt
Lemon juice (optional)

Another recipe is:

2 tsp sugar
1/4 tsp salt
juice of 1/2 lemon
1L of water

Feel free to experiment, and adjust the recipe to your own taste.

As well, during very hot weather, or if sweating a lot while working outdoors, you may find it helpful to increase your dosage of flori-nef either on hot days or every other day. If in doubt, discuss this with your medical advisor.

Highlights from Local Meetings:

Vancouver Island Support Group (Nanaimo)

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

Vancouver Island Support Group (Victoria)

The Vancouver Island support group met in Victoria, B.C. at the Victoria General Hospital on Saturday, Feb. 5, 2005. Topics discussed covered familiar areas of interest:

- The importance of taking some extra salt in our diet, when we are dehydrated by illness or other stresses, was suggested.
- It was noted that in the November 2004 Canadian Addison Society Newsletter, Dr. Killinger, Medical Advisor to the Society, stated "50% of primary Addison's

patients may have hypothyroidism". Antibody tests, prescribed by endocrinologists, can determine if thyroid antibodies are present.

- Most of those present noted a decline in height. Losses ranged from $\frac{3}{4}$ inch to 2 inches (however the $\frac{3}{4}$ inch loss was for a non-Addisonian). Regular bone density tests are advised when taking steroids and daily calcium supplements are recommended.
- The Emergency Letter by Dr. Pledger has been distributed to all Vancouver Island support group members and has already helped several people in visits to Emergency. If you have not received your copy, please contact Jim Sadlish jsadlish@horizon.bc.ca. The inclusion of the term "cardiac arrhythmia" as a possible symptom of Addisonian crisis was discussed. Aldosterone regulates kidney excretions of sodium and potassium. Lack of aldosterone, as in people with Addison's, can result in hyperkalemia, high levels of potassium in the blood. In extreme cases of crisis, hyperkalemia may lead to arrhythmias that require immediate medical attention. We will seek the advice of an endocrinologist and consult Dr. Pledger before editing the Emergency Letter. To read about hyperkalemia refer to:
<http://www.nlm.nih.gov/medlineplus/ency/article/001179.htm>.
- One attendee noted that prior to diagnosis she was advised that her blood tests showed a high potassium level. She was informed that high potassium increases the risk of heart attack. Other members have experienced kidney failure prior to diagnosis. However, our replacement medication is designed to take over the job of the adrenals and regulate the kidneys.
- One person planning a trip overseas requested and received a letter from her endocrinologist explaining why she must keep syringes for emergency meds in her carry-on luggage. Others present noted that MDs will charge a fee for writing a letter. A pdf manual for injecting Solu-Cortef is available at:
http://www.cc.nih.gov/ccc/patient_education/pepubs/mngadrins.pdf.
- Another member was advised by her doctor that everyone with Addison's should carry emergency medications with a syringe should they be in crisis and held up waiting in line at hospital Emergency. With the long waits for emergency treatment that seem normal these days, you may need to self-medicate if treatment is delayed.
- The recent news about a Vitamin E study was discussed. One person was advised by her MD to reduce daily intake of Vitamin E to below 400IU. To read a study review and responses to the study refer to:
<http://www.annals.org/cgi/content/short/142/1/37>.
- Several members are taking fish oil supplements to increase intake of omega 3 essential fatty acids and improve memory. Another found flax seed oil better for her and feels it helped to improve her eyesight. One member has found shelled hemp seeds are beneficial to his health.
- Most Addisonians attending the meeting were taking DHEA and felt it improved their wellbeing. However, one has stopped it because of the difficulty finding a

government-approved source in Canada. Dosages varied among those present, from 50 mg to 25mg every other day.

- Several people have been warned that they are developing cataracts. Long-term steroid use may contribute to the cause of cataracts and glaucoma but can be detected by regular eye exams and evidently can be treated.

The Vancouver Island support group will meet again on Saturdays, **June 4** and October 15, 2005.

Submitted by Jim Sadlish

For further information or to contact the Vancouver Island Support Group (Nanaimo), please contact Jim Sadlish at jsadlish@horizon.bc.ca or (250) 656-6270.

BC Lower Mainland Support Group

Thirteen members were present at the meeting February 19, 2005. Highlights:

- Discussion of recent emergencies members experienced
- Discussion of the value of the Canadian Addison Society to members. However, there were no volunteers for the positions of President or Secretary.
- One member has just had her application for long-term disability approved by her Union. She recommends that you keep a medical record diary of your condition. Anything that affects your lifestyle, fatigue, illness, how you recovered at home etc. Those who are not affected often misunderstand Addison's Disease and clear documentation can assist with your claim.
- A member reported her experience with a bout of the flu, during which she had chest pains, called for an ambulance and spent three hours on a stretcher in emergency. Fortunately she had injected herself at home before leaving for the hospital, as it took several hours before an IV was inserted.

Our guest speaker was Darlene Redman, Paramedic Chief for New Westminster, thanks to Michel White.

- For all emergencies (crisis or not) call 911, and the medical dispatcher will ask a series of questions to determine the seriousness of the call. Questions asked could cover whether the patient is conscious, has breathing difficulties, has chest pains;
- There are two levels of care: **Primary** which covers most calls and will monitor blood pressure, sugar levels etc; and **Advanced Care** which has a cardiac defibrillator and more advanced equipment on board;
- First responders are usually firefighters; they also have a defibrillator;
- Most paramedics have never seen an Addisonian; nor have some Emergency units;
- Medic Alerts that resemble jewelry are often missed as they are harder to recognize, a bracelet is easier to spot than a necklace;

- Emergency Doctors and Paramedics do not have time to phone the number on the bracelet so keep the information to a minimum i.e. condition and any severe allergies;
- An emergency form listing condition, medications, etc. which is kept on the refrigerator saves paramedics time;
- Have information ready for personnel - a list of medications and if possible available to take to the hospital, allergy to medication, what happened to bring the situation on, what prompted the call;
- If the patient is unconscious, they may have to search cupboards for medication if no other information is available;
- It can be hectic in a severe crisis while things are happening quickly and personnel can seem abrupt at times;
- They can assist to self-administer medication but can only insert an IV if needed;
- They usually don't look in wallets, backpacks etc.;
- For easy access information can be kept with your CareCard which will be asked for;
- Medical follow-up is done at the hospital. Only common information is kept on the CareCard which is swiped on entry to ER;
- If unconscious in a car accident, information obtained on site can be passed to ER personnel but not acted upon by ambulance personnel i.e. cortisone injection;
- Pharmanet is the only medical system for universal information;
- If you are not getting results in ER, try to contact someone more senior, if possible. Members felt this was extremely difficult in the situation.

We will follow up Darlene's suggestion to contact the Justice Institute, where all paramedics are trained in B.C., asking that Addison's Disease be included in their training curriculum. Also, their Director of Public Education suggested we write to the British Columbia Ambulance Service requesting it provide a public education officer similar to that provided by other emergency services. We will continue with our quest to have all ER's in BC on a common database to save time when entering the system.

Please note changes at the parking lot at 240 Sherbrooke Street which have increased costs. For RCH and Sherbrooke lots, paying with a credit card may avoid problems as the machines fail regularly. If you do experience problems, we suggest you fax a copy of all the dispensed tickets, any notes written, and any parking ticket to IMPARK with an explanation; it would be useful to call them first to explain the situation.

The next meeting will be held **June 4, 2005** Sherbrooke Lounge, Sherbrooke Centre, 260 Sherbrooke St. New Westminster BC 1:00 to 3:00 p.m. It will be a pot luck appetizer so bring a beverage and your favourite finger food to share; plates and napkins will be supplied.

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 or any upcoming meetings, contact Francisca Swist at francisca@shaw.ca or Ginny Snaychuk at glav@telus.net or (780) 454-3866 – both are from Edmonton.

Saskatchewan Support Group

If you wish information about this support group or upcoming meetings, contact Elizabeth Hill at Meadow Lake (306) 236-5483 kesahill@sasktel.net or elizabeth.h@pnrha.ca.

Southern Ontario Support Group

The Southern Ontario group was to meet on Saturday April 2, 2005.

For further information, contact Jordan Latter at annemarielatter@yahoo.ca or call (905) 893-4374

York / North Toronto Region Support Group

Bill Horlick is trying to set up a local chapter of the Canadian Addison Society in the York / North Toronto area. If you are interested, please get in touch with Bill Horlick at bhorlick@netrover.com.

Eastern Ontario Support Group

The group from Eastern Ontario met on May 28, 2005, to exchange experiences and ideas. Members came from as far as Peterborough, Kingston and Cornwall. There was no guest speaker for this meeting but numerous suggestions were made as to whom we could invite in the future. Some ideas were:

- Chief of Emergency Medicine from local hospital
- Chief of Nursing from local hospital
- Paramedics
- Medical School teachers/students
- Dietician
- Naturopath
- Medical Association representative

An announcement was made that the Society is urgently in need of a National Secretary to replace the out-going Elaine Hall.

A suggestion was made to move the May meeting to the weekend before the holiday weekend, since the weekend after is often very busy for members. All present approved

the suggestion. The May 2006 meeting will be on Saturday, May 13, 2006 – the weekend before the Victoria Day Weekend.

The next meeting is scheduled for noon on **Saturday, October 15, 2005**, at Robbie's Restaurant on St Laurent Blvd in Ottawa. For information, please contact Sue Steedman at (613) 726-7414 or steedman@magma.ca (or Teresa Seasons at tseasons@magma.ca.)

Québec Support Group

If you are aware of any support group activities in Québec, or have a contact name or address, please forward the information to the Newsletter editor, Steve McKenna at sgmckenna@cyberus.ca.

Reminders:

- **Medical Questions and Answers - Dr. Donald Killinger, MD, PhD, FRCPC**, from Ontario, who is the Medical Advisor for The Canadian Addison Society, will answer your questions about Addison's disease. Questions and answers that may be of interest to everyone will be published in the newsletter. Dr. Killinger has asked that we not write to him directly, but rather address your questions by letter/e-mail or fax through The Canadian Addison Society and they will be forwarded to Dr. Killinger. This will be easier to do once we have our web site fully operational.
- Please – If you are pleased with your **endocrinologist** – LET US KNOW. We have many requests not only from recently diagnosed Addisonians but other Addisonians from all parts of the country, who may be moving from one area to another and require the services of an endocrinologist knowledgeable about Addison's disease and its treatment.
- This will be the last copy of the **newsletter** that members who have not paid their dues for 2005 will receive, unless outstanding dues have been received before the next newsletter is ready for distribution.

The Ottawa Hospital - Emergency Department Policy and Procedure Manual

Policy:

Patients may present identifying themselves as having Addison's disease, adrenal insufficiency, hypopituitarism or being on long-term steroid therapy - either by way of their history, wearing a medic alert bracelet or during review of patient's medications.

Procedure:

1. Symptoms:

Patients presenting with:

Vomiting, diarrhea, decreased urine output:
Clinical signs of dehydration
HR>100
Systolic blood pressure less than 120.

2. Action:

Draw CBC, glucose, electrolytes, calcium STAT

- Patient to be seen by physician within 15 minutes
- Physician management:
 1. Normal saline (500 cc per hour for the first hour, monitor Fluid status, blood pressure, heart rate)
 2. Hydrocortisone (Solu-Cortef) (100 mg IV bolus)
 3. Hydrocortisone (Solu-Cortef) (100 mg IV Q8h)

If the patient condition stabilizes, tolerating oral fluids and normal vital signs then discharge with oral glucocorticoids tripled. Patient to contact their endocrinologist or family physician within 48 hours.

3. Mild cases:

In milder cases, dose can be either doubled or tripled depending on the physician's judgement.

Sample Letter Provided by a BC Specialist to the Vancouver Island Addison's Disease Support Group

Dear Triage Nursing

Re: Addison's Disease

The current health care crisis, with unacceptably long wait times for patients in the emergency department has led to inconvenience for some and a denial of access to timely health care for others. While presentations such as chest pain, shortness of breath and trauma lend themselves to straightforward triage, patients with Addison's disease represent a special sub-population.

Please be aware: patients with Addison's disease who present with seemingly trivial complaints (e.g. the flu) may be at risk for life threatening events. While it is often believed that these patients may self-medicate with steroids, or that they cannot be in imminent danger if they present with a normal (supine) blood pressure reading, neither of these is universally true. Accordingly, these patients are often in danger of acute adrenal insufficiency. Please triage these patients with care.

Doctor's name and credentials

Patient's Name: _____ Home Tel: _____

Family Doctor: _____ Tel: _____

Specialist: _____ Tel: _____

Medications and Dosages: _____

Diagnoses: _____

Addison's Disease, primary adrenal failure, is characterized by chronic glucocorticoid and mineralocorticoid deficiency. **Adrenal crisis is an acute, life-threatening emergency.**

The symptoms of Addisonian crisis include:

- extreme fatigue, drowsiness, possible mental confusion and loss of consciousness;
- nausea, vomiting, or diarrhoea;
- low blood pressure, low blood sugar, high potassium, low sodium, abnormal heart rate;
- abdominal pain;
- severe headache, feeling extremely cold, possible fever.

**Sample Letter Provided by an Ottawa, Ontario, Specialist to the Eastern Ontario
Addison's Disease Support Group**

Date

Re: XXX
Address

To whom it may concern:

XXX is a patient of mine. He/She was diagnosed with Addison's disease (primary adrenal insufficiency) in DATE. He/She requires cortisone NAME OF DRUG (Cortef, prednisone, etc) AND DOSAGE for the management of this condition, as well as fludrocortisone (Florinef) 0.1 mg daily.

Mr./Mrs./Ms. XXX requires urgent treatment for adrenal crisis in case of an emergency, or if he/she develops severe vomiting or dehydration, as he/she does not have the normal stress response of increased cortisol secretion.

Should he/she present to a hospital emergency room, he/she requires immediate intravenous normal saline at a rate of 250-500 ml/hour and immediate intravenous hydrocortisone 100 mg IV Q8H. This is generally tapered to 50 mg Q8H for 24 hours and the standard oral cortisone dosage can be resumed on the third day if his/her condition is improved.

Sincerely,

NAME OF DOCTOR and CREDENTIALS

Other Sample Letters Provided to Addisonians by their Doctors

On official letterhead

Whom It May Concern:

Re: Name of patient ; Date of Birth: xxxxxx

Please be advised that xxxxx has Addison's disease, a very serious medical condition, requiring regular daily dosing of corticosteroid medications. This condition may necessitate the need for intra muscular injection of medication via needle and syringe. Failure to receive his required medication may be fatal.

xxx is currently on: (Insert correct medications and dosages)

- 30 mg Cortef
- 0.1 mg Florinef

In case of an emergency, this person will need immediate intravenous cortisone and saline.

If you have any questions or concerns please feel free to contact (Name of doctor of medical center) at the above noted address and phone number.

Sincerely,
Name, credentials and signature of doctor

Whom It May Concern:

Re: Name of patient ; Date of Birth: xxxxxx

Please be advised that xxxxx has Addison's disease, a very serious medical condition, requiring regular daily dosing of corticosteroid medications. Because of his/her condition, s/he may have on his/her person the following:

- Hydrocortisone tablets (Cortef): S/He currently takes 30 mg
- Fludrocortisone (Florinef): S/He currently takes 0.1 mg per day
- Solu-Cortef emergency kit, including syringes

In case of an emergency, this person will need immediate intravenous cortisone and saline.

If you have any questions, please do not hesitate to contact my office.

Sincerely,
Name, credentials and signature of doctor



The Canadian Addison Society
La Société canadienne d'Addison
193 Elgin Avenue West
Goderich ON N7A 2E7
1-888-550-5582

Website: <http://www.addisonsociety.ca>

New Membership

Renewed Membership

Name: _____

Address: _____

Postal Code: _____ Telephone: _____

E-mail Address: _____ Fax: _____

How do you wish to receive the Newsletter:

- I will read it on the website at www.addisonsociety.ca
- by email (thereby saving costs for the Society). Ensure you provide us with your up-to-date email address.
- by snail mail.

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

The yearly fee for the Canadian Addison Society is \$25.00 due January 1 of each year.

You also have the choice of directing \$5.00 of the annual fee to an approved local support group of your choice. Please check box of your choice.

() \$25.00 to go to the Canadian Addison Society

OR

() \$5.00 to Québec Support Group – Quebec + \$20.00 to Society

() \$5.00 to Eastern Ontario Support Group – Ontario + \$20.00 to Society

() \$5.00 to Southern Ontario Support Group – Ontario + \$20.00 to Society

() \$5.00 to Saskatchewan Support Group – Saskatchewan + \$20.00 to Society

() \$5.00 to the Alberta Support Group – Alberta + \$20.00 to Society

() \$5.00 to B.C. Lower Mainland Support Group – British Columbia + \$20.00 to Society

() \$5.00 to Vancouver Island Support Group (Victoria) – British Columbia + \$20.00 to Society

() \$5.00 to Vancouver Island Support Group (Nanaimo) – British Columbia + \$20.00 to Society

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