The Canadian Addison Society
La Société Canadienne d’Addison

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ISSUE NO.34 NOV 2003

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PLEASE NOTE: The content of this newsletter is intended for basic information only and not as personal medical advice. We advise readers to consult their own doctor before making changes to their Addison management program.

President’s Message:

Dear Friends and fellow Addisonians:

I hope all of you are enjoying the last of the fall season before the snow flies. The advancing cold weather is also the time for flus and colds so be sure to ask your physician about the flu shot.

On Oct. 17th, I travelled to Ottawa to attend the annual meeting of The Canadian Addison Society. The meeting was well attended, with many members from the Ottawa area, members from Southern Ontario, as well as Quebec. There were some lively discussions, with some excellent points of interest raised. Our speaker was Dr. Weinberg who gave us information on several case studies and treatment of his Addisonian patients. It was a time of sharing, learning and meeting new people and it was so nice to be able to put a face to many of the names that I have had contact with over the years. All who attended seemed to feel it was a very positive experience, myself included.

The Emergency Department problems that many from across the country have experienced are being addressed. Recently we had speakers, Dr. Gene Jarrell from Ontario, and Dr. Urbain Ip from British Columbia as guests of two local support groups. With information from these two speakers, we will be more prepared the next time we enter the Emergency facilities across the country. I have sent a letter to both of these physicians to “introduce them” to each other, since they both indicated their willingness to help. A copy of the letter was also sent to Dr. Killinger and hopefully he will contact both of them for added support and information, particularly if he is approaching the Canadian Medical Association on our behalf.

These last few months have been a busy and frustrating time for some of our members. Several are having problems getting approval of DHEA or renewing their approved prescriptions for DHEA since the government has changed some of the forms and made obtaining the compounded, government-approved DHEA much more difficult. We will have to work as a group and individually to put pressure on the government to give us the opportunity to experience DHEA ourselves if we so wish. Look for the letter attached to the newsletter that can be sent to Mr. Ian MacKay of Health Canada, to the Honourable Anne McLellan Minister of Health Canada and to your local Member of Parliament. Dr. Killinger has also added weight to our cause by writing several letters himself to Mr. Ian MacKay.

We are looking for a Co-Chairperson for the Southern Ontario support group to work with Jordan Latter. If you would like to help out, please contact us.

If you have any concerns or any problems, don't hesitate to contact us.

My wish for you for this coming season is to have a happy, peaceful and above all healthy Christmas season.

Sincerely,

Joan Southam (jsoutham@rogers.com)

Important Announcements:

- **Annual Membership Dues** – Reminder that annual renewal fees are due on Jan 1st. Please find a membership renewal form on last page of newsletter. Thank you.
- **DHEA** – As outlined in several minutes of local meeting groups, this is a major concern for several of our members. A letter is attached for signature and mailing to Ian McKay, Health Canada Special Access and Minister of Health, Anne McLellan asking that they reconsider their position on the use of DHEA for Addisonians and continue to make it available through prescription from our specialists. Members may also want to send copies to their GPs, MPs endocrinologists, the Canadian Medical Association and the Centre for Rare Diseases.
- **NADF** is requesting feedback from women who have had a pregnancy since diagnosis to assist with enquiries and support for fellow female Addisonians who are interested in having children. They can be contacted by email at nadfmail@aol.com or by mail at 505 Northern Blvd, Great Neck, NY 11021.
- Report on genetic banking research discussion by Judy Stanley. On October 22nd, she attended a group discussion on topics related to genetic banking and genomics which could provide significant benefits to society. The forum was two hours with numerous topics covered, pros and cons. Of special interest to her were the problems related to ethics, privacy, legislation, consent for each use, resale of information, confidentiality, discrimination and the role of non-profit organizations in education, advocacy, data banking etc. The information obtained from the evening is confidential but she will receive a summary of the results.

The Genome British Columbia & BC Society of Laboratory Science are holding a seminar at Science World on December 6 anyone interested in attending go to www.bcsls.net or 1-604-714-1740 or if you would like more information about the research project http://gels.ethics.ubs.ca/

Definitions:
Genomics – the study of an organisms genome
Genome – all the genes in the organism
Genetic Banking – the collection of genetic material and health information for research related to human health
Such research information might be used to develop personalized treatment, identify inherited risks for disease, or understand the role of genomic and environment contribution to health populations. Genetic data banks have been or are being set up in various countries around the world.

- Watch for experiences from members participating in the DHEA research study at the MAYO clinic in the next newsletter.

New News:

Annual General Meeting – October 18, 2003, Ottawa, ON

1. Adoption of 2002 Minutes (Elaine Hall)

Minutes from the 2002 Annual General meeting were distributed and read. There were no questions.

Motion to adopt 2002 minutes: Skip Daniels
Seconded: John Gordon
Motion passed

2. Financial Report (John Gordon)

John Gordon (Treasurer) distributed a copy of the financial statements as of 30 September 2003.

He highlighted that the 2003 numbers reflect only 9 months as compared to the 2002 numbers covering the full 12-month fiscal year.

Financial statements to year-end will be printed in the first Bulletin in 2004.

Motion to accept these financial statements: John Gordon
Seconded: Teresa Seasons
Motion passed

3. Charitable Funds and Usage (John Gordon)

John Gordon distributed material from the Canada Customs and Revenue Agency on disbursement quotas and qualified donees which apply to The Canadian Addison Society since it is a registered charitable organization. A registered charitable organization must disburse 80% of donations to qualified donees in the year following receipt of the funds. Note that this requirement does not cover funds received as membership dues. To date, the Society has $3200 which should be disbursed.

There was a discussion of possible appropriate projects or other uses for these funds. Possible ideas include:

- funding the proposed stand alone website
- offering additional financial assistance to the UK survey
- supplying copies of the newsletter to endocrinologists, internists, family doctors
- creating a glossy poster to increase awareness of Addison’s for use in specialists offices, family doctor’s offices, emergency rooms, etc
- funding information packages sent out to non-members, members of the medical community, insurance companies, and distributed in other fora (e.g. endocrinologists’ annual meeting)
- creating an awareness campaign targeted to family doctors and insurance companies
- funding additional analysis of UK survey results with respect to Canadian data
- funding distribution to members and members of the of medical community information resulting from the UK survey
- talk show appearances to raise awareness of Addison’s
- funding information packages to go to medical researchers to encourage research on issues related to Addison’s
- supporting the presentation of a paper based on the UK survey to the annual meeting of endocrinologists

Motion by Joan Southam: To use the next Newsletter to get suggestions for charitable uses from all members; and, to empower the Executive Committee to make a decision based on all suggested uses
Seconded by: Anne Hubbard
Motion passed

4. Update on UK Survey (Joan Southam)

Survey results will not be available for awhile. Researchers (U.K. endocrinologists) are still receiving completed surveys. Any Canadian members who have not yet completed and returned the questionnaire are encouraged to do so immediately.

There are definite trends emerging. However, there are to date no new or startling findings.

Once the study is complete, The Canadian Addison Society will receive a copy of results. A précis will be available to all members, who will be encouraged to supply it to their endocrinologists and family doctors.

5. Portable Web and Email Address for Addison Society

At the moment, an individual member of the Society is hosting the email and web address for The Canadian Addison Society. It is suggested that The Canadian Addison Society purchase a website and email address which will be permanent (i.e. not depend on who the secretary is). This will also provide additional website space.

Motion by Joan Southam: that The Canadian Addison Society purchase a website and email address which will be permanent
Seconded: Teresa Seasons
Motion passed

6. Adoption of Executives for 2003/2004

Positions are for three years.

Dan Archi will not be available to act as Director for The Canadian Addison Society in 2003/2004. Nominations for one Director were requested.

Motion by John Gordon: to add Stephen McKenna to the proposed slate of officers
Seconded: Joan Southam
Motion passed

Proposed slate of officers for 2003/2004:

President: Joan Southam
Vice-President: Judy Stanley
Secretary: Elaine Hall
Treasurer: John Gordon
Director: Greeta McKague
Director: Francisca Swist
Director: Al McConnell
Director: Stephen McKenna
Newsletter: Sharon Erickson

Motion by Skip Daniels: to accept the proposed slate of officers
Seconded: Johanna Oosterhof
Motion passed

The President took this occasion to thank Lynda Daniels, who is leaving Canada, and presented her with a gift in appreciation for her work with the Southern Ontario Support Group.

The Brantford group will be co-chaired for the next year. Jordon Latter will act as one co-chair, and is currently looking for someone as the other co-chair. Anyone who is interested in working as a co-chairperson with Jordan please contact The Canadian Addison Society.

7. New Business

DHEA

Several documents were distributed. Joan Southam raised a proposal from the Vancouver Support Group with respect to lobbying/awareness around the Special Access Program clause “in a life or death situation or where authorized by a physician”. A discussion on the role of DHEA and its possible benefits/drawbacks ensued.

Motion by Steve McKenna: that the executive draft a letter to be used by members to send to MPs, GPs, Ministers of Health, MPPs, endocrinologists (cc. to CMA and Center for Rare Diseases)
Seconded: Teresa Seasons
Motion passed

Emergency Care

Joan Southam mentioned there had been two speakers on emergency care - Dr. Gene Jarrell from Brantford Ontario and Dr. Urbain Ip from Vancouver. Joan commented on some of the information from the Brantford group meeting and reported on information from the discussion period.

What Addison's patients should have available in case of emergency:

- health care card
- complete list of medications including alternative medicines, minerals and vitamins
- medical alert tag (bracelet or necklet)
- complete listing of medical history
- listing of associated medical conditions (e.g. heart murmur, diabetes)
- letter from physician (preferably one attached to the hospital) stating treatment necessary in event of an emergency
- you should have an emergency injection kit; you are advised to use it before going to the hospital emergency room
- it is preferable to use 911 to go to a hospital emergency room
- tell emergency room staff that you have Addison's, and that in the event of a crisis, you must receive immediate treatment
- have an advocate with you if possible to tell Emergency Staff that you have Addison's

If Addison's patients have problems receiving immediate emergency care in any hospital, they are advised to write a concise and succinct one-page letter outlining the facts of the case and problems encountered to the Hospital Community Relations Officer, with copies to: Hospital Administration, Head of Emergency Department, Emergency Department Room Manager, Department of Nursing. A copy can also be sent to the Executive of the Canadian Addison Society. However, members are reminded that the Canadian Addison Society is not empowered to act for the patient or lodge any complaint on behalf of a member.

A bulletin entitled Emergency Injection Kits from the Addison's Disease Self-Help Group in the UK (http://www.adshg.org.uk) was distributed.

If any members have solid information on emergency injection kits for steroids in the form of an epipen, they are asked to forward it to Joan Southam.

Motion by Johanna Oosterhof: that the Executive put together an information kit on emergency measures and injections
Seconded: Teresa Seasons
Motion passed

Travel Insurance

Members are advised to carefully check the provisions of any travel insurance they may carry or purchase. Many policies do not provide coverage for pre-existing conditions, such as Addison's. Royal and Sun Alliance/Global Excel Management Inc was one company cited seems to provide reasonable cost insurance if you have not had an Addisonian crisis within the previous six months.

Local Fund-Raising

Motion by Elaine Hall: that the Executive develop and distribute guidelines on fundraising by local groups
Seconded: Dan Gray
Motion passed

Presentation by Dr. Anthony Weinberg, Head of Internal Medicine, Ottawa Hospital

Highlights from Dr. Weinberg's presentation and the question and answer session include:

- symptoms of Addison's are so insidious that it can be difficult to diagnose Addison's until the patient is in crisis
- the longer the symptoms persist and the more advanced the case, the longer the period needed for recovery
- doctors and insurance companies under-estimate the time needed to recover health
- there is a very wide range in the severity of cases of Addison's
- the cause of Addison's is unknown although it is considered an auto-immune response
- if an under-active thyroid is diagnosed and treated in a patient with under-active adrenal function, this can precipitate an Addisonian crisis
- Adrenal dysfunction may be marked by a slow decline in basal steroid production. The question becomes: at what stage to intervene? If residual adrenal function remains, once a crisis is over, ongoing steroid medication may not be necessary. However, eventually supplementation will become necessary.
- Addisonians who have no adrenal function may need to adjust their dosages depending on the degree of stress they are exposed to.
- ACHT (adrenocorticotropic hormone): A fasting ACTH blood test should be below 10 in normal adrenal function. We want Addison patients to have levels between 10 – 20. U.S. data indicate that if levels are below 10, we are probably overmedicating and thus exposing the patient to the negative side-effects of steroids (e.g. osteoporosis).
- Connection of Addison's and diabetes? Type 1 diabetes is thought to be an auto-immune condition, as is Addison's. We do not know enough yet to know if there may be an underlying connection for auto-immune disorders. There is no connection between Addison's and type 2 diabetes.
- There seems to be a familial connection for Addison's.
- Beware of publication bias when researching Addison's and on the internet. Studies which show links are considered interesting; studies which show no links are unexciting and therefore not published. This skews the information available in one direction.
- Salt? If you increase your salt intake, you may need to reduce your florinef dosage. If you avoid salt, you will affect your potassium retention.
- Both hydrocortisone and cortisone acetate have a mineralocorticoid component. If you are on one of these forms, it is more difficult to adjust the gluco- or mineral component without affecting the other.

- Muscle cramping? Addison patients have high blood levels of calcium. Contractions of the muscle depend on calcium. Potassium shifts cause a form of paralysis rather than cramping.
- Severe joint pain can be the result of huge calcium deposits.
- Parathyroid conditions show low serum calcium.
- Stem cells? Since the body is destroying the cells of the adrenal glands, any stem cells which took on the characteristics of adrenal cells would be destroyed.
- In an emergency, tell others you “need saline now”. This may be even more urgent than the IV steroid.
- B12? To be effective, B12 should be taken intramuscularly. B12 is difficult to measure correctly in the blood. Symptoms of B12 deficiency include: burning sensations, stumbling, feel like there is cotton wool , poor positioning perception, anemia, depression, deterioration in the peripheral nerves. A lab can identify antibodies to B12 or intrinsic factor. You replace the villi in your intestines every 4 days. If B12 levels are low, the villi will be flat, causing nutrient absorption problems.

Elaine Hall presented with a gift of appreciation to Dr. Weinberg. The meeting adjourned at 2:30.

Submitted by Patricia McKenna

Memorial Donations

Several donations have been received by the Canadian Addisons Society the last month in memory of Robert J Hall previously of Salmon Arm, BC.

Highlights From Local Meetings:

Vancouver Island Support Group (Nanaimo)

Minutes of Oct. 18 meeting of the Vancouver Island support group in Nanaimo

MP Gary Lunn is asking Minister of Health Anne McLellan to help two of his constituents with Addison’s disease to obtain DHEA through the ministry.

The Saanich-Gulf Islands MP wrote the minister after two members of the local Addisons support group sought help with the now more difficult task of obtaining DHEA through Health Ministry channels.

The six members attending the Nanaimo meeting of the Vancouver Island support group Oct. 18 learned from member Jim Sadlish that the MP from the Canadian Alliance, soon to be the Conservative Party, has written a letter to the minister asking her to respond to concerns about the lack of availability of DHEA.

“At this point I am struggling to understand why it is necessary to make it more difficult, if not virtually impossible, for individuals to continue to obtain a naturally occurring body hormone to help address a serious medical condition.

My constituents are most anxious about this matter. I therefore respectfully ask that you respond to their concerns at the earliest possible opportunity.

Although studies have shown that DHEA offers an improvement in the quality of life to many Addisonians, the federal government recently implemented changes making it more difficult for a doctor to prescribe the medication. The doctor previously sought federal approval of the drug for his patient, and the medication was mailed to the doctor's office.

Available over the counter in the U.S., DHEA is normally produced largely in the adrenal glands, which do not produce it in those with Addisons disease."

Canadian Addison Society support group member Jane Palliser, the Vancouver Island group has asked the Canadian Addisons Society to take a proactive stance in asking the Health Ministry to ease the increasingly rigid restrictions.

Some members plan to write the health minister themselves explaining their views. The letters go to Hon. Anne McLellan, Minister of Health, Room 306, Justice Building, House of Commons, Ottawa, On. K1A 0A6.

The Nanaimo meeting also discussed varying ways in which members divide their daily dose of cortisone replacement. Two divided it into three doses of varying amounts; one into four; and one took two doses, both by noon.

Members also generally agreed they had a lot of difficulty adjusting to excess heat, and some tended to keep their homes cooler than normal.

Submitted by Christy Lapi

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)

DHEA, its potential to help Addisonians - and the Canadian government's refusal to make it available to them – held the floor for most of the meeting of the Vancouver Island support group of the Canadian Addison Society on September 13, at Victoria General Hospital. The meeting was planned for general discussion, but repeatedly the 11 members present returned to the same subject, the currently-denied - and in some cases desperately needed - DHEA.

This hormone, the major output of the cortices of normal adrenal glands, has previously been allowed into Canada only under severe restrictions that included special permits from Health Canada but now, as some of those at the recent meeting have discovered personally, prescribing physicians are finding even these permits refused. The official excuse is that DHEA is not essential to maintain life, as is the glucocorticoid cortisol and, generally, the mineralocorticoid fludrocortisone. However, as world-wide research is increasingly reporting, and as some of the Addison's disease patients at the Vancouver Island meeting reported, DHEA does improve life and can even make the difference between a restricted existence and virtually-normal activity (such as being able to work full-time without undue stress).

Those at the meeting reported various experiences with DHEA. Not all had tried it and among those who had there was definite indication of the benefits of adjusting the dosage according to individual physical response. Some women reported more problems with oily skin and acne on high doses but had dealt with this philosophically in exchange for the increased strength and energy. Before starting DHEA, one female member of the group had been able to do nothing more strenuous than take her dog for a morning walk, then rest and "take it easy" for the remainder of the day. On DHEA replacement, she no longer even needs afternoon naps to manage her household and is also enjoying trips to Mexico and other holiday places. Others reported similar help in keeping up with the demands of day-to-day living. As one pointed out, among the general population – whose adrenals produce their own – DHEA is looked on merely as a "feel good" supplement to their normal output, but for an Addisonian – whose adrenocortex produce little or none - replacement of this missing hormone means something more basic - "functionality."

Members reported that, since DHEA is sold (and cheaply) over the counter in the United States, their physicians have suggested they get it from there or from any of several Internet web sites. However, one who tried this had the drug stopped at the border and it was pointed out that anyone trying to bring it across could have their car impounded. Also, there is no guaranteed quality control over products sold over the counter or by Internet dealers.

Some have written individually to officials about the problem and it was finally decided to ask the Canadian Addison Society to take a proactive stance in the matter as a group. A motion to this effect was presented by Christy Lapi, seconded by Jane Palliser and passed unanimously.

Some other matters discussed: the importance of avoiding food poisoning and diarrhea and the extreme danger to anyone with Addison's disease of this latter condition; the record high temperatures of the just-passed summer which posed difficulty for some; sleep problems, which some members continue to try to resolve by varying the timing of their cortisone dosages; the possibility that Addison's and other auto-immune endocrine anomalies may be becoming increasingly heritable, with several reporting knowledge of families in which more than one relative is affected; what diet regimen is best for Addisonians and whether it would be helpful to eat meals with specific proportions of proteins and carbohydrates (as in a popular high protein/low carbohydrate diet plan).

Some discussion centered on information available on the Internet, its usefulness and also the need to be discriminating as to where it is coming from. A list of accepted medical sites was handed out for those wishing to learn more.

Submitted by Florence Weekes

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

BC Lower Mainland Support Group

October 18 meeting

At previous meetings, it was mentioned that the diabetes needles would not work as the injection needs to be intramuscular and the diabetes needles are subcutaneous and not long enough. Marilyn's endocrinologist felt this could work if injected into the thigh muscle unless one has a lot of body fat. Joan Southam is looking into alternate methods of obtaining DHEA. One website that looks promising and it is a reliable site I have been told is Women's International Pharmacy in Madison, WI (1-80 0-279-5708). The site is http://www.safemeds.com/women's-international-pharmacy.htm Joan is also looking into an epi-pen form of cortisone.

NADF News - With all the hype on Atkins diet Dr. Margulies, medical advisor for NADF, says quote "Although I wouldn't advocate this diet for more than a month or two even for normal (his words) people who need a jump start on weight loss, I do not think it is a good idea for Addisonians. One of the basic features of the diet is the production of ketosis via fat breakdown, which can be measured as ketones in the urine. This causes nausea and loss of appetite. The nausea concerns me because Addisonians need to be able to respond to nausea as a potential sign of an adrenal crisis. Better to just reduce portion of a well balanced diet and avoid ketosis."

NADF also advises to watch sources of information and/or chat rooms from the Internet on Addisons as some advice could be fatal if not researched and checked with your doctor before applying.

They are also requesting feedback from women who have had a pregnancy since diagnosis to assist with enquiries and support for fellow female Addisonians who are interested in having children. NADFmail@aol.com or write to them at 505 Northern Blvd. Great Neck NY 11021.

Addison News had a follow up report on the research study on DHEA being done at the Mayo Clinic. Elizabeth Hill from Saskatchewan also took part and hopefully will have her report in upcoming issues of our own newsletter. Many interesting subjects were covered with letters from all across the USA and some from Canada.

Dr. Urbain IP, Speaker

When we approached the BC Emergency Medicine division of the BCMA with a request for a speaker for our meeting, we met with a tremendous, positive response from the doctors. Dr. Urbain Ip was the first to reply, and volunteered immediately to speak to our group, although he was returning from vacation only two days before.

Dr. Ip has worked in Emergency Medicine for most of his professional career. He was instrumental in having Emergency Medical staff learn to do ultrasounds without having to call in a specialized technologist. He has taught Emergency Medicine in different locations and spent approximately 10 years as Head of Emergency at Surrey Memorial Hospital. Earlier this year Dr. Ip was appointed Medical Director of Surrey Health Services, which provides services to over 350,000 residents, including Surrey Memorial Hospital. Surrey Memorial Hospital is one of the top five hospitals in Canada in terms of volumes of Emergency patients, serving more than 75,000 per annum. Its Emergency department is the busiest one in BC.

Case History

Dr. Ip started his presentation with a case history in which he was personally involved. The patient was a 32 year old female, known to have Addison's Disease. She had presented at Emergency about 60 times in 24 months, (a "frequent flyer") and Dr. Ip himself had seen her about 24 - 30 of those times. She continually abused her condition, by not taking her meds, lack of proper nutrition, etc. Thus when she presented again, with the same symptoms, tummy pain, weakness, fainty, sweaty and pale, the resident applied the regular treatment of saline IV, IV Solu-cortef and pain killers, and did the regular blood tests and felt that her condition was under control. However, when the blood results came back, the resident called on Dr. Ip, because the blood tests showed a haemaglobin count of 76 and a slightly high white cell count. Dr. Ip examined the patient, and he said that this time she "looked different." He had seen her so many times, and he said there was just something different about her this time, so he investigated to find the real cause of this crisis situation. When questioned, she had said she was not pregnant. However, her abdomen was distended and very tender. Dr. IP performed an ultrasound, and found her abdomen was filled with blood. Within an hour the patient was in surgery for an approximately 10 week ectopic pregnancy that had burst. Dr. Ip was happy to report that the patient made a good recovery.

Dr. Ip used this case history, in part, to show that although we have Addison's Disease and must be treated for it in crisis, it is vital to determine the cause of the crisis in order to treat that as well. In this case, the patient had presented so very many times with the same symptoms and cause, that it would have been very easy for the resident and / or Dr. Ip to have missed searching out any other cause for the crisis.

Situation in Emergency Departments

Triage: process of diagnosis to determine priority for treatment. Diseases are rated according to the Canadian Emergency Triage and Acuity Scale. Thus a heart attack patient will be taken before someone with a broken hand.

All emergency medical physicians are trained in specialty diseases like Addison's. However, they may encounter only one or two in their entire professional careers, so may become complacent at times. Triage nurses are now also trained in specialty diseases, but the same situation applies to them. As well, there is an ongoing changeover of staff in Emergency wards.

The challenge in Emergency Departments is North America wide, with overcrowding and lengthening wait times. The problem is not input, but output. Because of staff shortages, in many hospitals patients who really belong in a ward are occupying emergency beds.

The current computerized information system does not allow one hospital access to patient information from another hospital. Some hospitals do have "codes" attached to the names of patients who have visited their emergency rooms, to alert staff to special needs for that patient, ie: Diabetes, to ensure proper care. People with Addison's are not automatically coded.

Paramedics - Ambulance Service

In the Lower Mainland, the ambulance response time is 4 minutes to reach the patient, and 10 minutes to get the patient to hospital. Paramedics here do not give injections of the patient's own medicine. In rural BC, most "First Response" personnel are volunteers. They are not trained to, and do not give, injections. However, if the need arises, the spouse, friend, or whomever is with the patient can give an injection of the patient's own medicine, even in the ambulance.

Even if we give ourselves an emergency injection at home or wherever, we should still go into Emergency to get the IV saline drip to increase our fluids.

Discussion and Recommendations by Dr. Ip

Emergency Department Staff

1. Send a letter from our group to the Head of the Emergency Departments of our local hospitals asking how our members in their catchment area can be identified in their computers, with information on treatment, or at least where to access that information.
2. Speak to the Emergency Nurses Association at the local hospitals, to educate them about Addisonian crisis and treatment. Dr. Ip feels they will welcome us to meet with their groups.

Personal

1. Make up an information card to attach to your BC Care Card in your wallet. (When people are unconscious, the medical staff will look in the wallet for next of kin, medical card, etc.) Gerry Ott has one made up, and Dr. Ip feels it is an excellent idea. With Gerry's permission, the text is repeated here, for your use:

Medic Alert

I am an Addisonian. I suffer from primary adrenal insufficiency. My adrenal glands do not produce cortisol. If I am found severely injured or unable to communicate, immediately give me 100 mg of Solu-cortef (Hydrocortisone sodium succinate) intramuscularly. Repeat every 6 hours. This medication will not harm or overdose, but will save my life. I carry an intramuscular injection in my red backpack or black fanny pack.

Adjust the text for your own situation. Dr. Ip also suggested adding "I have an electrolyte imbalance" to the card. A good place to insert it would probably be after the section "My adrenal glands do not produce cortisol.

2. Use Medic Alert. Ensure you wear your bracelet / necklace or whatever, and show it to the Triage nurse and emergency staff.

3. Educate family members so that they can give you your meds in a crisis situation.

Next Steps. . .

Dr. Ip does not want his involvement with us to end here. He would like to have a listing of all of our members. We will discuss this with our director, Judy Stanley, and obtain permission from our members. As well, we will let him know how we are progressing with his recommendations.

Submitted by Marilyn Thauburger and Debbie Doggett

Meeting for the upcoming year – Feb. 28, June 5 2004

Alberta Support Group

For information on this support group or any upcoming meetings, contact Francisca Swist at francisca@shaw.ca or Ginny LaValley at (780) 454-3866 – both are from Edmonton.

Saskatchewan Addison Support Group

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

Eastern Ontario Support Group

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

Southern Ontario Support Group

The Southern Ontario Support Group met on Saturday, September 27, 2003 at the Brantford Ontario Police Station. Our guest speaker was Dr. Gene Jarrell, head of The Brantford General Hospital Emergency Department.

We thank Lynda for all her hard work over the last 3 years as Chairperson of this support group and wish her every success in her missionary work in the Philippines.

Our group is now looking for a volunteer for Lynda's position as Chair Person. Jordan Latter, a member of our group from Toronto would be very willing to co-chair the group with another willing volunteer. If you would like to donate a little time to the group in this capacity or any other capacity, please let us know.

Dr. Jarrell began his talk with a brief description of Addison's Disease, followed by the anatomy and physiology of the disease.

He said that stress was one of the major players for Addisonians. He then discussed how to take care of ourselves when we are stressed with disease or facing minor events such as dental work and minor medical or surgical procedures. For most of these procedures, it is not necessary to increase your steroids, but if you feel really stressed about your appointment, then if would not hurt to take a little extra that day just before leaving for the procedure. If in doubt, talk to your doctor first. He also mentioned that you may wish to increase your fludrocortisone (Florinef) with excessive exercise, sweating, extremely hot weather or GI upsets. Adding extra salt at these times can help as well. Again, this may be something to check with your endocrinologist.

Dr. Jarrell emphatically stressed the importance of always wearing your medic alert bracelets/tags. These can save time and therefore lives of injured and ill patients who cannot speak for themselves. It is also a good idea, if at all possible, when you are going to the emergency department to take a person with you as your advocate who is familiar with your condition and can speak on your behalf if you become unable to speak for yourself. Do take with you a listing of all medications and amounts that you are on and any other underlying medical condition that you may suffer and/or be treated for. Also include all alternative medicine remedies and herbs that you may be taking as well.
A letter from a physician, either a family physician who practices at that hospital or an endocrinologist letter can help as well to outline expected treatment for the Addisonian patient.

He also stressed that everyone needs an Emergency injection kit. When you are ill and on the verge of an Addisonian crisis, use the Emergency kit and then go directly for medical treatment which usually consists of saline intravenous solution and intravenous injection of steroids.

If you do have a problem with your treatment or care in any Emergency Department, write a letter/letters. Most hospitals have a community relations person whose job it is to look into such problems. Also contact the manager of the Emergency Department and the director of the Emergency department for any alterations in departmental procedures. If you do write a letter, it HAS to be acted upon and hopefully the situation will be rectified as soon as possible. He also informed us that there is a national acuity scale for all triage nurses to go by so we should all get standardized treatment in the triage area from the nursing staff.

He then went on to outline several treatments for Addison's disease.

Treatment 1:

Standard replacement requires glucocorticoid and mineralocorticoid steroids. The standard accepted replacement dosage is 20 mg. in the morning and 10 mg. in the early afternoon. (Note: many patients may require less or more than these amounts since each of us processes the medication differently)

To add to this, most Addisonian patients require fludrocortisone - .05 –0.2 mg. a day. Many Addison patients also use liberal salt intake.

Treatment 2

This is acute illness coverage.

Increase steroids 3 times normal limits for the duration of the illness.

An emergency injection may be used (4 mg. intramuscularly of Dexamethasone OR 100 mg. Solu Cortef) then seek prompt medical help particularly if you are vomiting and cannot keep down the necessary medications.

Treatment 3

Surgical procedures

For minor procedures, no specific preparation is needed.

If the surgery is moderate e.g. Endoscopy or colonoscopy, 100 mg. I.V. steroid before the procedure would be in order.

If it is major surgery, give 100 mg. I.V steroid before the anesthetic and 100 mg. every 6-8 hours for the first 24 hours after surgery and then start tapering down rapidly decreasing each day up to 50% per day if well tolerated. It is conceivable to have 300-340 mg. a day of steroid in such situations.

Treatment 4 – Emergency treatment Indications:

Dehydration
Shock
Severe nausea and vomiting
Abdominal pain
Unexplained fever
Low sodium
Renal failure

High calcium
Low sugar

Treatment for these conditions:
Rehydration – IV fluids
Hydrocortisone 100 mg. every 6 hours
IV glucose

What they are particularly watching for is blood pressure, fluids and glucose.

Dr. Jarrell was quite shocked at some of the stories that many of us were able to communicate to him, either at the meeting, or brought in letter form from other patients to the meeting. He said that there is no need for most of these situations to happen anywhere in Canada and if they do, they MUST be addressed and dealt with at the administrative/medical level of the hospital which means for the patient, sitting down and writing letters outlining the problems that he or she as a patient encountered. Hopefully by us bringing these matters to light, we can make a difference in the future treatment of ourselves and other Addison patients in our hospitals.

Submitted by Helene Perry

Quebec Support Group

If you would like information about upcoming Quebec meetings or more information, please contact Sophie Lapointe at (514) 521-6538 or email sophiel@sympatico.ca

Dear Editor:

I am writing to you as I am puzzled by something.. I wonder if it is an Addison thing or just me.. I am getting a lot of little white bumps around the eye area and on one side of my face in the crease around my mouth.. When I was first diagnosed, the internist said that I would get fatty deposits under the skin. Is this what he meant? Does anyone else get these things? Just curious. If it is a thing that happens while taking steroids is there anything I should be doing?

- Please respond to ericksons@shaw.ca or to the Canadian Addison Society c/o the editor

Reminders:

- Medical Questions and Answers - Dr. Donald Killinger, MD, Phd, FRCPC, from London, Ontario, who is the Medical Advisor for The Canadian Addison Society, will answer your questions about Addison’s disease. Questions and answers that may be of interest to everyone will be published in the newsletter. Dr. Killinger has asked that we not write him directly, but to address your questions by letter/e-mail or fax through The Canadian Addison Society and they will be forwarded on to Dr. Killinger.
- Please – If you are pleased with your endocrinologist – LET US KNOW! We have many requests not only from recently diagnosed Addisonians but other Addisonians from all parts of

the country, who may be moving from one area to another and require the services of an endocrinologist knowledgeable about Addison’s disease and its treatment.

Kate Lawson has just moved to Kitchener/Waterloo and was referred to an endocrinologist named Dr. Nadira Husein, 525 Belmont St, Kitchener, ON (519) 585-7527. She would like to recommed her and states: I am very pleased with her. It can take time to get an appointment, however she does take phone calls and is very thorough, listens carefully and answers questions very well.

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

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Charitable Funds Usage

Please check off your preferences and include with your membership renewal.

... funding the proposed stand alone website
... offering additional financial assistance to the UK survey
... supplying copies of the newsletter to endocrinologists, internists, family doctors
... creating a glossy poster to increase awareness of Addison’s for use in specialists offices, family doctor’s offices, emergency rooms, etc
... funding information packages sent out to non-members, members of the medical community, insurance companies, and distributed in other fora (e.g. endocrinologists’ annual meeting)
... creating an awareness campaign targeted to family doctors and insurance companies
... funding additional analysis of UK survey results with respect to Canadian data
... funding distribution to members and members of the of medical community information resulting from the UK survey
... talk show appearances to raise awareness of Addison’s
... funding information packages to go to medical researchers to encourage research on issues related to Addison’s
... supporting the presentation of a paper based on the UK survey to the annual meeting of endocrinologists

The Canadian Addison Society
La Société Canadienne d'Addison
193 Elgin Avenue West
Goderich ON N7A 2E7

Website: http://members.rogers.com/jsoutham

New Membership Renewed Membership

*Name:*____

*Address:*____

____

Postal Code: ________________ *Telephone:*____________________

*E-mail Address:*___________________________*Fax:*_____________

*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, 2004

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 Montreal Support Group – Quebec +$20.00 to Society

( ) $5.00 to Ottawa Valley Support Group –Ontario + $20.00 to Society

( ) $5.00 to Brantford and District Support Group – Ontario + $20.00 to Society

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

( ) $5.00 to New Westminster Vancouver Group – British Columbia +$20.00 to Society

( ) $5.00 to Vancouver Island Support Group – 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