

The Canadian Addison Society La Société canadienne d'Addison

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President's Message:

Dear Friends,

Hello, and a happy and healthy new year to you all. This year we are looking forward to registration, and hopefully adding some new groups across the country. Also our web site is generating lots of interest and bringing in some new members. If anyone would like a support group in their area and are willing to help start one, please contact me, and I will work on it.

Recently Joan and I attended a workshop for similar support groups and it gave us some good ideas to work on in the future.

Most of the country is experiencing record cold and snow falls already this winter and I hope no one will overdo it moving snow. Please listen to your body and act accordingly,

Regards to all, Greeta

Democracy In Action

Results of your vote for choice of a name have been tabulated by Joan Southam and Don Archie. The results are as follows:

The Canadian Addison Society 50
The Canadian Adrenal Society 27

Everyone was instructed to sign their ballots when sending them in. This was made necessary for "legal reasons" as the ballots were photocopies. This practice is quite common. Some ballots were disqualified because they were sent in with no signatures. The outcome of the vote would not have been different had these votes been valid.

Thank you all for participating in this very important decision.

Just a friendly reminder that memberships fell due January 01, 2001. We have enclosed a membership form for your convenience in this newsletter. Please make cheque or money order payable to The Canadian Addison Society.

<u>Please note that our treasurer, John Gordon, has moved and his new</u> address is on this renewal form.

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.

Francisca Swist from Alberta would like to recommend her endocrinologist The name is Dr J. Ginsberg, 362 HMRC, U of Alberta, Edmonton, T6G 2S2. If you are located in that area and are currently looking for an endocrinologist, Francisca would like to recommend this doctor.

Medical Questions and Answers

Dr. Donald Killinger, MD, PhD, FRCPC

Dr. Donald Killinger, 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.

The following set of questions are the result a recent meeting in British Columbia, sent in by Judy Stanley and then forwarded to Dr. Killinger s office.

1. The question was asked about the relationship between glaucoma and cortisone treatment.

Answer: Glaucoma is a process in which there is an increased pressure inside of the eye and the chances of this increase with age. Patients who are taking normal amounts of cortisone for replacement therapy, such as patients with Addison's disease should not have an increased incidence of glaucoma although they would have the same incidence as is found in the general population.

2. A question was asked with respect to the relationship between rapid eye movements and Hypothyroidism or Addison's disease.

Answer: As far as I am aware there is no relationship between either Hypothyroidism or Addison's disease in eye movement problems. It's possible that patients with Hyperthyroidism or patients who are treated with too much thyroid hormone could have some suggestion of increased rapid eye movements but this would require a fairly significant excess of thyroxin and would be quite unlikely.

3. The question was raised with respect to the relationship between Pancreatitis and Addison's disease.

Answer: Pancreatitis is usually caused by some blockage of the duct draining the pancreas, such as a gallstone or less commonly with increased triglycerides in the blood, which can interfere with the out flow from the pancreas resulting in inflammation. There are other causes of Pancreatitis, but in someone who is not excessively overweight and who is not ingesting excessive amounts of alcohol, these would be the most common causes. Patients with Addison's disease are no more likely to have these problems than the general population.

4. A comment was raised between the relationship of high blood pressure and small hemorrhages appearing over the white part of the eyes.

Answer: First of all, we try to regulate the amount of Florinef to avoid causing high blood pressure but patients with adrenal problems can have the usual types of high blood pressure seen in the general population. In general, high blood pressure is less common in patients with adrenal insufficiency than in the general population. The small hemorrhages are possibly related to increased fragility of the blood vessels and this can be seen in patients who are taking a little more cortisone or prednisone than they might need. This problem can also result in increased bruising, usually on the legs or areas that receive minor trauma.

5. A question was asked about the use of a scan called MP59 or NP59 to detect adrenal tissue that may have been missed during surgery.

Answer: I have not heard of these particular code words and it would depend on what type of equipment is being used. The most common scan used to detect adrenal tissue that has escaped surgery is an iodocholesterol scan. This has radioactive cholesterol, which is taken up by tissues that are using cholesterol to make cortisone and this can be detected provided the area of uptake is large enough. If you can find some more information about MP59 or NP59, I would be more than happy to try to check it out for you.

We are always happy to have a chance to review any questions that come up, so please don't hesitate to send them on.

Dr. Donald Killinger, MD, PhD, FRCPC

Thank you Dr. Killinger for answering these questions. We appreciate your being there for us and giving of your valuable time to help keep us well informed.

Coming Together: Sharing Together - A Dialogue Workshop

A report sent in by Joan Southam:

The Canadian Addison Society was invited to attend a weekend conference in Orangeville, Ontario entitled "Coming Together: Sharing Together - A Dialogue Workshop". Greeta Fraser and I went to Orangeville to the Hockley Valley Resort on Friday afternoon for the weekend long conference (November 24-26, 2000). We were the guests of the Co-hosts Canadian Organization for Rare Disorders (CORD), The Coalition of National Voluntary Organizations (NVO) with the support of Health Canada.

Greeta and I made a presentation on Friday, along with each of the other 21 groups represented, (45 people). Our presentation was on The Canadian Addison Society - what Addison's disease was, who we were, who we represented and helped, our source of resources, our strengths and our weaknesses as well as our goals. We made a poster presentation to go along with this, which was on view for the whole weekend. Our sessions were worked in "Open Space" a "new concept that brings a group's collective energy together to address complex issues with high degrees of innovation and consensus." Greeta and I made a presentation on "How to get the medical professions aware of "us" and to spread the message " One of the outcomes of this discussion was to support a national voice, and to become aware of other voluntary groups and work together in some areas. Sessions were held, Saturday morning, after noon and Sunday morning with group events planned for Friday night and Saturday night. Angela Timms, Vice-President of the Canadian Addison Society, was also able to attend the Saturday afternoon sessions.

Each of the invited organizations was asked to pay \$200.00 for registration fee. The invited organizations from all across Canada were like us - small budget, voluntary and self-help groups. We saw how other organizations like ours were doing and how they coped with the current challenges. We established personal connections and built contacts that we are now familiar with.

We shared and talked about common problems that each of us as a group share and in turn developed some common solutions for both health and organizational issues. We learned about different ideas and potential activities that we may be able to put to use in the future for our organization. We found that the faces and the names were different but the problems were the same for the many organizations represented!

It was a wonderful and exciting weekend. We "educated" people about who we were and what we did as a national group and in turn, we participated in various discussion groups and joined in the discussion on various offered problems, thoughts and ideas. Both Greeta and I were involved in the initial and follow up discussions of a "National Directory of Voluntary Health Organizations" and we have been asked to be representatives on a national group for continued investigation.

It was a weekend, with lots of surprises. We were able to contribute, receive, and enjoy the fact that we are NOT alone as a voluntary group. There are others out there who understand and are going through the same problems as we are.

We would like to thank Maureen Gaetz-Faubert of CORD, Penny Marrett and Rhonda Hynds of NVO and Nancy Laberge of Health Canada and many others who were in the steering committee that made this a wonderfully enjoyable and working weekend.

South of the Border

Joan Southam was the guest speaker in Michigan this past fall, and sends you all this report:

I was invited by the Michigan Addison's and Adrenal Disease Support Group to be their speaker on October 7th/2000 at the McPherson Hospital in Howell Michigan. There were 27 at the meeting and it went very well. I spoke about my 41 years of being an Addisonian and talked about DHEA, the history of DHEA and the two year study that we were involved in. I also left them with some thoughts that I had accumulated as being important from my 41 years.

My thoughts to you – from one Addisonian to another

- Get as much information about Addison's disease as you possibly can, using the internet, the library, information from your doctor and/or specialist and by all means attend support group meetings.
- 2. Remember that your doctor is there for you not YOU for his/her convenience. Question and expect answers! If your doctor/specialist does NOT answer or feels intimidated by your approach find another specialist if at all possible!

- 3. Be aware that many Addisonians are over medicated and know that the lowest possible dose that we are able to function with, is the healthiest for us.
- 4. Consider using the <u>COMBINATION</u> of traditional and alternative medicines. Both have a lot to offer but again, make sure that you go to knowledgeable professionals in both areas. Check out the credential and where they received their training that includes your traditional specialists as well as the homeopath doctors and naturopaths to mention a few.
- 5. Consider getting involved with some of the other offered areas of help and healing Massage Shiatsu Reflexology Reiki and there are many more. Check with your library or a natural health center, nutritional stores and even some bookstores often offer short seminars with some of the well -known authors. Many of these areas can be free to try while actual treatments are more expensive but make wonderful and welcome gifts. Reiki especially is a great self-healing technique that is the reason that T personally got involved with Reiki.
- 6. Don't suffer from depression! Get help temporary or permanent, traditional or alternative -they all have something to offer. Find what is best for you and use it!
- 7. Consider taking some personal times for meditation or quiet times to listen to music, to sit under a tree or look out a window and just concentrate on your deep and regular breathing for ten or fifteen minutes. It helps your mind as well as your body to relax and to refocus.
- 8. Look for the positive! It's there but sometimes it takes a lot of looking to find it.
- 9. Laughter! Still the best medicine and it makes not only us feel better but those around us.
- 10. One thing quite important for me prayer. Scientists have now proven in experiments that those who had prayers said for them, unbeknown to them, healed faster. Pray to the God of your understanding it works!
- 11. It is our responsibility to make our body as healthy as it can be and that includes eating well, using whatever diet feels right for you, and exercising at whatever level you can.
- 12. Don't abuse your medication! Increase your medication sparingly. I have always used the combination of traditional and alternative and by using the alternative medication, I found I was not popping more of the heavy-duty drugs, including our own steroid replacements.
- 13. Wear a Medic Alert bracelet -preferred by emergency staff over a necklace.
- 14. Have a back up emergency kit including an injectable. Have an emergency card or sheet with your basic information as well as your medical history and medications and most importantly any allergies. Have this information available to "pickup and take" by a family member, neighbor or ambulance personnel.

- 15. Train you family! They are your vocal advocates when you need treatment and cannot speak for yourself.
- 16. Smile often! It takes less muscles and energies to smile than to frown and it makes the world a brighter place!

Of interest to us all:

Judy Stanley from our B.C. Lower Mainland Support Group is really on the ball. She has received some information which may or may not concern each of you. A batch of Prednisone 5mg tablets has been recalled by a manufacturer in the United States. The code lot numbers are 42129 exp. 12/02 and code lot number 42130 exp 12/02. The tablets are manufactured by and have been recalled by Mutual Pharmaceutical Company, Inc., Philadelphia, Pennsylvania. The recall is due to blend uniformity failure only.

Since this is an American recall it should not affect us. but just in case you have purchased your Prednisone from states side, we are passing this information along. If you feel you need further information, please see the following websites or contact your pharmacist:

Mutual Pharmaceutical Company Inc. Recalls Prednisone Tablets

Reason: Blend uniformity failure.

Distribution: Nationwide,

"http://www.safetyalerts.eom/recall/f/004/d037.htm"

Read Artic!e

http://www.safetyalerts.eom/recall/f/004/d037.htm

or

UDL Laboratories Inc. Recalls Prednisone Tablets Reason: Blend uniformity failure. Distribution: Nationwide,

"http://www.safetyalerts.eom/recall/f/004/d038.htm" Read Artic!ehttp://www.safetyalerts.eom/recall/f/004/d038.htm

Thank you Judy for passing on this information and helping to keep us informed.

Highlights From Local Meetings

Vancouver Island Support Group (Victoria)

Following is Florence Weekes' account of the meeting from October 21/2000:

Osteoporosis, a bone-weakening problem often caused by long-term use of glucocorticoids, was the subject at the October 21 meeting of the Vancouver Island Addison's support group, held at Victoria General Hospital, Victoria. Sixteen people heard a presentation by Barbara Anderson of the Osteoporosis Society of Canada. Ms. Anderson supplemented her talk with charts, slides, and information-packed hand-outs. There was even a brochure of recipes for cooking B.C. salmon, a good source of the calcium that can help prevent Osteoporosis.

Ms. Anderson explained how bone is continuously broken down by osteoclasts and rebuilt by osteoblasts, and how important it is to supplement this bone-remodeling process, particularly since the breaking down goes on at a greater pace than the rebuilding. Hormones, diet, exercise and extra calcium and Vitamin D are all important in this rebuilding activity. Postmenopausal women particularly need to check requirements for hormone supplementation.

The importance of testing for bone density was also stressed. This special x-ray procedure will show any osteoporotic tendency and indicate when extra treatment or precaution is necessary. Ms. Anderson recommended one always ask for copies of tests, and always get information about any prescribed drugs and their possible side effects or reactions with other drugs a person might be taking. There was discussion of different drugs available to prevent Osteoporosis, and note that one must not lie down, but remain erect, for two hours after taking Fosamax®. This is to prevent any back-flow, which can damage the esophagus. Recommended daily intake for calcium was 1,500 mg., and of Vitamin D, 400 mg. Ms. Anderson said extra magnesium is not necessary, as enough would be available in a normal, good diet.

Dealing with diet, it was noted that foods containing plenty of calcium include not only dairy products, but also many other foods such as salmon (canned or fresh), sardines, blackstrap molasses, soy and figs; whereas some foods, such as kale and rhubarb, actually cut down on the amount of calcium one can absorb.

Exercise was also stressed, especially weight lifting and weight bearing exercise such as walking. These help strengthen not only the bones but also the muscles that help prevent falls and injuries. Although Osteoporosis can have various causes, the introduction of glucocorticoid therapy in the 1940s has brought a great increase in its incidence. One of the charts handed out listed about 20 different conditions for which glucocorticoids are prescribed, and which can therefore possibly be followed by Osteoporosis. (Interestingly to this reporter, this official chart did not list Addison's disease - another attestation to its position as an "orphan disease," still in much need of public education.)

The Vancouver Island support group will meet again February 3, 2001 at the Victoria General Hospital, Room 1814, from 1:00 PM to 3:00 PM. Our speaker for this meeting will be Mr. Larry Thorne, pharmacist with Victoria Compounding Pharmacy. His talk will include hormone replacement therapy and topical medical applications. For information please call Jim Sadlish at 250-656-6270 or e-mail at wx699@victoria.tc.ca or Florence Weekes at 250-598-0321 or fmweekes@jslandnet.com.

BC Lower Mainland Support Group - October 14/2000

Following is a report from Judy Stanley:

Dues for 2001 are due Jan. 1, 2001. Your joining puts you in touch with others with adrenal failure, a newsletter each quarter with interesting personal stories, medical questions answered, a web page update and the option of paying \$5.00 of your renewal to supporting your local group, mailing costs etc. I have a few copies of renewals forms but will forward a copy with the meeting update letter as well.

The Annual General Meeting for The Canadian Addison Society was held September 23rd with some new officers being elected. Greeta Fraser has agreed to be President, Joan Southam -Secretary/Contact, Al McConnell - Director, for another year and new directors for more regional representation are Elaine Hall from Ottawa, Francisca Swist from Edmonton and myself representing BC.

Laminated medical cards are available. They are produced in New Zealand by Neil Atwood and are available from Joan Southam for \$10.00 each.

The DHEA study has now been concluded and as it is no longer banned in Canada, can be taken after requesting permission from Ottawa by your doctor. Anyone interested see me for further information.

Another interesting comment from Dr. Purdon at the Southern Ont. Support Group was that Graves Disease can cause your replacement med for Addison not to work. Anyone with hyperthyroidism should discuss this with their doctor.

I have information brochures from Connie Waterman of Osteofit for anyone interested.

Sherri would like to know if anyone has heard of a scan called the MP59 or NP59 which somehow detects the cortisol in other tissues that may have escaped while having a adrenalectomy. I have sent a request off to Joan Southam to ask Dr. Killinger about this Medic Alert news update.

Joan received an e-mail from Alice Groenveveld requesting addresses for all CAS members for information to be sent about "Young Living Essential Oils". If anyone is interested I have a copy of the e-mail for you to read.

I received a letter from Evelyn at 100 Mile House with a magazine article on Cushings. I have made 5 copies for anyone that has or has had Cushings.

I shall be making arrangements for the young people with adrenal problems to meet during Spring Break at Children's. If you know of anyone with children or have children yourself who are interested please contact me. I have about 10 names so far.

A reminder that meetings for the upcoming year will be. February 17th and May 26th, 2001. Please contact Judy Stanley at 604-936-6694 or e-mail bugbee@direct.ca should you have any questions or concerns.

Please note:

Judy Stanley has recently had her computer crash which left her e-mail address book lost. If anyone has not heard from Judy with meeting updates, she invites you to please contact her by e-mail in order to be added to her address book again. Judy's address is: bugbee@)direct.ca

Alberta Addison Support Group

Following is a report from Francisca Swist:

A few of the Alberta Addison's group got together on November 27/2000 for a casual dinner at Krickets in St. Albert. There were 8 members there of which one was new to the group and one was a spouse.

Francisca Swist was asked to speak at the University of Alberta December 7th and 8lh to approximately 150 medical students, which comprised the entire 2001 class. The future doctors were all receptive to her and asked a lot of appropriate questions. Hopefully, one day if they ever come across an Addisonian they will know how to treat — or at the least, remember something from the class and refer the patient to an endocrinologist.

Following is Francisca's account of how these classes usually unfold:

The hospital that my endocrinologist works out of (the University of Alberta) is a teaching hospital and I believe it was 3 years ago that he first asked me whether I would come and speak to the med students. Since then, another of the endocrinologists has asked me to come and speak and it was this same doctor (Dr. E. Toth), who asked me to come again this last time.

Dr. Toth would introduce me and then tell the class that I am coming to them with a problem. They were told to ask me questions and try and diagnose what I might have. They do have one huge clue because it is the endocrine section of their course studies. Anyway, I tell them that I am exhausted every day without any apparent reason as well as losing weight because of a marked loss of appetite. At this point, a lot of them ask, "what other symptoms do you

have?" To which I reply, "I don't know, I'm just a patient and you are the doctor - it is up to you to ask the appropriate questions".

So they continue to ask questions and often it seemed almost by chance that they would arrive at the crucial "Addisonian" questions - Have you noticed any change in your skin colour'? Have you noticed whether you are craving salt? Unfortunately, it seemed that in each class only one or two twigged on to the questions and therefore the diagnosis. Then I tell them the other symptoms that I was experiencing, such as purple gums. I let them know that I was at a GP 2 weeks prior to hospitalization but that she found nothing. She did not run an electrolyte test which would have indicated elevated potassium and decreased sodium levels.

Dr. Toth knew about the crises that I have experienced and asked that I tell them about them I have had 6 or 7 since my diagnosis but of the two I had this year, the last one was definitely the worst because of a lack of an immediate response at the ER and demonstrated the importance of an injectable as well as a 'doctor's letter' with instructions for treatment. By the time I got to the ER my blood pressure was 70/50 and I still had to wait 1-1/2 hours before a doctor saw me and had me put on IV and gave me steroids. Dr. Toth explained the importance of prompt treatment, particularly in a serious accident. Emphasizing the importance of the Medic Alert bracelet, etc. There was some discussion as to Paramedics and their ability to treat. Dr. Toth felt that they would be able to treat with a Doctor's permission but I am not sure about that. I think this is something that should be looked into. It is very likely that most of the ER doctors are not familiar with Addison's Disease and depending on how busy the ER is at that particular time -whether or not they have the fortitude to look it up. I was under the impression that the Paramedics were not allowed to treat, even if they were provided with your steroid injectable.

The students really appreciate it because it is very different from their regular lectures and it puts them in the doctor/patient scenario to give them a chance to ask questions and try to 'diagnose' the problem. It also puts a personal aspect to the teaching. After the classes I had a lot of the students express their thanks and explain that it really makes a big difference.

Francisca

There is no definite date set, as of this edition, for the next meeting of the Alberta Addison Support Group but they will be aiming for a spring time meeting.

Southern Ontario Support Group

The next meeting for the Southern Ontario Support Group will be on Saturday, January 20lh at I:30 pm at the Brantford Ontario Police Station on Wayne Gretzky Pkwy. The speaker will be Jean Ross, who is a diabetic and will be speaking to us on the care of our feet. This is a very important subject for anyone living with diabetes or who have family members or friends who are dealing with this disease.

Eastern Ontario Support Group

Following is a report from Elaine Hall:

Happy New Year and Good Health!

The meeting for Ontario East, was held on Oct 14th 2000 at Dan and Katie's home. Fourteen people attended the meeting, 9 of whom were Addisonian. Apologies from Al, Doris, Greeta, Sybil, Anne and Kirn. The lunch was "Pot-Luck"; we had lots of delicious food supplied by each member. Both our May and October meetings are always quite informal, with plenty of time to chat and catch up with everyone's news.

Welcome to Catherine and Elizabeth. Congratulations, Teresa and Raymond, who are expecting their first child in May.

Dr. Weinberg sends his profound apologies for missing our meeting, but promises to attend our May 26th meeting.

One of our members passed around a letter written by her doctor to give to emergency staff, so that they may be totally aware of her condition and the medications that she requires. This is something we should all do, and put it with our emergency medication, and our "medical alert" information.

We also talked about how much or how little medication each of us take, whether it be Hydrocortisone, Prednisone, Decadron and Florinef. Sleeping patterns were also a topic of conversation. Some people need to take naps during the day, some are heavy night sleepers, some suffer from mild insomnia, the differences were quite outstanding. This shows clearly that Addison's disease is extremely diverse in its effects on people young and old.

The next Ontario East Meeting will be held on May 26, 2001 at 12:30 at:

Robbie's Italian Restaurant 1531 St. Laurent Blvd. Ottawa Ont.

Tel: (613) 744-8585

Reservation will be made in the name of Elaine Hall; our speaker will be Dr. Weinberg. Please call Elaine Hall (613) 824-0160, if you have any questions or comments. Hope to see you in May!

Meetings are held twice annually at the following times:

MAY - The first Saturday following the Victoria Day weekend. The group meets at Robbies Italian Restaurant on St. Laurent Boulevard, Ottawa at 12:30 for an informal lunch.

OCTOBER - The first Saturday following the Thanksgiving weekend. The group holds this meeting at a members home and a "pot-luck" lunch is arranged. A speaker is invited to this meeting.

Please contact Elaine Hall at 613-824-0160 for further details.

Editor's Note: Your April 2000 edition contains a copy of a letter submitted by Pierre Corbeil of Golden Lake, Ontario, which was written for him by his doctor. It describes his condition and the appropriate action to be taken should he present himself at the emergency department. Mr. Corbeil carries this letter with him. You may wish to use this as a guide/suggestion for your own doctor.

PS: Don't forget your flu shots and vaccine for pneumonia

WOMEN'S ANTI-STRESS DIET

A witty little ditty submitted by Fransica Swist:

This is a specially formulated diet designed to help women cope with the stress that builds up during the day. After all, stress is a serious problem for Addisonians.

LUNCH

BREAKFAST

1/2 grapefruit

1 slice whole-wheat toast (no butter)

1 cup skim milk

AFTERNOON SNACK

The rest of the kisses in the bag 1 tub of Hagen Daas ice cream with choc-chip

OON SNACK

2 bottles of wine

1/2 cup of spinach

1 Hershev kiss

DINNER

1 whole loaf garlic bread

1 family size supreme pizza

1 cup herbal tea (no sugar)

small portion lean, steamed chicken breast

2 snickers bars

LATE NIGHT SNACK

whole frozen Sarah Lee cheesecake (eaten directly from the freezer)

REMEMBER: STRESSED SPELLED BACKWARDS IS "DESSERTS"



Letters to the Editor

This very interesting story comes from a recent former member from the Lower Mainland area of British Columbia. This gentleman's story reinforces the message that we must always be on top of your own medical circumstances. While we are happy that John does not have Addison's Disease, we are sorry he is now dealing with another chronic disorder and we wish him all the best.

I had previously been thought to have Addison's Disease. I had been on steroids for about a year. My specialist at that time said I should discontinue the medication, just quit he said!! Needless to say I did not do so. I then contacted the Addison's support group in this area and attended their meetings. I was referred by some of this group to another Dr. who then put me through a battery of tests and weaned me off the steroids over a period of 6 months; concluding that indeed I did not have Addison's Disease. More tests and several months later I was sent to see another specialist at V.G.H. This time they did a skin biopsy and sent it off to M.I.T. in the USA. Results of this indicated that I have a Fatty Oxidation Disorder called, Carnitine Palmitoyl Transferase Deficiency or CPT2.

Treatment has been a strict diet and avoiding all fatty foods, which seems to be working for me as I now feel much better and seem to more or less be getting back to normal. I do have times that I feel very lethargic and sometimes my muscles ache but I think I can handle it. The main thing is that I have to eat about six times a day with lots of carbohydrates, otherwise the needs of the body are taken from my muscular reserve, hence the aches and lethargy. There is an excellent site on the net at http://www.fodsupport.org/define.htm. You will be able to gain more knowledge than I can give you if you visit the site.

I thank you all for your support and advice to me while I was with the group. I will keep in touch and keep you up to date on my progress.

Sincerely, John.

John's dietitian, Ms. Ingrid Verduyn, RON, who is a metabolic dietitian, was most helpful to this editor in answering the obvious question as to how a patient could get into the situation of being placed on steroids for Addison's Disease. She contacted John's doctor and replied with the following answers for us:

"I spoke to John's doctor about the questions in your email. John's presentation was very atypical compared to most CPT2 clients and so would have tit the symptomotolgy of Addison's. In general, the symptoms for CPT2 are not the same as Addison's. Most people with CPT2 present with muscle aches, myoglobinuna and rhabdomyolysis.

John's doctor feels that the second opinion was most likely sought since the Addison's turned out to be a negative diagnosis. Sometimes steroids are given almost as a last resort and this may be why John was on steroids.

I hope this answers your questions and that I have relayed the information most accurately."

Yours truly, Ingrid Verduyn, RDN Metabolic Dietitian

Thank you Ingrid, for taking the time to assist us with this information.

Share your ideas/opinions/experiences/funny or horror stories, or just something to get off your chest, mail it to the address below or send by e-mail. You may remain anonymous if you wish. No names will be published without your consent.

Helene Perry 75 Wendover Drive #218 Hamilton, Ontario L9C2S7

Or e-mail to: hperry@interlynx.net

One hundred years from now, it will not matter what kind of car I drove, what kind of house I lived in, how much I had in my bank account, nor what my clothes looked like. But the world may be a little better because I was important in the life of a child.

Author Unknown

How can a society that exists on instant mashed potatoes, packaged cake mixes, frozen dinners, and instant cameras, teach patience to its young?

Paul Sweeney

A pat on the back, though only a few vertebrae removed from a kick in the pants, is miles ahead in results.

Bennett Cerf

Another flaw in the human character is that everyone wants to build and no one wants to do maintenance.

Kurt Vonnegut Hocus Pocus

Let's Hear It For Life!

Here's a recipe to make good use of the turkey bargains available at this time of year at your local supermarket. It's heart healthy and not time consuming to make. Most kitchens would have all the ingredients on hand. This recipe is great for family dinners and get togethers or your most fancy party treats. Teenagers love these served with a tray of fresh veggies. They freeze really well, so you can do them in batches for when you are short on time

Honey-Mustard Turkey Meatballs

1 pound ground turkey

1 egg, slightly beaten

3/4 cup crushed crackers

½ cup shredded mozzarella cheese

1/4 cup chopped onion

½ teaspoon of ground ginger

6 tablespoons Dijon mustard (divided in half)

11/4 cups unsweetened pineapple juice

¼ cup chopped green pepper

2 tablespoons honey

1 tablespoon cornstarch

1/4 teaspoon onion powder

Combine turkey, egg, cracker crumbs, cheese, onion, ginger and 3 tablespoons of the mustard in a bowl. Form into about 30 balls, one inch each. Place in a lightly greased 13 X 9 X 2 inch baking dish. Bake uncovered, at 350° for 20 to 25 minutes, until the juices are clear.

In a pot combine pineapple juice, green peppers, honey, cornstarch, and onion powder. Bring to the gentle boil stirring constantly. Cook and stir for 2 minutes and then reduce the heat. Stir in the remaining 3 tablespoons of mustard and blend smooth.

Brush the meatballs with about ¼ cup of the sauce and return to the oven for 10 more minutes. Serve the remaining sauce, warmed, as a dip for the meatballs. Yields about 2½ dozen.

Sorry that this recipe is in the old imperial measures, but it's quite easy to convert. You won't be able to keep these on hand very long. They are just plain yummy!

Do you have a favorite healthy recipe or tip that doesn't take too much of our stamina resources to create? If you would like to share your recipe or tip with other Addisonians, please send them to hperry@interlynx.net, or mail to Helene Perry, 75 Wendover Dr. #218, Hamilton, Ontario, L9C 2S7. Please let me know if you do not want your name used. Let's share with each other and we all win!