



Canadian Addison Society La Société Canadienne Addison

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Issue No. 12

Addison Info

April 1998

The year 1998 so far has been very kind to the Canadian Addison Society. We have reached several more Addisonians, both in Canada and outside of our borders. With the new policy for a paid up membership, unfortunately a few Canadian Addisonians decided not to purchase their memberships for this coming year. They will be missed. It would have been ideal if we could continue to send out the newsletters on a donation only basis but it was not a practical situation for us to consider at this time. Those that did renew, we thank you. We really appreciate your many nice comments that you added as well. You may find that your newsletters are a bit larger (even the print) with even more information in them. As usual your comments are welcomed. Thanks to Mary for letting us know of her concerns. We hope that we answered your questions satisfactory.

Sincerely Joan Southam

President's Message by Mrs. Greeta Fraser

Springtime greetings to you all! I strongly urge you now that the nicer weather is finally here, to attend the local support meetings nearest you if at all possible. They not only offer support but they have a lot of very useful information from speakers and/or other Addisonian members. If you are thinking about having a local support meeting, contact the Canadian Addison Society at 519-753-1271 for some guidelines and useful information - Sincerely **Greeta Fraser**

Highlights from local Meetings

If you wish to start a support group in your area, contact us at 1-519-753-1271 for any helpful hints and information and we may be able to give you.

Quebec:

A meeting was held in Montreal, Saturday, March 21, 1998 at the home of Al McConnell and his wife Doris. The meeting, although small in numbers, was great. It was a time of sharing and support for each other. Sophie Lapointe also volunteered to translate the membership form into the French language for those that it might help. For more information about the Quebec group, contact Sophie

at 1-514-288-7268 or e-mail her at [<sola@colba.net>](mailto:sola@colba.net) or Sybil at 1-514-486-9817. *Thanks to Sophie for sending us this information.*

Ontario:

A meeting was held January 31, 1998 at the Brantford Police Station Meeting Room in Brantford, with 35 people in attendance. We completed our short agenda and as our tradition, there was a round of self-introductions and several newcomers were warmly welcomed as well.

Our speaker for the afternoon was **Dr. Alfred Hauk**, a naturopathic doctor who has had an active practice in Brantford for several years. He also teaches part time at The Canadian College of Naturopathic Medicine (CCNM) in Toronto, the only one licensed and recognized in Canada. An excerpt from the hand out literature reads "***the naturopathic doctor views the individual as an integral whole where symptoms are seen as warning signals of improper functioning of the body and underlying cause of the disease***". One area of discussion by Dr. Hauk with regards to Addison's Disease, was the lymph system, over taxed by Addison's disease. This area needs extra help, which include moderate exercise, relaxation techniques, having a positive outlook plus foods that are naturally high in sodium. These include beets, spinach, Swiss chard, pomegranates, strawberries, tomatoes, figs, raw honey, almonds, beechnuts. Foods rich in iodine, phosphorus and silicon play an important role in maximizing sodium and blood chemistry into balance. They include sea vegetables (kelp, dulce), turnip greens, egg yolk wheat germ, lecithin, sesame seed butter (high in calcium), seeds and nuts such as cashews, almonds, raw goat's milk, romaine lettuce and carrot juice. He also recommended these three vitamins - C (300-500mg. 3 x daily), B5 for adrenal function and B6 to help with water balance and breakdown of food. Other natural products helpful for Addisonians are Licorice root (not candy) which maximizes steroid use, Milk Thistle which is useful in chronic fatigue, and is also anti-viral and anti-inflammatory, extract of Adrenal tissue, which goes directly to that organ, extract of thymus tissue which inhibits thymus destruction. Dr. Hauk also cautioned certain things that were hard on the adrenals, these include alcohol, caffeine, tobacco, high fats, fried, processed foods (e.g. pork or ham), sugars and sodas. We have some handouts and naturopathic newsletters left over from the meeting as well, for those that wish more information. It was a very informative and thought-provoking lecture, which from the positive responses and questions from the audience was very much appreciated.

Our next support group meeting will be Saturday, April 25, 1998 at the Brantford Police Station meeting room from 1:30-4:00. Our speaker will be **Ms. Monica Lavis**, a dietician working at St. Joseph's Hospital, Brantford and in Hamilton. She will go over the "good diet" we need as Addisonians to go along with a healthy lifestyle and exercise. She may be able to offer some advice as well to Addisonians with diabetics, as well as those with thyroid problems and those with osteoporosis. Ms. Lavis is very enthusiastic about meeting with our group and I am sure it will be a very informative and interesting meeting. For more information call Joan Southam at 1-519-753-1271 or e-mail her at

<jsoutham@worldchat.com>. *Our minutes were prepared courtesy of our excellent recording secretary, Mrs. Angela Timms. Complete minutes available.*

Saskatchewan:

A meeting is not scheduled at this time but if anyone in Saskatchewan would like more information, contact Elizabeth Hill at **1-306-236-5483**.

Alberta:

The first meeting of the Alberta self support group will be held May 2, 1998 at the Sturgeon Hospital in St. Albert, Alberta. Because it is their inaugural meeting, they have decided not to have a speaker but to instead introduce their previously prepared purpose, goals and guidelines for discussion. The meeting will also present an opportunity to meet other Addisonians. For some Addisonians who have never met another person with Addison's Disease, this will be a very important meeting. There will also be an "evaluation form" for input from the attendees as to what type of speaker they might like to see presented and what form they feel the meetings should take. At previous planning meetings, a dedicated core group of volunteers have elected Richard Evans as Chair and Ginny LaValley as Co-Chair. Francisca Swist was elected as secretary and Peter Little is the contact person for Alberta. This group has worked very hard to arrange this meeting and we wish them every success. For more information on the Alberta support group, contact Peter Little at (403) 922-5307 or e-mail him at <litt019@ibm.net>

British Columbia:

The second meeting of the British Columbia support group was held Saturday, March 28, 1998 with a good turnout of 13 present. **Dr. Clarissa Wallace** was our speaker and answered a variety of questions. She suggested that especially menopausal women get a density test for future reference. She commented that our questions of weight gain, muscle cramps, methods of managing medication were certainly helpful and informative to her as well. She agreed that we have to find what works for each of us. The merits of Gatorade versus "*Oral Rehydration Therapy*" which consists of 2 tablespoons of sugar and 1/4 to 1/2 teaspoon of salt dissolved in a liter of water were discussed. There was concern about the potassium in the Gatorade and similar brands. As potassium is usually elevated and sodium loss is evident in a crisis, this simple solution is probably better for quick sodium replacement. Several Addisonians in attendance shared some of their situations, problems and concerns.

Literature on Addison's medication was made available from Joan Hoffman's newsletter (USA). Other literature, books (Dutch report on Addisons and Addison kids) and brochures are now available through the Canadian Addison Society.

The next meeting for the British Columbia support group will be July 11, 1998 from 1-3 p.m. The meeting will be in the Sherbrooke Centre, Lecture Room 1, 330 E. Columbia St., Royal Columbian Hospital, New Westminster, B.C. Tentatively a speaker from the C.P.P. has been arranged and will speak on "**disability benefit changes**". For more information contact Judythe Stanley at 1-604-936-6694 or e-mail her at <bugbee@direct.ca>

The possibility of a group meeting in Victoria, B.C. was discussed. (Contact Judy for more info) Thanks to Judy for sending us this information to share.

Logo Search

- **Entries are still welcome for a logo for the Canadian Addison Society. We have received five excellent ideas, two from Dave Steadman and his wife, from Ontario and three entries from Patti Nauta and her children from Saskatchewan. Thank you, your efforts were much appreciated. Keep those ideas coming in!**

Computer Bytes of Information

- One of the most popular sites still remains the ***Addison, Schmidt and Cushings disease Forum*** at **<www.healinglight.com/addisons>** (or try **<www.elitehost.com/cgi-bin/kris>**) as the site has just undergone a face lift. It is user friendly and there is a lot of information to be gained as well as meeting some very nice people from this forum. Don't forget, there is "Chat page" for Addisonians at this site and as well there is a Chat page for Addisonian children at **<www.healinglight.com/addisonkids>**
- There is also a new site for parents with Addisonian children. Thanks to Tommy from the Healinglight forum who found this one and thanks also to Lynda, a parent of an Addisonian child, one of our newest members, for trying it **<http://rainforest.parentsplace.com/dialog/get/addisons.html>**
- The ***NADF (National Adrenal Diseases Foundation)*** site has a lot of very good information, for yourself, your family and friends or even an interested family doctor. The site is at **<http://medhlp.netusa.net/www/nadf.htm>**
 - For those with Addisonian children, the Barbara Davis Centre for Childhood Diabetes in Denver Colorado is conducting a study of the genes that cause susceptibility to Addison's Disease along with type 1 diabetes mellitus and celiac disease which are often associated with Addison's Disease. You can contact Dr. Peter Gottlieb at 303-315-8796 for more information on this study and the Centre. Their website is restricted.
 - An interesting site **<www.centerwatch.com>** provides information on over 5,000 clinical trials taking place including the DHEA study by Dr. Samuel Yen and Dr. Brian Berger from the University of San Diego.
- For those that like a challenge - type in Addison's at **<www.infoseek.com>** and that will give you 1,764 pages to review. This includes a few excellent forums for pets, specifically dogs and cats with Addison's disease as well.
- ***NIDK (National Institute of Diabetes and Digestive and Kidney Disease)*** has some good information at **<www.nidk.nih.gov>**
- Another member Francisca from Alberta sent this web site called ***Internet Grateful Med*** at **http://www.ncbi.nlm.nih.gov/PubMed/**
- Another site to add to your favorite list is Joan Hoffman's, (who writes the Addison News from U.S.A), at **<http://www2.dmci.net/users/hoffmanrj>**.
- For those with different types of autoimmune diseases as well, be sure to check out ***Circle of friends*** site at **<http://members.aol.com/mycircle/index.htm>**

- Last but certainly not least is the International site of **ACIF (Addison and Cushing International Federation)** at <http://www.spin.nl/nvap0302.htm> and be sure to read the Canadian contribution as well. This is a site for Addisonians and others, with contributions from many different support groups around the world.
- A recommendation came from Judy from British Columbia and she has suggested that for those that wish, the newsletter could be available through e-mail rather than "snail mail" (regular post). As she pointed out, it would be a good way to save money. She, herself, receives other newsletters from different groups in this way. If anyone else is interested, let me know.

Tidbit Section

DHEA Study: The DHEA study conducted by Dr. Jeff Mahon and Dr. Don Killinger is still continuing. For some of us, we are approaching our six-month testing time. We hope that the findings will be of benefit to Addisonians everywhere. Contact Dr. Jeff Mahon 1-519-663-3756 for more information.

Junior Edition: It has been suggested that there are several young people in our Canadian group with Addison's disease now and these young people were wondering if they could get other young people to write to them - either by snail mail or e-mail. If you (or your Mom) are interested, in corresponding let us know and we will try to help match you up with someone or add your name to a pen pal list.

The Addisonian Book Store: The figures are all in, as well as the books! Yes, we finally have several copies of the **Addison Patients in the Netherlands Book** for sale, thanks to the helping hand of Joan Hoffman in Michigan. The books will sell for **\$25.00 Cdn** and that price will include postage. Please send your cheque or money order payable to the Canadian Addison Society along with your order. We also have a few books **Our Addison Kids** by Joan Hoffman, made available to parents of Addisonian children through the kind generosity of Joan Hoffman. Joan, your kindness is much appreciated from us all.

Old Newsletters: We now have a full set of Canadian Addison Newsletters (No1 through to No12) in our possession! Thanks ever so much to **Christine Forsyth**, Ontario, for her kind gift of a **complete set** of Canadian newsletters. Thanks also to Don Archi and Angela Timms for their generous contributions as well.

Specialists' Recommendation: If you wish to put forth your "specialists" name as a doctor that you personally would recommend for the excellent and knowledgeable care you received in treatment for your Addison's disease, send it along. **Shirley Shier**, Ontario, recommended her doctor, Dr. A. Williamowicz, Oshawa and in appreciation, we sent along to her doctor a copy of our latest newsletter as well as our information brochure. This type of recommendation will be particularly appreciated by those Addisonians who have to move to another

city, area or province and will have to start looking for a knowledgeable doctor, one who has other Addisonian patients. This will certainly cut down on a lot of time and stress!

Osteoporosis: Many Addisonians suffer as well from osteoporosis. There is a four-page newsletter put out called the **Osteoporosis Advisor**. Either ask your doctor about this publication or write for information to the **Osteoporosis Advisor**, Maclean Publishing, Research Department, 777 Bay Street, 5th Floor, Toronto, Ontario M5W 1A7. The latest advisor that I received had a lot of information about exercises, life style, menu planning, recipes as well as an excellent compact paper fold out with lots of condensed information. We thank **Peter Little** for sending us a newspaper article on Osteoporosis from the Calgary newspaper. It will appear in one of later newsletters.

Please note: If you find an article that you think may be of interest to the rest of the members, send it (or a copy) along to the Canadian Addison Society. Be sure to tell us where you got it so that we can give credit for it and we will find space for it in an up and coming Canadian newsletter.

Medic-Alert: Now is a good time to remind all Addisonians that wearing some type of emergency identification symbol is a **must!** It could save a lot of valuable time in a medical emergency as well as possibly saving your life. For information on Medic-Alert, ask your doctor or call 1-800-668-1507 (in Toronto call (416-696-0267) or write 250 Ferrand Drive, Ste.301, Toronto, Ontario M3C-2T9.

Medical History Sheet: We are including a Medical History sheet with the newsletter. You can either use this one, reprinted from the NADF News Vol. X No.4 (1997 (Fall) or use it as a guide to form your own. You may wish also to use this as the first page of your medical history that we should have available for "emergency" use.

Annual Meeting: The annual meeting will be held in Brantford, Ontario some time in *September 1998* and will be incorporated with the Brantford and District Support Meeting. It will be a full day with a potluck lunch. The exact date and speaker will be announced at a later date. **Keep it in mind!** Any comments or issues you wished to be discussed, send them along to Joan at the Canadian Addison Society, 8 Francis Street, Brantford, Ontario N3R 7CR or by e-mail.

International Interest

As many of us are aware, there are several different Addison support groups around the world. We have had regular contact with a few and on a regular basis, receive their newsletters. One such support group is the **Addison's Disease Self Help Group** in the U.K. The contact person for this group is Mrs. Deana Kenward. I wrote and asked if she would like to contribute some information about her group for us to share. She agreed and this is what she had to tell us:

"This group is a self help group and have as their patron, Daniel O'Donnell, an Irish singer. A patron is a person who sponsors, usually in name only, or aids charities, artists, etc. I, myself an Addisonian, started the self-help group in 1984. We now have approximately 550 active group members.

I open my home once a year for any member who can travel to Guildford in Surrey (England) and they spend the day discussing Addison's Disease plus numerous other subjects. A few members have held open houses for members who live in their area. *I am* basically the Self Help Group for the U.K. and have continued to answer all written correspondence first, by hand, then by typewriter and now by computer, made possible from extra donations with their membership fees. I now have a friend Lynda who is starting to do the group accounts for me, which will be a big help. The membership fee is £7.50 (approximately \$18.45 Cdn) and for that each member received 6 newsletters a year plus any new information that comes my way. I also try to put members in contact with other fellow group members in the area. "

Mrs. Kenward has also given her kind permission to reprint any of the Addison's Disease Self Help Group's newsletters. If anyone is interested in reprints contact Joan Southam at 1-519-753-1271 or e-mail: < jsoutham@worldchat.com >

We also received some very interesting information from Mrs. Laurie Wizgird, who heads the support group from Michigan. She was a representative at a conference in Michigan on "Autoimmunity: A women's Health Issue" conducted by the American Autoimmune Assoc. (AARDA). There is a lot of information for us all, whatever the gender and will be featured in an upcoming newsletter.

Setting the Record Straight:

Our past treasurer Al McConnell has asked that this message be inserted in the Canadian Addison newsletter.

"In early October 1996, I attended "the first International Conference for Addison/Cushing and Acromegaly Patients" in Oslo, Norway. The meeting was sponsored by Morbus Addison Forening of Norway.

The purpose of the meeting was to determine if Addisonians in all countries encountered the same problems associated with rare diseases and to discuss our common problems in general.

It appears that some members are of the mistaken impression that I received funding from our society or possibly some other source. This is to advise all members that the trip was made entirely at my personal expense. This, of course, is verified by last year's Annual Report.

As indicated in my report, included with the December 1996 Newsletter, the meeting was very successful and I was proud to attend as the Canadian Addison Society Representative, and happy to do so at my own expense"
D.A. McConnell

Treasurer's report by Don Archi

I am submitting the Treasurer's Report this year as acting treasurer due to the untimely passing of our Treasurer, Richard Moore. Richard was a gentleman in the true sense of the word. He will be sadly missed by his many friends.

For the year ending December 31, 1997

The year ended on a positive note with increased membership throughout most parts of the country and a healthy bank balance of **\$4,949.91**.

Many local branches are springing up. We need to put in place procedures for approving of local branches and for adopting procedures for the use of portions of the membership dues to support the approved local branches. I will be bringing forward such motion at the annual meeting scheduled to take place in the fall of this year. I would also hope to bring forward for approval, documentation required for the obtaining by the Canadian Addison Society of a charitable registration number so that any donations would be tax deductible. Please forward any suggestion you may have with respect to these matters to me at 134 West Street, Brantford, Ontario N3T 3G3.

Respectfully submitted March 20, 1998 - *Donald A. Archi*

My Addison Story

By Beatrice Collins, Grande Prairie, Alberta

I was 83 years old on November 16, 1997 and have had Addison's for approximately forty years. I have had five children, the last two being a set of twins born in 1956 when I was forty-two. All were born in England where I resided, near London, with my husband who is a physician. I moved to Canada with my family in 1966.

Once we settled in Grande Prairie, I opened a craft store, which I ran for approximately twenty-five years. I have taken various courses at our Regional College along with participating in many theatrical productions. Twenty-one years ago I started a local production of a Christmas pantomime which continues to be produced every year. I enjoy keeping busy with our children and grandchildren, travelling and camping. Last fall my husband and I bought our first canoe, which we are looking forward to sharing on outings with the family. I also like to spend time painting, both watercolor and oil and also help with feeding patients in the long term care facility.

I have survived some accidents due mainly to quick treatment. A bad car crash after a driver ran a stop sign, resulted in broken ribs and lacerations and a slip caused a broken wrist. At approximately fifty-five I was thrown from a horse which resulted in a left leg being broken in five places requiring one of the breaks to be plated. After six months of casts followed by another six months on crutches then a period of regaining leg strength, I was able to walk again.

Last summer I achieved a long time ambition while camping in Jasper National Park with some of the family. With the support of the grandchildren we went on a white water rafting trip on the Athabasca River. It was very pleasant and only mildly rough and we all ended up the day with a sense of achievement.

I do not feel that having Addison's is a doom and gloom, maybe take an extra pill, and then do what you want to. I generally eat what I fancy and drink lots of homogenized milk and have so far kept osteoporosis at bay. I also like plenty of fruit, fish, meat and vegetables. I sleep very well but if I feel tired during the day, I sit down to rest and enjoy a good book. A strange thing is I do not really like salt, never take it on my plate and rarely use it when cooking. I do sometimes crave chocolate and anything sweet.

Our special thanks to Mrs. Collins.

Please send in your "Addison stories" - we all have different stories to offer and which we can all benefit from, the highs as well as the lows of our Addisonian life.

Medical Questions and Answers
with
By D. Killinger, MD, PhD, FRCPC

Dr. Killinger has asked that we NOT write directly to him but address your letters or e-mails through the Canadian Addison Society and they will be forwarded on to Dr. Killinger. Those questions that will be of greatest value and interest to us all will be printed in our newsletters. There are still some questions that an answer has not been received back yet but will be sent along to you at a later date

Q: Do we, as Addisonians need to eat more salt than normal? Joan, Ontario

A: No - if you are on an appropriate amount of Florinef, a drug with salt retention features, then the salt in a normal diet should be enough. The exception is on hot summer days when you are sweating and losing fluids, you may wish to increase your salt a bit

Acknowledgments:

Thank you so very much for all those that added an "extra" amount when you paid your annual membership fees. Those include:

William Rees, Jeanne Hall, Bea Collins, Maurice Holmes, Ruth Visinski, Carolyn Allan, Gwen Leik, Angela Timms, Elaine Mattson, Florence Gour and Mary Braun. Thanks to Elizabeth for all those very useful 45¢ stamps.

Enjoy life!

